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Creating Space For Seldom Heard Voices

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Portfolio for Professional Doctorate in
Counselling Psychology

City University London
Department of Psychology
October 2014



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Acknowledgements

Firstly, I would like to express my heartfelt thanks and gratitude to my supervisor, Dr. Karen Ciclitira. I am eternally grateful for how generously you have given of your time and energy. I have benefited enormously from your supportive presence throughout the project and have enjoyed every single one of our conversations. Thank you for everything.

Thank you to each of the seven participants who took part in the research study. I appreciate that your involvement required a leap into the unknown. Without your openness and willingness there would be no study. I hope you found some value in taking part and in the research findings.

Thinking back over the past four years of training, I feel incredibly lucky to have interacted with many wonderful colleagues, peers and supervisors, all of whom have helped me to complete this training. In particular, I would like to thank Penny, Janis, Claire, Patsy, Patricia, Edyta and Aylish from North Essex Partnership NHS Trust where I spent three happy and fulfilling years. Thanks for your support, encouragement and wisdom. Thanks for helping me to develop as a therapist and to learn to believe in myself. The experiences of working with you will stay with me long after I leave the Trust.

A big thanks also to my classmates and lecturers at City University. I learned a lot from all of you and I treasure the close friendships I have made from the course. Thanks also to my close friends from outside of the course for your interest in what I was doing and tolerance for me rambling on about it.

In particular, I would like to thank my friend Emma who has helped me at every single stage of training. I can remember talking to you when thinking about applying to the course at City and you have been a wonderful source of advice and insight every step of the way. I cannot thank you enough for all your help. I also want to thank my friend Camilla for helping me to put the finishing touches to the portfolio.

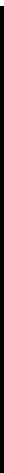
Thank you to my wonderful family, my brothers David and Peter, sisters-in-law, nieces and nephews. You mean the world to me and I'm looking forward to getting to spend more time with you now that the course is over. Thanks also to Judy and Marilyn, and all the Deignans for your encouragement and support. To my loving parents, Peter and Mary, I owe so much to you. Your constant involvement and interest are an inspiration. The only question is what university I should go to next!

To my wonderful son Dylan, thank you for enriching my life in ways that I never knew possible. You have filled my life with love and laughter. You constantly remind me about what really matters and to try live in the present moment.

Lastly, to the love of my life, Karen. I don't have words that will capture the love I feel for you and how grateful I am for everything. You possess a sensitivity, wisdom and balance that astound me. I know you have made a lot of sacrifices over the past four years. Thank you for helping me to follow this dream.

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Introduction to Portfolio

Creating space for
seldom heard voices

This portfolio brings together two aspects of my counselling psychology training: a critical review of research exploring how men seek psychological help and an original research study about the lives of men after testicular cancer treatment.

Having contemplated the idea many times, in 2009, I made the decision to leave a career as a qualitative market researcher working in the non-profit sector in order to train to be a psychologist. I hoped that a doctorate in this field would provide rigorous clinical and research training. The decision to pursue counselling or clinical psychology felt less straightforward and my understanding of the similarities and differences between these trainings was very limited. The application processes seemed to suggest that counselling psychology placed greater emphasis on the relational components of therapy, reflective practice and the humanity of the therapist. I made this assumption because the counselling psychology application form invited reflection about how my life experiences could help me as a therapist, and because of the mandate to have personal therapy during training. I share this anecdote not because I believe it reflects a real difference between all counselling and clinical psychologists, but because it illustrates that the human and relational components were particularly significant to me.

During the last four years of working towards the doctorate, I learned more about how ambiguity and multiplicity are at the heart of counselling psychology (Goldstein, 2010). Kasket's (2012, p. 65) attempt to capture the values and aspirations of counselling psychology feels particularly illuminating:

"I see counselling psychology as a particularly honest, realistic, pluralistically orientated member of the family of applied psychologies, in that it is willing to expand its horizons to accommodate a plurality of view-points, a multitude of possibilities, and an infinite variety of potential 'truths'. Our world is unimaginably diverse, our experience is full of paradoxes, and our selves are multifaceted. Much depends on the contexts in which we are always inescapably, relationally-embedded. Much is unknown and never can be known. Very little can be reduced to bare fact or absolute certainty."

To date, most of my therapeutic experiences have involved working with people who have severe and enduring psychological difficulties, within NHS multidisciplinary community and inpatient settings. Indeed, I hope to be able to work in the NHS post-

qualification, and to provide psychological therapy to individuals, many of whom would be unable to access this resource privately.

There are many dimensions to this challenging and stimulating work that draw on the pluralistic ethos that is central to counselling psychology (McAteer, 2010; Orlans & Van Scoyoc, 2009). This includes: employing multiple therapeutic models and approaches, working within a medical model framework while thinking critically about psychiatric diagnoses and treatments, and adopting a number of ontological or epistemological positions on the spectrum from realist to relativist.

Perhaps one of the most important components is a curiosity and openness that is central to my attempts to value and respect clients' subjective experiences, meanings and priorities. I try as much as possible to experience parts of the world as they feel to my clients, by listening and engaging with their perspectives with attentiveness and compassion. Therapy can involve helping people to express perspectives or experiences that are seldom heard elsewhere in a society in which emotional difficulties continue to be associated with considerable stigma.

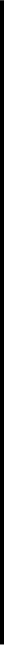
Having experienced a significant bereavement in my early 20s, and feeling a certain amount of social pressure associated with the expression of grief, the topics of marginalised perspectives, or seldom heard voices, hold deep personal significance. These experiences and the associated wounds inform some of my interests, ways of engaging with others, and attempts to understand the world (Martin, 2011). The theme of valuing and attempting to create opportunities for the expression of seldom heard perspectives is present in both components of this portfolio.

Part one of the portfolio presents a critical literature review of research about men's experiences of seeking help. It represents a seldom heard perspective because, instead of following the well-worn track of focusing on the 'barriers' to seeking help, it attempts to illuminate the processes associated with men who managed to access support for psychological difficulties. It includes a discussion of how experiences of being marginalised can be used as a means of constructing alternative masculinities. This topic is particularly meaningful for me as a practitioner, and also as a man who benefited greatly from psychological therapy during a difficult time in my own life.

In **part two** of the portfolio, I present a qualitative study of how men manage life after testicular cancer treatment. Seven men had individual, face-to-face, semi-structured interviews, which started with a broad and open question. The direction and focus of the study was driven largely by the participants themselves and what they wished to talk. The data was analysed using constructivist grounded theory (Charmaz, 2006). Most testicular cancer research has focused on a fragmented aspect of men's experiences, often related to sexual functioning. This study aimed to create the space for these participants to discuss their lives in a broader sense, and attempted to analyse and synthesise the breadth of these experiences and processes. The study, therefore, can be considered to have explored different or seldom heard perspectives. Also, the findings shed light on these men's post-treatment interpersonal experiences. In doing so, this study emphasised the relational, social and cultural aspects of cancer that can be marginalised by the cultural construction of cancer as an individual responsibility (Clarke, 2004; Seale, 2001). Finally, the reflexive writings about the study explore not only how my subjectivity may have impacted on its construction, but also how engaging with participants and their stories has left me feeling somewhat changed.

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Part 1: Critical Literature Review

Beyond helplessness and hopelessness:
How men sought help for emotional
difficulties

Abstract

Research exploring help-seeking for physical health and psychological difficulties is a well-established field. Historically, much of this research has focused on psychological and structural barriers to seeking help. In recent times, a new strand of help-seeking research has emerged that explores how some men successfully manage to seek help. Many of these studies have been informed by social constructionist and feminist perspectives, which view masculinities as multiple and enacted through a plethora of situations and interactions. This paper presents a critical review of these new developments in help-seeking research, centred around four main themes related to the psychological and social processes involved in how men sought help, to the resources they drew on and conflicts they experienced. These themes have been labelled: having 'permission', striving for a 'manly' expression of distress, reframing help-seeking and drawing upon experiences of 'otherness'. While recognising the challenges of seeking help, it is hoped that by examining how men can manage to overcome these difficulties, this paper can prompt practitioners to reflect further on how to engage with men and masculinities.

1. Introduction

1.1 Rationale for the review

The intentional focus on gender in this review is supported by the UK Equality Act (2010) which requires that public bodies such as the NHS consider differences in men's and women's experiences when designing and delivering services (Branney & White, 2008). There has been a new wave of interest in the psychology of men in recent years, illustrated by the publication of numerous books on the subject and the launch of new academic journals, including *Men and Masculinities* (1999), *Psychology of Men and Masculinity* (2000) and *International Journal of Men's Health* (2002) (Smiler, 2004). The study of help-seeking remains a vibrant line of inquiry within this discipline.

As a man who benefited from therapy, and a counselling psychologist in training working with male and female clients, I have personal and professional reasons for being interested in help-seeking. Initially, I set about conducting a review of recent literature exploring the barriers to men seeking help. However, after becoming immersed in the literature, I began to question some of the assumptions underpinning the notion of 'barriers' to seeking help and the usefulness of this approach to exploring the topic. The 'barriers' conceptualisation can result in emphasising external factors, such as the design of services or ways in which therapy is marketed, that may prevent

willing men from accessing this support. Alternatively, it has been translated into a focus on men's attitudinal barriers to seeking help, an approach that can be interpreted as suggesting that the route to encouraging help-seeking starts with changing attitudes. While I believe there is merit in focusing on both external factors and on attitudes to help-seeking, these are just two parts of a complex and dynamic process. Furthermore, these ways of thinking risk glossing over the diversity of men and masculinities and presenting 'men' as a relatively homogenous group (Crawshaw, 2009). It is also possible that these conceptualisations draw on and contribute to a discourse that positions men as passive victims of an increasingly feminised society (Gough, 2006).

Additionally, as I gained more clinical experience, I noticed how some psychology services, when reflecting on limited numbers of male clients, seemed quite quick to resort to often unchallenged 'truths' such as 'men don't talk' or 'men don't ask for help'. I was concerned that yet another paper about the barriers to men seeking help might add to this pessimism, ignoring the fact that some men, myself included, do manage to seek help. Although historically under-researched, the topic of how some men manage to seek help has been the subject of a number of fairly recent studies (Gulliver, Griffiths, & Christensen, 2010; O'Brien, Hunt, & Hart, 2005; Willig, 2000). This paper seeks to explore this new strand of help-seeking research with a view to drawing attention to how some men manage to seek help. It is hoped that this paper can help practitioners to adopt an attitude of pragmatic optimism about engaging with men and masculinities.

1.2 Scope of the review

This review seeks to explore the following question:

According to research, how have some men managed to seek help for psychological difficulties?

Two databases, PsycINFO and Medline, were searched using various combinations of the terms:

'help-seeking'	'emotional'	'men'	'masculinity'
'seeking help'	'psychological'	'male'	'masculinities'
	'mental health'	'gender'	

These keywords were chosen because an initial review of literature suggested they were among the most commonly used.

This review focused on papers and books published between January 2000 and March 2014. Its primary focus was on seeking professional help for emotional or psychological difficulties but some studies related to physical health conditions were also included. The analysis was based on reviewing 24 studies, further information about which can be found in table 1. This included studies employing a range of analytic approaches, such as grounded theory, thematic analysis, content analysis, discourse analysis and interpretative phenomenological analysis. Some studies employed a combination of these different analytic approaches. In a small number of cases, details about analytical approach had to be inferred because they were not directly reported in the published papers.

Table 1: Details of studies reviewed

Author(s)	Journal / Book	Analytic approach	Method	Sample
Anstiss, D., & Lyons, A. (2013)	Journal of Health Psychology	Discourse Analysis	Men's Help-seeking Letters and Expert Replies	Two magazines - Men's Health and FHM
Biddle, L., Donovan, J., Sharp, D., & Gunnell, D. (2007)	Sociology of Health and Illness	Grounded Theory	In-depth Interviews	23 men and women, aged 16-24
Brownhill, S., Wilhelm, K., Barclay, L., & Schmied, V. (2005)	Australian and New Zealand Journal of Psychiatry	Grounded Theory and Content Analysis	Focus Groups	77 men and 25 women, a mix of students and teachers from tertiary education sites
Calasanti, T., Pietilä, I., Ojala, H., & King, N. (2013)	Health Psychology	Thematic Analysis and Discourse Analysis	In-depth Interviews	24 men, aged 40-61
Chuick, C. D., Greenfeld, J. M., Greenberg, S. T., Shepard, S. J., Cochran, S. V., & Haley, J. T. (2009)	Psychology of Men & Masculinity	Grounded Theory	In-depth Interviews	15 men, aged 24-75
Clarke, J. N., & van Amerom, G. (2008)	Issues in Mental Health Nursing	Content Analysis	Internet Blogs	45 men and 45 women, self-identified as depressed
Danielsson, U., & Johansson, E. E. (2005)	Scandinavian Journal of Primary Health Care	Grounded Theory (modified version)	In-depth interviews	18 men and women, diagnosed with depression

Author(s)	Journal / Book	Analytic approach	Method	Sample
Davidson, K., & Meadows, R. (2010)	<i>Men, masculinities and health: Critical perspectives</i>	Mixed Methods	In-depth Interviews	85 men, aged over 65
De Visser, R. O. (2009)	Men and Masculinities	Thematic Analysis and Discourse Analysis	Focus Groups and In-depth Interviews	2 men
De Visser, R. O., & McDonnell, E. J. (2013)	Health Psychology	Mixed Methods	Online Survey and In-depth Interviews	731 men and women (survey) 16 men and women (interviews)
De Visser, R. O., Smith, J. A., & McDonnell, E. J. (2009)	Journal of Health Psychology	Thematic Analysis	Focus Groups	27 men, aged 18-21
Emslie, C., Ridge, D., Ziebland, S., & Hunt, K. (2006)	Social Science & Medicine	Qualitative Secondary Analysis	In-depth Interviews	16 men, aged over 18
Farrimond, H. (2012)	Health	Thematic Analysis	In-depth 'Episodic' Interviews	14 men, aged 20-60, higher socio-economic status
Green, G., Emslie, C., O'Neill, D., Hunt, K., & Walker, S. (2010)	Social Science & Medicine	Thematic Analysis	Semi-structured Interviews	20 ex-servicemen, aged 23-44
Griffith, D. M., Allen, J. O., & Gunter, K. (2011)	Research on Social Work Practice	Thematic Analysis	Focus Groups	105 African-American men, aged 33-77

Author(s)	Journal / Book	Analytic approach	Method	Sample
Hale, S., Grogan, S., & Willott, S. (2007)	British Journal of Health Psychology	Interpretative Phenomenological Analysis	Semi-structured Interviews	20 men, aged 51-75
Hale, S., Grogan, S., & Willott, S. (2010)	British Journal of Health Psychology	Interpretative Phenomenological Analysis	Semi-structured Interviews	10 male GPs, aged 35-53
Johnson, J. L., Oliffe, J. L., Kelly, M. T., Galdas, P. M., & Ogrodniczuk, J. S. (2012)	Sociology of Health and Illness	Discourse Analysis	Semi-structured interviews	38 men, diagnosed or self-diagnosed with depression
Levenson, R. L., & Acosta, J. K. (2001)	International Journal of Emergency Mental Health	Thematic Analysis	Clinical Case Studies	Police officers and support officers
Noone, J. H., & Stephens, C. (2008)	Sociology of Health and Illness	Discourse Analysis	In-depth Interviews	7 men, aged over 50
O'Brien, R., Hunt, K., & Hart, G. (2005)	Social Science & Medicine	Thematic Analysis	Focus Groups	55 men, aged 15 to 72
Sloan, C., Gough, B., & Conner, M. (2010)	Psychology & Health	Discourse Analysis	In-depth Interviews	10 'healthy' men

Author(s)	Journal / <i>Book</i>	Analytic approach	Method	Sample
Seymour-Smith, S., Wetherell, M., & Phoenix, A. (2002)	Journal of Health Psychology	Discourse Analysis	In-depth Interviews	9 doctors and nurses, aged 34-58
Timlin-Scalera, R. M., Ponterotto, J. G., Blumberg, F. C., & Jackson, M. A. (2003)	Journal of Counseling Psychology	Grounded Theory	Semi-structured Interviews	22 male high school students, 4 female adolescent counterparts, 4 male parents, and 5 high school staff members

As a means of synthesising and attempting to make sense of how these men sought help, I collated themes identified by other researchers and tentatively interpreted the findings of a range of studies. Some of these studies were focused on the topic of men's help-seeking and others incorporated experiences of help-seeking within a broader investigation.

It is important to acknowledge that the studies included in this review employed a number of different research methods and analytic approaches, thus representing considerable methodological diversity. The decision to include such a wide range of studies stemmed from the desire to produce an analysis that would be as rich and as useful as possible to professionals interested in men's help-seeking. This was facilitated by a pragmatic analytic approach that involved staying close to the interpretations provided by the researchers who conducted these studies, while also attempting to articulate my own critical analysis of individual studies and this 'bank' of contemporary help-seeking literature overall.

Professional help-seeking is not always necessary or appropriate, nor is it proposed as an unproblematic, universally positive experience, or a panacea for all psychological difficulties (Biddle, Donovan, Sharp, & Gunnell, 2007; E. Lee, 2010; Ridge, Emslie, & White, 2011). Nonetheless, given increasing evidence of the effectiveness of psychological therapy for a wide range of difficulties, it is reasonable to assume that more men could benefit from seeking help of this kind (Vogel, Wade, & Haake, 2006).

1.3 Perspectives on gender and masculinities

It is widely accepted that a great diversity exists within the category of 'men' (Hyde, 2005; Mahalik, 2008), and the concept of gender is seen to intersect with ethnicity, age, socio-economic status, sexuality and other factors. Masculinity and femininity can be viewed as dynamic concepts that are socially constructed and enacted in particular practices, such as the practice of health (Branney & White, 2008; Courtenay, 2000; Gough & Robertson, 2010). This way of conceptualising gender, health and help-seeking places significant emphasis on constructing knowledge that is localised and sensitive to its context.

At any given moment in history, culturally dominant constructions of masculinity are likely to influence the construction of health-related masculinities, including approaches to help-seeking (Noone & Stephens, 2008). As Connell and Messerschmidt (2005)

explain, standards or ideals of masculinity can be established by dominant groups who have greater access to power, and are viewed as a means of maintaining the status quo and of subordinating women and other men. The concept of hegemonic masculinity (Connell & Messerschmidt, 2005; Connell, 2005), although used in a number of different ways even within the same text (Gough & Robertson, 2010), is one of the most widely referenced in this area. Attempting to adhere to hegemonic masculine ideals has been associated with unhealthy practices including denial of weakness, attempts to maintain the appearance of being invulnerable and not seeking help (Courtenay, 2000).

1.4 Evidence of psychological distress in men

The question of how to encourage more people to access psychological help is relevant to both men and women, since it is suggested that as few as one in three people with a diagnosable mental health problem seek help (Andrews, Issakidis, & Carter, 2001; World Health Organization, 2002). See Addis & Mahalik (2003) for a summary of the evidence that men of different ages, nationalities, racial and ethnic backgrounds tend to be less likely to seek help than women. Research suggests that fewer men seeking professional help cannot be explained by men having fewer psychological difficulties than women (Addis, 2008; Kessler, Chiu, Demler, & Walters, 2005; Möller-Leimkühler, 2002; Wilkins, 2010). Almost three quarters of people who commit suicide are men (Baker et al., 2006). More than 90% of prison population is male and three quarters of all prisoners meet the diagnostic criteria for at least two mental health problems (Ministry of Justice, 2009; Social Exclusion Unit, 2004). Men in the lowest income groups are significantly more likely to meet the criteria for a common mental health problem (McManus, Meltzer, Brugha, Bebbington, & Jenkins, 2009; Ridge et al., 2011). Black men are more likely to be detained and treated under the Mental Health Act and African Caribbean men are more likely to be diagnosed with schizophrenia (Healthcare Commission, 2005; Mind, 2000). Gay men have higher rates of common mental disorders than heterosexual men, and a similar pattern was observed in the differences between lesbian and heterosexual women (King et al., 2003).

1.5 Brief overview of barriers to help-seeking literature

It is not possible to provide a comprehensive review of help-seeking research within the scope of this paper. Therefore, I focused on providing a brief review of the barriers to help-seeking studies informed by social learning theories due to their prominence in

terms of the number of studies they influenced, and because they provide a useful contrast to the recent research about how men can seek help.

Social learning theories, which posit that gender is learned through reinforcement, punishment and social roles, have acted as a foundation for many studies of help-seeking. The concept of gender role conflict suggests that individuals experience conflict when socialised gender roles have negative consequences for them or for others in their lives (O'Neil, Good, & Holmes, 1995). A review of more than 200 empirical studies using the Gender Role Conflict Scale found masculine gender roles were associated with psychological distress and dysfunctional relationships for men in many countries across the world (Blazina & Shen-Miller, 2011; O'Neil, 2008). Some of these studies conclude that men's reluctance to seek help may be a consequence of trying to live up to social prescriptions or rules about how men are supposed to think, feel and behave (Ricciardelli & Williams, 2011).

Much of this research has been based on asking convenience samples of (primarily white, middle-class, heterosexual) undergraduate students about their general attitudes to seeking help or how they might respond to hypothetical problems. Many of these studies have explored associations between static measures of masculinity, attitudes towards help-seeking and symptoms of psychological distress. These approaches struggle to explain why some men are willing to seek help for particular problems but not for others (Addis & Mahalik, 2003). Despite this noticeable limitation, this work has successfully drawn attention to the topic of men, masculinities and help-seeking and acted as the impetus for further research. Furthermore, it has highlighted the need for greater understanding of why, how, when and where specific groups of men seek help for problems they are facing.

1.6 Relevance to counselling psychology

Counselling psychology tends to position itself in opposition to dogmatic or overly simplistic ideas about people and their lives (Strawbridge & Woolfe, 2010). Historically, the topic of men's help-seeking has been of considerable interest to counselling psychology and a number of the papers identified in this review, particularly those related to barriers to seeking help and gender role conflict, come from this discipline. This review seeks to build on this history, in a way that may contribute to challenging stereotypes about men and masculinities. An endeavour that attempts to

compassionately shed light on the diversity of men's experiences and realities fits well with the values to which the profession aspires.

2. How men managed to seek help

During this review, I identified four themes about how men seek help within a new area of help-seeking research.

2.1 Having 'permission'

In certain circumstances, some men appear to be able to give themselves 'permission' to seek help for difficulties they are facing. This idea of 'permission' seems to suggest a feeling that they are entitled or justified in seeking help. There seemed to be a number of different reasons for, or sources of, this 'permission'.

For some men being confronted with certain painful life experiences seemed to act as the basis for this 'permission'. At what seem like extraordinarily difficult moments, either in men's private lives, or in their social worlds, it is possible that 'rules' about not seeking help cease to apply. The types of experiences deemed to provide this kind of 'permission' include being bereaved, living with a chronic illness or caring for a partner who is ill or has a disability (Davidson & Meadows, 2010; O'Brien et al., 2005). Additionally, it also seems to include painful personal confrontation with the consequences of inaction or not seeking help. For example, some urban African American men described how the deaths of their fathers from cancer, that went undiagnosed until at an advanced stage, acted as a prompt to ensure they sought help when they needed it (Griffith, Allen, & Gunter, 2011). These men used their father's birthdays as an annual prompt to take care of their own health and to be proactive in seeking help. Similarly, it is suggested that with traumatic events, such as natural disasters, military conflicts or terrorist attacks, it can become 'normal' to express emotions and seek support (Levenson & Acosta, 2001; Mahalik, 2008). However, it is reasonable to assume that there will be considerable variation in what individual men deem sufficient reason or justification to seek help, and also that this may vary within men over time.

In other cases, 'permission' to seek help seemed to be derived from internal, identity-related processes. It is suggested that some men feel they have earned the right to seek help by proving their masculine 'credentials' in other domains of life. This is informed by the concept of "masculine capital" (de Visser & McDonnell, 2013; Gough,

2013). For example, men can address what might be perceived as a shortcoming in one aspect of masculinity, related to their body, personality or behaviour (e.g. having a slight physique, not drinking alcohol or being thoughtful) by attempting to compensate or prove their masculinity in other areas (e.g. sporting prowess or achievement at work) (de Visser, 2009). Thus help-seeking, if seen as a traditionally non-masculine practice, can be accommodated if a man believes he has demonstrated sufficient masculinity or built up enough masculine 'credit' in other arenas.

However, this trade-off is not straightforward, since there seems to be considerable variation in how personal characteristics or behaviours are evaluated on a masculine-to-non-masculine spectrum (de Visser, Smith, & McDonnell, 2009). In addition, an individual's own evaluation of their masculine capital may be impacted by social factors. A study about help-seeking within the military found that the expression of emotional distress and seeking help was tolerated and supported by military peers, if the individual in distress had already established a reputation as an effective soldier (Green, Emslie, O'Neill, Hunt, & Walker, 2010). This support was not given automatically or seen as a right; it was conditional and had to be earned, thus bringing to mind the idea of masculine 'credit'.

These findings provide an illustration of the complexity and diversity of help-seeking experiences. Within this analysis, the notion of 'permission' stemming from abnormal and distressing circumstances seems relatively unique because it suggests that, although originating in difficulty, the act of seeking help was not seen as particularly problematic. It did not seem to require these men to engage in complex internal or social negotiations. However, 'permission' based on "masculine capital" may involve negotiating complex psychological and social evaluations about the masculine credentials of certain individuals and behaviours. The suggestion that help-seeking often involves the negotiation of complex processes is supported by the three other themes in this review.

2.2 Striving for a 'manly' expression of distress and help-seeking

Several studies have explored how men and women experience and express emotional distress (Brownhill, Wilhelm, Barclay, & Schmied, 2005; Clarke & van Amerom, 2008; Danielsson & Johansson, 2005). While there appear to be considerable commonalities in men and women's experience of emotional difficulties, such as depression, there seem to be important differences in how this distress is communicated to others. This

work has contributed to the development of concepts such as “masked depression” or “hidden depression” in men, suggesting that antisocial or risk-taking behaviour, anger, anxiety and relational problems can sometimes be seen as attempts to communicate emotional distress (Addis, 2008; Brownhill et al., 2005; Chuick et al., 2009). These ways of communicating may be influenced by attempts to locate culturally acceptable ways for men to express distress.

In analysing how some men sought help, it is possible to see signs of these attempts to communicate in a ‘manly’ way. This can include explaining that help-seeking was delayed or resisted for a long time. Numerous studies have discussed how men only sought help only when their difficulties became very serious or reached a crisis point (Biddle et al., 2007; Davidson & Meadows, 2010; Johnson, Oliffe, Kelly, Galdas, & Ogradniczuk, 2012; Timlin-Scalera, Ponterotto, Blumberg, & Jackson, 2003). Perhaps this can be understood as an attempt to demonstrate stoicism, and to avoid being judged as ‘weak’, or a hypochondriac. It may also be understood as a way of demonstrating that, with all other avenues exhausted, they had no option other than seeking help.

Some men cite encouragement or pressure from significant others, often female partners, as the reason for presenting at health services (Hale, Grogan, & Willott, 2010; Seymour-Smith, Wetherell, & Phoenix, 2002; Timlin-Scalera et al., 2003). This theme was so prevalent in one study, that it was incorporated into the title of the journal article: “my wife ordered me to come” (Seymour-Smith et al., 2002). In doing so, it seems that these men are experiencing difficulties accepting or acknowledging responsibility for seeking help. This seems potentially disempowering for all involved. It also raises the issue of how men without intimate relationships may be further isolated or disadvantaged (Davidson & Meadows, 2010). However, this is a complex issue and it would be wrong to suggest that men seeking help in a solitary fashion is preferable to those who seem to rely on, or implicate, others in their help-seeking. Several studies have highlighted how significant others can provide important encouragement and practical support for men to seek help (Cusack, Deane, Wilson, & Ciarrochi, 2004). For example, such support was seen as vital in enabling access to specialist services for young people experiencing a first episode of psychosis (O’Callaghan et al., 2010).

Searching for a ‘manly’ way to seek help seems to suggest that help seeking required the negotiation of discomfort or conflict for these men. It brings to mind the idea that

help-seeking must be justified, perhaps because it is not acceptable to the individual, to others or perhaps to hegemonic masculine ideals of being invulnerable or self-sufficient.

Research has shed light on factors that may contribute to the apparent anxiety about seeking help. Men may be appropriately concerned about being patronised, judged or criticised by healthcare professionals and other social 'experts' (Hale, Grogan, & Willott, 2007). Seymour-Smith et al. (2002) found evidence that GPs and primary care nurses can hold confusing and contradictory ways of making sense of why male patients seek help. While criticised for being indifferent or irresponsible about their health, male patients were also respected for being stoical and only seeking help for serious problems. In addition, Hale et al. (2010) found that GPs had ambivalent attitudes towards some male patients, and viewed men who consult regularly as less 'manly' than others. Analysis of the responses to help-seeking letters in *Men's Health* and *For Him Magazine (FHM)* magazines found that 'experts' responding to letters sometimes humiliated or belittled men who were judged to have failed to seek help in a sufficiently 'manly' way (Anstiss & Lyons, 2013).

Although not setting out to focus on barriers to help-seeking, this review highlights how some men's journeys to seeking help involved overcoming internal conflicts and potentially judgmental and confused interactions with care providers. Locating 'manly' ways to communicate their distress and ask for help may have involved considerable effort for these men and may, in part, been motivated by a desire to reduce the likelihood of having their masculine status further questioned or undermined by others.

2.3 Reframing help-seeking

A number of studies have shown how some men have been able to reframe help-seeking as a means of restoring or protecting valued aspects of masculinities and feelings of control. In this case, the negotiation was focused on how the act of help-seeking was conceptualised and framed.

People can use language and ways of talking to construct or position themselves, their actions and other people (Noone & Stephens, 2008). Several studies from around the world have shown how men can create subject positions that accommodate, and sometimes even value, help-seeking. Noone & Stephens (2008) conducted a study of older men in rural New Zealand. They found that these men drew on "the legitimate

user" of health services position, to describe themselves and other men who use services willingly and wisely and relatively frequently seek help. Simultaneously, this involved positioning women as frequent but trivial users of health services. In contrast to much attitudinal research in this area that suggests men believe help-seeking is a sign of weakness, this study highlighted how this new subject position was also used to reposition men who do not seek help as weak, naïve or ignorant. This seems consistent with the findings of a study among men from higher socio-economic backgrounds in the UK who symbolised a conflict between two aspects of masculinity as "Neanderthal Man versus Action Man" (Farrimond, 2012). "Action Man" seems to share much in common with Noone & Stephen's (2008) "legitimate user" position, in that it emphasises qualities such as control, responsibility, agency and rationality. Some men describe help-seeking as a means of actively "doing" something in response to depression, rather than it being about passively receiving or submitting to treatment (Johnson et al., 2012). Thus, in this case help-seeking seems to be conceptualised as a means of achieving, maintaining or restoring qualities that are seen as consistent with masculine ideals.

Help-seeking can also be re-framed as a means of protecting valued aspects of masculine identities and roles (Emslie, Ridge, Ziebland, & Hunt, 2006; Griffith et al., 2011). For some men, preserving valued social roles, such occupation, was presented as a primary reason for seeking help (Farrimond, 2012; Griffith et al., 2011). O'Brien et al. (2005) brought this idea to life by highlighting how a fire-fighter justified help-seeking as a means of preserving this valued masculine role, its associated identity and social status. This can also extend to social roles related to being a partner, parent, grandparent or family member (Davidson & Meadows, 2010). Similarly, Kim, Atkinson & Unemoto (2001) suggested the value placed on academic achievement within some Asian cultures means that help-seeking was experienced as less problematic when focused on protecting this domain. Other men justified help-seeking on the basis that it related to protecting or restoring aspects of sexual functioning and matters related to the male body (Calasanti, Pietilä, Ojala, & King, 2013; O'Brien et al., 2005; Sloan, Gough, & Conner, 2010).

These approaches illustrate how health can become seen as a source of social achievement and a means of demonstrating superiority over others (Farrimond, 2012). The re-framing of help-seeking to fit more comfortably with normative ideals of masculinity, including being in control, courageous and being a problem-solver, seem

to have influenced the development of male-focused initiatives, services and campaigns, such as “Men’s MOT” health check-ups or “Well-man clinics” (Galdas, 2013; Linnell & James, 2010). They illustrate an important dilemma about the extent to which practitioners choose to tolerate and engage with these discourses as a means to facilitate help-seeking or whether they risk colluding with or reinforcing oppressive social ideas (this topic is explored further in section 3.3).

2.4 Drawing upon experiences of ‘otherness’

The final theme relates to circumstances in which men sought help by seeming to align themselves with alternative masculinities. Some men drew on involuntary past experiences of ‘otherness’ in their help-seeking processes. For example, being diagnosed with depression or cancer can result in some men feeling set apart from masculine norms of invulnerability or control over body and mind. This may prompt reflection on notions of masculinity and what it means to them to be a man (O’Brien et al., 2005). Subsequently, some men report aligning themselves with alternative, potentially healthier, masculinities within which help-seeking can be reasonably accommodated.

Studies that have included diverse samples of men have made valuable contributions to these understandings. For example, in a study of recovery from depression, Emslie et al. (2006) interviewed 16 men, three of whom were from ethnic minority backgrounds and five self-identified as gay. During recovery, most participants tried to reconstruct their sense of masculinity in line with hegemonic ideals of control and independence. However, some gay men and men from ethnic minority backgrounds seemed to draw on their experience of ‘otherness’ in order to resist what they saw as unhealthy or restrictive ideals in their recovery, and found a space that seemed to sit outside of hegemonic discourses. This seemed to involve appreciating their difference from others and valuing qualities such as sensitivity and creativity. Similarly, a study from Sweden, found that men from lower socio-economic backgrounds were more open about discussing ‘weakness’ and contemplating change in their lives than men from higher socio-economic backgrounds (Danielsson & Johansson, 2005). Furthermore, the ageing process and its multiple transitions can represent a form of ‘otherness’ that can also be used by some men to create opportunities for the construction of alternative masculinities that incorporate help-seeking more easily (Kaye, Crittenden, & Charland, 2008).

It is also possible that seeking help becomes a form of 'otherness'. Several studies suggest that past help-seeking behaviour, in particular previous positive experiences of seeking and receiving help, are strong predictors of future help-seeking (Biddle et al., 2007; Timlin-Scalera et al., 2003).

The men who contributed to these studies seem to suggest that they were making active choices to align themselves with masculinities that were more focused on health and wellbeing and on taking care of themselves. However, it also feels important to avoid trivialising or glossing over the fact that they reached this position after what may have been painful experiences of feeling like 'the other' and of being marginalised, discriminated against or oppressed. Within these alternative masculinities, some men drew upon rarely-heard discourses. For example, Johnson et al. (2012) identified how help-seeking could be explained as motivated by a desire to feel listened to, understood, validated by and genuinely connected to another person. However, in other cases, these alternative masculinities seemed to involve men positioning themselves as superior to those who adopt more stereotypically male practices, including a reluctance to seek help for distress. Perhaps this involves the unconscious repetition of a pattern of dismissing, belittling or subjugating others, to which they themselves have been subject. It may also be suggestive of the persistence of hegemonic norms, such as autonomy, self-reliance and rationality, even within individuals who have managed to resist social pressures to be a certain kind of man in other domains of their life (Sloan et al., 2010).

2.5 Summary

This paper presented four themes located within published research studies about how men sought help for psychological difficulties or physical health problems. These four themes may represent distinctive approaches to solving the problem of how to seek help, but equally it is possible that they are interlinked and that some of these men have employed multiple approaches, even within a single help-seeking interaction. This review provides an illustration of the existence of multiple masculinities that are dynamically constructed and re-constructed. The actions of these men highlight how masculinity is not an all or nothing concept.

It seems that factors which influence men's help-seeking can stem from their subjective experiences, the attitudes of and interactions with service providers, and wider social and cultural expectations. These examples serve as an important reminder

of how men can, and do, manage to negotiate complex processes in order to seek help. Their approaches to managing this task involved locating 'permission' for seeking help, communicating their distress in a way that may be judged as 'manly', re-framing help-seeking so that it fits with masculine ideals and drawing on experiences of 'otherness' and alternative constructions of masculinities.

3. Discussion and implications

3.1 Limitations and contributions of this review

A number of factors, including the keywords used to guide the search, the exclusion of unpublished work, and the focus on English language papers published between 2000 and 2014, may have limited the range and relevance of this review. Additionally, the inclusion of studies about seeking help for physical health conditions could be seen as problematic. Given the importance of local contexts, it could be argued that including physical health difficulties undermines the clarity of this endeavour. However, this decision was justified on the basis of the considerable overlap between physical and mental health.

These limitations notwithstanding, this review demonstrates that the field of help-seeking research remains vibrant. The new 'generation' of studies analysed for this review emphasises that seeking help is not a hopeless situation where men, as a homogenous group, can be reasonably perceived as passive or hopeless victims. These studies provided a nuanced understanding of how some men managed the processes of seeking help, the diversity of approaches employed and the sophisticated use of resources this involved. Research has also highlighted how complex these processes can be and how it can involve navigating through competing or paradoxical social discourses, such as those that suggest 'real men' don't care about their health but that good moral citizens take responsibility for their own wellbeing (Robertson, 2006, 2007). This review provides encouragement for practitioners and those designing and commissioning psychology services and trainings to reflect upon the ways in which they are engaging with concepts such as gender and the constructions of masculinities and femininities, within considerations related to multicultural sensitivity (McCarthy & Holliday, 2004).

3.2 Implications for further research

Becoming immersed in this help-seeking research has been a stimulating experience. Perhaps above all, these studies demonstrate the value of studying the topic of help-

seeking using real life examples rather than hypothetical situations. Attempting to understand the experiences of men who actually need to seek help has contributed to a greater depth and richness of understanding.

It is possible to see several areas which research could usefully explore. Firstly, much of this research has focused on depression and a small number of studies on psychosis (Murphy, Shevlin, Houston, & Adamson, 2012). Given the importance of being context-specific when studying help-seeking, it would be useful to conduct research among men who are experiencing other issues, including, for example, anxiety, trauma and eating disorders (Clement et al., 2014; Drummond, 2010). Much of my clinical experience has been with populations experiencing severe and enduring mental health problems. It would be interesting to explore how people who experience profound interpersonal difficulties, such as diagnosed with personality disorders, contemplate and navigate help-seeking for specific difficulties (Strike, Rhodes, Bergmans, & Links, 2006). Given that issues related to absent, unresponsive or abusive care are often at the heart of these individual's difficulties, seeking help feels like an important and worthwhile topic for further exploration.

In addition, there seems to be a paradox between examples of how flexibly and skilfully men can construct and employ different masculinities, yet at the same time the persistence and prevalence of certain hegemonic ideals. Longitudinal qualitative research, taking into account individual life histories, could make a useful contribution to this topic. It could potentially shed some light on how, when, where and why individual men might choose to align themselves with alternative masculinities and how this changes over time. Perhaps it could also explore and create greater understanding of the circumstances in which these men choose to adhere to more hegemonic masculine ideals.

Furthermore, it is noticeable that recent research in this area has made considerable strides towards creating greater diversity, for example by including often marginalised groups such as refugees (DeAnstiss & Ziaian, 2010). These developments also include more nuanced ways of exploring help-seeking, including examining the intersection of ethnicity and gender (Brown et al., 2011; Dornelas, Fischer, & DiLorenzo, 2014; Galdas, Cheater, & Marshall, 2007; Shim, Compton, Rust, Druss, & Kaslow, 2009) and challenging myths about homogeneity within ethnic minority groups such as black Americans (Taylor, Woodward, Chatters, Mattis, & Jackson, 2011; Woodward, Taylor,

& Chatters, 2011; Woodward, 2011). However, certain groups remain noticeable in their absence from many of these studies, including disabled men, gay and bisexual men (de Visser et al., 2009). Efforts should be taken to understand more about the help-seeking experiences of to-date often excluded groups of men. Such endeavours are necessary in order to avoid contributing to the ongoing subordination or invisibility of these men and their needs (Seymour-Smith et al., 2002). But it must also be conducted in a way that attempts to explore the diversity that exists within these groups. Furthermore, it would be useful to include men and women in future studies, as a way to try to avoid essentialist conclusions, and to gain greater understanding of the dynamic ways in which men and women adhere to or resist social constructions of gender (Ridge et al., 2011).

Finally, it is noticeable how little of the reflexive process was communicated by researchers in most of these published works. The apparent centrality of reflexivity to qualitative research did not often translate into its inclusion in published articles about these studies. The reader is left wondering what the researchers felt about the ways in which their subjectivities were implicated in the research and their thoughts on how this may have influenced what was found (Willig, 2008). This feels like a baffling omission. For example, some published articles about studies involving the use of film clips to stimulate discussion do not include reflection on why these particular items were chosen, what alternatives were considered, what impact they might have had and on the meanings these items had for researchers (Noone & Stephens, 2008). Surely, this leaves researchers open to accusations of paying little more than lip-service to the topic of reflexivity. Perhaps it is suggestive of an ongoing discomfort, and reluctance to grapple, with researcher subjectivities (Gough & Madill, 2012). It would be beneficial and enriching for future researchers to incorporate more about their reflexive process; how they thought and felt about their own subjectivities and to make their presence in the studies more visible.

3.3 Implications for clinical practice

Many researchers, whose work has been covered in this review, have made recommendations for how to encourage help-seeking. Their proposals seem to highlight a dilemma between using aspects of hegemonic masculine ideals to engage men but being mindful of the potential to reinforce unhelpful and oppressive stereotypes (Robertson, 2006). This dilemma seems to translate into a spectrum of recommendations. At one end, some researchers advocate the flexible tailoring of

psychological approaches in order to make them more palatable to social prescriptions of masculinities. For example, this might involve engaging in task-orientated, problem-solving or psychoeducational approaches, such as those sometimes used in Cognitive Behavioural Therapy, that might be quite rational and may reduce the risk of men feeling out of control (Johnson et al., 2012; Kaye et al., 2008; Millar, 2003; Seymour-Smith, 2010; White, 2009). Gough (2010) highlighted the need to tread carefully when tailoring approaches to these constructions of masculinity, and how it can be easy to create incoherent or contradictory messages that may undermine programmes or campaigns. At the other end of the spectrum, some researchers are resistant to amending psychological approaches to suit these constructions of masculinity. They discourage others from making concessions to potentially damaging ways of being for these men and those in their lives. They warn of the dangers of colluding with or bolstering stereotypes about how men and women are.

Personally speaking, I do not adhere universally to a single position on this spectrum and see value in adopting a flexible approach. In my work with some men, perhaps I have inadvertently contributed to unhelpful and simplistic discourses about the ways men and women are. However, I can see considerable value in being pragmatic in terms of promoting help-seeking for psychological difficulties that speaks in a language that might appeal to a range of different men. Without some flexibility, I fear that these men are being expected to change *before* coming to therapy, not change *with the support of* therapy, and this may exclude men who are grappling with more traditional ideas of masculinity. Robertson (2007) suggested the possibility of adapting approaches in order to engage men in the tricky early therapeutic stages. This may create opportunities for the subsequent exploration of constructions of masculinities, and their impact, within a supportive therapeutic relationship.

Therapy can present a unique space for critical reflection on the social constructions of gender and the consequences for the psychological wellbeing of individuals and those in their lives. This activity can help men and women to reflect on the choices they may have in how they construct their masculinities and femininities (Berger, Addis, Green, Mackowiak, & Goldberg, 2013; Kilmartin, 2005; C. Lee & Owens, 2002; Mind, 2009). However, that is not to suggest that constructing alternative masculinities is a simple task. As Courtenay (2000) explains, it involves a subtle negotiation and the failure to adhere to ideals of masculinity can be accompanied by significant social and interpersonal risks for the individual. In my own practice, I have worked with a number

of men where simply acknowledging and exploring influential, but often taken-for-granted, ideas about masculinities became a powerful part of therapeutic work. It also seemed helpful to normalise these conflicts in light of the paradoxical messages they are likely to be given in this society. A number of researchers have presented different ideas about how to work with men on this important topic and may be useful resources for interested practitioners (Connell, 2005; Good & Robertson, 2010; Kiselica & Englar-Carlson, 2010; Kiselica, 2011; Mahalik, Levi-Minzi, & Walker, 2007; Tremblay & L'Heureux, 2011).

However, helping clients to reflect on gender requires professionals to explore their own attitudes, stereotypes and personal experiences of gender and constructions of masculinities and femininities (O'Neil, 2008). Several studies have suggested that training institutes, including those in the field of counselling psychology, seem reluctant to incorporate external, material factors, including gender, into training (Ciclitira & Foster, 2012; Mellinger & Liu, 2006). It is difficult to see how practitioners can be expected to work in a reflective way with topics such as gender if there is not space and support during their clinical training. It seems to me that many important strides have been taken to develop this field in recent years, but much important work remains to be done.

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Part 2: Doctoral Research

Life after testicular cancer treatment:
Negotiating intrapersonal and
interpersonal disruptions

Abstract

Testicular cancer is the most common form of cancer affecting young adult men, and the number of men in England diagnosed annually has more than doubled since the 1970s. Much of the existing research about testicular cancer has focused on diagnosis, treatment, and post-treatment sexual functioning and fertility. This study therefore addresses the lack of research about the lives of men after completing treatment.

This qualitative study involved face-to-face semi-structured interviews with seven men, aged between 26 and 39 years, who completed treatment between one and seven years prior to taking part. It aimed to explore these men's post-treatment lived experiences, as well as their ways of managing life after treatment finished. The interviews were audio recorded and transcribed verbatim. The data were systematically coded and categorised according to the principles of constructivist grounded theory.

This study has facilitated a broad and nuanced understanding of life after testicular cancer treatment, including individual men's subjective experiences and meanings, the diversity of masculinities, influential social and relational components, and the potential impact of cultural constructions of cancer. The findings of this study challenge the suggestion that life after treatment for testicular cancer is unproblematic. These participants discussed how they experienced psychological inner turmoil, a painful confrontation with mortality at a young age, and were faced with significant disruptions to their relationships and masculine identity. Thus, life after treatment seemed to involve negotiating intrapersonal and interpersonal disruptions. Often, these men engaged in solitary ways of managing their lives, some of which seemed to intensify their difficulties.

These participants' experiences highlight the complexity of life after testicular cancer treatment, by illustrating how psychological growth is possible, but often occurs alongside personal losses, changes and vulnerabilities. This suggests that some men's lives can feel simultaneously enhanced and challenged after their treatment for testicular cancer.

Chapter 1: Introduction

1.1 Overview

This chapter contextualises, and communicates the rationale for this study about life after testicular cancer treatment. It begins with an overview of theories about men's health and masculinities, including the social constructionist approaches that influenced my thinking. This is followed by a review of research literature about cancer, including its psychological impacts and cultural constructions. The main part of the chapter is dedicated to exploring the literature about testicular cancer and life after treatment. The rationale for this particular study, its relevance to counselling psychology and my personal relationship to the topic are explored in the final part of the chapter.

1.2 Theories about men, masculinities and health

1.2.1 Men's health

Psychologists are urged to consider social and cultural factors when exploring men's health (Courtenay, 2002; C. Lee & Owens, 2002). Thinking about health, gender and masculinities is a challenging endeavour given that there are few commonly agreed upon definitions of these concepts. Confusingly, sometimes terms such as sex, gender and masculinity are used interchangeably (Buchbinder, 2013). For the purposes of this study, the term 'sex' is taken to mean biological differences between men and women (Courtenay, 2002). 'Gender' is defined as a dynamic, socially-constructed concept that is shaped by the meanings, assumptions and values about men and women in a particular culture at a given time (Buchbinder, 2013; Courtenay, 2000b).

The World Health Organization (1948) defines health as a state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity. Researchers have critiqued this definition, arguing that it should take into account the ability of men and women to adapt to and self-manage illness, given the existence, in many countries, of ageing populations experiencing increasing rates of chronic illness (Huber et al., 2011). Researchers in the social sciences also highlight how health holds highly personal meanings for individuals, and that these meanings can change according to life experiences (Luck, Bamford, & Williamson, 2000).

While thinking about health from a gender perspective is not a new idea, historically most of this work has focused on women's health (Courtenay & Keeling, 2000;

Courtenay, 2002). Drawing inspiration from the field of health inequalities, and impetus from the Equality Act (2006), the topic of men's health has received renewed focus in recent decades. Numerous studies have generated worrying data about men's health (Wilkins, 2009), and Robertson (2007) categorises these concerns in terms of mortality, morbidity and health behaviours. Consistent with patterns in mortality data from most other developed countries, men in England and Wales die approximately four years younger than women (Wilkins, 2009). Throughout their lives, men are more likely to experience most forms of injury or diagnosable health problems, to develop illnesses at a younger age, and often die more quickly from these illnesses. Furthermore, a greater proportion of men than women engage in health behaviours that are linked to ill health, illness and premature death (Wilkins, 2009).

Data of this kind is frequently used to support the notion of a 'crisis' in men's health (Connell, 2001; Luck et al., 2000; Whitehead & Barrett, 2001). Critics of this discourse cite how there is considerable variation in health and illness between men, as revealed within data about mortality, morbidity and health behaviours. To provide an extreme and alarming example, average life expectancy for men in the most socio-economically deprived areas of Glasgow is believed to be 28 years less than men who live a relatively short distance away in the more affluent parts of the same metropolitan area, and is eight years less than the average for all men in India (CDSH, 2008; Savoye, 2009). Furthermore, men who live in more economically and socially deprived conditions are more likely to engage in behaviours such as smoking and consuming alcohol, getting limited physical exercise and having an unhealthy diet (White et al., 2011).

Ethnicity has also been associated with different life expectancies with, for example, Maori men in New Zealand being expected to live approximately eight years less than non-Maori men (Jones & McCreanor, 2009). There is also considerable variation within morbidity data, with cardiovascular disease implicated in 61% of male deaths in Bulgaria compared to 25% in France.

Researchers are urged to be cautious about drawing definitive or simplistic conclusions about data based on gender or socio-economic group differences (Gough, 2006). However, there appears to be widespread agreement for the idea that, although there are no easy solutions, much of this morbidity and premature mortality could be prevented (Barton, 2000; Courtenay, 2002, 2003; White et al., 2011; Wilkins, 2009).

This conclusion highlights the need for further exploration and understanding of men's health, and is one of the premises for this study. A number of different approaches to exploring potential reasons for men's health difficulties will now be discussed.

1.2.2 Sociobiological factors

In the past, it was largely taken for granted that men and women were fundamentally different, for example, by virtue of having different reproductive organs, but this belief is no longer credible within the social sciences (Courtenay, 2002). Many researchers now work on the premise that men and women are more similar than different (Hyde, 2005). However, some researchers suggest that men's biology, genes and hormones leave them predisposed to illness and prone to act in ways that compound their difficulties (Robertson, 2007). They propose that men may inherit a biological tendency towards being fragile, or vulnerable to certain health problems, which starts from the point of conception and persists throughout their lives (Kraemer, 2000; Stillion, 1995).

There are ongoing investigations into hypotheses about the role of the X chromosome and sex hormones in cancer in men (Phillips, 2013). However, sociobiological approaches have been criticised for creating a sense of impossibility for change and for failing to adequately explain variation within men as a group (Robertson, 2007). That is not to deny the possibility that biological factors may play a role, but to accept that this role is likely to be complex. For example, research into brain functioning suggests the possibility that women may have greater capacity to move between the two sides of the brain more quickly, which may be linked to greater ability to identify and express emotions (Courtenay, 2002). However, given that it is now widely believed that experiences can shape brain development, we cannot confidently conclude that this is a result of a fundamental, permanent and hard-wired gender difference. Therefore, explanations of men's health that rely solely on genes or hormones tend not to be widely supported today (Courtenay & Keeling, 2000; White et al., 2011).

1.2.3 Role theory

Role theory emerged as an alternative to biological explanations for male and female behaviour and suggests that social expectations of gender roles are internalised by individuals. The extent to which behaviours, such as those related to health, are deemed to be compatible with stereotypical male and female roles, can have a significant impact on whether men and women engage in these behaviours (Waldron, 1995). Role theory suggests that male roles are often detrimental to health, both

because they encourage stressful and unhealthy lifestyles and because they create strain and stress for men who fail to live up to these expectations (Robertson, 2007). Brannon (1976) identified four pivotal components of male gender roles, including differentiation from women ("no sissy stuff"), superiority to others ("the big wheel"), independence ("the sturdy oak") and being more powerful than others ("give 'em hell"). Needing to hide any sense of vulnerability or fragility is associated with traditional male roles and this can lead to men denying their needs and avoiding seeking help (Courtenay, 2000b; Gough, 2013). For example, researchers suggest that the influence of gender roles can result in men with cancer being reluctant to reveal their emotions and can leave them struggling to cope with feelings of dependence and loss of control (Liss-Levinson, 1982). However, it seems reasonable to assume that not all men will be troubled to the same extent by these difficulties and that women may also be troubled by cancer-related feelings of loss of control.

As a means of explaining men's health, role theorists are criticised for suggesting people are born in a state akin to a blank slate (Robertson, 2007); for exaggerating the extent to which social life is determined by fixed roles (Annandale & Hunt, 2000); (Robertson, 2007); for assuming a singular male and female personality (Connell, 2001); for ignoring agency and individual personality characteristics (Connell, 2005; Watson, 2000); and for neglecting historical factors and power dynamics. Several researchers have warned about the dangers of drawing essentialist conclusions about "how men are" as a result of role theories due to the blurring of the concepts of sex/gender and role/identity (Connell, 2001; Robertson, 2007). These perceived shortcomings in role theories paved the way for alternative ways of thinking about masculinities and their relationships to health.

1.2.4 Social constructionist approaches to gender, health and bodies

Masculinity is not a simple, coherent concept and there are many different attempted definitions (Connell, 2005; Moynihan, 1998). Social constructionists suggest gender can be understood as a way in which social life is organised and conducted, and they view masculinities and femininities as relating to what men and women 'do' rather than what they 'have' or 'are' (Connell, 2001; Moynihan, 1998; Whitehead & Barrett, 2001). In other words, masculinities can be understood as sets of social practices that are fluid, varied and flexible (Gough & Robertson, 2010). Furthermore, recognising that these practices of masculinity are intersected with ethnicity, socio-economic status, sexuality, age and other factors, social constructionists suggest the existence of

multiple masculinities. Analysis of cultural representations also supports the idea that there are many different ways masculinity can be performed or constructed (Peberdy, 2011).

The concept of hegemonic masculinity emphasises the relational nature of masculinities and incorporates ideas about struggles for power and privilege (Connell & Messerschmidt, 2005; Robertson, 2007). Informed by Antonio Gramsci's perspectives on class relations, it suggests a cultural tendency for a group to claim dominance over others. One form of masculinity will be idealised or valued more than others at any given moment in time. Connell (2001, pp. 38–39) explains that:

"Hegemonic masculinity can be defined as the configuration of gender practice which embodies the culturally accepted answer to the problem of the legitimacy of patriarchy, which guarantees (or is taken to guarantee) the dominant position of men and the subordination of women".

It is suggested that although few men will rigidly practice a hegemonic approach, many men will benefit from how it can create advantages for them and disadvantages for women and other groups of men. However, it is perpetually open to be challenged or contested. The theory of hegemonic masculinity has informed much research in this field but is not without its critics - see Seidler (2007) or Wetherall and Edley (1999). The 'doing' of health is understood as an arena for enacting or performing masculinities and femininities (Courtenay & Keeling, 2000; Robertson, 2007). Indeed, health is believed to be a particularly powerful and symbolic domain and the consequences of how men engage in these practices can be a matter of life and death (Courtenay, 2000b). The body is seen as central component of the practices of health-related masculinities (Stephens & Lorentzen, 2007). Dominant forms of masculinity are often accompanied, in the Western world at least, by an interpretation of the body, sexuality and emotion as primitive aspects that need to be controlled or tamed (Seidler, 2007). Historically, it was imagined that women *are* their bodies, whereas men *use* their bodies (Buchbinder, 2013). However, research suggests that men have complex relationships with their bodies, employ a number of different discourses or narratives about its subjective meaning and that their bodies serve both functional and discursive purposes (Robertson, 2007). Historically men have not been subjected to the same body image pressures as women but recently male bodies have come under more scrutiny, from men who take a greater interest in their physical appearance, and

within popular culture and the media (Drummond, 2010; C. Lee & Owens, 2002; Whitehead, 2002).

1.2.5 Health beliefs and behaviours

Another strand of men's health has focused on health beliefs and behaviours (Moynihan, 1998; O'Brien, 2006). This approach emphasises how men tend to believe that they are less vulnerable to various health problems, despite data stating the opposite, and that they are more likely to behave in ways that are actively damaging to their health (Banks, 2001; Courtenay, 2000a, 2002; S. Payne, 2004). A review of more than 30 factors associated with physical and psychological health suggested that men and boys' health-related beliefs, behaviours and interactions are significant factors that contribute to illness and premature death (Courtenay, 2003). It is suggested that these unhealthy beliefs and behaviours may be a way of demonstrating their masculinity (C. Lee & Owens, 2002; S. Payne, 2004). It is possible that, growing up, boys face greater pressure than girls to adhere to behaviours that are seen as in keeping with gender stereotypes (Courtenay, 2000c; Golombok & Fivush, 1994). This led Courtenay (2000c) to suggest that a man attempting to adhere to social prescriptions of health-related masculinity would be unconcerned about his health, see himself as invulnerable, place great value on being independent and separate, not ask others for help, take significant risks, have limited vocabulary with which to describe his embodied experiences and would reject any behaviours that could be interpreted as feminine.

While the evidence of many men engaging in unhealthy or harmful behaviours is compelling, there is a danger that this way of explaining men's health data can result in conclusions such as 'masculinity is bad for your health' (Gough, 2013; O'Brien, 2006). This could be misinterpreted as suggesting that masculinity is a fixed and uniform attribute that men 'inherit' by virtue of being male. Furthermore, it ignores the fact that masculinity is not inextricably linked to unhealthy behaviours, and can be the stated reason for adopting healthy behaviours (Sloan, Gough, & Conner, 2010).

This review highlights how complex and contested many of the concepts related to men's health can be. There is merit in Courtenay and Keeling's (2000, p. 245) assertion that:

"The answer to the question, "what causes problems in men's health?" will undoubtedly have genetic, neural, biological, social, cultural, generational and

environmental components. Mind and body are, after all, connected and men's lives are lived in relation, not in isolation."

Men's health is recognised as an under-researched area and the belief that more needs to be done to shed light on the complexity of the interactions between masculinities and health underpins this study. Additionally, much of this thinking has been done by academics, practitioners and researchers, and frequently men have not been widely consulted about their own health perceptions and experiences (O'Brien, 2006; Popay & Groves, 2000; Watson, 2000; Wilkins, 2009). Perhaps this tendency is a product of cultural 'truths' such as "men don't talk" or "men aren't interested in their health". However, in order to avoid reinforcing these stereotypes, there is a clear need for research that consults and involves men in discussions about their lives and their health.

1.3 Review of cancer literature

1.3.1 Cancer definition and prevalence

Cancer is the term used to describe a group of diseases affecting any part of the body, a common feature of which is the creation and expansion of abnormal cells which can produce tumours and spread to other organs (Ogden, 2000; World Health Organization, 2014). It is believed that cancer is caused when a single normal cell is transformed into a tumour cell through a multi-stage process that can result from the interaction of an individual's genes and physical, chemical and biological carcinogens (World Health Organization, 2014).

Already the leading cause of death worldwide, cancer is becoming increasingly prevalent. The Department of Health (2011) estimates that 1.8 million people in England are living with or beyond cancer and forecasts an increase to 3 million people by 2030. Annually in the UK, approximately 320,000 people are newly diagnosed with, and more than 150,000 people die from, cancer (Office for National Statistics, 2012). Lifetime risk of cancer is 35% for men and 25% for women (White, 2013). Men are at greater risk of being diagnosed with nearly all of the common cancers that occur in both sexes, excluding breast cancer, and have poorer survival outcomes than women for many cancers (Cancer Research UK, 2013b; White, 2009). However, it is worth reiterating that men are not a homogenous group and cancer data varies considerably by factors such as age and socio-economic status (Men's Health Forum, 2013). For example, cancer survival rates for non-White men in America are estimated to be

between 5% and 15% lower than for White men (Bloom, 2002; Greenlee, Hill-Harmon, Murray, & Thun, 2001).

It was only in the 1970s that five-year cancer survival rates reached 50% in the United States (Rowland, 2007) and so until recently cancer was justifiably seen as a death sentence (Bloom, 2002). Advances in the diagnosis and treatment of cancer mean more people are cured or can live for many years with this chronic health condition (Coleman et al., 2004). See Dolbeault, Szporn and Holland (1999) for a useful analysis of how perceptions of cancer have changed over time, with reference to advances in medical treatment, attitudes towards death and the role of psychiatry and psychology in society.

1.3.2 Psychological and relational impacts of cancer

Social constructionists explain that diseases or illnesses can be loaded with powerful cultural meanings (Conrad & Barker, 2010). They emphasise the distinction between a biological disease and a socially constructed illness, and believe that individuals are not merely passive recipients of disease, rather they tend to enact their illness and bestow meaning on it (Conrad & Barker, 2010).

The 'human side' of cancer, including the psychological, social and spiritual aspects for patients, families and professionals, was given scant consideration until relatively recently (Dolbeault et al., 1999). It is now taken as uncontroversial that cancer is more than simply a medical or biological problem (Jarrett et al., 2013; Little, Sayers, Paul, & Jordens, 2000). It is suggested that cancer can create or exacerbate psychological difficulties which can persist for many years and have profound impacts on people's lives (Adler & Page, 2007; Harrington, Hansen, Moskowitz, Todd, & Feuerstein, 2010). Even after cancer treatment is finished, people can struggle with a wide range of practical and physical impacts, including loss of energy, fatigue, pain, genitourinary problems, difficulties eating, sexual problems, sleep disruption, cognitive dysfunction and financial strain (Bloom, 2002; Foster, Amir, et al., 2009; E. Gilbert, Ussher, & Perz, 2013; Syme, Mona, & Cameron, 2013). They can feel less confident about and comfortable with their body, both its appearance and their ability to 'read' their body for signs of illness (Foltz, 1987; Snöbohm, Friedrichsen, & Heiwe, 2010).

In addition, some people seem to experience considerable social and relational difficulties, such as feeling abandoned or isolated after treatment finishes (Abbey,

1996; Scullion, Rudge, & Davies, 2010), facing disrupted family dynamics, positions and roles, and loss of valued social activities (Macmillan Cancer Support, 2006; McDaniel, Hepworth, & Doherty, 1992; Papadopoulos, 1995). Sometimes, people with cancer can feel constrained in how openly they can talk about their difficulties (Knott, Turnbull, Olver, & Winefield, 2012; Rowland, 2007) and they can feel blamed for their illness and criticised by others (Willig, 2009). These experiences highlight the need to think about the dynamic interactions between a person with cancer and their social worlds (Grunfeld, Drudge-Coates, Rixon, Eaton, & Cooper, 2013).

It is common for emotional difficulties to surface only after treatment finishes (Brodsky, 1995; Harvey, 2007; Macmillan Cancer Support, 2009), and they can be among the most challenging parts of people's experiences (Macmillan Cancer Support, 2006). They can leave individuals feeling stigmatised in two ways: first by cancer and then by emotional or mental health difficulties (Dolbeault et al., 1999). See Foster et al. (2009) for a useful meta-analysis of more than 1,500 primary research studies about the psychosocial wellbeing of people with a range of cancers. This review found what they believe is moderate to strong evidence of post-treatment emotional distress, depression, anxiety, fear of recurrence, cognitive and sexual functioning difficulties. Life after cancer treatment can involve profound uncertainty and existential questions related to loss and mortality (Harvey, 2007). Some people with cancer, and their family members, meet the diagnostic criteria for post-traumatic stress disorder (PTSD) (Alter et al., 1996; Dolbeault et al., 1999; Pelcovitz et al., 1996; M. Y. Smith, Redd, Peyser, & Vogl, 1999). It is even suggested that cancer patients may be twice as likely as the general population in the USA to commit suicide (Misono, Weiss, Fann, Redman, & Yueh, 2008).

Despite much exploration, research has struggled to shed light on why between 10% and 30% of people with cancer seem to experience persistent, long-term psychological difficulties (Armes et al., 2009; Foster, Wright, Hill, Hopkinson, & Roffe, 2009; Livneh & Antonak, 1997). Numerous studies have explored the associations between psychological coping styles, including "emotion-focused coping", "problem-focused coping", denial/avoidance or "benefit-finding", and measures of quality of life, adjustment to cancer, psychiatric disorders and health outcomes (Cho, Park, & Blank, 2013; Epping-Jordan et al., 1999; Pascoe & Edvardsson, 2013). Despite the apparent popularity of these studies, reviews suggest there is scant evidence of the link between these measures of coping and cancer outcomes (Petticrew, Bell, & Hunter, 2002).

These reviewers warn of the dangers of pressurising people with cancer into adopting particular ways of thinking, feeling or responding to cancer experiences. Qualitative studies have highlighted how living with cancer can involve dynamic, multidimensional transitions (Sarenmalm, Thorén-Jönsson, Gaston-Johansson, & Öhlén, 2009) and can involve challenging negotiations with masculinities and femininities (Cecil, McCaughan, & Parahoo, 2010; Wenger, 2013). This research suggests that much is lost when living with cancer is reduced to a measure of a simple psychological coping style.

Furthermore, it is reasonable to assume that if attempting to shed light on why psychological difficulties persist long-term for some people it would be useful to know more about these individual's pre-cancer lives. For example, studies of PTSD in people with cancer demonstrated that significant pre-cancer trauma histories increased the likelihood of meeting the criteria for this disorder after cancer treatment finished (Alter et al., 1996; Dolbeault et al., 1999; Pelcovitz et al., 1996; M. Y. Smith et al., 1999).

Although it has not been widely studied, researchers suggest that individuals can also experience some positive impacts on their life after cancer treatment (Bloom, 2002). This may be considered a form of post-traumatic growth, involving a deeper appreciation of life, relating to others in new ways and making life changes in line with revised values and priorities (Hoffman, 2013). Thus, although probably painful and troubling, experiencing emotional upheaval and disruptions related to identity, social roles and relationships, may also present opportunities for growth and development (E. Gilbert et al., 2013; Tallman, 2013).

NICE (2004) recommends that the psychological and social needs of people with cancer are continuously considered. Although there is an ongoing need for further research into the effectiveness of formal psychological interventions for cancer patients (Lepore & Coyne, 2006; Okamoto, Wright, & Foster, 2012), it is suggested that psychology can play an important role in helping with the emotional consequences of getting cancer and in living with, or beyond, a cancer diagnosis (Ogden, 2000). In particular, there has been a call for greater involvement of mental health professionals in the identification of needs, and the design and provision of support to people affected by cancer (Dolbeault et al., 1999).

1.3.3 Cancer in young adulthood

Given that testicular cancer is most commonly diagnosed during young adulthood, it seemed relevant to consider the existing, admittedly sparse, literature about the post-

treatment lives of young adults diagnosed with other cancers (Albritton, Barr, & Bleyer, 2009; Eiser, Penn, Katz, & Barr, 2009).

Researchers suggest that cultural associations linking youth with health can make getting cancer as a young adult feel particularly problematic, and it can be experienced as a disturbing break in a 'natural order' for the individual and significant others (Hilton, Emslie, Hunt, Chapple, & Ziebland, 2009). For some, it can involve a shattering of pre-cancer youthful feelings of invulnerability and naïvety (Miedema, Hamilton, & Easley, 2007). Young adults can struggle to make sense of conflicting emotions, including feeling afraid about the future, feeling angry at having to deal with such adult 'realities' at a young age, feeling guilty at having survived and feeling sad at being a 'burden' to their families (Cantrell & Conte, 2009). Researchers highlight how experiencing cancer at a time of major transitions can be particularly problematic (Levinson, 1978; Ofman, 1993; Rabin, Simpson, Morrow, & Pinto, 2011).

Research among young adults with cancer has drawn attention to a relational component of the difficulties sometimes experienced. Feelings of isolation and alienation seem to be common and this may be understandable given how unlikely it is that young adults will have direct experience of others their age with cancer (Branney, Witty, & Eardley, 2014). Sometimes significant others may struggle to find a middle-ground between being over-involved (Kameny & Bearison, 2002) or, at the other extreme, denying the illness and pretending nothing is wrong (Stewart, 2003). They can also feel frustrated and angry if pressurised by others into adopting a happy, grateful and positive mind-set. However, it is also suggested that relational strain may be created by conflicts in how young adults with cancer wish to be treated by others. For example, it is reported that sometimes they may crave opportunities to talk openly about cancer and other times desperately want to avoid being singled out as different (Cantrell & Conte, 2009). These different needs and instincts may be difficult for others to understand, interpret or predict and this can contribute to relational difficulties (Frank, 2002). These findings are reminiscent of Erik Erikson's (1959) suggestion that young adults can face a dilemma relating to searching for intimacy and loving relationships versus choosing isolation and separateness. Although social constructionists would question the existence of such an objective reality of young adulthood (Watson, 2000), this research has drawn attention to the significance of relational components of young adults' cancer experiences.

1.3.4 Cancer survivorship discourses

Discourses related to survivorship are arguably the most influential within cancer today. The term “survivor” was first used by an American doctor, Fitzhugh Mullan, writing about his personal experience of cancer (Mullan, 1985 as cited in Rowland (2007), p29). Today, it is common for most people with cancer to be called a survivor.

Inspirational stories of cancer survivorship abound. Frequently, cancer is portrayed as an opportunity, and in extreme cases, perhaps even a gift (Ehrenreich, 2009). It is proposed that for men, cancer presents the opportunity to demonstrate strength and character, and for women to demonstrate skilful emotional expression and self-transformation (Seale, 2002). It is likely that inspirational cancer stories are useful and encouraging for some. However, survivorship discourses seem to have become the dominant way of talking about cancer. These discourses, that resulted from a desire to empower people with cancer, may have become a source of pressure for people with this condition to engage in mandatory, perpetual positive thinking and to avoid talking about the ‘down sides’ of their experiences (Moynihan, 2002; Park, Zlateva, & Blank, 2009; Pertl, Quigley, & Hevey, 2014; Willig, 2009). Thus, the survivorship discourse may have inadvertently become a source of further distress for, or victim-blaming of, people who do not share this positivity or those who are not ‘winning the fight’ against recurrent or terminal cancers (Ehrenreich, 2009; Little et al., 2000). This is a worrying state of affairs given the range of practical, psychological and relational cancer-related difficulties suggested in the research literature. It also seems unfortunate, and ironic, given the volume of news coverage devoted to ‘bad’ news stories, that cancer should be often portrayed in such a one-dimensionally positive light.

The common metaphors associated with cancer relate to war/battles or sporting heroics, where willpower, bravery and courage are the required ingredients for victory over this disease and human fragility (Seale, 2001). This relies upon cancer being depicted as a largely preventable disease, caused by unfortunate and irresponsible individual lifestyle choices, which can be defeated or controlled (Seale, 2001, 2002). This is seen to locate the ‘problem’ within the individual, perhaps part of a larger discourse related to the individualisation of responsibility for health (Clarke, 2004; Crawshaw, 2009). It may be that this discourse represents an attempt to maintain a cultural denial of death and an illusion of control over our undeniable fate.

Despite its prevalence in the media, several studies have suggested that many people with cancer do not easily identify with the 'survivor' identity, choose to reject parts of it, or prefer to associate themselves with other identity labels (Kaiser, 2008; Khan, Harrison, Rose, Ward, & Evans, 2012). We may be beginning to witness a backlash against the one-dimensional depiction of diverse experiences of cancer, a perspective powerfully expressed by Barbara Ehrenreich (2009, pp. 43–44):

"Breast cancer, I can now report, did not make me prettier or stronger, more feminine or spiritual. What it gave me, if you want to call this a "gift", was a very personal, agonizing encounter with an ideological force in American culture that I had not been aware of before – one that encourages us to deny reality, submit cheerfully to misfortune, and blame only ourselves for our fate."

From a social constructionist perspective, these constructions and discourses can exert a significant influence over how people talk about their experiences of cancer in everyday interactions, including research interviews.

1.4 Review of testicular cancer literature

1.4.1 An overview of testicular cancer and its treatment

Testicles, oval-shaped organs located below the penis in the scrotum, are important parts of the male reproductive system. From the age of puberty, the testicles produce sperm which can fertilise female eggs. They also produce the hormone testosterone, which is responsible for sex drive, penile erections, a deepening of the voice and the growth of facial and bodily hair (Cancer Research UK, 2013a; Macmillan Cancer Support, 2010).

Approximately 95% of testicular cancers are classified as germ cell tumours and the remaining 5% are rare non-germ cell testicular cancers and conditions such as lymphoma (Bosl & Motzer, 1997; Orchid, 2013). Germ cell tumours are broadly categorised as seminomatous or non-seminomatous. The most common form of germ cell tumour is called a seminoma, which most commonly occurs between the ages of 25 and 45 (Orchid, 2013). Testicular cancers are further classified based on tumour size, the extent to which they have spread to lymph nodes, and whether there is associated metastasis, or secondary cancers (Cancer Research UK, 2013d). This is referred to as tumour staging.

The Office for National Statistics (2011) estimates that approximately 2,000 men in the UK are diagnosed with testicular cancer every year, making it the most common form of cancer affecting 20 to 34 year olds. Testicular cancer is increasing in prevalence in industrialised countries (Buetow, 1995; Garner, Turner, Ghadirian, & Krewski, 2005; Huyghe, Matsuda, & Thonneau, 2003), for example the number of men in England diagnosed annually has more than doubled since the 1970s (Office for National Statistics, 2005; Power et al., 2001; Robertson, 2007). There are many unknown factors about testicular cancer incidence, including why the condition is observed more frequently in White men than Asian or African-Caribbean men (Bosl & Motzer, 1997; Daniels Jr, Stutzman, & McLeod, 1981), in men from wealthier social groups (Macmillan Cancer Support, 2010) and why there is such significant geographic variation, even within northern European countries (Richiardi et al., 2004).

While the exact causes of testicular cancer are not known, several factors have been associated with an elevated risk, including having an undescended testicle in childhood (cryptorchidism), having a family history of testicular cancer, or the presence of abnormal cells in the testicle (carcinoma in situ) (Cancer Research UK, 2013a; Manecksha & Fitzpatrick, 2009; Shabbir & Morgan, 2004). Without being able to identify a definitive cause, the most effective means of limiting the condition is through early diagnosis and effective treatment (White et al., 2011). Treatment often includes the surgical removal of a testicle (orchidectomy/orchiectomy), chemotherapy or radiotherapy, and a period of monitoring or surveillance (Fosså, Travis, & Dahl, 2007; Macmillan Cancer Support, 2010). Currently, overall testicular cancer survival rates are estimated at more than 95% (Cancer Research UK, 2013c) and may be up to 99% for men identified with stage I disease (Oldenburg & Fosså, 2014). To put this in context, in the 1970s, ten-year survival rates were 68% (Cancer Research UK, 2013c). This medical achievement has resulted in some researchers calling it the most controllable human cancer (White et al., 2011).

As is common across most cancers, the necessary treatment can result in distressing impacts and side effects. Testicular cancer treatment can involve coming to terms with temporary infertility, reduced testosterone levels, fatigue, low mood, weight gain, reduced muscle mass, breast enlargement and loss of sex drive (Orchid, 2013). For most men, these changes are temporary and are expected to return to levels within a normal range in a matter of months or years. Treatment protocols are under continuous review, and men with stage I seminoma are increasingly offered treatment

by orchidectomy and surveillance, thus avoiding the impacts and risks associated with chemotherapy or radiotherapy (Albers et al., 2011; Horwich, Shipley, & Huddart, 2006).

1.4.2 Historical theories and cultural narratives about testicular cancer

Testicles and testicular cancer are rarely mentioned in psychological and cultural sources. A Google search reveals a number of websites listing up to 100 different names or terms for testicles, ranging from the precious "*family jewels*" to the trivial "*nuts and bolts*" (Clarke & Robinson, 1999). In common parlance, "*to have balls*" is a phrase used to describe displays of courage, strength, or fearlessness. In the early to mid-twentieth century in Britain, there was a popular song mocking Adolf Hitler because it suggested he had "*only got one ball*" (Wikipedia, 2014). This notion seems to remain within the public consciousness and was mentioned by two participants in this study.

Van Basten et al. (1996) explored cultural myths and fantasies about the testes. They found that in many cultures around the world, it was common practice to place a hand on the testicles or genitals when swearing an oath, an act depicted in Book of Genesis in the Bible. They identified that testicle size holds evolutionary associations with sexual potency and that anxieties about losing testicles can be found in ancient Chinese writings, dating back to 200BC. The first recorded mention of the condition we now know of as testicular cancer was by Saint Donat in 1696, and for some time it was interpreted as a sign of partial hermaphroditism, where the testicular tumour was believed to result from female germ cells misplaced into the testicle during foetal development (Damjanov & Wewer-Albrechtsen, 2013; Ewing, 1911). Given the psychoanalytic interest in psychosexual development linked to parts of the body, it is interesting to note that the testicles have been largely ignored in this context, with rare exceptions related to male transvestism or transgender considerations (Winship, 2009).

Aside from texts which focused on the medical components of testicular cancer, I could locate only a few books on the subject. Some focus primarily on the subjective experience of diagnosis, treatment and recovery (Jowett, 2009; Koehler, 2010); others are written by mothers whose sons have been affected or had died from testicular cancer (McWhirt, 2010; J. Payne, 2012); and perhaps the most well-known being written by the now infamous American cyclist Lance Armstrong (2001).

Through internet searches, I could locate only two mentions of testicular cancer within what could be considered mainstream or widely distributed films. The Australian 'rom-com' *Not Suitable for Children* (2012) depicts the story of happy-go-lucky character Jonah and his attempts to find a girl willing to get pregnant within a few week 'window' before he starts testicular cancer treatment and becomes infertile (he is unable to bank sperm for other reasons). Perhaps the most famous English-language film portrayal of testicular cancer is in the film *Fight Club* (1999). In this film, Edward Norton's character derives pleasure from attending cancer support groups under false pretences. At a testicular cancer support group he meets Bob Paulson, played by Meat Loaf. Bob is depicted as the epitome of diminished masculinity. Previously a champion body builder, Bob's body is now out of shape and he is described as having "bitch tits" due to having his testicles removed. Bob no longer spends his time in the stereotypically masculine domain of the gym, instead being relegated to the stereotypically feminised realm of the support group. In place of pumping iron, his activities now seem to centre on uncontained emotional outpourings. Potential compassion for Bob's current situation is mitigated by the fact that it is suggested he may be to blame for his illness, having been engaged in unhealthy behaviours, such as being a "juicer" who abused steroids.

There is also limited media coverage about testicular cancer (Clarke & Robinson, 1999). What coverage there is tends to communicate both fear about increasing prevalence and hope due to effective treatment and high survival rates. Frequently, it depicts the testes as the 'source' of masculinity, and suggests the most damaging impact of this cancer may relate to professional lives, income-potential, sex life and relationships (Clarke, 2004). The emotional or psychological impacts of testicular cancer are rarely mentioned or explored.

In some cases, testicular cancer is portrayed as a welcome opportunity for self-enhancement for men who are stereotypically portrayed as competitive, aggressive, and focused on money (Clarke & Robinson, 1999). Some articles suggested that men felt a need to reassert or demonstrate their masculinity after treatment finished, through physical activities, running marathons or walking long distances. Lance Armstrong's book represents a number of different narratives about cancer, including cancer as an all-powerful condition that changes everything, cancer as an opportunity and the cancer-survivor as a cherished identity. Armstrong (2001, p. 4) summed up his perspective on testicular cancer as follows:

"The truth is that cancer was the best thing that ever happened to me. I don't know why I got the illness, but it did wonders for me, and I wouldn't want to walk away from it. Why would I want to change, even for a day, the most important and shaping event in my life?"

Perhaps the most significant observation about testicular cancer is that there seems to be a powerful silence surrounding the topic. In addition, paradoxical narratives abound within discussions of testicular cancer. Testicles have been related to honour, virility, bravery, but also simultaneously the source of anxiety. From its earliest mentions, through to the song about Hitler and the depiction of Bob Paulson, testicular cancer or the loss of a testicle seem to be associated with shame and compromised masculinity. Simultaneously, the condition is depicted as threatening important domains of a man's life, i.e. his occupation and sex life, while also being portrayed as a gift to be cherished, one that offers the promise of personal growth and transformation. This seems to be consistent with other analysis which highlights how media content related to masculinities and health can be seen as a product and a producer of confused and paradoxical narratives (Anstiss & Lyons, 2013; Coyle & Morgan-Sykes, 1998; Gough, 2006).

1.4.3 Psychological impacts of testicular cancer

The experiences and impacts of being diagnosed with and treated for testicular cancer have been a popular focus for research. For example, studies have covered:

- Processes and experiences of help-seeking once symptoms are noticed (Chapple, Ziebland, & McPherson, 2004; Gascoigne, Mason, & Roberts, 1999; Gascoigne & Whitear, 1999; O. J. Mason & Strauss, 2004).
- Psychological responses to diagnosis (Skoogh, Steineck, Johansson, Wilderäng, & Stierner, 2013).
- Reasons for accepting or rejecting the offer of a prosthesis (Adshead, Khoubehi, Wood, & Rustin, 2001; Chapple & McPherson, 2004).
- The long-term impacts of different types of treatment on cognitive functioning (A. D. Pedersen et al., 2009), cardiovascular health (Huddart et al., 2003) or quality of life (Trask, Paterson, Fardig, & Smith, 2003).

The relatively young age at which most men with testicular cancer are diagnosed, and the high survival rates, have created an impetus for research that shed light on life after treatment finishes (Carpentier & Fortenberry, 2010). Overall, there seem to be

considerable paradoxes within the literature, with some studies suggesting that men experience numerous, sometimes long-term, problems. Other studies suggest that life after treatment is best described as a time of positivity, including greater enjoyment and appreciation of life. As the following analysis will demonstrate, many studies fall into one camp or the other, suggesting a quite black and white picture.

Sex and fertility after testicular cancer treatment

Much of the research about life after treatment has focused on topics related to sexual functioning, satisfaction and fertility. Carpentier and Fortenberry (2010) highlighted how some men experience significant sexual and body image disturbance as a result of treatment. A significant proportion of men treated for testicular cancer, perhaps between 30% and 50%, report a decrease in sexual functioning compared to their life pre-diagnosis (Aass, Grünfeld, Kaalhus, & Fosså, 1993; Arai, Kawakita, Okada, & Yoshida, 1997; Fosså et al., 2007; Rieker, Edbril, & Garnick, 1985).

Studies have revealed that some men express profound feelings of loss, uneasiness or shame about their post-treatment bodies and genitals (Skoogh et al., 2011). It seems that starting a new intimate relationship post-treatment can involve confronting considerable insecurities about their bodies and sexual functioning, which can negatively impact on sexual enjoyment (Bloom et al., 1993; Tuinman, Fleer, Sleijfer, Hoekstra, & Hoekstra-Weebers, 2005). Keeping in mind the cultural discourses about men *using* their bodies and being in control of them, perhaps these men feel that by experiencing these difficulties they are failing to live up to what is socially expected of men. It has been suggested that, in extreme cases, some men completely avoid sexual contact with others, due to how diminished they feel by the illness, its treatment and side effects (Caffo & Amichetti, 1999). Some studies suggest that the greatest disturbance to sexual functioning commonly occurs within the first two years post-treatment (Nazareth, Lewin, & King, 2001).

There seems to be a lack of information and support related to post-treatment sexual difficulties (Jonker-Pool et al., 2004). Family members may be reluctant to discuss sex life and fertility (Sandén & Hydén, 2002). Professionals, due to their own discomfort about openly discussing topics such as erections, ejaculation, impotence and prostheses, may adopt a passive stance and not bring up these topics directly (Moore, Higgins, & Sharek, 2013). It is possible that this lack of open discussion about these

issues could reinforce feelings of embarrassment or shame for men who experience distress and difficulties related to their post-treatment sex lives.

Research among men who experience erectile dysfunction long after treatment finishes suggests that it may be influenced by negative changes in body image, rather than being purely a physiological problem (Rossen, Pedersen, Zachariae, & Von Der Maase, 2012). Although not necessarily rated as less attractive by existing partners, there is evidence that some men feel less attractive, less happy with their bodies, and symptoms such as gynaecomastia (enlargement of breast tissue), can have a significant negative impact on how they feel about themselves and their masculinities (Branney, Witty, & Eardley, 2014; Carpentier & Fortenberry, 2010). It is suggested that a dynamic interaction between physiological, psychological and sexual spheres of life, including fatigue, weight loss or gain, anxiety, worries about prognosis, and low mood, can create a complex web that acts as a barrier to sexual desire or enjoyment (Arai et al., 1997; Van Basten et al., 1996).

However, data in this area is equivocal and sometimes contradictory. While some studies suggest that men may experience a significant decrease in fertility after treatment (Huyghe et al., 2004), other studies have found no evidence that testicular cancer has a negative impact on the likelihood of fathering children (Kim et al., 2010). Furthermore, other researchers have found limited evidence of an impact on sexual activity or satisfaction (Incrocci, Hop, Wijnmaalen, & Slob, 2002).

The volume of testicular cancer research studies focused on sex and fertility is noteworthy. Conducting the literature review for this study, although not directly searching for this topic, I was able to locate more than 30 such studies and reviews, making it the most commonly explored topic within the testicular cancer literature. This seems to mirror a pattern from the prostate and penile cancers (Wenger & Oliffe, 2013; Witty et al., 2013) where most of the existing psychosocial research literature seems to be primarily focused on sexual functioning. These endeavours are adding to our understanding of this aspect of men's lives after completing treatment. However, there is a danger that the dialogue about testicular cancer is restricted to considerations related to sex. This could become quite a limiting focus for research and risks suggesting that the impact of this condition is limited to focusing on the genitals and how they are used.

Relational components of testicular cancer

Several studies have focused on the relational components of life after testicular cancer treatment, a topic which overlaps with sexual functioning. There is considerable support for the idea that being in a committed intimate relationship during and after treatment may act as a protective factor against post-treatment difficulties or adjustments (Carpentier & Fortenberry, 2010). It may be that men going through these experiences without this potential source of support are more vulnerable to post-treatment difficulties (Sheppard & Wylie, 2001). It is suggested that testicular cancer can represent a 'make or break' situation in certain relationships, with some couples feeling more tightly bonded by sharing this experience (Gritz et al., 1989) and others being pushed to breaking point as existing relationship tensions become exacerbated or amplified (Carpentier & Fortenberry, 2010). Furthermore, research has found testicular cancer can contribute to young adult men feeling like "damaged goods", alienated from and different to other men (Carpentier, Fortenberry, Ott, Brames, & Einhorn, 2011).

A small number of studies have explored the impact of testicular cancer on the lives of partners and family members. Research suggests that significant others can feel isolated from the world around them and from their previous familial lives and roles (Sandén & Hydén, 2002). These partners and family members sometimes focus so much on caring for the man with testicular cancer that they neglect themselves and their own needs (Sandén & Söderhamn, 2009).

Testicular cancer and its relationship to masculinities

Given that health can be considered an important arena for the construction and enactment of masculinities, it is useful that some studies have explored the impact of testicular cancer on masculinities. It is suggested that testicular cancer can present considerable threats to masculine identities (Moore et al., 2013; Oliffe, 2005; Van Basten et al., 1996). Men can be faced with challenging situations, such as whether to have a prosthesis (Chapple & McPherson, 2004) or how to seek emotional and practical support (Seymour-Smith, 2010), that involve complex considerations related to masculine identities and disclosure of illness to others.

However, Gordon (1995) suggested that testicular cancer can actually strengthen a man's sense of masculinity, by providing an opportunity to demonstrate bravery and effective coping with the 'test' of cancer, or to re-evaluate the nature of masculinity

and ways of being a man. Other researchers have highlighted the possibility that testicular cancer can simultaneously involve feelings of masculinity-related loss alongside opportunities for liberation from rigid, stereotypical notions of what it means to be a man (Gurevich, Bishop, Bower, Malka, & Nyhof-Young, 2004).

It seems likely that our current understanding of masculinities post-treatment for testicular cancer is limited. Even talking about testicular cancer and how it impacts on masculinity is a problematic terrain, possibly because talking about masculinities involves enacting masculinities. For example, research among 'healthy' young men suggests they seemed to find it difficult to discuss testicular cancer, frequently trying to change the subject. When pushed to stay on topic, they seemed to associate the loss of a testicle with a loss of masculinity and feelings of inadequacy, and stated that they would be reluctant to speak to a friend about testicular cancer in a group situation (Daley, 2007; Singleton, 2008). Furthermore, despite many of their participants denying any detrimental impact of testicular cancer on their masculinities, both Gordon (1995) and Moynihan (1998) concluded that there was subtle evidence of greater discomfort and conflict related to masculinities, but that it could only be indirectly inferred.

Evidence of post-treatment psychological distress

There is a range of research that supports the notion that life post-treatment can be problematic. This can include experiencing higher levels of anxiety and depression (Andersen, Kiecolt-Glaser, & Glaser, 1994), perceptions of personality change (Gascoigne & Whitear, 1999), cancer-related fatigue (Orre et al., 2008), and reduced quality of life compared to the general population (Fosså, Dahl, & Loge, 2003).

There seems to be stronger empirical support for the idea that post-treatment anxiety is a problem for some men (Fosså et al., 2003), who live with deep uncertainties about how to manage life after treatment (Fosså et al., 2007; Martin, Turner, Bourne, & Batehup, 2013), and even 10 years later would meet diagnostic criteria for an anxiety disorder (Dahl et al., 2005). This may be related to fear of cancer recurrence (A. F. Pedersen, Rossen, Olesen, Maase, & Vedsted, 2012), which has been positively correlated with psychological distress and negatively correlated with self-esteem (Skaali et al., 2009).

Some objective factors, such as being in a relationship and being in paid employment are quite consistently associated with better psychosocial outcomes, such as lower scores on questionnaires measuring psychological distress (Fleer, Sleijfer, et al., 2006). However, a lot remains unknown about why some men, at certain points in time, seem to be struggling with life post-treatment compared to others. It is suggested that subjective perceptions of the impacts of testicular cancer and fears about future consequences can influence levels of stress and anxiety that men may feel (Fleer, Sleijfer, et al., 2006). Such work highlights how it can often be difficult to tell how a man may react to life after treatment simply by looking at objective factors such as medical history or the type and intensity of treatment. Therefore, the subjective experience of an individual and their perceptions of their lives are critical areas for further understanding.

Many of these studies seem to set out to answer questions such as 'do testicular cancer patients meet diagnostic criteria for depression or anxiety?' or 'are their scores on standardised questionnaires for depression and anxiety, such as the Hospital Anxiety and Depression Scale (Bjelland, Dahl, Haug, & Neckelmann, 2002; Zigmond & Snaith, 1983), higher than control groups?' While such work can usefully highlight the absence or presence of these difficulties, they tell us little about what it means to these men to feel low or stressed post-treatment, the impact it is having on their lives and what other emotions they may be experiencing. Furthermore, there is evidence that the ways in which men may define and express difficulties such as depression can often be different from the ways they are defined in standardised psychiatric questionnaires (Brownhill, Wilhelm, Barclay, & Schmied, 2005; Clarke & van Amerom, 2008; Danielsson & Johansson, 2005; Prior, Wood, Lewis, & Pill, 2003).

Nonetheless, it is uncontroversial to suggest that failure to adequately meet psychological needs can result in men experiencing considerable emotional distress and having difficulty fulfilling desired social roles after cancer treatment finishes. Adler and Page (2007) argue that this can also negatively affect adherence to treatment. Some research suggests that testicular cancer can have dire consequences, and it estimated the risk of committing suicide is 20% higher in men with testicular cancer compared to the general population (Alanee & Russo, 2012).

Evidence of post-treatment positive consequences

As previously mentioned, research related to psychological difficulties after testicular cancer treatment finishes is equivocal (Carpentier & Fortenberry, 2010). Some studies challenge the suggestion that life post-treatment is problematic and suggest that these men tended not to experience long-term elevated levels of psychological or psychiatric difficulties (Malec, Romsaas, & Trump, 1986; Siafaka et al., 2008), reduced quality of life (Rudberg, Nilsson, & Wikblad, 2000), disruption to occupational roles (Edbril & Rieker, 1989), or increased likelihood of being unemployed than the general population (Rieker et al., 1989). Studies have also suggested that many of these men demonstrate effective coping strategies, and that post-treatment psychological support may not be widely necessary (Moynihan, Bliss, Davidson, Burchell, & Horwich, 1998).

Some researchers find not only an absence of psychological distress but also evidence of positive consequences for some men, including increased capacity for enjoyment and appreciation of life, emotional growth, increased sensitivity towards the needs of others and an enhanced capacity to cope with adversity (Brodsky, 1995; Fleer, Hoekstra, Sleijfer, & Hoekstra-Weebers, 2004; Fosså et al., 2007; Kim et al., 2011).

While most research in this field has used quantitative methodologies, some relevant qualitative studies have been conducted. Brodsky (1995) interviewed 11 men about the impact of testicular cancer on their lives, at least three years after treatment finished. This researcher observed that experiences of testicular cancer appeared to enhance participants' capacity to live meaningfully and happily in the present moment. Numerous positive consequences were reported, including greater self-belief, relationships that were predominantly enriched and more open, and a relatively speedy return to emotional 'normality' after some initial upheaval. Thus, testicular cancer was described as presenting a substantial opportunity for personal growth and self-understanding. Excluding what were described as a few minor difficulties, which related to deterioration in certain relationships, difficulties connecting on an emotional level with others and tolerating perceptions of loss of control over life, this study seemed to conclude that testicular cancer was an overwhelmingly positive experience.

Comparison between testicular cancer studies is often difficult due to the use of different measurement scales and significant variation between the samples on factors such as age, type and intensity of treatment, and the length of time since diagnosis or since treatment was completed. There is a noticeable lack of methodological diversity

in research about testicular cancer, with the vast majority of studies being quantitative. Furthermore, some of this research has been critiqued for using measures that have not been validated, for the lack of 'healthy' control group comparisons (Jonker-Pool et al., 2001).

Most of these studies seem to suggest that either life after treatment is problematic or it is not. However, Brennan (2001) points out the importance of considering the possibility of both positive and negative consequences of life after cancer treatment. One study of testicular cancer survivors found evidence of greater emotional fluctuation or volatility, with these men feeling fitter and more satisfied with life than a control group, while simultaneously reporting higher levels of anxiety and depression (Kaasa, Aass, Mastekaasa, Lund, & Fosså, 1991). These findings suggest a less black and white picture and encourage a more nuanced understanding. This is supported by the findings of Wraith (2005), who explored the self-perceptions of men who had finished testicular cancer treatment between six and 24 months prior to the interview. While many participants appreciated the ways in which they had changed, felt more content, and were living lives altered in line with revised priorities, these positive outcomes occurred side-by-side with difficulties such as decreased confidence, disrupted masculinities, dissatisfaction or insecurity with appearance, feelings of vulnerability and anxiety or pessimism about the future. Thus, Wraith (2005) suggested that these positives and negatives occurred simultaneously within the same individual.

Very little of the research about life after treatment for testicular cancer has focused on understanding how men cope, adjust or manage their lives. Chapple and Ziebland (2004) shed some light on coping strategies, including the use of humour to reduce tension, to create a feeling of solidarity with others and to dispel common myths about testicular cancer. For some men, making or sharing jokes with others helped to create a sense of normality, but at other times humour contributed to men feeling hurt, embarrassed, alienated or stigmatised. A recent study exploring the lived experiences of Lebanese men at least three years after testicular cancer treatment revealed that these men often chose not to tell others about their cancer and actively rejected what they perceived as pity from others (Saab, Nouredine, Huijjer, & DeJong, 2014). These men seemed to view cancer as a turning point in their lives that had both enhancing and restricting components. Religious faith was identified as a significant factor in helping them to adjust to life after cancer treatment. This study also found that these

men were concerned and troubled about the impact their illness was having on significant others and the researchers wondered if this was a sign of a 'collectivist' Middle Eastern culture. Similar to Brodsky (1995), they found evidence that some men preferred not to find out whether their fertility had been compromised by the illness and its treatment.

1.5 Rationale for this study and personal reflexivity

This qualitative study of men's experiences of life after testicular cancer treatment can make a valuable contribution in a number of ways. Firstly, it can contribute to the under-researched areas, including men's health, cancer in men, and cancer in young adults. Most of what is known about life after cancer treatment is derived from samples of women with breast cancer and it seems to have proven difficult to engage men in research (Armes et al., 2009; Foster, Wright, et al., 2009; Moynihan, 2002). Therefore, studies that successfully manage to recruit and involve men with cancer are a welcome addition to the field.

Secondly, when studying men's cancers, researchers have been encouraged to contribute to greater diversity by exploring less-frequently occurring types than prostate cancer (Wenger & Oliffe, 2013). Testicular cancer has been less frequently researched than other cancers, and given that most of these men will live for many years after treatment finishes, this highlights the importance of gaining a deeper understanding of their post-treatment experiences (National Cancer Survivorship Initiative, 2010a, 2010b).

Thirdly, there is a need for greater understanding of the psychological impacts of cancer, in particular because psychological and emotional needs seem particularly troubling to both men and women, and analysis suggests they are among the needs most likely to be unmet in the long-term (Armes et al., 2009; Sanson-Fisher et al., 2010). This is further supported by the fact that, when consulted about different possibilities for further research, cancer patients identify research into its psychological impacts as among their top priorities (Okamoto et al., 2012).

Other studies have focused primarily on the post-treatment lived experiences of individuals and have been criticised for neglecting social, cultural and relational components (Knott et al., 2012). Furthermore, very little is known about how men manage life after treatment. Therefore, this study aims to provide men with an

opportunity to share the experiences of life after testicular cancer treatment that feel particularly significant to them, in their own words (Carpentier & Fortenberry, 2010; Gough, 2013) and will be focused on how they managed their lives afterwards. This endeavour may help to fill gaps in existing knowledge and to shed light on some of the apparent paradoxes in the existing testicular cancer research.

1.5.1 Relevance to counselling psychology

Research within the field of counselling psychology is a fitting 'home' for a study aiming to contribute to creating greater focus on the 'human' side of cancer (Dolbeault et al., 1999). The emphasis on respecting and valuing individual's subjective experiences and meanings provides counselling psychologist-researchers with the opportunity to play an important role in identifying, exploring and attempting to meet the psychosocial needs of men and women with cancer (Hoffman, 2013). It is hoped that the knowledge constructed in this study will be useful to men affected by testicular cancer and those seeking to care for them. Such an endeavour can be located within efforts to reduce the extent to which cancer survivors' psychological needs are unmet, and to reduce health disparities, aspirations that fit well with the values and practices of counselling psychology (Armes et al., 2009; Buki, 2007).

1.5.2 Personal reflexivity

A combination of personal and professional experiences makes the topic of life after testicular cancer feel particularly meaningful and interesting to me. When I was 23 years old, in the final semester of an undergraduate psychology degree, my beloved girlfriend Mary died in an accident. This experience and several painful years spent trying to come to terms with a profound sense of loss, and how I was changing as a result, created an interest in trauma and post-traumatic experiences, the broad context for this study.

In particular, I became interested in young adult men's experiences of, and responses to, traumatic events, because it felt as if my gender became a central feature of how some people engaged with me as I grieved. Although I felt supported by close family and friends, I often experienced direct and indirect pressure from others to grieve in certain ways and not in others. Sometimes it seemed as if I was being chastised for not grieving in the 'right' ways, which I interpreted as meaning ideally in silence and in private. Frequently, I was instructed to focus on the positives, to 'move on', 'get over it' and 'meet someone else'. I felt disturbed by these interactions and, at the time,

struggled to understand why such an intensely personal experience could be met with such a lack of compassion. I wondered why some people seemed so uncomfortable in my presence and why their attempts to direct my grief might feel so forceful. I wondered if this might relate to powerful ideas about how men 'should' be in Irish society at the time: stoic, invulnerable, self-sufficient, and perhaps above all, light-hearted. While these experiences were deeply unwelcome, they have contributed to shaping my sincere respect for subjective experiences, an interest in how social constructions of experiences or groups can interact with personal processes, and a passion for men's mental health.

When reflecting on a topic for this doctoral research, I decided that it did not feel healthy or helpful to conduct a study directly mirroring my own experiences, for example one that might involve research among young men whose partners had died suddenly. I imagined it might be so personal that it would be difficult to be open to others' experiences, particularly those that differed from or challenged my own. The decision to focus on cancer was made because, having conducted a number of qualitative market research studies with cancer patients, I found it an incredibly varied, rich and interesting topic. I chose to focus on testicular cancer because it is so closely associated with young adulthood and is increasingly prevalent in the UK. In addition, I wondered about the possible impacts of having cancer in a part of the body that is so strongly associated with being male.

Engaging in this personal reflexive process helped me to understand more about my preconceptions, expectations and agendas. I became aware of expecting to find that life after testicular cancer was problematic. I noticed a personal interest in exploring how this experience interacted with masculinities and could identify an element of campaigning about men's mental health within my hopes and aspirations for the study. For example, I became aware of the potential that I would struggle to hear or facilitate discussion of experiences that might be understood to represent 'positives' in life after treatment finishes. I might become dependent on a lens of 'life as a problem' through which to interact with participants. Akin to reaching increased awareness through therapy, gaining insight into my preconceptions created the feeling of having some choices and reduced the possibility of blindly imposing these agendas on participants or the data. Having a written record of the starting points of my relationship to the study also proved a useful reminder to carefully check assumptions I would make

about topics or experiences that felt particularly personal or that related to these initial preconceptions.

Chapter 2: Methodology

2.1 Overview

This chapter provides an account of the rationale for adopting many of the key decisions related to methodology, including the development of the research question, locating the study within a constructivist-interpretivist paradigm and the choice of grounded theory. It includes detailed description about the research procedures, analytic process, and ethical considerations.

2.2 Research question

The development of the research question is a fundamental stage in the research process (Burck, 2005; Mays & Pope, 2000). The research question guiding this study was expressed as follows:

How do men who complete treatment for testicular cancer manage life afterwards?

Some of the assumptions underlying this research question are listed below:

- Being diagnosed with and treated for testicular cancer is a potentially important and influential experience.
- There may be distinct or unique aspects to life after testicular cancer, perhaps due to the age at which it tends to occur, and the site of the cancer, that justify the focus on this particular cancer.
- Life after testicular cancer treatment may include some real psychological or social processes.
- The period after completing testicular cancer treatment may include transitions, adjustments or other processes related to managing life. Shedding light on how men approach managing their post-treatment lives is a worthwhile endeavour.
- Some men may be interested in and willing to share their experiences as part of this research study.
- It is possible for men to find ways to represent parts of their post-treatment experiences in language and for me to construct an understanding or interpretation of their stories.

2.3 Research paradigm

Researchers should articulate the philosophical and theoretical framework or paradigm underpinning a research study and the knowledge it aims to produce (Annells, 1996; Carter & Little, 2007; Drisko, 1997; Elliott, Fischer, & Rennie, 1999; Madill, Jordan, & Shirley, 2000; Ponterotto, 2005). Primarily, this relates to four main criteria:

- **Ontology** – which is concerned with the nature of reality and what can be known about reality (Ponterotto, 2002).
- **Epistemology** – defined as a "*fundamental theory of knowledge and the ways in which it can be produced*" (Pidgeon & Henwood, 1997, p. 247).
- **Axiology** – the role of the researcher and their values within the research process (Ponterotto, 2002, 2005).
- **Methodology** – the actual research procedure (Ponterotto, 2005).

2.3.1 Overview of research paradigms

For the purposes of locating the research paradigm that is the best fit for this study, I drew on the work of Lincoln, Lynham and Guba (2011) because it is a comprehensive, accessible and contemporary source produced by authors who, collectively, have been writing about this topic for several decades. Lincoln et al. (2011) identified five main research paradigms: positivism, postpositivism, critical theory, participatory-cooperative and constructivism.

Positivists propose that there is a single true reality that can be known, a position labelled naïve realism. This paradigm tends to propose a direct relationship between this reality and objective knowledge that can be gleaned about it (Pidgeon & Henwood, 1997; Ponterotto, 2005; Willig, 2008). In ontological terms, postpositivists also tend to believe in the existence of a single true reality, but suggest it cannot be fully captured or understood in perfectly objective terms (Lincoln et al., 2011; Ponterotto, 2002, 2005). Methodologically speaking, positivists and postpositivists have much in common. They act as the main foundation for quantitative research and both aim to produce objective knowledge (Finlay, 2006). It follows logically then that researchers' values are excluded from this process – they are expected to strive for a position compared to a chemist in a sterile lab (Lincoln et al., 2011; Ponterotto, 2005).

Critical theory, based on an ontological position called historical realism, proposes that reality is shaped by a range of social, political, cultural, gender and ethnicity-related influences (Lincoln et al., 2011). Based on foregrounding power relations and historical

struggles for privilege, this approach emphasises how knowledge has the potential to contribute to reducing or tackling inequalities and to the emancipation of oppressed groups. Researcher values are conceptualised as central to the ultimate goal of disrupting the status quo, and intense researcher-participant interactions are seen as key to empowering participants and groups (Ponterotto, 2002, 2005).

In terms of ontology, the participatory-cooperative paradigm is based on subjective-objective reality that is a co-creation of the mind and the surrounding world or cosmos (Heron & Reason, 1997; Lincoln et al., 2011). This paradigm is based on an epistemology that prioritises practical and experiential knowledge. It advocates a methodology based on partnership and democratic decision-making between all parties in the research process, including deciding on the questions of interest and suitable methodologies (Heron & Reason, 1997). Researcher values are central to the inquiry and are directed towards the goal of facilitating human flourishing (Heron & Reason, 1997; Lincoln et al., 2011).

Finally, constructivists, sometimes labelled constructivist-interpretivists, deny the existence of single real world and instead perceive multiple, constructed realities (Ponterotto, 2002, 2005). This is based on an ontological position labelled relativism, where truth is relative, reality is subjective and inevitably influenced by experience, social interactions and context. Therefore, this paradigm recognises 'knowledges' rather than knowledge (Willig, 2008), which are constructed in the mind of the individual, influenced by intersubjective interaction, and thus not a pure reflection of a single 'true' reality (Finlay, 2006; Hansen, 2004; Lincoln et al., 2011). Researchers are conceptualised as part of a social interaction and cannot be isolated from the research process, but steps should be taken to describe and explore the researcher's values, experiences and preconceptions. In epistemological terms, knowledge is produced in deep, sustained interpersonal engagements between researchers and participants, which lends itself to qualitative research methods such as face-to-face interviewing or observation (Ponterotto, 2002, 2005).

2.3.2 Identifying the research paradigm for this study

Due to the perceived fit with the research question, and my values and assumptions as a researcher, this study was positioned within a constructivist-interpretivist paradigm. As discussed, the research question driving this study suggests the possibility of some reality to life after testicular cancer treatment. However, the choice of this paradigm

reflected the belief in the existence of multiple, constructed realities of life after treatment. This broad and open research question prioritised participants' subjective experiences and allowed the direction and focus of the study to be heavily guided by what they chose to share. I saw myself as an integral part of the research process and believed that whatever knowledge was generated would be influenced by my presence, and was likely to differ from that which another researcher might generate. Furthermore, I believed that a constructivist-interpretivist paradigm offered a philosophical framework that was coherent with many aspects of the ways in which I practice as a counselling psychologist (see the introduction to the portfolio for more information).

Madill et al. (2000) propose that all epistemological positions can be placed on a spectrum somewhere between naïve realist (described above) and radical constructionist, which asserts that there is no such thing as objective knowledge and individual reality is all that we can know (Hansen, 2004). I entered into this study with an epistemology located between realist and relativist, that perhaps might be described as contextual constructivist. By this I meant that while there may be some realities to life after testicular cancer treatment, they would be influenced by local contexts, and any understanding of these realities derived in this study would be mediated by the language participants used to represent their experiences and my own interpretations (Madill et al., 2000; Willig, 2008).

2.4 Research design

2.4.1 Rationale for qualitative research methodology

In general terms, quantitative research tends to focus on testing hypotheses or causal relationships, evaluating reliability and validity, and measuring generalisability across different populations (Elliott et al., 1999; Elliott, 1995). Qualitative research tends to focus on developing understandings or theories based on analysing and interpreting participants' perspectives and stated meanings (Elliott et al., 1999; Elliott, 1995). Qualitative research was deemed a better fit with the open-ended research question driving this study and with the goal of developing understandings inductively rather than testing a hypothesis (Willig, 2008). This decision was further supported by the recognition of an opportunity to contribute to greater methodological diversity within the fields of psychology (Ponterotto, 2005), the psychology of men (Whorley & Addis, 2006), cancer and testicular cancer (Fosså et al., 2007) which, historically, have all been dominated by quantitative approaches. Since different methodologies can

produce quite different understandings (Marecek, 2003), the potential value in creating greater methodological diversity lies in the hope that it will contribute to greater understanding of the lives of men after testicular cancer treatment.

2.4.2 Rationale for choosing grounded theory

Grounded theory (GT), an approach to developing theories that are grounded in participants' data, was developed by sociologists Barney Glaser and Anselm Strauss (1967). GT resulted from a desire to find a middle ground between deductive hypothesis-testing research on one hand, and 'armchair theorising', disconnected from empirical data, on the other (Dey, 1999; Glaser & Holton, 2004). It can also be seen as an attempt to gain greater respect for qualitative research by developing a rigorous research process aimed at theoretical development (Charmaz, 2013; K. Smith & Biley, 1997; Walker & Myrick, 2006).

The decision to choose GT was made while acknowledging that other qualitative approaches could also make a useful contribution to this topic. In particular, I considered the merits of interpretative phenomenological analysis (IPA), discourse analysis, and narrative analysis. See Burck (2005) for an interesting illustration of how different qualitative approaches can contribute to different ways of understanding a single topic.

The decision not to pursue IPA was based a desire to leave open the option to go beyond description into tentative explanations of why men might manage life after testicular cancer in certain ways (Willig, 2008). The decision not to pursue discourse or narrative analyses was based on a desire not to close off avenues of potential inquiry such as the emotional impacts of testicular cancer and altered social identities, which I felt might be difficult to do using these methods (Willig, 2008). I decided to adopt GT as the method for this study because I believed it offered the flexibility to study a broader range of topics than these other approaches might offer individually. This included *"individual processes, interpersonal relations, and the reciprocal effects between individuals and larger social processes"* (Charmaz, 2008, p. 83). Thus, I hoped that GT might enable an exploration of subjective experiences alongside potentially real, social and psychological processes associated with life after treatment. I believed it might be possible, within a GT framework, to reflect on topics such as social discourses or narratives if the data warranted it. Furthermore, I saw value in its ultimate aspiration of model-building or theory generation and believed this approach

offered the option to become more interpretative or hypothesis-driven in the later stages of the study. In addition, as Fassinger (2005) explains, GT is a particularly interesting method for counselling psychologists because of how it seeks to bridge theory and practice, in line with a scientist-practitioner model.

2.4.3 Rationale for choosing constructivist grounded theory

GT is described as a "*contested concept*" (Bryant & Charmaz, 2007, p. 5) and it is suggested that there are as many different versions of GT as there are grounded theorists (Dey, 1999). Despite sharing some common features, GT is a 'broad church' and GT researchers occupy a wide range of epistemological positions (Fassinger, 2005; Greckhamer & Koro-Ljungberg, 2005; Henwood & Pidgeon, 1994; Madill et al., 2000). Charmaz (2008) proposed a way to distinguish the different versions of GT based on epistemological assumptions. She located 'classic' or Glaserian GT at the objectivist end of the spectrum by associating it with a positivist paradigm which assumes that data is an objective, real and a true reflection of the world. In other words, the researcher simply unearths what is already there (Charmaz, 2008). At the other end of the spectrum, constructivist GT, developed by Charmaz, assumes that there are multiple social realities and that data and analyses are socially constructed by the participant, the researcher(s), their unique interaction, and individual personal and social histories (Charmaz, 2008; Hallberg, 2006). The third main version of GT, developed by Strauss and Corbin (2008), is characterised by some as a 'happy medium' between the two other versions (Robinson, 2011) and by others as a muddle of positivist undertones and constructivist assumptions (Charmaz, 2006).

The constructivist version of GT was deemed the best fit for this study because it was most compatible with the research question and paradigm in which the study was located. Adopting 'classic' or Glaserian GT is an all or nothing decision, it cannot be taken à la carte (Holton, 2007, 2009). In terms of my personal values and professional identity as a counselling psychologist, I could not unreservedly identify with the positivist position of a single true reality of life after testicular cancer treatment which would emerge unfiltered by my presence and values (Bryant, 2003; Evans, 2013). Both the Charmaz and Strauss and Corbin versions of GT reflect a movement away from a positivist epistemology, by emphasising the subjective involvement of the researcher. Ultimately, I chose to adopt the Charmaz version because it seemed to offer greater flexibility. I was concerned that the highly detailed and prescriptive coding framework developed by Corbin and Strauss (2008) risked being a restrictive force on the study

and might limit the potential to creatively and openly engage with the data (Melia, 1996; Willig, 2008).

There are a number of perceived shortcomings of constructivist GT. They include the concern that by conceptualising research as a form of co-construction, there is a danger that researcher perspectives become privileged over those of the participants (Hernandez & Andrews, 2012). I hoped this could be avoided by directly including participants' words at all stages in the coding process and in the write-up, and by engaging in and communicating about the process of researcher reflexivity throughout the study. The other main criticism of constructivist GT is that it has abandoned theory development in favour of rich description (Glaser, 2002). In this study, I aspired to construct abstract explanations of life after testicular cancer treatment that were grounded in descriptions that participants' shared with me. This aspiration is summed up by Mills, Bonner and Francis (2006, p. 11):

"There is no question that to reconstruct theory, as opposed to writing a descriptive account, there is a need to make meaning that is abstract in nature as well as cognizant of the wider context that has influenced participants in the telling of their stories. For constructivists, though, there is a necessity to write such abstractions in such a way that they remain transparently grounded in the lives of those who co-constructed the data – the participants and the researcher."

2.4.4 Rationale for selecting semi-structured interviews

Kvale & Brinkmann (2009, p. 3) define an interview as a *"conversation that has a structure and a purpose"*. I chose semi-structured interviews as the best fit for this study because they offered a flexible approach where questions could be tailored to suit interesting topics that came up during interviews, where rich areas of uncertainty or complexity could be investigated, and where individual participants might feel sufficiently comfortable discussing personal or intimate experiences of life after testicular cancer treatment. Focus groups were considered but discounted at the initial stage of this study based on a fear that it might be even more difficult to discuss intimate or personal topics in a group setting (Willig, 2008). Time permitting, I was open to the prospect of inviting interview participants to take part in a focus group to discuss initial categories or concepts at a later stage in the study.

When conducting semi-structured interviews, researchers must be mindful of the tendency to focus on intellect and cognition at the expense of emotion, behaviour and social context (Kvale & Brinkmann, 2009). However, I trusted that my training would create a natural interest in emotion and that constructivist GT would contribute to creating a focus on social and interpersonal contexts and processes.

2.4.5 Evaluating the quality of this study

It is generally agreed that evaluating qualitative research requires a different approach to traditional measures of generalisability, reliability and validity (Drisko, 1997; Elliott et al., 1999; Lincoln et al., 2011; Mays & Pope, 2000; Morrow, 2005). My thinking about quality measures in this study drew on three sources: Elliott et al. (1999); Morrow (2005); and Charmaz (2008).

Elliott et al. (1999) developed a comprehensive yet accessible set of quality guidelines for qualitative studies. Their recommendations include the disclosure of researchers' personal and theoretical perspectives, sharing aspects of the reflexive process and including specific examples from the data. In addition, I sought guidance on how counselling psychologists think about quality in qualitative research. Morrow (2005), drawing heavily on the work of Elliott et al. (1999), developed additional considerations including the researcher's understanding of the fit between the research paradigm and research question, the extent to which the study informs and stimulates interest in the topic, and how it acts as a bridge between research and practice. Finally, I believed it was worthwhile to take into account guidance that was specific to evaluating constructivist GT studies. Charmaz (2008, pp. 182–183) identified four key quality criteria: credibility, originality, resonance and usefulness. See section 4.3.1 for further information about the steps taken to contribute to the quality of this study.

2.5 Ethical considerations

Researchers engaged in qualitative research about potentially distressing subjects must engage with ethical considerations throughout their study. They must avoid falling into the trap of believing, simply by virtue of using qualitative, not 'cold' quantitative, methods, they have some inherent ethical superiority (Brinkmann & Kvale, 2005). Informed by the British Psychological Society's (2010) Code of Human Research Ethics, a set of procedures were adopted in this study. These procedures, summarised below, were approved by the City University Psychology Department Ethics Panel (appendix 1):

- Participant wellbeing was prioritised above any other considerations during the study, including obtaining rich data or achieving an academic qualification (Christians, 2011; Kasket, 2012).
- Informed consent was sought, verbally and in writing, from all participants. A pre-interview briefing sheet was provided before consent was requested (appendix 4). This consent was based on attempting to provide truthful and realistic information about the aims of the study and how their data might be stored and used (appendix 5).
- The right to withdraw without explanation or prejudice was clarified at all stages.
- Debriefings were conducted at the end of each interview and participants were given the chance to talk about how they were feeling. They were also given a debriefing information sheet that included signposting to sources of support (appendix 7). In addition, I provided contact details for my research supervisor in case they wanted to raise any concerns about the study.
- In compliance with the Data Protection Act (1998), several steps were taken to protect participant confidentiality. Transcriptions of the audio recordings of the interviews were carried out by the researcher and were fully anonymised. Principles of confidentiality were extended to third parties who were mentioned during interviews and biographical or personally identifiable details were excluded or amended in the transcripts (Haverkamp, 2005). All audio and written materials were kept in a locked cabinet in the researcher's home and computer files were stored on an encrypted memory stick. Signed consent forms and pre-interview questionnaires (appendix 6) were kept in a separate locked filing cabinet and all files related to the project will be securely destroyed afterwards.

See section 2.6.4 for further information about the implementation of these approaches in practice. Researchers are also encouraged to recognise that unpredictable ethical dilemmas can occur at any stage and so they must remain alert and reflexive throughout the study (Guillemin & Gillam, 2004; Haverkamp, 2005; Kvale & Brinkmann, 2009; Willig, 2008).

2.6 Participants and procedure

2.6.1 Inclusion and exclusion criteria

A set of inclusion and exclusion criteria were established, guided by the research question, prevalence statistics about testicular cancer and gaps in the existing literature. Participants who met the following criteria were invited to volunteer to take part:

- Men aged 18 to 40.
- Resident in the UK.
- Diagnosed with testicular cancer and treated with surgery and/or chemotherapy/radiotherapy.
- Completed treatment at least one and not more than 10 years ago.

At the design stage, I envisaged including participants aged 18 to 35, who had finished treatment one to five years ago. Several of the people who responded to the promotional materials met some but not all of the criteria and so I requested, and was granted, revised ethical approval to expand the inclusion criteria (appendix 2). I saw this amendment as a pragmatic choice to enable the participation of those who came forward without fundamentally changing the research question or focus for the study.

The following exclusion criteria were established:

- Men under the age of 18 due to the ethical challenges this presents and the focus of counselling psychology training on working with adults.
- Men older than 40 whose perspectives have been included more often in other research on this topic (Carpentier & Fortenberry, 2010).
- Men currently being treated for testicular cancer, or within the first 12 months post-treatment, due to the focus of this study on life after treatment finished.
- Those who did not speak English with a sufficient degree of fluency due to the need to develop rich qualitative data.

2.6.2 Sample and participants

There are no simple answers to the question of what size a qualitative sample should be. In a review of 174 GT PhDs, Mason (2010) found sample sizes ranging from 4 to 87. This study is based on a sample of seven men who, at the time of the interview, were aged between 26 and 39, and had completed treatment for testicular cancer between one and seven years ago. All of the participants identified themselves as heterosexual. One of these participants was from an ethnic minority background. For

the sake of confidentiality I have not identified this individual in the table. See table 2 for further information about the sample.

There were two distinct approaches to sampling in this study, purposeful and theoretical, as recommended by Charmaz (2006). The initial sample was made up of five participants who were in a position to provide rich data about the experience of life after testicular cancer treatment and informed the trajectory of the study (Morse, 2007). Based on analysis of these five interviews, I developed tentative categories, related to intrapersonal and interpersonal difficulties, that merited further exploration (Charmaz, 2008). Therefore, according to the principles of theoretical sampling, I recruited a further two participants who were in a position to develop the emerging categories (see 2.8.4 for more information about theoretical sampling).

Table 2: Sample profile

Name*	Age	Age diagnosed	Years since treatment finished	Cancer type and treatment	Relationship status and dependents in the post-treatment phase
Alan	39	32	6.5	Stage 2 seminoma (orchidectomy and chemotherapy) Ongoing testosterone treatment	Single, no children
Dean	27	20	6.5	Stage 1 seminoma (orchidectomy and chemotherapy)	Single, no children
Phil	29	26	3.5	Stage 1 seminoma (orchidectomy and chemotherapy)	In a new relationship, no children
Dave	36	35	1	Stage "1.5" seminoma (orchidectomy and chemotherapy)	Married, 2 children
Stephen	26	25	1	Stage 1 seminoma (orchidectomy and chemotherapy)	Living with partner, no children
Mark	38	32	6.5	Stage 1 seminoma (orchidectomy and chemotherapy)	Married, 2 children
John	30	28	2	Stage 2 mixed germ cell (orchidectomy and chemotherapy)	Single, no children

* In keeping with recommended practice, participants were allocated a pseudonym to protect their confidentiality (McCann & Clark, 2003c).

2.6.3 Recruitment

In order to promote the study, I developed a promotional flyer (appendix 3) and a basic website www.lifeaftertreatment.com. Grounded theorists are encouraged to seek out participants wherever they are likely to be, including from organisations that provide support or services (Morse, 2007). With this in mind, I contacted and secured agreement from a UK-based cancer charity who promoted the study via their website, social media and events.

2.6.4 Procedure

Interested parties contacted me by email or phone and I provided further information and attempted to answer any questions. Initially, seven men contacted me but two were excluded due to finishing treatment more than 15 years ago and were aged over 45. One of these men agreed to take part in a pilot interview for the study on the understanding that his contribution could help to shape the process rather than contributing to the content (see section 2.7.2).

Interviews were conducted in a private room within a social sciences building at City University in London. Following the initial briefing (appendix 4) and the consent process (appendix 5), I gathered some basic demographic and treatment-related information (appendix 6) before conducting the interview. Given the sensitive nature of the research topic, I actively monitored participants' verbal and non-verbal communication for signs of distress and conducted a thorough debriefing at the end of each interview (appendix 7). I contacted all participants by telephone approximately four weeks after the interview in order to conduct a second wellbeing check. None of the participants disclosed any psychological difficulties or other forms of harm related to the interview and none required further support. Participants were not financially compensated for taking part. By way of thanking participants, I intend to offer a summary of the key findings upon completion of the study.

2.7 Interviews

Semi-structured interviews lasting between 90 and 120 minutes were conducted and audio recorded.

2.7.1 Interview philosophy

Without a basic level of trust, rapport and comfort, participants in qualitative research are unlikely to be willing or able to share experiences, perspectives and stories that go

beneath surface depth (Charmaz, 2008; Pidgeon & Henwood, 1997). Research interviews can involve complex power dynamics and can be challenging for some men, particularly when they involve discussions related to masculinities (Schwalbe & Wolkomir, 2001). Mindful of these challenges, I tried to create a professional but informal atmosphere and to communicate my respect, acceptance and genuine interest in their lives and experiences (Charmaz, 2006). I did not alter my informal, conversational approach and hoped this might help participants to feel comfortable talking to me. I offered participants the opportunity to have the first word, to say when they felt ready to start the interview, and to have the last word, by finishing the interview (Kvale & Brinkmann, 2009). I hoped these approaches would contribute to creating an environment that might be conducive to meaningful discussion.

2.7.2 Pilot interview and developing the interview schedule

Consistent with the recommendations of Charmaz (2006), I developed a loose interview guide (appendix 8). This included asking a general question or invitation to speak about their personal experiences of life after testicular cancer, in their own words. I also incorporated a question asking participants to give titles or names to their experiences of life after treatment, because this has been shown to be an interesting means of exploring underlying processes (Kacen, 2008). Towards the end, I invited participants to speak about their experience of the interview, what we had discussed and any important parts of their experiences that had not been discussed.

The pilot interview provided a valuable opportunity for a trial run of the interview schedule. Before the pilot, I noticed worries about whether I had enough questions to ask, and whether the interview might grind to a halt, perhaps mindful of ideas such as “men don’t talk”. I was pleased with how the interview went; there was no shortage of topics to discuss and the participant seemed to enjoy taking part. When asked to sum up his experience of the interview he said:

"It's been really useful to have as big and frank a conversation about what I went through mentally subsequent to the treatment. It's been really really useful in being able to verbalise my thoughts"

Based on the pilot interviewee’s recommendations, subsequent interviews were conducted in a smaller therapeutic room at the university, which did not have the appearance of a classroom and had more comfortable seating.

This interview schedule was used for the initial five interviews. A revised interview schedule was developed for the final two interviews which sought to develop the emerging categories of intrapersonal and interpersonal difficulties (appendix 9).

During the interviews, I focused on gathering rich description of thoughts, feelings, experiences, actions, explicit explanations, implicit or hidden assumptions and personal meanings (Charmaz, 2008). In practical terms, I asked a range of follow-up questions (Kvale & Brinkmann, 2009). This included prompts to describe further ('can you help me to understand that more'), requests for specific information ('how did you feel/react... when... where') and tentative interpretations ('I'm not sure I understood correctly... did you mean that...'). I was conscious of trying to identify actions and processes – who was doing what, when, under what circumstances or conditions (Charmaz, 2006). I used many of the skills I developed during my training as a counselling psychologist, including being attentive to participants' language and body language and trying to uncover subtleties, nuances and complexities.

2.8 Analytic process

Charmaz (2013) explained that a primary goal of GT analytic procedures is to help researchers to maintain momentum in a conceptual direction. McGhee et al., (2007, p. 335) characterised GT analysis as an *"inductive-deductive interplay"*, that starts with an inductive approach where researchers explore a topic of general interest with an open mind and prioritise their data over pre-existing theories or literature. The process becomes more deductive as categories or concepts are constructed from the data and developed through further data collection (McGhee et al., 2007). Thus, the process of constructivist GT requires *"researchers' persistent interaction with their data, while remaining constantly involved with their emerging analyses"* (Bryant & Charmaz, 2007, p. 1).

2.8.1 Initial literature review

The timing of the literature review is a bone of contention in GT and 'classic' grounded theorists recommend avoiding a literature review until late in the process (Evans, 2013; McGhee et al., 2007). However, consistent with the principles of constructivist GT, an initial review of testicular cancer literature was conducted during the design of this study (see chapter 1). Its purpose was to identify what research into testicular cancer had already been conducted and to develop a research question and approach

that provided the possibility of generating new knowledge and making an original contribution.

2.8.2 Data collection and transcription

I transcribed the audio recordings shortly after each interview. I agree with Hammersley's (2010) assertion that a transcript can only capture some of the data in a research interview and cannot be considered an objective or full account of the interaction. See appendix 10 for the transcription key I used, informed by the work of Gail Jefferson (cited in Potter & Wetherell, 1994). I adopted a relatively conservative approach, transcribing specific details, such as volume, tone or pacing, if it seemed extraordinary and the meaning of the text seemed substantially changed by this detail. In addition, I noted the length of pauses that were five seconds or longer.

2.8.3 Coding, memo writing and constant comparisons

Coding involves defining the actions and meanings from the data, and represents one of the key stages of GT analysis (Charmaz, 2008). The very first step in the analysis was line by line coding, aimed at breaking up the data. I completed an initial line by line coding relatively quickly, writing short, action-oriented codes in a spontaneous and uncensored way. Later, I reviewed these initial codes against the transcript, in order to ensure I stayed close to the data at this stage.

This early in the research process, I noticed an instinct or tendency to look for themes in the transcript. Perhaps this is because this is similar to the kinds of ways I would engage with clients in the early stages of therapy and to many of my past research experiences. Therefore, it took concerted effort to code in a way that felt more appropriate to GT. In order to help me with this I kept a note of some of Charmaz's (2006, p. 51) key questions close to hand during coding:

- *"What process is at issue here? How can I define it?"*
- *"What are the consequences of the process?"*
- *"How does each participant act while involved in this process?"*
- *"When, why and how does the process change?"*

In constructivist GT, the second phase of coding is called selective or focused coding. I understood this as the first step in starting to put the data back together after its fragmentation in line by line coding. I attempted to synthesise larger amounts of data, or a number of different codes, according to those that felt most meaningful. By

meaningful, I mean they occurred frequently in the data, they helped to account for large amounts of data, or they seemed particularly pertinent to the research question (see appendix 11 for an extract of transcription and coding).

My analytic approach was informed by the principles of constant comparison that encourage researchers to try to do justice to the richness of their data (Willig, 2008). This involved comparing bits of data with other bits of data, codes with data, and codes with codes. Furthermore, I found it useful to write a list of the main processes that I could identify in each transcript and to include this within the comparative work.

In GT, writing memos, or informal analytic notes, is one of the main tools to help move the analysis in a conceptual direction (Lempert, 2007). From early in the analytic process, I started to write memos. Thinking about these notes as being primarily for my own records helped me to write more freely and spontaneously. My approach to memo-writing involved including participants' words and my codes in each memo, in order to try to stay connected to the data, particularly in the early stages. This also helped me to check my ideas against the data and to identify gaps in my knowledge (Charmaz, 2013). See appendix 12 for a sample memo entitled 'not talking about it' and appendix 13 for a list of the titles of an initial set of 32 memos that I wrote, and a revised list of 17 memos.

Sometimes, my attempts to remain grounded in, or in contact with the data left me feeling like I was carrying a very heavy load or a box so big that it blocked my view. I tried to create moments of freedom and disconnection from the volume of data to which I was attempting to do justice. Charmaz (2013) recommends that researchers ask themselves 'big questions' such as 'what is this data a study of?', 'how does this compare with what I thought it was a study of?' and 'what is the larger story at play here?' as a means to keep the process moving forward and not getting stuck. At a few moments, I appreciated the feeling of having some distance from the data.

2.8.4 Theoretical sampling and towards theory development

Categories in GT are intended to be interpretative, conceptual, precise, and based on substantive processes that can be constructed from the data (Charmaz, 2006). Based on analysing the first five interviews, I engaged in a number of attempts to develop categories that captured the processes identified in the codes and memos. For example, *'living with uncertainties'* and *'you think it's the end but it's not –*

experiencing change and loss’ were two potential categories that I started to develop. While both of these elements are visible in the final analysis, they were not selected as main categories because they did not capture major processes sufficiently well. I also attempted to develop a category entitled *‘reconnecting with agency’* but felt that there was insufficient data to support the development of this category at this point. See appendix 14 for further information about a number of different attempts to develop categories from the data and appendix 15 for a table illustrating the connection between categories and codes.

Based on the analytic approaches previously outlined, I developed three initial categories that I felt represented the data, and my codes, reasonably well (Charmaz, 2006). These initial categories were labelled *‘negotiating relationship with self’*, *‘negotiating relationship with others’* and *‘negotiating relationship to cancer’*. When participants are recruited with the explicit purpose of category or theory development this is called theoretical sampling (Glaser & Holton, 2004; Hallberg, 2006; Yardley, 2000). Therefore, the next stage in the analytic process involved the theoretical sampling of additional participants with a view to developing these categories. I produced a revised interview schedule with questions related to these three initial categories. During these interviews, I asked participants questions about how they felt about themselves, what they noticed about their relationships and about the meaning of cancer in their lives. In keeping with the process-focus of GT, I asked a number of questions about what choices they faced and what actions or decisions they took related to their intrapersonal and interpersonal experiences (see appendix 9 for the revised interview schedule). Using identical recruitment approaches as before, I publicised the need for further participants. Two men volunteered to take part and were interviewed shortly afterwards. While I felt confident that the initial categories were grounded in the first five interviews, I remained open to the possibility that subsequent interviews might lead to the development of new ideas or categories. The final two interviews were put through the same analytic process of transcribing, coding, memo writing and categorising as the first five interviews.

In theory, data gathering stops when theoretical categories are saturated or when new data no longer alters the properties of core categories (Charmaz, 2006). In practice, the notion of saturation has been challenged by several authors who ask how it is possible to predict with certainty that no new insights would arise (Bruce, 2007; Hallberg, 2006; Willig, 2008). Given the practical constraints of a doctorate, several

authors have recognised that many studies conducted in this context represent an abbreviated form of GT (Pidgeon & Henwood, 1997; Willig, 2008). Thus, I was aiming for Charmaz's (2008, pp. 132) "*plausible account*" of how men manage life after testicular cancer treatment, which was based on rigorous and creative interpretation of this phenomenon.

The final stage in the analytic process involved theoretical sorting of categories, including a number of attempts to elevate categories to main category or core connecting category status, before arriving at the approach presented in the next chapter.

See table 3 for an illustration of the journey from an extract of transcript data, through different stages of coding, towards category development.

Table 3: An illustration of the links between transcript data, codes and categories

Transcript data	Initial codes	Focused codes	Sub-category	Main category
<i>"No it's just... it's just... .hhh... to be honest, life isn't easy. There are so many things in life that are there to test us and I've just got to find a solution to everything that I'm given"(John, 17:15)</i>	<i>"Life isn't easy"</i> Feeling (constantly) tested Needing to find solutions Feeling under pressure?	Seeing difficulties as 'tests' Assuming responsibility	Framing techniques	Finding <i>"survival strategies"</i>
<i>"I still have my days where I think THIS IS HARD (yeah). We all have a a low day but I mean THE LOW DAYS NOW ARE LOWER THAN I EVER HAD BEFORE (yeah) BUT I THINK THE HIGH DAYS ARE HIGHER THAN I EVER HAD BEFORE. BEFORE I WAS A VERY FLAT PERSON. Before it was a bit more there {makes gesture of a flat line} whereas NOW YOU HAVE YOUR UPS AND DOWNS {motions up and down}"(Stephen, 35:31)</i>	Acknowledging continued struggles Having lower lows... and higher highs Comparing himself and his feelings before and after cancer	Reflecting on being changed Finding positives and negatives	Processing losses and gains	Developing new perspectives

2.8.5 Adopting a pluralist-pragmatist analytic perspective

The analysis presented in the next chapter reflects the conscious choice to adopt a flexible analytic approach that could be labelled 'pluralist-pragmatist'. Different levels of analysis were included as a means of attempting to do justice to the diversity of the data. For example, aspects of the data were explored at a phenomenological level. Elsewhere, social constructionist and cognitive approaches were considered with regard to other parts of the data. In practice, this results in the use of different types of language and terminology to represent these different levels of analyses. That is, I use psychological language to attempt to capture inner feeling states, I draw on cognitive approaches related to beliefs and ways of managing difficulties, and I draw on cultural discourses of cancer and masculinities and explore potential discursive functions of language. This pluralistic analytic approach was not planned in advance, it was developed in response to what I saw as the richness of the data, and it allowed me to consider a number of different 'levels' of the data. In practical terms, I attempted to be data-driven and move between these different levels of analysis. For example, when participants mentioned ideas about how men 'should' cope with difficulties or how people 'should' manage life after cancer treatment, I explored how these reflected social constructions of men, masculinities and cancer discourses. See Chamberlain (2012) for further information about the pragmatic and flexible use of qualitative methodologies in the pursuit of meaningful findings.

2.9 Reflexivity

Willig (2008, p. 10) explains that *"reflexivity requires an awareness of the researcher's contribution to the construction of meanings throughout the research process, and an acknowledgement of the impossibility of remaining 'outside of' one's subject"*. This involves the researcher engaging in a process of thoughtful self-reflection about their subjectivity and the dynamics of intersubjective interactions with participants (Finlay, 2002; Kasket, 2013). It is not enough to just engage in this process silently and independently. Researchers should aim for a level of transparency about their reflexive activities. This can contribute to the credibility of the study by providing interested others with the opportunity to examine and reflect on the knowledge it produces with an impression of the researcher and their values in mind (Elliott et al., 1999; Kasket, 2012). In addition, reflexivity is a central component of the constructivist-interpretivist research paradigm underpinning this study and of counselling psychology.

I engaged in a range of reflexive activities (Etherington, 2004; Finlay, 2002) such as:

- Writing a personal reflexive statement at the start of the project to highlight my own motivations, interests and preconceptions (see section 1.5.2).
- Maintaining a reflexive diary throughout the study to capture feelings, responses or preconceptions, including writing a note after each interview and at various points during analysis and write-up (appendix 16).
- Making notes on transcripts when significant personal associations or memories arose, as a prompt to reflect carefully on the data.
- Incorporating reflexive notes throughout the write-up of this thesis, including within the analysis chapter, in an attempt to reflect the importance of reflexivity.

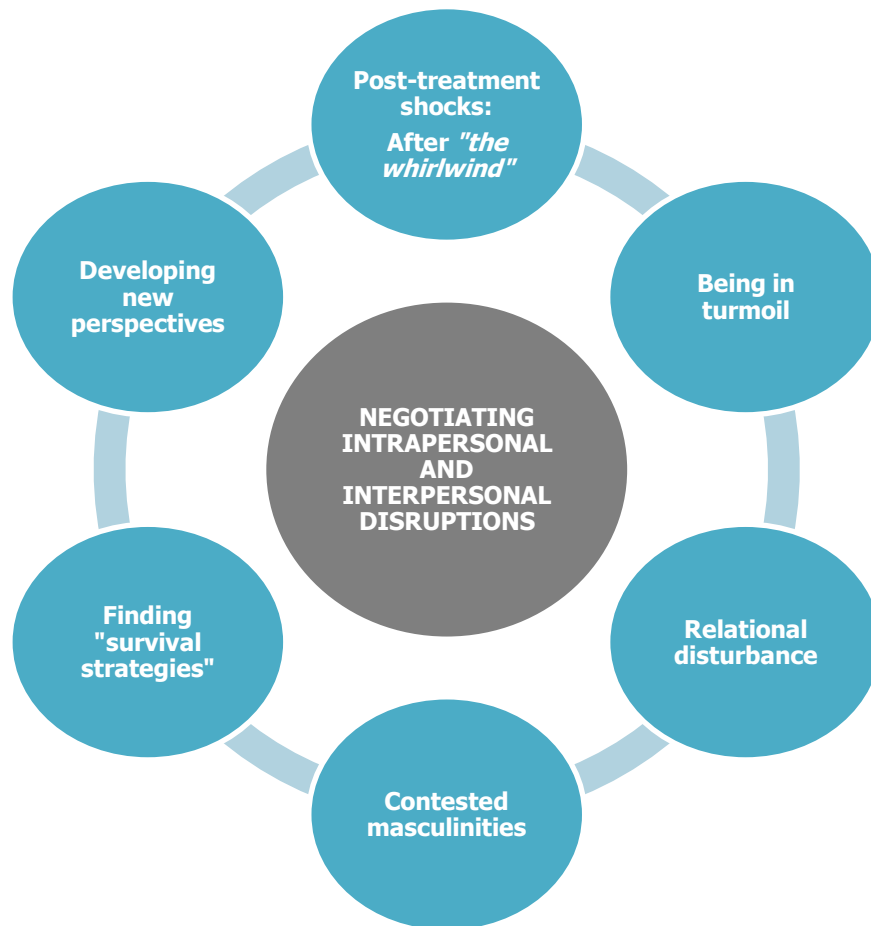
I organised these activities into three categories - personal, epistemological and methodological reflexivity (Willig, 2008). While I recognise that my reflexive endeavours can only be partial, I entered into the process with a desire to be open about my own experience and the possibility that I would both have an active role in shaping the study and potentially be personally impacted by this experience (Cutcliffe, 2000; Finlay, 2002). However, I also recognised that reflexivity could 'go too far' and could end up obscuring or overshadowing the contribution of the participants (Finlay, 2002). Therefore, I aimed for a balance and tried to ensure that reflections were in the service of the research project.

Chapter 3: Analysis

3.1 Introduction to the analysis

This chapter presents a core connecting category and six main categories based on extensive analysis of participants' ways of managing life after testicular cancer treatment. Each category is grounded with extracts of participants' stories and experiences. In addition, a tentative model of life after testicular cancer treatment is presented at the end of this chapter.

Figure 1: Illustration of the core connecting category and six main categories



3.2 Negotiating intrapersonal and interpersonal disruptions – the core connecting category

Being diagnosed with testicular cancer at a relatively young age was described as a defining moment in participants' lives. All participants reported grappling with significant ruptures to their sense of self, their masculine identities and their relationships with others. The experiences shared by these participants suggest that managing life after testicular cancer treatment can involve negotiating dynamic, multi-dimensional intrapersonal and interpersonal disruptions. The main categories and their relationship to the core connecting category are introduced in table 4.

Table 4: Relationship between core connecting category and main categories

Category title	Category overview	Link to negotiating intrapersonal and interpersonal disruptions
Post-treatment shocks: After "the whirlwind"	Presenting painful post-treatment realisations that followed " <i>the whirlwind</i> " of testicular cancer diagnosis and treatment	Initial post-treatment context: Setting the scene for the analysis
Being in turmoil	Exploring participants' reported uncertainties, conflicts and inner turmoil	Illuminating intrapersonal disruptions
Relational disturbance	Outlining participants' social worlds and the alienation and disconnection they described	Illuminating interpersonal disruptions
Contested masculinities	Focusing on the perceived threats to participants' masculine identities	Drawing on intrapersonal and interpersonal disruptions
Finding "survival strategies"	Identifying what seem to be instinctive or automatic attempts to manage post-treatment difficulties in the midst of profound upheaval	Initial attempts to manage post-treatment disruptions
Developing new perspectives	Examining participants' attempts to create more considered, consciously-chosen ways of managing life after treatment	Subsequent approaches to managing post-treatment disruptions

3.3 Post-treatment shocks: After "*the whirlwind*"

Almost all participants indicated that being diagnosed with and treated for testicular cancer felt somewhat disempowering, including having to put their lives in the hands of medical professionals. In the immediate aftermath, participants described painful, "*dawning realisations*" about difficulties they were facing after treatment finished.

Perhaps unsurprisingly, most of these participants described feeling deeply shocked when they were diagnosed with testicular cancer:

"I'd never really thought about testicular cancer... I'd never really heard of anyone I know having it" (Phil, page 1:line 6)

At the time of diagnosis, almost all participants felt physically well, in good health and were not experiencing many symptoms that might suggest a 'serious' health problem. The speed with which they were diagnosed and treated seemed quite disconcerting:

"A very very quick process" (Dean, 1:9)

"It was... cos like all the way through it you're pulled... it's such a FAST PROCESS so you're pulled all the way through it very quickly" (Stephen, 1:34)

Several participants likened diagnosis and treatment to "*a whirlwind*" or a "*bolt out of the blue*". The use of metaphors associated with natural disasters such as bolts of lightning, tornados or hurricanes brings to mind violent, unpredictable, disorientating and destructive experiences. They seem suggestive of a world out of control or turned upside down. Perhaps participants symbolised their experiences in these ways because it felt difficult to put into words, or precisely define, what they were experiencing.

During treatment, most participants reported being focused on survival. There seemed to be an unspoken assumption that treatment may be the most difficult part of their experience and that life afterwards might feel a little less difficult. Realising that they were faced with a new set of difficulties post-treatment was compared to being shocked for a second time or "*an aftershock*":

"You think it's the end but it's not" (Alan, 10:14)

"After that it did just seem like a void... like out of the hospital, you're all right, see you later and you you don't quite feel all right at that point. You're kind of thinking I don't feel normal (hm:m), I don't look normal, nothing was quite... it

took me a long time to get my head back into a normal routine. I COULDN'T GO STRAIGHT BACK TO WORK. I got six months off... just couldn't register on what HAPPENED NEXT cos nobody got me prepared for how you should feel. I I I suppose you should feel a bit of an empty void at that point. I I don't know. I STILL don't know to this day (hm:m) how... IF I WA FEELING NORMAL...The DIFFICULTY STARTED FOR ME THEN"(Stephen, 2:3)

Stephen seemed to describe a contrast between being told by others that he is "*all right*" and his own sense of not "*feeling normal*". The repeated use of the word "*normal*" may provide an insight into how abnormal life felt to him at this moment. He emphasised a feeling of confusion and not knowing by saying "*I STILL don't know to this day*".

Although they were not directly asked about diagnosis and treatment, all of these participants used their experiences of treatment as a reference point to explain why life afterwards felt so difficult. Analysis of these comparisons is provided in table 5:

Table 5: Comparison of treatment and post-treatment experiences

Topic	During treatment	Post-treatment
Focus or orientation	Specific and contained: Getting through treatment and 'free' of cancer	Vague and not clearly defined: Coming to terms with life after treatment
Level of information and preparedness	Well informed about illness, treatment and monitoring, as prepared as could be	Unprepared and unable to find much information about life after treatment, unsure what to expect
Reassurance	Reassured by survival statistics and perceived confidence of medical teams	Anxious and struggling to locate sources of reassurance
Support of healthcare professionals	Feeling supported and well cared for by medics	Feeling abandoned or marginalised after treatment
Support of family and friends	Peaked during treatment	Reduced and sometimes withdrawn after treatment

Responsibility	In hands of doctors and nurses	Being responsible for self
Length of process	Quick process with clear steps and possible start-end points	Drawn out and vague, little idea when life after treatment might feel less challenging
Recognition of their needs or vulnerabilities	Widespread recognition of difficulties of cancer diagnosis and treatment such as chemotherapy	Needs related to managing life after treatment not clearly understood by self or others

Reflexive note: Methodological struggle to account for data about treatment

The fact that almost all participants spoke about their experiences of diagnosis and treatment presented a methodological dilemma for the study, given its focus on life after treatment. Initially, I wondered if this data fell outside of the remit of my research question and considered whether to exclude it from the analysis. However, the ways in which participants spoke about treatment felt like an important message. Perhaps they were attempting to resist what might have felt like a fragmentation of their experience into treatment and post-treatment phases (Riessman, 2001), in a way that might have felt artificial or unnatural. Ultimately, the frequency with which participants spoke about their experiences of treatment, and the seeming importance attached to these experiences, suggested they were an integral part of attempts to understand life afterwards. Therefore, it felt appropriate to include aspects of their experiences of treatment in this analysis.

3.4 Being in turmoil

Navigating post-treatment uncertainties, internal conflict and overwhelming emotions were core challenges described by these participants. These struggles seemed to shed light on the ways in which participants related to their internal 'world' of thoughts and emotions.

Figure 2: Sub-categories of being in turmoil



3.4.1 Living in uncertainty

Life after treatment was compared to *"being in the dark"* by several participants. This phrase is often used to suggest a state of being uninformed, ignorant or lost. Following the shock of testicular cancer, several participants described feeling vulnerable and worried about what else might go wrong:

"For the first couple of months it was it was... CRIKEY you've just been through this sort of LIFE-CHANGING EVENT and and em:m you know WHAT NOW? WHAT NEXT?" (Mark, 1:33)

"Because your initial point was this will never happen to me, and it already has, so I think your view of that will never happen to me has already gone out the window. So from then on it's no holds barred, who knows what's going to happen?" (Dean, 21:23).

Dean identified how a world-view, or perhaps an unspoken optimism about life, had *"gone out the window"*. By choosing the phrase *"no holds barred"*, he seemed to draw on associations with physical confrontations such as wrestling or war. Perhaps he was communicating a belief that the usual (or pre-cancer) 'rules' no longer applied and that he felt more aware of the dangers or risks in life.

Uncertainty seemed to permeate many aspects of participants' post-treatment lives, including sex, fertility, illness disclosure, daily activities, current relationships, potential future relationships and the impact of their illness on others. They seemed to describe the feeling that cancer was dominating their perspective on life at this time:

"THERE'S ALWAYS SOMETHING IN YOUR HEAD ABOUT IT... THE CLOUDS BUILD UP AGAIN... YOU NEVER SEEM TO BE ABLE TO ESCAPE IT" (Dave, 45:28)

Anxiety about health and physical vulnerability were frequently mentioned:

"I kept going back with silly little things like THE MINUTE YOU'VE HAD SOMETHING LIKE THAT EVERY LITTLE LUMP AND BUMP THE DOCTORS... I MUST HAVE BEEN AT THE DOCTORS EVERY OTHER WEEK FOR THREE OR FOUR MONTHS, going in with all sorts of different things" (Stephen, 15:15)

In addition to regular visits to his GP, Stephen described how he also he went to Accident & Emergency at his local hospital three or four times because he was afraid he was having a heart attack. After checking on the health of his heart, doctors seem to have suggested he was experiencing 'attacks' of anxiety related to his health.

Uncertainties about when, if ever, the side effects or physical health difficulties might subside, were reported as troubling for most participants:

"...When it gets to a year afterwards and you still feel shit you're like 'oh god', it's NEVER-ENDING. But there's not a lot you can do about it. You've just, you've got to have it. It's how it is, isn't it? I STILL FEEL KNACKERED THOUGH, ALL THE TIME... every time I get up in the morning it feels like I've got a HANGOVER without having beer" (Dave, 7:17)

"YOU would be paranoid if you'd gone through an illness, you've lost a testicle, your body has changed, your life has changed and... well if you put all this weight on my cholesterol became high then they said oh we have to check for diabetes. We want you to lose weight. It was like it was so fast...one consultant wanted me to do one thing, the other said do this... it's only a human body you know, at the end of the day. I just want to get used to what's sort of happened you know" (Alan, 14:22)

Alan sounded frustrated and angry at this point. At a time when he may have been finding it difficult to process a number of changes, he seemed to feel that he was being pulled in different directions. He reported gaining weight due to testicular cancer and its treatment. From discussions throughout the interview, it seemed that Alan was concerned that people might judge or blame him for being overweight. Perhaps Alan's frustrations may also be linked to a feeling of it being unfair or unjust that he was faced with the prospect of other health problems such as diabetes, in addition to testicular cancer.

Many participants described feeling disappointed to discover that it might take a long time to recover from the ordeal of cancer treatment:

"My employer didn't UNDERSTAND em:m that I still wouldn't be 100% for a long period afterwards. There's not that much information about after and as you come back they kind of think oh HE'S BACK TO NORMAL and I kind of DIDN'T KNOW MYSELF really. I mean looking back I can kind of think actually I wasn't wasn't 100% and maybe I was pushing myself too much because people kind of expect you to be"(John, 2:27)

The emotional impact of these wide-ranging uncertainties was described as "*being on edge*" and "*unable to relax*". Many participants also indicated that they felt their confidence was diminished. The most vivid depictions of these anxieties came from the participants who had more recently finished treatment. For example, Dave, who finished treatment 18 months before the research interview, compared his experience of deep uncertainty to the last day of work before going on holiday:

"You know you've got HUNDREDS of things to do (hm:m) and you don't know where to start, and you feel you've got to rush everything and you just yeah... you go 'I can't sit down, I can't sit down' and I felt all the time that I couldn't... I HAD TO RUSH EVERYTHING. There was always something to, 'I've got to do this, got to do that' (hm:m) there's always something else I've got to do that's MORE IMPORTANT than anything else and then when I'd do the thing I was doing I'd go well actually there is nothing to do... my head was SPINNING with stuff that I thought I had to, I felt I had to do. I mean I couldn't sit down at home. I couldn't just sit down... it was a bizarre feeling all the time just feeling like all the time I had to be doing something"(Dave, 9:13)

Dave's words seemed to suggest a feeling of being overwhelmed, struggling to know what mattered most or what to prioritise. It sounded as if he felt he was racing against the clock, as if time was running out, which may relate to the topic of mortality.

3.4.2 Internal conflict

Most of the participants seemed to share Dave's sense of being "*in flux*". Several of them described a sense of internal conflict, or tension between different "*parts*" of themselves:

"...There's lots of sides that kind of that you're constantly... but you you your MIND'S constantly at ODDS to each other that like you your mind's sort of... your rational mind is going you're fine, you're going to be fine, just get back to a normal life, go back to uni, study, kind of do all that, and then the other half of you is going no no this could be it, go out, like studying doesn't matter (hm:m) like if you do die in six months of cancer then you've WASTED ALL THIS TIME and (hm:m) and your... it's not kind of one thought it's just it's the fact that from MOMENT TO MOMENT your mind just JUMPS ABOUT and you you constantly, depending on your mood... and your mood constantly changes" (Dean, 15:20).

Dean and many other participants created the impression of an internal dispute between two instincts or drives, one to "*get back to normal*" and another to be changed by cancer. Most of these participants described the strongest drive as being related to moving back or maintaining a pre-cancer life, identity and mind set. They reported associating this with notions about holding onto what was familiar, wanting to reduce uncertainty and trying to limit change or loss:

"There was nothing, not a lot I could do really (hm:m) apart from just carry on as normal... and just get on as normal... DO normal stuff" (Phil, 3:32).

The second, conflicting drive, seemed to relate to moving forward and acknowledging that they were going through a profound experience that was likely to change them in some ways:

"CERTAINLY IT MADE ME REASSESS WHAT'S IMPORTANT TO ME and what I want to get out of life" (Mark, 5:5)

In the context of these uncertainties and inner conflicts, the prospect of change seemed to feel complicated:

"I mean like kind of... imagine one of these kind of kids' toys where you put a square into a square shaped hole. Going through cancer kind of turns you from a square into a circle or something and trying to slot back into where you were before CAN FEEL QUITE HARD but you've kind of GOT NO CHOICE, have you?"
(John, 12:34)

John's attempt to symbolise how he had changed and how the 'new' him might fit into his 'old' life was striking. He seemed to say that, despite feeling fundamentally changed, he had no choice but to slot back into his old life. John told me that he was the only 'breadwinner' in his family home at this time and he was responsible for paying the mortgage. Struggling to fit a circle into a square seems like it would be uncomfortable and subsequently John described how he experienced emotional difficulties.

3.4.3 Overwhelming emotions

Many of these participants spoke about experiencing extensive emotional difficulties and indicated that much of their experience of the world at this time was dominated by powerful emotions. Participants described a range of feelings including anxiety, stress, depression, sadness, anger, embarrassment and shame. Some participants suggested that these emotional struggles emerged when physical recovery processes were under way:

"As soon as I started feeling, started to feel better physically, you know feeling I could almost get through an eight-hour day at work and... not sleep for 12 hours a day and just you know... then that's when I started to feel you know, mentally a bit sort of, wobbly {spoken quietly}. It almost pretty much kicked-in at the same time (right). My body went 'eh you're starting to feel better now, your mind can start thinking about it now'"(Dave, 8:21)

It seems interesting that Dave, in a hushed voice, described his psychological state as "wobbly". I wonder if Dave was trying to conjure up an image of instability, vulnerability or perhaps even weakness. Perhaps it suggests a difficulty or reluctance to try to verbalise troubling emotions, an experience which other participants seemed to share:

"Everything just started to get a bit much really. I think I was obviously having anxiety attacks. I think things mentally were going the opposite way. I think work was getting quite hard again at that point. It was just everything really.

Things at home, things at work... I think it was all getting a bit much and it it... normally I'm able to cope, I mean life's not easy but I think it was because I was a bit weaker and more susceptible to that pressure was why I was suffering. I had that lower resilience maybe. I was... I'm not really too sure because I... I kind of... again I said to the doctors I originally self-diagnosed myself again... I said I think I'm having anxiety attacks. I'm I'm... struggling a little bit em:m"(John, 6:16)

Jon's words provide a vivid impression of how he grappled with distressing emotions and how overwhelmed he felt at certain moments. He seemed to be struggling to make sense of why he was feeling this way and he considered the roles that life pressures, psychological conditions and perhaps even his own 'weakness' might have played.

The range and intensity of emotions was reported to be profoundly challenging for some participants. Paraphrasing the title of Lance Armstrong's (2001) book, Stephen suggests that, of all the difficulties he experienced related to testicular cancer, it was the emotional turmoil that he found most troubling:

BG: So if we think about either writing a book about your personal experience of life after testicular cancer treatment finishes what would it be called and what would the main themes be in it? Or if we thought about making a Hollywood film about your experience again what would it be called and what would the main themes be?

Stephen: "...If I had to pluck a title out it would be "It's not about the cancer" or something like that because it would be about the emotional sides of after it rather than the going through it"(40:7).

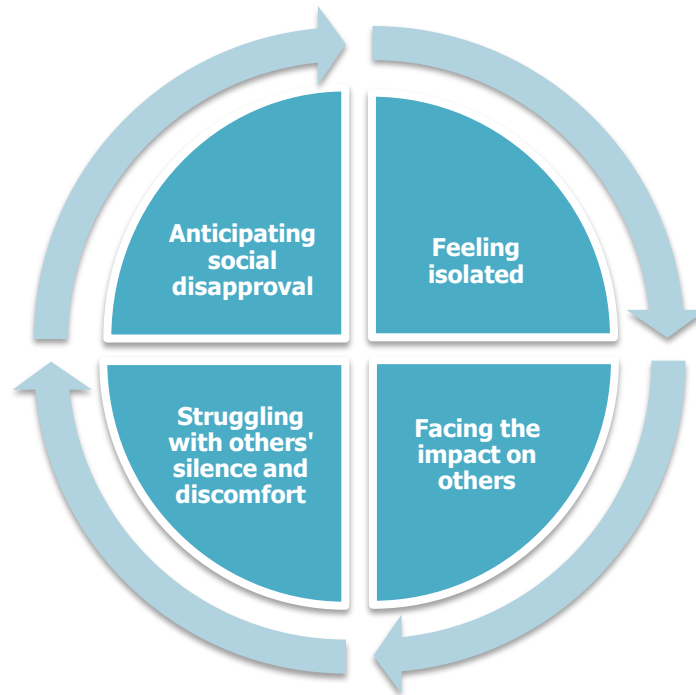
3.5 Relational disturbance

Each of the seven participants described experiencing changes in social relationships which they often associated with feelings of loss. This seemed to contribute to a feeling that cancer was having an impact on most aspects of their lives, that little was left unscathed. That is not to suggest that every facet of all of their relationships was damaged or changed. In fact, most participants expressed gratitude for the support they received from others in their lives:

"The wife was brilliant at sort of supporting me"(Dave, 7:9)

"My managers said 'take as much time as you want' you know... don't even come into the office or anything... so they were superb, so I couldn't have asked for a better company to be working for"(Phil, 5:6)

Figure 3: Sub-categories of relational disturbance



3.5.1 Feeling isolated

Several participants emphasised feeling alienated from others after treatment finished:

"ISOLATED. LONELY... yeah just just feeling out of place"(Dave, 21:32)

Dean, the youngest participant in the sample, who was at university during diagnosis, treatment and post-treatment, seemed to describe this sense of isolation even more intensely than others:

"AT 20 IT WAS MY BIG EXPERIENCE. It was the one thing that in a weird way that SET ME ASIDE from everyone else, it was the one thing with me and my friends that I was the only person... who had had that so it kind of set me apart in a weird way from... no-one else could relate to it, no one had been th... I mean people had had sort of had parents who had been through it but no-one had personally been through it so... like there was no-one to talk to about it in that sense and it kind of did set me apart but then as as time goes on... so it was kind of MY DISTINGUISHING FACTOR"(Dean, 33:2)

Dean's repeated use of the words "*weird*" and "*set aside... set apart*" seem to create an impression of considerable disconnection from others. During this passage, he also seems to be reluctant to say the word 'cancer'. I wonder if this might relate to how painful this reported isolation was for him, separating him from his peers and perhaps meaning he had, for a time, more in common with their parents' generation.

Dave described feeling separated, for a time, from colleagues that he had previously felt close to:

"Oh I went to the pub the other month and they'd all laugh and you'd feel... you know...they're not trying to isolate you but they're talking about things they've done where you've been away for the last five months. You'd feel a little bit of ah... it was almost like going back to work and STARTING AFRESH. You know, you know these people but not... it felt like you didn't know them as well"(Dave, 13:8)

At this moment, Dave seemed to feel like a stranger to people he knew well, as if their shared history was, temporarily at least, obscured. As he described this social experience, he seemed to speak with a palpable sense of loss.

All participants indicated that certain close friends or family members either distanced themselves or did not provide significant support post-treatment. The phrase "*you realise who your friends are*" was expressed by several participants. At a moment when participants described a great need for support, some seemed hurt and angry when reporting others' inaction or insensitivity:

"One thing it does make you realise is is who YOU DO MEAN SOMETHING TO, WHO YOUR TRUE FRIENDS ARE (hm:m) because there's people that I've been close to for years... YOU WANT TO SEE PEOPLE that that you've cared for all your life, good friends, and there's one guy who lived half a mile away from me who I never saw, who I've been knocking around with since I was really young. NEVER SAW HIM. NEVER GOT A PHONECALL. NOTHING"(Stephen, 25:6)

"Some of my family were pretty awful throughout the entire time. I love some of them and others I don't always see eye to eye with. Like even when I had the all clear, or that was the term I WAS USING, em:m some didn't seem PARTICULARLY BOTHERED and it just... that was one thing that kind of just THREW ME"(John, 13:12)

3.5.2 Facing the impact on significant others

The perceived impacts of their cancer experiences on the lives of significant others, including parents, children, siblings and partners, seemed to be a source of considerable concern for most participants:

"It was quite upsetting to see how my family was reacting cos they were REALLY WORRIED and... stressed out" (Phil, 2:34)

"I WAS MORE WORRIED ABOUT MY KIDS THAN WHAT I WAS ABOUT MYSELF you know. I wasn't particularly worried about dying. I was worried about what would happen if my kids had to grow up without a dad" (Mark, 4:27)

For several participants there seemed to be a sense of feeling responsible for, and guilty about, how their cancer seemed to be affecting others:

"It makes you feel even more guilty about the fact that you're YOU'RE PUTTING THEM THROUGH IT" (Phil, 5:12)

"You know my wife was getting tired because when I was feeling rough she was obviously you know DOING EVERYTHING" (Dave, 17:20)

Sometimes participants struggled to speak about this topic and became visibly upset. It seemed particularly anxiety-provoking and distressing when it related to children:

"...Used to feel GUILTY QUITE A LOT because of the effect it was having on them especially I mean... we went to see my son doing a play and he was meant to have a leading part and he just looked up, saw me... and just burst into tears... and came running over to me... in front of everyone, I was like oh... I felt terrible that night" (Dave, 12:24)

3.5.3 Struggling with others' silence and discomfort

Most participants mentioned having experiences where other people did not ask them directly about cancer and did not seem to want to speak about it:

"NONE OF MY COLLEAGUES HAVE EVER ASKED ME [ABOUT IT]" (Dave, 27:5)

"Even now people don't really want to talk about it" (Alan, 23:24)

This seemed to be associated with feeling hurt and confused about why important people in their lives did not ask them about it directly. This seemed to make them wonder about the nature of these relationships and whether others cared about them.

Sometimes they learned that others had enquired about their wellbeing to a third party, for example, a partner, friend, parent or even the Human Resources department at work. This was described as an uncomfortable experience:

"BEEN ON THE RECEIVING END OF PEOPLE CREEPING AROUND YOU and asking someone behind your back" (Dave, 28:21).

Most participants also described a sense that other people seemed uncomfortable, uncertain and ill at ease around them. This seemed to be interpreted in indirect ways, such as from non-verbal cues and ways of speaking and it appeared to reinforce feelings of isolation:

"PEOPLE TIP-TOE AROUND YOU" (Dave, 18:21)

"It's just something I picked up (hm:m) and people being like sort of... treading on egg shells... because they know I've had cancer so they sort of you can tell they're... the change in in their attitude when they're talking about it sort of thing em:m... so it's not a bad thing at all really, but it's just sort... then you sort of feel a bit... tiny little bit self-conscious because you think... oh cos they know cos I've had cancer sort of thing" (Phil, 22:27)

In addition to potentially feeling guilty and responsible for the impact cancer was having on others in their lives, some participants also felt guilty about these social interactions. They seemed to feel that they had become a source of social discomfort:

"You know if I'd said I had lung cancer or something then I'm not sure there would have been such an awkwardness because MAYBE CANCER OF THE SEXUAL ORGANS IS JUST A LITTLE BIT MORE... Christ I don't know... em:m bit more of a TABOO about it. I mean there shouldn't be but it's sort of the SOCIAL AWKWARDNESS" (Mark, 14:12)

Reflexive note: Personal reflexivity on the interview as a social interaction

There seemed to be moments of social awkwardness during the research interviews, where our interactions perhaps mirrored this social awkwardness they described. Primarily, this seemed to occur when discussing topics such as sexual performance, erections, prosthetic testicles, masturbation or depositing sperm were mentioned. This became apparent at times when participants struggled to get their words out, spoke in stop-start sentences, smiled or laughed or used quite indirect language:

"I mean FERTILITY is another thing that they say is affected by chemotherapy. They sa... I was told I stood a 30% chance of being infertile... so I had to go through the sperm bank. I went there before the chemotherapy... and em:m... I successfully managed to make a deposit {laughs} em:m"(John, 3:17)

In the first interview, I was aware of feeling uncomfortable at certain moments. Looking back at the transcript this seemed to come across in my silence, in the fact that I did not ask directly about sex, and also when I seemed reluctant to 'name' or speak directly about related topics. My own upbringing in Ireland towards the end of the 20th century did not include much practice at speaking openly about sex. Having noticed this issue, I asked directly about sex in subsequent interviews, tried to be open to these discussions and to encourage participants to speak about topics if they wished. However, there may only have been certain aspects of these intimate topics which participants felt willing to, or comfortable in, sharing with me.

3.5.4 Anticipating social disapproval

Most participants described moments of anticipating criticism, disapproval or rejection from others. This seemed to involve imagining that others were thinking about them in quite a harsh and judgemental ways.

Dave elaborated on a feeling of being closely observed or scrutinised by others:

"I mean one stage at work I felt like every time I was doing something I felt like I had EVERYONE LOOKING AT ME and it felt like everyone was seeing if he was up to speed still at work, seeing if he can still do that. I felt... and it was probably my imagination because of feeling slightly out on a limb I felt like I

was being watched at work (hm:m)... has he... can he still do stuff?"(Dave, 19:2)

Sometimes this perceived criticism related to topics such as talking too much about their difficulties, for bringing other people down or being "a burden":

"People want to know about and people want to be there for you eh they don't know what you're going through and you kind of don't want to tell them because you don't... not you don't want to bring them down but a lot of it is very personal (hm:m) and it's about your own body and sort of a lot of it you kind of think well, not it's no-one else's business but it sounds a bit sort of when you think about it like you're complaining too much. Like the more you... like you talk about it a lot and there's only so much I've always felt that people could listen to (hm:m) because you start to talk about the same things over and over again"(Dean 12:30)

Others imagined being criticised for letting people down or not being good enough. This appeared to be linked to feeling that they were potentially replaceable:

"Because em:m I'd recently got with the then girlfriend em:m I suppose it was wanting to impress her and look as well as I could and then looking back at the photos I didn't, I didn't look you know VERY WELL REALLY, so it was eh... again the frustration at not being able to look as well as I could... or can and em:m I dunno, it's that feeling of sort of let, of LETTING HER DOWN"(Phil, 16:10)

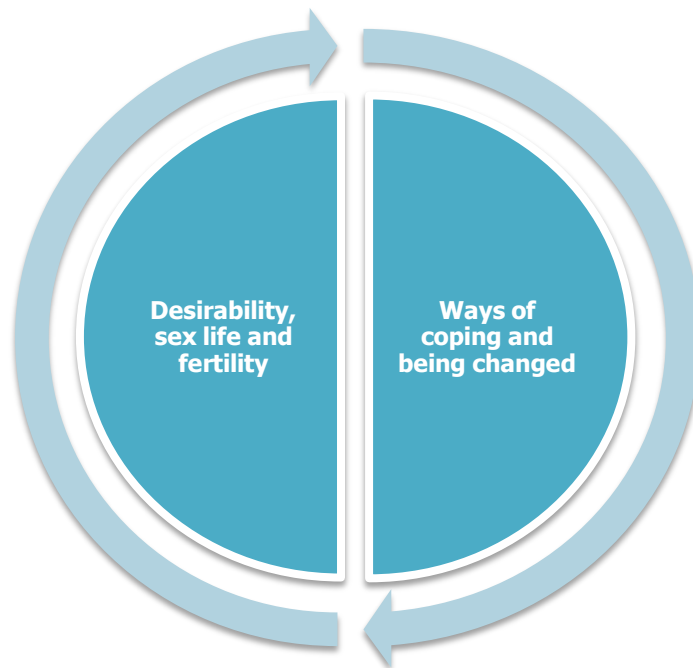
"There was always this little bit in the back of your mind you know d... you know how the job market is, there's always someone else out there who could do your job, I was just... I was starting to think about... I started to, I started to.... I never told my wife that but I think I started to get this little thing in the back of my head (hm:m) 'you're gonna have to go back to work at some point' {spoken quietly} they've been without me for four months, they'll probably think well if they can do without me for four months they can probably carry on doing without me for four months (hm:m) dunno if that started to creep in in the background a little bit maybe"(Dave, 11:11)

These experiences seemed to suggest that participants may have felt quite awkward, insecure, and vulnerable about aspects of their social relationships.

3.6 Contested masculinities

All of these participants reported that life after treatment included feeling that their masculine status or identities were threatened. The phrase "*less of a man*" was expressed by all seven participants.

Figure 4: Sub-categories of contested masculinities



3.6.1 Desirability, sex life and fertility

At a fundamental level, the loss of a testicle was described as bringing their masculine status into question. Dean and Phil's words illuminated a fear that they might become defined, by others, as less of a man because of this:

"Having only one testicle, less of a man" (Phil, 31:11)

"I worried that I would be the guy with one testicle" (Dean, 41:3)

The idea of being known as "*the guy with one testicle*" sounded like a frightening prospect for Dean. It suggests being permanently labelled by this experience and defined as diminished or less than other men. I wonder if perhaps Dean's words also imply the expectation of a lack of compassion from others, that they would mention the absence of a testicle, and not the fact it had been lost due to cancer. However, not all participants shared this concern. Although he described feeling that his sense of being a man felt threatened in other ways, Stephen indicated that losing a testicle did not seem to be a significant issue for him:

"One thing that did make me laugh when I was reading up about it was men saying they FELT LIKE HALF A MAN NOW THEY HAD LOST A TESTICLE {sounds perplexed} IT'S A TESTICLE! You look at me now and you wouldn't know if I've got two or one. It makes NO DIFFERENCE" (Stephen, 37:9)

Phil emphasised how the impacts of treatments such as chemotherapy made him feel more self-consciousness and less physically attractive:

"I just looked so different... quite pale and no hair and I'd lost my eyebrows as well so it was so... yeah quite alien-like" (Phil, 15:32)

From getting to know Phil during the interview, it seemed that his appearance was particularly important to his sense of himself as a man, and how appealing he might be to his partner. Comparing his appearance to that of an alien seemed to capture quite painful and disturbing experiences for him. The Oxford Dictionary defines an alien as *"unfamiliar and disturbing or distasteful... supposedly from another world"*. I wonder if this choice of words also suggests how disconnected and different Phil felt from others at these moments.

Alan lamented that he had *"lost the masculinity...the masculinity was totally gone"* due to experiencing gynaecomastia, an enlargement of breast tissue associated with hormone imbalances such as reduced testosterone. It seemed that struggles related to changes in his body contributed to him feeling like less of a man:

BG: You've talked about masculinity a couple of times... at one point you said you felt you'd lost your masculinity. Am I getting that=

Alan: "Well masculinity is kind of like, I dunno, I don't think internally I've lost my masculinity within myself because I do feel that...but it's the sort of overall body image, isn't it? You know? If I took off my shirt you would see these sort of man boobs here and that is you know... when I put on something that I really like and that part doesn't look right it kind of thinks, that's kind of another person's body. That's when I feel like I'm a 50 year old because they're sort of hanging there which they, which a 50 year old man would have that, not a 40 year old" (Alan, 36:11)

For a few participants, experiencing difficulties related to maintaining erection seemed to contribute to feelings of failing to live up to their hopes, and others' expectations, of masculine sexual performance and potency:

"It's just... I just had issues with the performance side of things and there was one incident when... I mean I haven't got like a eh:h.... as I said I'm single and I've had a couple of occasions where I did try to eh:h have relations with a woman and I couldn't and obviously that's that's {laughs} not a good thing. That's that's quite... it's quite difficult. I tried with both of them, I tried to explain that and I mean that could have been partly what got me down a little bit because I kind of... you try to do it and you can't and it it... YOU FEEL LESS OF A MAN FOR THAT" (John, 9:20)

John seemed to find it difficult to put words to this part of his experience. He laughed at a moment when remembering two painful memories. I wonder if this might be a demonstration of how difficult it can be to speak openly to others about these topics and how easy it might be to choose not to speak about them.

In this sample, three participants were single for the initial years after treatment, three were married or living with a partner, and one was in a new relationship. It is possible that participants who were single during the post-treatment period reported experiencing the greatest disturbance to their masculine identities. However, this is difficult to tell because two of these participants, Alan and John, both experienced additional side effects related to body image and sexual performance, which they felt negatively impacted their sense of being a man. They described worries about how they would be seen by potential partners and, sometimes, seemed to imagine future partners being quite scornful or dismissive of what they might have 'to offer':

"How's he going to fulfil me?" (Alan, 34:20)

"I said to somebody I maybe can't father children you know in a natural way we may have to go down that way. Is that gonna be OK? You know. Because I don't know if that's... because the fertility the sperm I've stored or not. I've got a high percentage it will but what if it doesn't work? Can you live in a marriage without a child? (hm:m) Those are the hard parts which even today I still put behind my mind and don't sort of bring back to the front" (Alan, 34:26)

Although the participants in long-term relationships reported fewer difficulties related to desirability or sexual performance, there were other aspects of life where they seemed to experience threats to their masculinities.

3.6.2 Ways of coping and being changed

Several participants spoke about feeling that the ways in which they tried to cope with life after treatment could result in a questioning of their masculinities. These ways of coping seemed to touch upon what they imagined was socially expected of a man in the aftermath of testicular cancer treatment. For example, most participants perceived that they did not have permission to express their emotional upheaval or to "break down":

"THE THE ASPECT OF MEN ARE JUST SUPPOSED TO DEAL WITH IT AND BE OK AND GET ON WITH IT... IT'S THE EMOTIONAL SIDE I STRUGGLED WITH. THE PHYSICAL SIDE OF IT I DIDN'T STRUGGLE WITH AT ALL. THE EMOTIONAL SIDE YEAH VERY VERY DIFFICULT. YOU DON'T REALLY KNOW WHERE TO TURN" (Stephen, 38:36)

Stephen helped to illustrate how complicated this topic could be. He explained how he felt restricted in expressing his own emotions by virtue of having previously held and articulated quite damning attitudes towards others experiencing emotional distress:

"See I've always been one of these people that when you hear the words depression and you hear all this kind of stuff... I'm one of those people that goes 'oh THEY'VE PUT THEMSELVES IN THAT... THEY'VE MADE THEMSELVES LIKE THAT. THEY JUST NEED TO PICK THEMSELVES UP AND GET ON WITH IT... That's when it's difficult to talk to family and partners about it because you had such a strong opinion about people you hear who are depressed and they're this and they're that (hm:m) and then you think 'they've got nothing to be depressed about, I don't get it'. But looking looking at it now I don't know the pressures they're going through and you don't... I'M A VERY NAÏVE FOOL" (Stephen, 10:23)

The impact that testicular cancer had on participants, and the ways that they might be changed, or choose to change, were also identified as factors that might present challenges to their masculine status. This could include the development of different parts of their personalities:

"Em:m In some funny way it almost makes you question... I think I've become more SYMPATHETIC to people, more EMPATHETIC to people than I probably was before treatment. And actually you know... this is probably COMPLETELY WRONG but they're probably traits that you probably wouldn't naturally yeah they would be more sort of feminine traits than what you would call masculine traits I guess. But I'd actually say I'd gone more the other way and not been too concerned about it"(Mark, 9:30)

For example, Mark made the decision, at a young age, to work part-time in his career on an on-going basis in order to allow him to spend more time with his family and to pursue a richer, more varied life. He described how many work colleagues seemed disapproving about this because it was not "*the done thing*" by men:

"It's actually quite hard at work because, you know, as a bloke, wanting to go part-time you you have a BIG CREDIBILITY GAP to get over. People don't understand why ANY man would want to work part-time (hm:m). IF YOU WANT TO WANT PART-TIME IT EITHER MEANS YOU'RE ON THE VERGE OF RETIREMENT OR ACTUALLY YOU'RE YOU'RE THE MOTHER OF YOUNG CHILDREN. Em:m traditionally. I GUESS SOME HM:M {laughs} SO THERE IS A BIT OF A CREDIBILITY GAP BUT SOME OF ME WAS LIKE WELL I WANT TO CHANGE THAT SO WHY NOT A BLOKE OF 38 WANT TO WORK PART-TIME? THERE'S NOTHING WRONG WITH THAT. But an element of me was just REBELLING against the norm in terms of what the work place was BUT actually it's quite challenging. Even at work not you still still do... you're working with people who still CAN'T quite grasp the concept that you're working part-time. Why would you want to be part-time?"(Mark, 8:25)

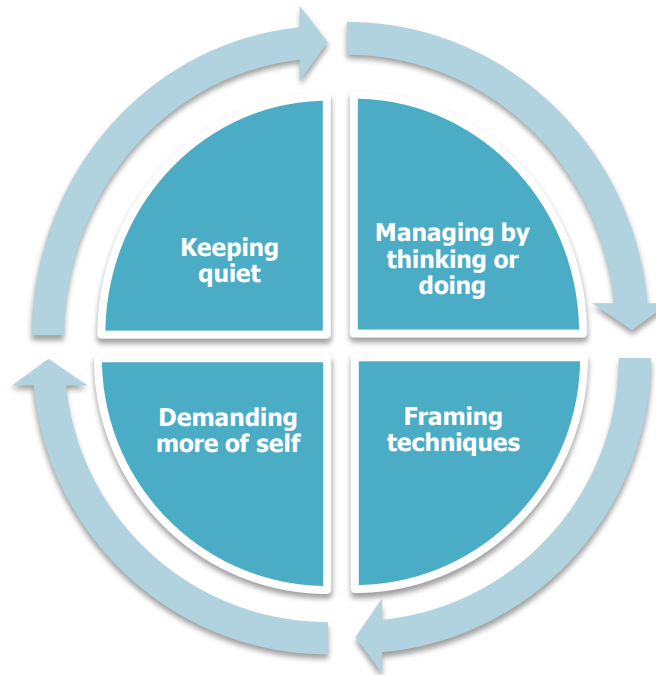
Here, Mark provided an interesting example of how the ways in which he may have coped with, or been changed by, testicular cancer seemed to have a public or social component. He seemed to describe mixed feelings, on the one hand feeling comfortable with making choices about his career that were not the norm, but on the other hand perhaps feeling somewhat troubled by the fact that these choices were being regularly questioned by others.

3.7 Finding "survival strategies"

Participants in this study identified a range of initial strategies aimed at managing the complex intrapersonal and interpersonal disruptions they seemed to experience.

Although physical survival was highly likely, most participants seemed to be feeling overwhelmed by post-treatment difficulties and were struggling to cope, or survive in that sense of the word. These strategies were reported to be quite instinctive, as if employed without much conscious reflection.

Figure 5: Sub-categories of finding "survival strategies"



3.7.1 Managing by thinking or doing

Although participants did not directly use these words, managing by thinking and managing by doing seem suitable ways to describe two broad approaches they outlined.

Managing by thinking appeared to involve participants trying to think their way through difficulties. It suggested they were engaged in extensive introspection or self-reflection:

"I didn't know didn't know what I was doing, where I was going in eh:h at that moment, what I SHOULD BE DOING, whether I should be going back to work, whether I should be getting back to normal, whether I should be having a lot of time out or whether I should be..and that might have been down to MY MINDSET CHANGING A BIT ASWELL... WHAT DO I WANT TO DO? (hm:m) and maybe at the time I couldn't decide and just got a bit confused and just sat around for for a good three or four months thinking... what next?" (Stephen, 2:25)

Here, Stephen emphasised the range of topics he was attempting to manage by thinking. Perhaps his words also suggest that managing by thinking and doing were quite enmeshed approaches. The repeated use of the word 'should' may suggest he was grappling with social rules, permissions or expectations. He also seems to highlight the possibility of tension between these 'shoulds' and his own personal 'wants'.

Participants engaged in managing by thinking seemed to find that it could be difficult to limit the amount of thinking they did. They could sometimes feel overwhelmed by a spiral of worrying "what ifs":

"I would say as far as it's FRUSTRATINGLY REPETITIVE that you DON'T WANT TO BE THINKING ABOUT IT but it's just NAGGING and you know you shouldn't be thinking about it and you you would do anything not to be thinking about it but you just can't help it... it's constantly just ticking away in the back of your head" (Dean, 24:26)

Some of the participants suggested that attempts to manage by thinking contributed to feelings of social isolation:

"Whereas most people lose weight, I actually put on weight because I spent a lot of time at home, I couldn't really leave the house because of the chemo and stuff (hm:m) so was sitting about, sort of moping, drinking a lot of beer, just not getting drunk but just sitting, nothing else to do so (hm:m) watching just REALLY BAD daytime television drinking beer... em:m my brother came back one weekend and he was like 'DEAN YOU'RE NOT IN A GOOD PLACE', he was like you're just... you need to get out of the house" (Dean, 25:5)

Perhaps Dean's description of drinking beer on his own, "moping", watching daytime TV and putting on weight suggest he saw himself as somewhat lost, lonely or in a hopeless position at this point in time.

In contrast, managing by doing involved not thinking about, or "dwelling" on, difficulties. It seemed to rely on participants keeping busy and re-engaging with pre-cancer roles and activities as quickly as possible afterwards. It seemed suggestive of a 'business as usual' approach:

"That was probably why I was so good at coping with cancer because I just GOT ON WITH IT" (John, 16:33)

"You can't stop doing everything can you? (No?) You can't PUT EVERYTHING ON HOLD and not do anything... you can't WRAP YOURSELF UP in a BUBBLE and stay indoors for a year, you've got to try and carry on with things and try and get back to normal to try and make you feel better that you're... doing stuff" (Dave, 4:12)

Dave's words suggest he felt he had no choice in the matter. Given that he had previously compared how exhausted he felt every morning to being "*hungover without the beer*"; I wonder if a part of him may have wished he could wrap himself in cotton wool and stay indoors for a long time.

Alan's approach to managing by doing involved taking "*small steps*"; which included visiting friends, going on a trip to London on his own, and attending a music concert in a crowded venue. He suggested that his religious faith helped him to manage life afterwards and visiting a holy site to give thanks was identified as another significant "*step*":

"Yes very small very small steps. Faith played a very strong role in that because I didn't have to question why this happened and where I was supposed to go. And all that sort of stuff. Because I had to, once I got over that then I wanted to make a journey to Saudi Arabia because that was my journey to say thank you to God.... You know giving me new life and that was another sort of emotional journey" (Alan, 13:9).

3.7.2 Framing techniques

Several participants described actions that seemed to be part of positioning cancer in a certain light, or constructing certain narratives about their approach to managing life after cancer treatment. For some participants this meant focusing on the point in time when, hopefully, they would get "*the all clear*":

"Obviously the doctors were quite good in telling you you're doing 9 weeks of chemo. If this doesn't work then there's one more operation, then then you should be ok, then we'll go from there so... you could sort of plan what you were going to do anyway (hm:m) em:m if all went well you.. I'd sort of given myself a goal, if the doctors were correct, that for an ALL CLEAR DATE" (Phil, 5:25)

Adopting a positive mind-set was identified as a central part of this for a few participants:

"When I was going through the treatment I was VERY POSITIVE. I mean... I think people were quite surprised that I just took it like it was just a bad cold and just got on with it. I was told what I needed to do and I did it. I was very DETERMINED" (John, 4:9)

The notion of using the experience for personal gain was mentioned by a few participants:

"There are so many things in life that are there to test us and I've just got to find a solution to everything that I'm given" (John, 17:14)

"I've used it as part of my LIFE EXPERIENCES to date you know, having all my career experiences, educational experiences and yeah I had a bloody great health scare as well, THAT'S given me experience as well" (Mark, 17:20)

These descriptions and approaches seem to be suggestive of the narrative of cancer as a battle or a war that must be won. I wonder if they may also be influenced by a philosophy of positive thinking that suggests there is no such thing as a problem, only an opportunity.

3.7.3 Demanding more of self

Being highly demanding, perhaps even unforgiving of themselves was another survival strategy adopted by several participants. Alan labelled it *"the self beat-up"* and it had the quality of a bullying teacher or coach. Almost all of these participants described how they blamed themselves for some of their difficulties:

"THAT WAS A COMMON FEELING OF NOT BEING ADEQUATE OR GOOD ENOUGH, AT WORK OR AT HOME, for a long period. DESPITE the fact of being in the back of your head saying oh actually you've just gone through this and you should maybe give yourself a break, but definitely yeah, definitely a feeling of being TOO HARSH on myself" (Dave, 34:16)

Alan seemed to feel that pushing himself was a part of what prevented him from sinking into a hopeless position:

"I could easily have just resorted to the sofa thinking I'm depressed, I can't do anything, but you know I didn't really want to go down that route" (Alan, 10:1)

It is possible that this approach relied on an underlying attitude that any difficulties they encountered were their own fault and that they 'should' be able to cope with what was happening to them. For some, this seemed to result in *"doing too much too soon"*. This seemed to suggest that they found it quite difficult to know what they were capable of and how much to push themselves. Dave elaborated on the topic of *"overdoing it"* at work:

"I went back to the HR department twice and said can I reduce my hours again? Because I'VE OVERDONE IT AGAIN. And they were they were really good...the trouble is you start to feel better and then instead of going well actually I'll give it another couple of weeks of doing the same thing I thought well, middle of next week let's just do it, let's go for it again and two weeks later you're like 'oh bloody 'ell' {laughs}... IF TRUTH BE TOLD even now I could probably, if there wasn't any driver into doing a full day I could still be doing eight 'til two or three now because, I've got to be honest with you, I still don't feel lively enough to be sitting there going I'm doing a full day but there's a bit of you that you know you've got to.... To prove to yourself that you feel better you've got to start doing things at home and you've got to start doing things at work and you want to start exercising and you want to get back to normal again" (Dave, 31:26)

It sounds as if, sometimes, it felt difficult for Dave to feel he could be *"honest"* or could tell the *"truth"* about what he felt capable of doing. Perhaps Dave's words suggest that demanding more of himself was somehow easier than trying to reduce his workload or accept his limitations at this time.

3.7.4 Keeping quiet

All of these participants explained that keeping significant parts of their experiences to themselves, and not discussing them with others, was part of how they attempted to manage life after treatment. The extent, content and context of what was kept hidden from others varied between participants. Mark reflected that, in the initial post-treatment period, he did not want to say that he had testicular cancer:

"I think when I first had it and people used to ask what have you had? And I'd say CANCER but I'D NEVER SAY TESTICULAR CANCER. I'd say CANCER. And they'd go 'oh right' {wincen}. And INEVITABLY the question is well 'what sort of cancer did you have'? And then that would be the 'oh I had testicular cancer'.

And it was always a... at the outset it was always a... it was... you felt I dunno ashamed somehow”(Mark, 12:7)

For others, it seemed to relate, primarily, to aspects of their sex lives. Phil spoke of desperately wanting to avoid disrupting the first few months of an intimate relationship that began shortly before diagnosis:

"I thought I don't really wanna talk to her too much because..... you know... having, having the operation in a sensitive area (hm:m) so to speak em:m it was something that I think I don't think she'll wanna know anyway really em:m it was something... and especially being be a a new relationship, I couldn't really talk to her too much em:m because it was the same thing that went on, I didn't really want to PILE IT ON TO HER (hm:m) sort of thing so em:m it was just yeah maybe just em:m PROTECTING THEM FROM MY WORRIES"(Phil, 6:14)

As previously mentioned, several participants seemed reluctant to speak about issues such as erectile dysfunction:

BG: "Were there parts of your experience that you didn't share with people?"

John: "Em:m... the... em:m the... erectile dysfunction side of things very few people know about. I did.. I have told... I mean... I haven't told my family I've got any of those problems because I didn't feel like it was something I could talk about with them, but I have tried to talk to some female friends em:m... some of sort of gone 'nah that's a bit too much for me' I mean... more to the side of saying 'I don't really understand, why don't you talk to a guy about it?' But sometimes it's not talking about specifically... I mean guys wouldn't always understand as much either because they haven't been through it"(John, 19-20)

Most of the participants spoke about keeping quiet about their emotions after treatment finished. Often this seemed to relate to emotions such as sadness, hurt, anxiety or anger. There seemed to be an element of feeling that these emotions were not acceptable, to themselves, others or both:

"I used to cry and if I cry it's to myself not in front of any not in front of anybody"(Alan, 29:18)

"I remember standing at my kitchen and looking out at the school near us. And there's always parents picking up their kids and there was like a dad walking along with his kids at a similar age to mine. And for AN INSTANT I was like SHIT WHY IS THIS HAPPENING TO ME? WHY CAN'T IT HAPPEN TO YOU? WHY HAS THE ROLL OF THE DICE MEANT I'VE GOT IT AND YOU HAVEN'T? THIS ISN'T FAIR. YOU SHOULD HAVE IT AND I SHOULDN'T. And I felt TRULY BLOODY AWFUL about thinking that because all of a sudden... like I've said I wouldn't wish it on my worst enemy, but here I am wishing it on someone I don't even KNOW... who has GOT KIDS.. and you think bloody hell that's JUST AWFUL... I wouldn't... THIS ISN'T ME... this is NOT WHAT I'M ABOUT... and actually that's a REALLY NEGATIVE EMOTION. This is not helping me at all, feeling anger and wishing it on someone else is not HELPING. It was something I'm just embarrassed about. So I didn't really... never really shared it"(Mark, 27:30)

It sounded as if Mark felt a maze of complex and confusing emotions at this time. He seemed to communicate an anger about the unfortunate "roll of the dice" and feeling of being singled out in getting testicular cancer. It sounded as if he found it difficult to allow himself to feel this anger and he judged himself quite harshly for having these feelings. I wonder if perhaps he and other participants expected that they should be perfectly rational and reasonable in how they felt post-treatment.

3.8 Developing new perspectives

Participants in this study identified other approaches to managing post-treatment difficulties that were based on creating new perspectives about themselves, their relationships and their lives. These approaches were described as more consciously chosen and a product of reflection.

Figure 6: Sub-categories of developing new perspectives



3.8.1 Locating signs of recovery

All the participants spoke about searching for signs of recovery or tangible 'evidence' that they may be coming to terms with aspects of their difficulties or indeed that some of the difficulties might be subsiding. Participants spoke in terms of "*milestones*", "*pivotal moments*" and "*epiphanies*". For all of these participants, the passage of time seemed to incorporate a feeling of recovery, in that worries about worst case scenarios had, generally, not come true. Dave described reaching the 12-month mark post-treatment was an important point:

"IT'S A BIG LANDMARK TO GET TO" (Dave, 37:37)

Participants were quite individual in the signs of recovery that felt particularly meaningful to them. It is possible that they were related to a sense of improvement in an aspect of life that had felt most troubling to them personally. For example, Phil seemed to experience a sense of recovery related to his appearance:

"My hair had started to grow back and I could start being active again" (Phil, 38:14)

Referring to ideas about masculinity, Mark identified an influential encounter with another man diagnosed with testicular cancer:

"He used to do Iron Man competitions, a real sort of man's man... a big guy. And THAT sort of ... I guess THAT helped because actually you think crikey well if he's got testicular cancer it's no, it isn't a big deal" (Mark, 13:23)

I wonder if perhaps Mark is describing some unspoken assumptions or fears about why some men got testicular cancer and not others. Did he, at one point, assume that it was not something which affected highly masculine men? Meeting this "man's man" and admiring his physical accomplishments may have helped him to challenge these ideas.

Re-engaging with valued social roles seemed to help many participants, including Dave, to feel that things were improving:

Dave: The first big project I did when going back to work because I kind of had that as a milestone in my head for work purposes (hm:m)... and once I did that I felt mentally in my head better that I'd achieved something, that I'D PROVED SOMETHING TO YOUR COLLEAGUES but then that's probably mentally me putting too much pressure on myself em:m=

BG: Maybe I suppose that proves something to yourself as well?

Dave: Yeah it proves you can... you still can work and still fit in the team and do the job that you've been doing for the last eight years, and the four months you've been out of it have not affected things... so that certainly did help me to feel a bit better" (Dave, 42:13)

Stephen elaborated about how social interactions encompassed signs of recovery:

"... No-one now comments on my actions and attitudes and the way I'm doing things so I must be all right again. Like they used to do...cos people were really pointing it out before" (Stephen, 11:3)

For Dean, this process included confronting fears, such as being naked and having sex for the first time post-treatment:

"The first time I had been naked in front of anyone and she didn't notice... I think you just need something like that to shock you out of it" (Dean, 26:4)

Locating signs of recovery seemed to suggest the possibility that their intrapersonal and interpersonal experiences did not always have to be dominated by testicular cancer. They appeared to indicate the possibility of hope or improvement in the future.

3.8.2 Processing losses and gains

Attempting to reflect on and acknowledge what was lost and also what was gained, post-treatment for testicular cancer, was another approach to developing new perspectives. A few of these men mentioned the feeling of having had both bad and good luck in getting testicular cancer at an early stage:

"So I kind of found it a bit weird that I know yeah I know I have had cancer but I've got the... I had the.. the easiest one to cure, at a very curable stage"
(Dave, 25:24)

Dean highlighted how, for him, this involved acknowledging and accepting some of life's inherent risks or dangers. Perhaps this involved re-engaging with life and attempting to let go of some of the fears associated with not being in control:

"LIFE IS CHAOS and {laughs} why worry about things? Like, it's that mentality of like they say you shouldn't ride a motorbike because you might come off and kill yourself but you're statistically more likely to be hit by a bus but that doesn't mean you shouldn't cross the road {laughs}. So I think LIFE IS DANGEROUS IN A CERTAIN SENSE so you might as well go and embrace that chaos and be around it... I think you do sort of LET GO OF SOME OF THE FEAR of getting ill and sort of, there is a side of it that's whatever happens happens so why worry about it?"(Dean, 27:24)

All of these participants spoke in ways that suggested that had become more aware of their mortality and that this was part of a new way of thinking about life. It seemed to be associated with a desire, or need, to try to make the most of their lives:

"You just take this, grab opportunities really because you don't know sort of what's around the corner do you?"(Alan, 44:12)

"If I wasn't doing that I'd be like... well that's good you had that, all you're doing now is WAITING UNTIL THE NEXT TIME YOU GET SOMETHING LIKE THAT... cos something like that is going to happen AT SOME STAGE, whether that's 10 years, 20, 30, doesn't matter, it's going to happen. Why wait for it?"

Why not do something... you know I'm not prolonging life by doing a Masters but at least I'm doing something with it (Mark, 24:36-25:4)

"You do kind of get a spur to go out and just do things that you always wanted to do because THERE MAY NOT BE A TIME TO DO THEM LATER" (Dean, 29:1)

In addition, all of these men spoke about taking steps towards becoming more active in making choices and decisions about their lives. This seemed in stark contrast to the feeling of being unprepared to make choices about their lives in the immediate aftermath of "the whirlwind" of diagnosis and treatment:

"IF YOU SEE SOMETHING YOU WANT I'D GO AND GET IT NOW. IF I WANT SOMETHING NOW I'LL GET IT. THERE'S NO TWO WAYS ABOUT IT. NO MATTER HOW HARD OR WHERE IT IS I'M GOING TO HAVE THAT" (Stephen, 31:3)

Phil, Stephen, Mark and Alan made fundamental career changes, including moving jobs, searching for an employer that matched their personal values, changing career and re-evaluating the importance of work in their lives:

"I went from a six day a week to five days a week to shorter hours. Yes less money but enough money to pay my mortgage and enough money to do what I had to do. So I had that fine balance of work and life (hm:m) whereas before it was COMPLETELY WORK. I was working six days a week, eight o'clock finishes, nine o'clock starts. Didn't care. But I was earning very good money doing that but then once you go through this you think 'I don't really care'. I just want enough to be able to do what I want to do" (Stephen, 12:20)

Perhaps Stephen is describing a sense of having permission not to live up to the "shoulds" or social pressures he seemed to previously feel overwhelmed by.

Part of this taking stock of their life post-treatment involved acknowledging what they felt were substantial positive aspects. Almost all participants reported a heightened self-respect and appreciation for themselves post-treatment, seemingly based on acknowledging what they had been through and how they had found ways to cope with considerable disruptions:

"... I DON'T WANT TO GO BACK TO HOW I WAS THEN. I PREFER THE PERSON I AM AND I GENUINELY THINK I'VE CHANGED A LOT FROM THAT PERSON..."

MORE SO IN MY ATTITUDE AND THE WAY I AM AND THE WAY I'LL TALK AND I'LL HAVE A DEBATE ... SO WHEN I LOOK NOW I DO PREFER THAT... I DON'T WANT TO GO BACK TO THE PERSON”(Stephen, 35:17)

"It is it is a confidence thing. It's also sort of a pride thing as well (hm:m) you feel you're a member of this sort of exclusive club I guess. I think well actually I've seen that off and dealt with it and actually if it comes back, it comes back, and I'll deal with it again. But it.. so it is quite it is quite a lot of emotion actually. I never really expected to feel proud of it”(Mark, 3:4)

Participants also described feeling that there were positive developments or improvements in their relationships with others. This seemed to include feeling more strongly bonded to certain others, and believing they had become more caring and compassionate towards others as a result of their own struggles:

"My relationships were (pause) they've become very strong (hm:m). They learned more about me, I learned more about them. The good friends remain. Actually no actually none of them departed in that sense. They just said you're sort of inspirational in what you had sort of conquered and what you you know what you were concerned about they understood every journey (hm:m) and what I was going through (hm:m) you know?" (Alan, 27-28)

"THAT'S ONE OF THE BEST THINGS THAT'S COME OUT OF IT. IT'S MADE ME LOOK AT THINGS DIFFERENTLY WITH WHAT OTHER PEOPLE ARE GOING THROUGH AS WELL. And again it's the thing of someone doing that little thing to help"(Stephen, 26:21)

Knowing Stephen from the interview, developing the compassionate side of his personality felt particularly significant for him, given how he regretted previously speaking about depression and emotional difficulties in quite a judgemental way.

Several participants expressed the idea that gains and losses seemed to be sometimes interlinked:

"I JUST WANT TO GO BACK TO TO FEELING NORMAL. I HAD NO FEARS BEFORE. YOU DON'T BELIEVE THAT ANYTHING LIKE THIS CAN HAPPEN TO YOU. SO I WANT TO GO BACK TO THAT... but unfortunately I don't think you can ever go back to that {spoken quietly}. Now you have that fear of could it

be coming back? You have them days when all of a sudden you don't feel right and you feel worried but that's what I mean... when I say go back to I mean just go back to normality because I do miss that. I still have my days where I think THIS IS HARD (yeah). We all have a a low day but I mean THE LOW DAYS NOW ARE LOWER THAN I EVER HAD BEFORE (yeah) BUT I THINK THE HIGH DAYS ARE HIGHER THAN I EVER HAD BEFORE. BEFORE I WAS A VERY FLAT PERSON. Before it was a bit more there {makes gesture of a flat line} whereas NOW YOU HAVE YOUR UPS AND DOWNS {motions up and down}"
(Stephen, 35:24)

Thus, these reflections on self, relationships and life seemed to allow space for the acknowledgement and acceptance of both post-treatment gains and losses.

3.8.3 Breaking the silence

Most of these participants described how, over time, they all sought ways to speak about aspects of their experience that had been previously hidden from others:

"I I think that the longer it goes on as well that em:m the more personal stuff that you don't want to tell people you do start to tell people because it seems less personal the more time that goes on"(Dean, 24:3).

That is not to suggest that speaking about their experiences was easy or always well received by others. Some participants found that their attempts to speak about their experiences could sometimes be misunderstood or even perhaps invalidated by others:

"I don't really like my body image but then everybody said to me you know you should be fortunate that you're alive. I said yeah but when you're at 32 or 33 you sort of want to bounce back to what you originally were but you sort of can't do it and that's taken me a good six, seven, eight years to sort of get back"(Alan, 6:22)

John seemed to indicate that he found it difficult to speak to men about his concerns:

"Sometimes it's easier to talk to women about things, some blokes struggle to... if it's not about football or drinking they don't want to know {laughs}. I've kind of ended up with more close female friends than blokes"(John, 20:4)

By contrast, although he reported speaking openly about testicular cancer to men, both those he knew and strangers, Phil seemed to feel reluctant to speak to women, particularly those he was attracted to, for fear of being judged to be less of a man:

"I'M QUITE OPEN WITH LADS ... and em:m with the girls I dunno maybe they'd think you're less of a man {spoken quietly} Is that, is that why? Cos I suppose looking at who... the lass... I quite like her as well (hm:m) so maybe I didn't really want her to think em:m that there's something wrong with me" (Phil, 30:9)

A number of participants described how humour could be an important part of helping them to "open up" and talk about their lives:

"THE BIG QUESTION everyone asks, cos I'd like long shoulder-length hair back then, everyone would ask, did you lose your hair? (hm:m) Which when you've just LOST A TESTICLE seems like the stupidest question. Everyone gets really concerned with hair (hm:m). 'Ah did you lose your hair?' It's like 'NAH I LOST A NUT' (hm:m)... still got the hair {laughs}'... and you you meet these really weird people so my book was going to be called 'This Product May Contain Nuts' {both laugh}...the central theme would be the kind of... the dark humour behind it" (Dean, 37:1)

Several participants emphasised how the topic of humour seemed to help facilitate conversations about their experiences:

"I think that, I think if you can get a laugh out. I mean a lot of the stories are quite self-deprecating because they're me being in very awkward position {laughs} and having to go through very awkward things but... em:m.... .hh (7) the... yeah I think that sort of it's kind of a problem halved is a problem shared kind of thing... like you share a story and people laugh and it makes it from an awkward story to kind of a shared story and it gives you a good gateway to talk about more serious things because if people know it's not going to be completely awkward, they're more likely to listen and care and share so it's a good sort of it it's good to kind of keep your sense of humour and nice to be able to share stuff in a funny way because it distracts away from the fact that you've been through a terrible thing" (Dean, 37:25)

Given that Dean, the youngest participant, was perhaps most expressive about feeling set apart from his peers, it is interesting that he also seemed to be describing quite

sophisticated uses of humour. I wonder if perhaps these were necessary developments in order for him to 'bridge' a substantial gap to his peers?

3.8.4 Searching for an enduring connection

In contrast to narratives about "moving on" from or "getting over" difficulties, several participants reported a desire to try to find ways to remain connected to their experience of testicular cancer:

"I mean this is CRAZY but I probably wish I could have more THIS KIND OF CONVERSATION with my wife. We probably haven't I'd say... and it's em:m yeah it probably just turned out to be the status quo... just the way we moved on. We just don't... em:m I dunno... funny how you ask why did I volunteer when I saw the advert... it's almost because ACTUALLY I STILL WANT TO BE TALKING ABOUT IT... I STILL WANT IT TO BE PART OF MY LIFE... actually and there's... are there other people that I can talk to about it? Actually THIS was a great way of of sort of coming in and talking about it" (Mark, 29:21)

There seemed to be several other expressions of this desire to remain connected including taking part in fundraising activities for testicular cancer, giving out educational leaflets about testicular self-checks and facilitating a local male cancer support group:

"Young men should be talking about and knowing about it. So em:m since obviously I've been diagnosed and I've had the treatment and everything em:m I've been doing work with {charity name}, raising money for them (hm:m) and I've been doing em:m events where I've raising awareness, so I'll give out leaflets now and again at em:m carnivals or you know so just really speaking to young men em:m... like I was and and let them know that, you know, they should be checking themselves quite regularly and... cos it was something that we never really. We heard about checking ourselves but we didn't really think about it too much" (Phil, 1:13)

Mark spoke about choosing to get a more permanent mark or reminder on his body:

"Mark: I actually ended up getting a tattoo too

BG: Can you tell me what you got?

Mark: I can show you. This was a Lance Armstrong thing as well because it's the Live Strong banner around my arm with the date of 2007"(Mark, 4:16)

Most of the participants seemed to describe their decision to take part in the research as a way of trying to remain connected to their experience of testicular cancer. They also described a belief that more needed to be done to help men after treatment finished and wanted to share their experiences as a way to contribute to such an endeavour:

"My little way of trying to help... making a difference"(John, 1:17)

"I still feel not enough is being done"(Alan, 1:17)

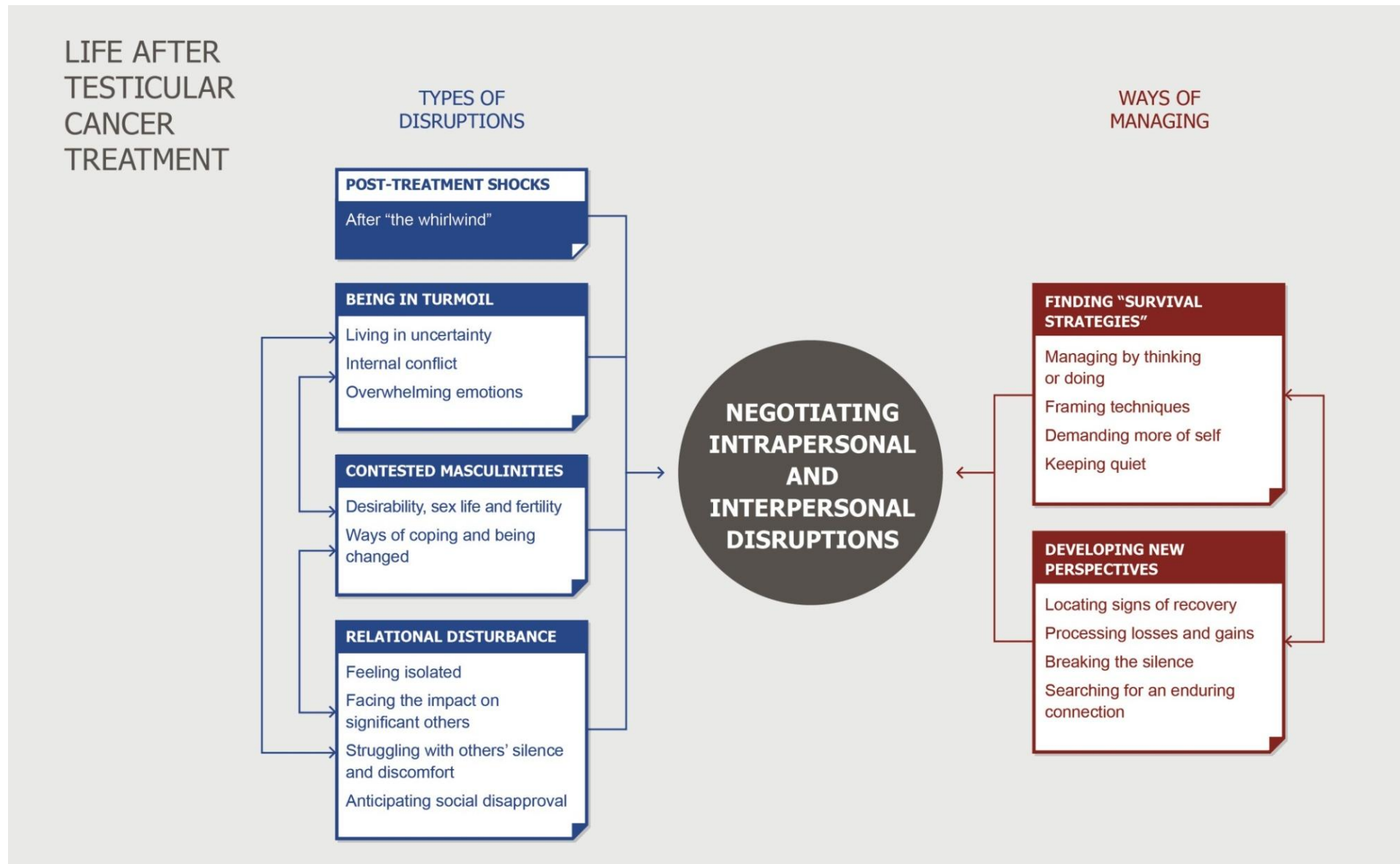
"A lending ear to someone who doesn't want to talk to their family about their worries, which is how I was feeling"(Phil, 34:6)

Despite beginning with an enforced and unwanted experience, at these moments, these men seemed to be describing the desire to remain connected to what happened to them, and to remember their experiences of testicular cancer and life after treatment.

3.9 A model of life after testicular cancer

This proposed model is based on the premise that life after testicular cancer treatment involves **negotiating intrapersonal and interpersonal disruptions**. It is possible to group the six categories detailed in this analysis under two distinct headings: the types of disruptions (**post-treatment shocks, being in turmoil, contested masculinities and relational disturbance**) and the ways of managing these disruptions (**finding "survival strategies"** and **developing new perspectives**). Further exploration of the possible links within this model are discussed after the presentation of a schematic (figure 9).

Figure 7: Schematic of a grounded theory of life after testicular cancer treatment



The six categories described in this analysis, and these two ways of grouping them, seem to be fluidly interconnected and mutually-influencing.

The shocks that occurred **after "the whirlwind"** of diagnosis and treatment seem to mark the beginning the post-treatment phase. This category seemed to relate to a specific time, the initial weeks and months after treatment, and the start of the difficulties that these participants experienced.

There seems to be a close association between the intrapersonal disruptions categorised as **being in turmoil** and interpersonal dimensions outlined in **relational disturbance**. For example, citing an intersection of culture and gender, Alan explained that both he and his brother were involved in creating a silence about testicular cancer:

"I mean the Asian community are even further behind on that. Me and my brother never talk about that"(Alan, 47:1)

While these categories are presented separately, participants described how difficulties in one part of life could have ramifications for other domains. For example, John believed that social isolation (**feeling isolated**) contributed to his **overwhelming emotions**:

"MENTALLY I think I did deteriorate afterwards. Because you kind of don't have as much support from the hospital, you don't have so much support from your friends, cos they they're great, I mean I couldn't have done it without them, but you kind of get all of that support as a peak and then it slowly drifts, goes from under you with... and with the testosterone and fatigue it did... it did get very hard about a year afterwards"(John, 5:13)

Similarly, Dave wondered if feelings of post-treatment anxiety (**living in uncertainty**) were visible in how he sometimes engaged with his children (**relational disturbance**):

"I used to get really frustrated when the kids wouldn't do what they were told straight away, but that's not a common eh:h that's not an uncommon parenting situation. But it was almost like I was trying to kind of control them more than what I was before. I don't know if it was because I'd felt I hadn't been in control of what happened to me"(Dave, 12:11)

Contested masculinities warranted a separate category in this analysis due to how prominent and troubling problems in this aspect of life seemed to be. These disruptions related to how they felt about themselves as men and how their masculinities might be perceived by others. Thus, **contested masculinities** could be seen as resulting from, and contributing to, **being in turmoil** and **relational disturbance**.

There also seems to be a close association between the two categories defined as ways of managing post-treatment disruptions. Most participants suggested that their **"survival strategies"** were being constructed in response to the difficulties they experienced in the first two years post-treatment. However, it also seemed that **new perspectives** were being created as early as 12 months after treatment finished, and so they were being constructed simultaneously.

Furthermore, there may be links between the two ways of managing disruptions, at a sub-category level. For example, **keeping quiet** and **breaking the silence** are about talking or not talking about the problems they experienced post-treatment. Perhaps **framing techniques**, such as thinking of cancer as a 'test', may be linked to ideas about having a 'spur' to make the most of post-treatment opportunities (**processing gains and losses**).

However, there also seem to be differences between the two categories that constitute their ways of managing. Perhaps the most apparent difference is that while **"survival strategies"** seemed to be constructed in the midst of profound intrapersonal and interpersonal turmoil, **new perspectives** seemed to take time to develop. Processes associated with **developing new perspectives** included an ability to stand-back, momentarily at least, and reflect on their experiences. Perhaps this suggests that post-treatment difficulties and concerns related to mortality occupied slightly less of the foreground of their perspectives on life at this point in time:

"I THINK THAT'S THE BIG CHANGE when it's not your core focus and you go off and you start to do other things and you... like the fact that you MIGHT DIE isn't the SOLE FACTOR behind you like, you book a holiday and you go and do things. You have concerns with work and you just you... your mind just as LIFE EBBS BACK IN and sort of, a bit like a tide it's like the cancer... ONE EATS THE OTHER, like the shore and the tide... one kind of... they overlap and as the tide comes in, cancer's the beach, you kind of think less about it as the other one kind of consumes it in a weird way em:m... and it it goes in and out, so

mentally kind of it's always shifting but as the tide comes in you think less about it because other things start to occupy your mind and it... that's kind of how I would view it"(Dean, 32:20)

Dean's words evoke a sense of dynamic interaction and movement back and forth which seems to be a prominent pattern within this model. For example, although developed in response to post-treatment disruptions, some of the ways of managing could inadvertently become a source of further intrapersonal and interpersonal disturbance. Sometimes their **"survival strategies"** could compound feelings of isolation, disconnection and separateness from others. Furthermore, these strategies seemed to bolster the expectation that they should be able to constantly cope with, and be permanently positive about, life after cancer. At moments when they faced significant problems, or felt they were struggling, these expectations could quickly translate into quite harsh, almost bullying ways of relating to themselves. This was apparent when Dave spoke about feeling *"not good enough"* and was *"too harsh"* on himself, despite knowing that he was going through a tough time.

Similarly, although all participants spoke about experiencing reduced distress with the passing of time, and the development of **new perspectives**, it seemed that certain experiences or challenges could evoke some of their intrapersonal and interpersonal difficulties. For example, medical check-ups, ongoing for many years post-treatment, could jolt participants back to a state akin to the shock and anxiety associated with **after "the whirlwind"**:

"I get the appointment to sit back in front of my oncologist then I think IT ALL COMES BACK and you're thinking HERE WE GO, HERE'S THAT ANXIETY AND FEAR AGAIN OF SITTING IN HIS ROOM and sitting in front of the same person who gave you that SLAP AROUND THE FACE a few years ago"(Stephen, 9:15)

"I had a few, quite a few sleepless nights after because everything just came FLOODING back"(Dave, 36:16)

Outside of the medical context, it seemed that other factors, such as contemplating a new relationship or disclosing testicular cancer to others, could also evoke related intrapersonal or interpersonal problems. Mark, who spoke eloquently about how he negotiated threats to aspects of his masculinity, seemed to illustrate how these challenges could be re-evoked. Having had two children pre-cancer, Mark explained

that he and his wife had tried, unsuccessfully, for several years post-treatment to have more children. He seemed to believe this was likely to be because he was infertile as a result of testicular cancer and its treatment. However, he declined the offer of a fertility test because he was concerned it would undermine his sense of being a man:

"I think if it was written down on paper that 'Mark YOU'RE INFERTILE' I think that's sort of final for me and that would be em:m right you're infertile, you're not having kids, and maybe that would be, in my mind, take away some of that masculinity side"(Mark, 11:4)

Thus, perhaps these post-treatment experiences can create certain vulnerabilities that can be evoked again or re-awoken by new experiences, even many years after treatment finished. This seems to support the suggestion of a more multi-dimensional and cyclical model, rather than a linear process based on disruptions that could be resolved once and for all.

Chapter 4: Discussion

4.1 Overview

In this chapter, the categories and model constructed in this study about life after testicular cancer treatment are further developed in light of existing research. This includes highlighting how this study contributes to knowledge in this field, evaluating its strengths and limitations, and considering the implications for future research and clinical practice.

4.2 Discussion and interpretations of research data

4.2.1 Post-treatment disruptions

All of the participants in this study described difficulties related to their experiences of self, their masculinities and significant relationships, which challenged the characterisation, from existing research, that life after testicular cancer treatment is relatively unproblematic (Incrocci et al., 2002; Malec et al., 1986; Rudberg et al., 2000; Siafaka et al., 2008).

The findings from this study provide further support for the suggestion that anxiety can be particularly prominent post-treatment (Dahl et al., 2005; Fosså et al., 2003, 2007; Martin et al., 2013). While psychiatric questionnaires used in some studies highlighted the presence of symptoms of anxiety (Bjelland et al., 2002; Zigmond & Snaith, 1983), beyond the fear of cancer recurrence (A. F. Pedersen et al., 2012), they have generally been unable to suggest potential explanations for these difficulties. The findings of this study propose a number of reasons why anxiety may be a common post-treatment experience. Several of these participants described their anxiety related to a confrontation with their mortality (Harvey, 2007). Generally, people try to immerse themselves in everyday life as a means of distraction from painful awareness of their mortality (Van Deurzen, 2010; Yalom, 2008). Anxiety can be viewed as a natural response when the inevitability of death is acknowledged (Willig, 2009). Participants' existential anxieties can be recognised from their use of metaphors about racing against the clock, the descriptions of "*the void*" of life after treatment, and the feeling of being "*in the dark*". Having the misfortune of being one of a relatively small number of men who get diagnosed with testicular cancer seemed to create a heightened awareness of how life can be randomly and shockingly disrupted. Thus, it seemed to

create an enforced encounter with their fragility and diminished confidence in their ability to cope with some of life's difficulties (Miedema et al., 2007).

For a certain period of time, worries about cancer, the damage it had done to their lives, and how it might impact their futures, seemed to dominate many of these men's world-views. This seems consistent with the suggestion that, particularly in the early stages, efforts to grapple with the evolving impacts of chronic illness can feel all-consuming (Bury, 2001), and the world can feel chaotic and disorganised (Frank, 2013). These worries seemed to increase feelings of anxiety and further removed participants from the here and now of their social networks (Taylor, 2001).

Three of the participants in this study were interviewed between 12 and 24 months after completing their cancer treatment. They seemed to provide the most vivid descriptions of anxiety and this may be because they were closest to this enforced confrontation with their fragility and mortality. Anxiety and uncertainty related to illness can sometimes stem from difficulties attaining personal meanings or satisfactory narratives (Frank, 2013; Mishel, 1988; Sarenmalm et al., 2009), an activity seen as vital for humans, particularly in the light of suffering and loss (Frankl, 1962).

By providing an opportunity for these participants to talk about their post-treatment lives in their own words, this study has contributed to a greater understanding of their broader emotional experiences. Many of these participants described a complex, confusing and overwhelming 'web' of emotions, which included sadness, loss, loneliness, alienation, anger, frustration, gratitude, relief, embarrassment and shame. It is possible that, at these moments, they may have experienced their emotions as occupying a more prominent and intense part of their lives than was previously the case. These findings support the suggestion that emotional difficulties can 'surface' after treatment finishes (Brodsky, 1995; Harvey, 2007; Macmillan Cancer Support, 2009), and that emotional distress can be among the most troubling parts of life for people with cancer (Macmillan Cancer Support, 2006).

Wortman and Dunkel-Schetter (1979) suggested that people with cancer often feel a great need for social contact and support but can experience difficulties receiving or eliciting it. This study seems consistent with the literature, which suggests that relational difficulties can be particularly troubling for young adults after cancer treatment (Cantrell & Conte, 2009; Kameny & Bearison, 2002; Stewart, 2003).

Relationships may have represented a 'double-edged sword' for the participants in this study. At moments when they felt supported by and connected to others, these relationships seemed to reduce their distress. However, at other moments relationships seemed to deepen feelings of alienation, and to become a source of distress, misunderstanding and frustration.

Much of the research exploring the relational impacts of cancer has focused on romantic relationships (Badr, Acitelli, & Taylor, 2008; Carpentier & Fortenberry, 2010; Foy & Rose, 2001; Goldsmith, Miller, & Caughlin, 2007; Manne, Taylor, Dougherty, & Kemeny, 1997; Manne, 1998; Street et al., 2010). This study has the potential to make an additional contribution, by virtue of these participants sharing many stories about their relationships with friends and peers.

Consistent with other studies exploring cancer in young adulthood (Daley, 2007; Singleton, 2008), almost all of these participants described how some friends, colleagues or family members did not acknowledge their cancer experience or seemed unwilling to talk about it. In extreme cases, some friends stopped contacting them after their diagnosis and participants spoke about feeling confused, hurt and angry as a result. In addition, many participants spoke about subtle social cues, often non-verbal, which suggested that some people felt ill at ease in their presence, and that they had become a source or cause of social discomfort or awkwardness (Koehler, 2010). It is suggested that interacting with a person with cancer can be disquieting and anxiety-provoking for others because it can create an unwelcome reminder of their own vulnerability and mortality (Willig, 2009). Such interactions can evoke powerful and unsettling emotions in others (Wortman & Dunkel-Schetter, 1979). For example, in this study, Alan remembered his brother saying that he felt as if he was "*suffocating*" when they spoke about, or when he witnessed an aspect of, testicular cancer.

The fact that testicular cancer occurs in men, generally in young adulthood, may contribute to this discomfort. Youth tends to hold cultural associations with health, vitality, virility and innocence, and research has suggested that these associations can lead to the feeling that the 'natural order' has been disrupted when cancer is diagnosed at a relatively young age (Hilton et al., 2009). Furthermore, by getting cancer, it may be that these men have inadvertently contributed to undermining cultural fantasies about invulnerability and control which are associated with

hegemonic masculinity, and may have revealed a disconcerting truth about the frailty and ordinariness of the male body (Reeser, 2010).

Sometimes, others interact with people with cancer in a falsely positive, optimistic and upbeat way, which can include attempting to hide the negative feelings they have about the condition and the lives of people affected by it (Wortman & Dunkel-Schetter, 1979). Perhaps these ways of interacting reflect conscious or unconscious attempts to move conversations to a 'safer' and more optimistic terrain, removed from the painful aspects of cancer and mortality. As such, people with cancer can sometimes become aware of being caught up in, or used as part of, other peoples' narratives and meaning-making processes (Willig, 2009). It is possible that participants' descriptions of subtle signs of social awkwardness may be considered forms of social constraints, or pressures to modify or restrict ways of talking or behaving, which are often communicated in subtle and indirect ways (Lepore & Revenson, 2007). This suggestion is supported by a belief that much of the processing of social events is unconscious and non-verbal (Gillies, 2010). These findings may also extend into interactions with healthcare professionals. Research has found that men can be justifiably concerned about the potential to be criticised, or judged to be less-manly, by healthcare professionals (Hale, Grogan, & Willott, 2007, 2010; Seymour-Smith, Wetherell, & Phoenix, 2002) or other social 'experts' (Anstiss & Lyons, 2013).

All of these participants used words such as "*less of a man*" or "*lost masculinity*" to describe how they felt about themselves or how they might be perceived by others. In doing so, these participants seemed to be more open about discussing masculinity-related difficulties than has been the case in other studies (Gordon, 1995). For some, it seemed to relate to a specific part of their lives, or for a limited period of time. For example, these findings are consistent with other research which suggests that sexual functioning difficulties are experienced by a minority of men after treatment finishes (Aass et al., 1993; Arai et al., 1997; Fosså et al., 2007; Rieker et al., 1985), and can contribute to feelings of masculinity-related loss and shame related to their bodies (Carpentier & Fortenberry, 2010).

The male body is seen as a central component of health-related masculinities (Chapple & Ziebland, 2002; Stephens & Lorentzen, 2007). Losing a testicle was experienced by most of these participants as creating, in the short-term at least, feelings of diminished masculinity. This could be understood in a number of ways. Firstly, it represented a

bodily reality – they had lost a testicle and, for a period of time, may be infertile or have lower testosterone levels (Orchid, 2013). It also involved significant relational concerns about how they might be judged by current and potential sexual partners and by others in their social network (Skoogh et al., 2011). Furthermore, it seems to contain symbolic or representational components regarding the complex associations of masculinity with testicles, cancer, fertility and sexual potency. For example, Dean's fear of becoming known as "*the guy with one testicle*" seems to allude to the multifaceted nature of the threats to his masculinity that he experienced.

However, for other participants this feeling of diminished masculinity was more global, pervasive and continued to be experienced more than five years after treatment finished. These findings challenge some of the existing literature which suggests that testicular cancer is associated with strengthened or enhanced masculinities (Gordon, 1995) and seem to be more consistent with the suggestion of the possibility of both positives and negatives related to post-treatment masculinities (Daley, 2007; Gurevich et al., 2004; Saab et al., 2014; Seymour-Smith, 2010; Singleton, 2008; Wraith, 2005).

4.2.2 Searching for ways to "survive"

For some of these participants, the combination of intrapersonal, interpersonal and masculinity-related disruptions may have created a feeling that very little of their lives was unaffected by testicular cancer. In response, participants described a range of approaches or attempts to survive these post-treatment disruptions and uncertainties. Here, the word 'survive' alludes to the extent of their difficulties, and to the apparent presence of dominant cancer survivorship discourses within the ways these men attempted to manage life after treatment.

Bury (2001) suggests that personal illness narratives can act as a link between the body, self and society, and recommends that such narratives are considered alongside potential personal motives and the social context in which they take place. Most of these men described these initial "**survival strategies**" as being instinctive or automatic. They seemed to suggest a feeling of being in the midst of difficulties and needing to find immediate ways of responding, rather than having time for conscious reflection. One of their most noticeable features is that they are predominantly solitary activities. **Managing by thinking or doing; framing techniques; keeping quiet** and **demanding more of self** are activities that went on in the thoughts and feelings of these men, seemingly hidden from others most of the time, even within reportedly

close and supportive relationships. Perhaps these approaches provide real-life examples of how the cultural constructions of cancer as an individual's responsibility (Ehrenreich, 2009; Seale, 2001, 2002; Willig, 2012) can be internalised. Since the 'battle' against cancer is believed to take place within each individual (Little et al., 2000; Moynihan, 2002), perhaps it is understandable that many of these participants looked inwards for ways to survive in the immediate aftermath of treatment. Although Hilton et al. (2009) found that men can be open to disclosing testicular cancer, the findings of this study seem to be more consistent with the suggestion that men can be reluctant to engage in significant disclosure or discussion of their diagnosis or cancer-related difficulties (Carpentier et al., 2011; Gordon, 1995; Gray, Fitch, Phillips, Labrecque, & Fergus, 2000; Gurevich et al., 2004).

These findings emphasise common misunderstandings about life after cancer treatment. Most of these participants suggested that they and others had limited understanding about how difficult life after treatment would be. This may be partly a consequence of how cultural pressures to imbue cancer-related discussions with boundless positivity, optimism and certainty (Moynihan, 2002; Seale, 2002) can make it difficult for individuals to talk openly about their difficulties, and has restricted social understanding of the diversity of post-treatment experiences (Park et al., 2009; Pertl et al., 2014). These findings provide further support for the assertion that cultural constructions of cancer can act as a reference point for, or perhaps even a set of instructions about, how people are expected to respond, act or even speak about their cancer experiences (Willig, 2012).

It is possible that social constructions of cancer may be prominent in these **"survival strategies"** because, in the immediate aftermath of treatment, these men's personal narratives or meaning-making processes were in a fragile infancy. Willig (2009, p. 183) described the need for *"a serviceable narrative"* that provides meaning to experience, and perhaps for these men, in the early stages of life after treatment, their narratives felt easily disrupted by others and by existing cultural constructions. Given the relative lack of research about how men manage life after testicular cancer treatment, these findings represent a new contribution to the literature, and may provide an insight into the links between social discourses and the practices associated with managing life after treatment that are employed by some men.

However, to suggest that these participants were merely responding to social pressures or constraints risks oversimplification and denies their individual choices and agency (Connell & Messerschmidt, 2005; Watson, 2000). Therefore, we must consider their personal explanations, and potential motives and consequences, for attempting to manage life after treatment in these ways.

Consistent with other research (Cantrell & Conte, 2009; Hilton et al., 2009), most of these participants explained that looking inwards for ways to cope was a means of avoiding further burdening, or placing demands on, others. For example, Phil spoke about not wanting to "*pile*" his worries and anxieties onto his girlfriend when they had only recently started a new relationship. These explanations seem to allude to processes related to dependence-independence, which research suggests may be particularly problematic for young adults with cancer (Hilton et al., 2009). At a time when many of their peers are developing their independent identities and lives beyond their families, negotiating substantial support needs with others can be particularly difficult. Given that almost all of these participants seemed to feel they were in a quite uncomfortable and perhaps precarious social position (O'Brien, Hart, & Hunt, 2007), perhaps these actions can be understood as ways to try to 'fit in' or not further highlight their differences from others.

Although not directly stated in this way, it is possible that these approaches had protective functions for these participants. For example, perhaps by looking inwards for understandings these men may have felt a temporary reprieve from existential anxieties (Yalom, 2008). It has been suggested that a certain amount of denial can be an effective way of coping with initial cancer-related psychological distress (Livneh & Antonak, 1997). It is possible that these approaches may have created a feeling of control at a time when much of life felt out of control (Willig, 2012), and may have facilitated the impression or mind set of having choices and options, instead of being powerless against, and colonised by, cancer.

How men are seen to cope with life after treatment can be understood and evaluated, by themselves and others, as a performance of masculinities (Cecil et al., 2010; Courtenay & Keeling, 2000; Gough & Robertson, 2010; Wenger, 2013; Whitehead & Barrett, 2001). For example, Stephen referenced stereotypical expectations of men as stoic, invulnerable and inexpressive (Brannon, 1976; Sabo & Gordon, 1995) when saying he felt he was expected just to "*get on with it*" and "*deal with it*". This seems

consistent with other research which found that men, more than women, tend to allude to a link between their gendered (i.e. masculine) identities and their cancer disclosure (Hilton et al., 2009) and cancer-related help-seeking (Seymour-Smith, 2010). It is possible that **keeping quiet** was part of how these men attempted to demonstrate their masculinity post-treatment (Seidler, 2007). Perhaps feeling that their masculinities were already threatened, some of these men responded by attempting to enact elements of what can be considered traditional or stereotypical masculinities.

O'Brien et al. (2007) conducted an interesting analysis of differences in the negotiation of masculine identities related to coronary heart disease, prostate cancer and depression. In their sample, men with depression seemed to report greater social restrictions around disclosure or open discussion. However, the findings of this study emphasise the blurred nature of the boundaries between health and mental health, and how managing life after testicular cancer can involve negotiating masculine identities in the context of a combination of physical and psychological difficulties.

4.2.3 Creating new perspectives and meanings

Consistent with other qualitative studies about testicular cancer (Brodsky, 1995; Gordon, 1995) all of these participants described some reduction in post-treatment disruptions over time. This study helps to shed light on possible reasons why there may be a reduction in distress. For most of these participants, the passage of time seemed to have a significant impact, and they spoke about "*milestones*" in terms of calendar years or reduced frequency of medical check-ups.

These findings support the suggestion of Fleer et al. (2006) that subjective interpretations of the impacts of testicular cancer can be a significant determinant of post-treatment distress. These participants cited a diverse range of experiences that helped them to feel a bit better, including having sex for the first time after treatment, feeling less intensely observed by or different from others, meeting other men who had testicular cancer and returning to valued social roles. These experiences suggested that cancer, while still being a prominent part of their thoughts, felt like a less dominant part of their view of life. Perhaps they can be considered, at least partially, as a return to losing themselves in everyday life, distracting themselves and focusing less on their mortality (Van Deurzen, 2010; Yalom, 2008).

These experiences, reduced disruptions, and the passage of time seemed to contribute to the context where these men were able to develop a range of more consciously-chosen approaches to managing life after treatment. This incorporated meaning-making processes and constructions of masculinities. It has been suggested that creating narratives about experiences can be a way to reaffirm identities and restore meaning to lives that are threatened by illness (Bury, 2001; Sarenmalm et al., 2009).

The suggested importance of post-treatment meaning-making activities is reminiscent of the findings of Gordon (1995). However, there are also some significant differences in these findings. Gordon suggested that most of his participants made sense of their experiences in ways that re-established their masculine identities as unaffected by testicular cancer. In contrast, one of the most noticeable aspects of the **new perspectives** constructed by these participants is that they often relied on an acknowledgement of having had testicular cancer, and of their lives and identities having been impacted, in ways they believed were both positive and negative. For example, their reported confrontation with mortality seemed to become a central part of the meaning-making processes for almost all of these participants. Consistent with the findings of Saab et al. (2014), these participants described using this existential anxiety as a prompt to make the most of their lives. Based on qualitative interviews with young adults who were diagnosed with cancer during childhood or adolescence, Parry (2003) suggested that acknowledging the uncertainty of life, and perhaps the certainty of death, can create a deeper appreciation of life and a drive to create experiences and relationships that are personally meaningful. Wilber (1991 cited in Koehler, 2010, p. 9) seems to sum up this idea by saying *"since I can no longer ignore death I pay more attention to life"*. Most participants in this study spoke about wanting to have *"no regrets"* at the end of their lives, suggesting that this experience had created an enduring awareness of their mortality. They described their experiences of testicular cancer as a *"catalyst"* and a *"spur"* which prompted reflection on their values and priorities (Wraith, 2005) and led to their making important changes in their personal and professional lives, in line with revised values and identities.

All of these participants identified parts of themselves, their lives or relationships that had changed in ways they appreciated or associated with personal growth (Brodsky, 1995; Fleer et al., 2004; Fosså et al., 2007; Kim et al., 2011). Several participants described a feeling of greater self-respect and appreciation for themselves. This was captured in the sentiment *"preferring the person I am today"*. Several of these men

reported enhanced self-belief, based on acknowledging their resilience at having come through profoundly challenging experiences. Additionally, most men in this study suggested that close relationships had not been negatively affected by testicular cancer, and some suggested they felt closer to others in their lives who supported them during and after treatment (Gritz, Wellisch, Siau, & Wang, 1990). These findings seem in contrast to the feelings of inadequacy and self-criticism associated with **demanding more of self** and support the belief that an individual's identity can be simultaneously enhanced and challenged by illness (Charmaz, 1995; Robertson, 2006; Wraith, 2005).

Overall, the findings of this study should be seen as more consistent with research highlighting the possibility of both positives and negatives after treatment finishes (Brennan, 2001; Cantrell & Conte, 2009; E. Gilbert et al., 2013; Kaasa et al., 1991; Saab et al., 2014; Tallman, 2013; Wraith, 2005). Therefore, even if cancer could present opportunities for growth and change, this process would not necessarily be smooth, easy or unanimously welcomed. Therefore, suggesting that cancer was experienced as a 'gift' or a 'blessing' by these participants would be inaccurate (Armstrong, 2001; Ehrenreich, 2009). Incorrectly assuming that personal growth post-cancer treatment is inevitable, universal, or tells the 'full story' of people's post-treatment experiences, would place a considerable burden on people with cancer (Wortman, 2004).

Many of these ways of making sense of their lives seem suggestive of constructions of masculinities outside of the hegemonic norm or stereotypical male gender role (Brannon, 1976; Sabo & Gordon, 1995). For example, most of these men seem to acknowledge vulnerabilities, the existence of limits to their ability to control life, and the importance of social support. They seem to place a greater emphasis on emotional expression and compassion towards self and others. Perhaps this can be interpreted as another example of the diversity of the practices of masculinity (Gough & Robertson, 2010) and of how men can draw on an experience of 'otherness' to facilitate the construction of alternative and potentially healthier masculinities (Danielsson & Johansson, 2005; Emslie, Ridge, Ziebland, & Hunt, 2006; Kaye, Crittenden, & Charland, 2008; Korobov, 2011).

Breaking the silence or finding ways to speak about cancer can also be seen as involving the construction of alternative masculinities. While other studies have focused

on the disclosure of a cancer diagnosis (Gray et al., 2000; Hilton et al., 2009), this study has explored the topic of talking about subjective and relational experiences of cancer more broadly. For many of these participants, talking more openly about cancer and their experiences, including their difficulties, was also identified as a significant post-treatment process. Perhaps **breaking the silence** relates to an internal process of greater self-acceptance. This seems to support the finding that talking openly and candidly about experiences of cancer can help the speaker and the listener to reach deeper understandings and can feel validating (Wortman & Dunkel-Schetter, 1979). It also suggests a potentially important role for psychological therapy for some men who complete treatment for testicular cancer. Furthermore, these findings support the literature that illuminates how some men can use illness-related humour in sophisticated ways to reinforce social bonds (Branney, Witty, Braybrook, et al., 2014; Williams, 2009) and to release tension (Chapple & Ziebland, 2004). This study adds to this knowledge by highlighting an alternative use of humour – as “*a gateway*”. This involved using humour to get people ‘on side’, in order to create opportunities for more ‘serious’ conversations about cancer.

The presence of three participants who were interviewed more than six years after treatment contributed significantly to these findings and represents a relative rarity in cancer research (Jarrett et al., 2013). Charmaz (1999) suggested that sharing a story about past suffering can differ from one about present suffering. She explained that people can speak of past suffering while demonstrating a present self that is in control and unaffected. However, in this sample, separating past and present suffering was not a simple matter. Indeed, it seemed that most of the participants who had finished treatment between three and six years prior to the interview, described, either directly or indirectly, some long-term vulnerabilities or ‘scars’. They explained how attending testicular cancer check-ups, experiencing another health ‘scare’, starting a new relationship or experiencing difficulty having children, could reignite aspects of the disruptions they described in the aftermath of treatment, including internal turmoil, anticipating rejection by others, coping in a solitary fashion and experiencing threats or loss related to masculinities. Whereas Gordon (1995) interpreted his findings as suggesting three stages of cancer-coping, the tentative model developed in this study seems less clear-cut and less linear.

Finally, this study highlighted what seems like a new finding for the testicular cancer literature. Many of the participants in this study expressed what may be suggestive of

a desire to remain connected to their experience of testicular cancer, in contrast to social ideas about 'moving on' or 'getting over'. This was evident in wanting to talk about testicular cancer, taking part in fundraising or education campaigning about the issue, in volunteering to support others affected by testicular cancer, and, in one case, getting a tattoo that symbolised their experience. It is possible that this may draw on what Frank (2002) described as a sense that cancer never fully disappears from life. Perhaps this finding only relates to some men affected by testicular cancer, since those who do not wish to have an ongoing connection may be less likely to take part in a research study of this kind. However, this finding brings to mind a number of possible interpretations. Perhaps these participants' meaning-making processes relied upon some element of remembering the "*catalyst*" or "*spur*" they experienced. Alternatively, and potentially paradoxically, perhaps this way of allowing their experience of fragility into awareness helps to reduce anxiety. Rogers (1951) suggested that anxiety and defensiveness can stem from denial and the need to prevent what is being denied from coming into awareness and potentially threatening the self or identity. Setting aside differences in therapeutic models, the concept of remembering is central to psychoanalytic (Freud, 1924), person-centred (Joseph, 2005) and cognitive (Ehlers & Clark, 2000) therapeutic approaches to processing trauma. Therefore, perhaps this desire to retain a connection to their experience can be understood as a healthy response to a traumatic and life-changing experience.

4.3 Evaluation of the study

The aim of this study was to contribute to the understanding of how men manage their lives after finishing testicular cancer treatment.

4.3.1 Quality approaches and procedures

Evaluating the standards of quality, trustworthiness and credibility in qualitative research is not straightforward (Denzin, 2011). As previously stated, my thinking about standards of quality in this study was informed by guidance from qualitative researchers (Elliott et al., 1999), grounded theorists (Charmaz, 2006) and counselling psychologists (Morrow, 2005). Having identified areas of common interest across these three sources, I grouped their recommendations under the headings of locating the research and researcher, credibility, clarity and usefulness. See table 6 for a brief summary of their guidance and the measures adopted in this study.

Table 6: Quality criteria and measures adopted in this study

Quality standards	Approaches adopted in this study
Locating the research and researcher Elliott et al. (1999, p. 221) emphasised the importance of "<i>owning one's perspective</i>", including being clear about theoretical orientations and personal values. Morrow (2005) added the importance of striving for clarity about the fit between the research paradigm and research question	○ Engaged in personal, methodological and epistemological reflexive process throughout the project. ○ Reflexive notes documented throughout the thesis and further information provided in appendix 16. ○ Fit between paradigm and research question explored in section 2.3. ○ Thesis includes passages written in the first person, in order to acknowledge researcher's role in constructing the analysis (Marecek, 2003).
Credibility Elliott et al. (1999) identified the need to provide clear information about the nature of the sample, facilitating credibility checks and acknowledging the limitations of the study. Charmaz (2006) also emphasises credibility as a relates to deep engagement with the topic and GT analytic approaches	○ Sample description provided in methodology chapter and contextualising details about participants are provided in the analysis chapter. ○ Participants quotes provided throughout the analysis chapter and also included in the discussion. ○ Extensive coding and analytic process detailed in the methodology. Extracts of transcription, coding, memos and a number of attempts to organise data into categories all provided in the appendix. ○ Approach to coding, memo writing and category development were discussed with peers engaged in grounded theory studies and with research supervisor. ○ Following the coding of first five interviews, theoretical sampling provided a means of further developing tentative categories. ○ Limitations of the study are explored in section 4.3.3.

Clarity and usefulness

Elliott et al. (1999) highlight the need to provide a coherent synthesis of the data, without over-simplifying or losing nuances. All three sources emphasise the importance of producing analyses that resonate with and spark interest in the topic. In addition, Charmaz (2006) identifies the importance of originality, while Morrow (2005) draws attention to the need to 'bridge' the gap between research and clinical practice

- Developed tentative model, core connecting category and six categories by way of communicating my analysis and interpretation of the data.
- Identified and included a diversity of responses, including nuances or differences within the sample or situations.
- The original contribution of the study is explored in sections 4.2 and 4.3.2.
- The potential applications of these findings to clinical practice and to the lives of men with testicular cancer is explored in section 4.4.

Participant wellbeing is a priority for research of this kind (Christians, 2011; Kasket, 2012) and is another measure against which this study should be evaluated. I believe that the briefing, interview and debriefing processes felt, at the time, like a positive and worthwhile experience for these participants, as illustrated in some of their own words:

*"It's good to talk about these things, to be honest"*John

"I feel ok. I feel good about it and I'm pleased I've been able to do it and I'm pleased that I've talked more than I thought I would. I thought it would be a lot more questions that you needed answering that I'd struggle to answer"

Stephen

*"I enjoyed it. I walked out buzzing. I hadn't spoken about it in that depth for a long time. It was interesting. A good experience"*Mark

4.3.2 Strengths and contributions of the study

This study can make a contribution to multiple, sometimes overlapping, historically under-researched topics and samples including: men's health and masculinities; men with cancer; young adults with cancer; testicular cancer (beyond sexual functioning); and life after cancer treatment.

Based on a belief that some men would be willing and able to, and interested in, sharing their experiences (Oliffe & Mroz, 2005), one of its main strengths is that it has allowed these men to shape the direction and focus of the study, a quite rare feat in testicular cancer research (Carpentier & Fortenberry, 2010) and in the field of men's health and masculinities, which has historically been dominated by 'expert' perspectives (O'Brien, 2006; Popay & Groves, 2000; Watson, 2000; Wilkins, 2009).

By providing an overview of how these men seemed to manage their lives, these findings shed light on a breadth of experience, compared to studies that are more fragmented or focus on particular components, such as sex life (Aass et al., 1993; Arai et al., 1997), individual coping styles, or emotional distress (Fosså et al., 2003). Through undertaking this ambitious endeavour, and engaging with it in a flexible way, the findings can create greater understanding of the nuances of these men's experiences. Despite starting with a research question that could have been in danger of bolstering individualistic conceptualisations of cancer, this study includes

considerable focus on the social and relational components of life after testicular cancer treatment. It emphasises that relationships seem to have the potential to offer invaluable support and to become a source of distress for these men. The study illuminates subtle but powerful experiences of social awkwardness that were difficult to put into words. In addition, by focusing on individual and social processes, and ways of managing life, it can make a distinct contribution compared to studies focused solely on subjective experiences (Brotsky, 1995; Saab et al., 2014). Furthermore, it draws attention to the apparent presence of powerful, sometimes restrictive, constructions of cancer within these men's accounts. Thus, it may provide an example of how these discourses can be internalised and enacted.

This study can help to address the apparent paradoxes in the testicular cancer literature. It is tempting, when reading the existing literature, to wonder whether getting and surviving testicular cancer is a 'good' or 'bad' experience? This study provides a more in-depth and nuanced insight into these men's experiences of self, identities, masculinities, emotions and relationships (Marecek, 2003). It highlights how these men experienced complex, multifaceted disruptions to many areas of their lives after treatment finished, and how the end of treatment was not the end of their difficulties. However, it also demonstrates how some post-treatment growth is possible and indeed was described by all of these participants.

The study also contributes to the literature relating to testicular cancer and masculinities. It suggests that, for these men, concepts related to masculinities were involved with their bodies, sex life, fertility and also in the performative aspect of how they were seen to cope with testicular cancer. It also highlights how men can, and do, manage to construct alternative masculinities that may be associated with healthier choices and less social restrictions around self-expression and expectations of control.

The field of psycho-oncology seems to be searching for 'answers' about why a significant minority of people, perhaps between 10% and 30%, experience psychological distress long after treatment has finished (Armes et al., 2009; Foster, Wright, et al., 2009; Livneh & Antonak, 1997). In this study, a few objective factors, including experiencing relationship difficulties, erectile dysfunction and having gynaecomastia, were reported as the source of ongoing distress and turmoil. However, there were many other more subjective factors that seemed to have an impact on their lives, including the nature of their illness narratives and meaning-making processes.

Therefore, while the suggestion of the need to develop standardised assessment measures of cancer-related psychological distress (Dolbeault et al., 1999) has some merit, these subjective factors may not translate easily into a standardised questionnaire. Therefore, perhaps there can be no substitute for healthcare practitioners, and significant others, who are willing to listen openly, curiously and attentively to the unique meanings and narratives of men post-treatment for testicular cancer.

4.3.3 Limitations and implications for future research

Constructivist grounded theorists recognise that their findings represent one of a number of possible theories or models. I understand that my personal history and perspectives have influenced the development of these findings. Perhaps my own painful experiences of feeling social pressure to restrict openly expressing grief has meant that I have placed greater significance on parts of participants' experiences that fit with this. Alternatively, it is possible that my subjective experiences helped me to empathise with participants' difficulties, and was an asset in enabling me to reach certain understandings (Gough & Madill, 2012). However, I took measures to ensure I treaded carefully when interpreting data that touched upon meaningful experiences from my own past. During the initial coding phase, I made a note on the transcripts at points that held particular resonance for my own life. I then used this as a prompt to check carefully that assumptions I was making were reasonably grounded in, and supported by, the data.

Perhaps my greatest regret for the study is that it was not possible to conduct follow-up focus groups or interviews with these participants. This could have provided an opportunity to involve the participants more deeply in the analytic process and to further develop the model. As a novice GT researcher, the demands of the analytic method meant that there was insufficient time in this doctoral project to conduct further fieldwork. If developing the study further, the next step I would take is to invite these participants, and later perhaps other men affected by testicular cancer, to provide feedback on the model and to identify areas for further development. Focus groups could constitute an interesting method for research about testicular cancer, particularly related to masculinities (Singleton, 2008).

The suitability of GT for psychological research has been questioned and constructivist GT has been criticised for abandoning the goal of theory generation in favour of rich

description (Willig, 2008). I attempted to strike a balance between describing participants' experiences and striving for tentative explanations and links to social processes. This included suggesting potential links within and between categories while also recognising the limits of knowledge constructed here. However, it is fair to say that this study may be considered an abbreviated version of GT (Willig, 2008), rather than a fully-fledged theory of life after testicular cancer treatment. Indeed, this sample of seven men is relatively small. Mason (2010) suggested that 31 participants was the mean of the GT PhDs he reviewed. The decision not to pursue further interviews in this study was based on the desire to be able to do justice to the richness of data generated in relatively long interviews with each of these seven participants. However, in a sense the breadth of the study is perhaps its most significant contribution, and simultaneously, its most substantial limitation. It has highlighted some important issues and processes for these men, although it has only outlined some of these issues, rather than providing more comprehensive explorations or explanations. The sample changes made at the start of the project, to allow for men aged up to 40 and up to 10 years post-treatment, have broadened the study further and contributed to this challenge. However, including people who are more than five years post-treatment is relatively rare in cancer research (Jarrett et al., 2013) and made a valuable contribution to this study. Therefore, to paraphrase Charmaz (2008), I hope the study represents a plausible, if admittedly unfinished, account.

These findings could be supplemented with additional fieldwork, and the theoretical sampling of participants who are in a position to fill gaps in the data and the model. There are several areas that would benefit from further exploration, including the perceived threats to these participants' masculinity, how they were managed, and the process of constructing alternative masculinities. It would be interesting to examine potential links between **"survival strategies"** and **new perspectives**, and the routes to developing these new meanings and narratives. It remains unclear under what circumstances **new perspectives** started to be constructed. Furthermore, some studies have suggested that the ways in which young adults cope with cancer can draw heavily on pre-cancer coping strategies (Miedema et al., 2007). However, it remains unknown the extent to which that was the case in this study. In addition, I believe there is merit in exploring the idea of **searching for an enduring connection** further. Finally, it would be interesting to try to understand more about the apparent sensitivity or vulnerability to certain other experiences which seemed to

re-ignite the types of post-treatment disruptions these participants experienced, even more than six years post-treatment.

There are also a number of further limitations related to the sample and recruitment method. Many qualitative researchers apologise for the lack of generalisability of their findings. However, generalisation is an issue for all research (Marecek, 2003), even if it is not always recognised as such. The recruitment of participants from only one source, a cancer charity, may have excluded other potential participants. An unpublished study of men who completed treatment for testicular cancer in the Netherlands suggested that those recruited from charities were younger, more highly educated, had more extensive cancer treatment and were more likely to have experienced a second cancer, compared to a sample recruited from a medical centre (Fleer, Hoekstra, Stewart, et al., 2006). While the participants in this study differed from those in the Dutch study on many dimensions, it is possible that there are differences in men who are connected to cancer charities to those who are not. For example, I wonder if men who had less problematic post-treatment experiences may be less likely to engage with cancer charities. Alternatively, perhaps there are groups of men who continue to experience profound difficulties, and are struggling with meaning-making processes, who because of this may find it particularly difficult to volunteer for a study of this kind.

It would be useful for future research to attempt to recruit men post-treatment for testicular cancer from other sources, including NHS services and community settings. Future research could also make a useful contribution by seeking to include the perspectives of gay or bisexual men, since all of the men in this study self-identified as heterosexual. Similarly, one of these seven participants was from an ethnic minority background. Although rates of testicular cancer are higher in men of white ethnicity (Jack, Davies, & Møller, 2007), it remains important to try to strive for further understanding of the diversity of men's experiences of testicular cancer. Given the significance of relational components of the findings of this study, it would be useful to include significant others, such as partners, family members and close friends, in future research. Facilitating conversations between men living with testicular cancer and significant others may run the risk of blurring the boundaries between research and therapy, but if there were ways of managing this challenge it could be an interesting area to explore.

Another significant limitation of the study is its total reliance on the interview method. It is reasonable to assume that studies of this kind, publicised based on a willingness to share experiences, may exclude men who find it more difficult to articulate their intimate personal experiences. This study has also added to the reliance on the self-reporting of experiences that seems to dominate psycho-oncology research (Beach & Anderson, 2003). Future research could usefully contribute to greater diversity in this field by also considering using conversational analysis or participant observation (Willig, 2008). For example, I would be interested in attending and observing testicular cancer groups or analysing online forums, which present opportunities for different ways of learning about how men manage their post-treatment lives.

4.4 Implications of the study

As discussed, these participants outlined an array of difficulties which involved **negotiating intrapersonal and interpersonal disruptions** after completing testicular cancer treatment. This included challenges related to their thoughts and feelings, identities, their masculinity, values and priorities, and even their very existence and mortality. It also related to many aspects of their social relationships with family members, intimate partners (both real and imagined), and wider social networks of friends and peers. The existence of considerable diversity of experiences within this sample of seven men highlights the challenge of generalising about the needs of men who complete treatment for testicular cancer. While acknowledging this limitation, I can still envisage implications for counselling psychologists, therapeutic practice and wider support networks of these men, as discussed below.

This study draws attention to the needs of these men and there are a number of areas where some could benefit from support, or which could represent a focal point for therapeutic endeavours. The concept of self-compassion feels central to many of their difficulties. Many participants seemed to embrace the idea that they must be a 'success' at life after treatment (Bury, 2001; Frank, 1997), and that this must be 'achieved' on their own. Several participants spoke about how, although they knew they were going through a hard time, they struggled to offer themselves much compassion or understanding, instead often seeming to criticise or bully themselves to do more, or do better. Perhaps the first step in self-compassion would involve the acknowledgement of their suffering, loss and disruptions (Neff, 2009). Self-compassion involves treating oneself kindly, acknowledging and accepting one's humanity and relating to oneself in caring and nurturing ways at moments of difficulty, and perceived

failure or inadequacy (D. A. Lee, 2005; Neff, 2011). If working therapeutically with these men, I would seek to explore ideas related to self-compassion (see Gilbert (2005) for a review of the history of compassion-focused approaches and philosophies and Gilbert (2010) for therapeutic approaches to self-compassion).

The isolated and solitary nature of these men's attempts to manage life after treatment also feels significant. The profound silence associated with their experiences, often maintained by these men and others in their lives, brings to mind the topic of shame. Indeed, a number of participants referred to the idea of being associated with a "*taboo*" around genitourinary cancers. Brown (2013) conducted research into men's experiences of shame and the impacts it had on their lives. She suggested that feeling defective, a failure, feeling afraid or revealing weakness can be triggers for shame, which can have a devastating impact on men's lives. Many of the participants in this study described experiences of this kind. Experiencing traumatic events can evoke feelings of self-blame and shame, which can be maintained by a veil of silence (Ainscough & Toon, 2000). Counselling psychologists can work with clients as a compassionate other who can bear witness to trauma (Kopf, 2010). Talking openly about experiences that evoke shame can undermine the power this emotion can have over people's lives (Brown, 2013). It is possible to interpret the acknowledgement and discussion of traumatic experiences and shame as an act of self-compassion (P. Gilbert, 2009).

Therapeutic work which focuses on shame and self-compassion might also benefit from including psycho-education about contemporary cultural constructions of cancer and masculinities, in order to deconstruct these, and to reflect on their impact. This kind of work can be easily neglected within individual psychological therapy. Historically, psychologists have been seen as culpable in victim-blaming, locating problems within individuals and ignoring influential social and cultural factors (Pilgrim, 1997; Rose, 2009). In contrast to Gordon (1995), I believe many people need support and help to reflect on concepts such as gender, its social constructions, and how they may impact on their lives. These concepts are so fundamental and ever-present that they can be taken for granted or almost rendered invisible.

Counselling psychologists and other therapists may also be in a position to help some of these men during their meaning-making processes, as they try to make sense of their experiences. As a discipline that places great emphasis on subjectivity (Orlans &

Van Scoyoc, 2009), counselling psychologists are well-placed to facilitate an exploration of a wide range of experiences and emotions, and to tolerate and normalise seemingly contradictory or conflicting ideas or processes. For example, thinking in narrative terms, Frank (2013) suggests that there are likely to be multiple narratives at play in any situation, and even if dominant personal narratives are suggestive of illness as a 'quest' or journey, there are likely to be other narratives, such as those relating to 'chaos', vulnerability, powerlessness and meaninglessness. Perhaps therapy can help some men to express a wider range of their experiences of testicular cancer. There may be some benefit in bringing these into awareness, as a means of creating greater self-understanding. It is possible to think about constructions of masculinities in a similar way, in terms of their multiplicity, and the potential for therapy to be a helpful place for their exploration.

While many individual therapeutic models could contribute to helping these men, my experiences in the interviews suggests that a relationally-focused approach, sensitive to the potential for invalidation and shame has considerable merit. This research highlights the importance of people with cancer being allowed to discuss the diverse range of their experiences, including difficulties or 'negative' aspects. The semi-structured nature of these qualitative interviews seemed to work well for these men, by providing them with an opportunity to talk about what mattered to them, in their own words, and it may be worth incorporating aspects of these approaches into therapy. However, it is also worth acknowledging that, in the current climate, such an approach may not be easily available within NHS primary care settings in which CBT tends to be offered as the treatment of choice (Department of Health, 2007).

As part of encouraging compassionate, reflective practice, healthcare professionals, counselling psychologists and other therapists should be encouraged, and supported through clinical supervision, to be aware of their own personal values, attitudes and responses to clients (Strawbridge & Woolfe, 2010). These practitioners are also culturally-embedded and influenced by social constructions. They can sometimes inadvertently repeat patterns that oppress certain groups or marginalise certain discourses (Reeve, 2000). In the case of illness, it is suggested that healthcare professionals can restrict personal and existential discussions (Bury, 2001; Frank, 1997), and may put pressure on people with cancer to adhere to mandatory positive thinking.

I believe that professionals working with people with cancer have a responsibility to familiarise themselves with the social constructions, dominant and marginalised discourses associated with the topic. Indeed, this point is not cancer-specific, it relates to most topics or client groups we endeavour to support. Practitioners should be encouraged to reflect on how their interactions with clients might relate to these social constructions. However, it is also worth mentioning the need for compassion and care for all practitioners working with emotionally-demanding topics, including those that evoke unsettling reminders and confrontation with mortality. Within and beyond counselling psychology, the topic of self-care (Schneider, 1984) is often not given sufficient consideration.

Counselling psychologists are encouraged to think about the application of their research beyond the therapeutic room (Milton, 2010) and how they can contribute to society (Rafalin, 2010). Almost all of these participants said they would have appreciated more support with their lives after treatment finished, including the opportunity to talk more openly about emotional difficulties. This conclusion emphasises the need for much greater focus on the emotional and psychological needs of young adults post-cancer treatment (Rabin et al., 2011). Four participants described attempts to discuss emotional difficulties with their GP or oncology team. One successfully accessed group therapy, which he described as useful. Two participants felt frustrated at being offered anti-anxiety medication, rather than talking therapies. The remaining participant was offered counselling related to erectile dysfunction. It may be that they are illustrative of a lack of understanding of the impacts of testicular cancer beyond the genitals, and of the medicalisation of emotional distress. Most of these participants expressed the feeling that their medical needs were very well cared for but that there was almost no support with emotional or psychological impacts.

Based on these experiences, there is a need for oncology teams and primary care services to be provided with a greater understanding of the post-treatment challenges facing some men. Consistent with other studies (Wraith, 2005), it seems that the first few years after treatment can be a particularly tumultuous period where some men may benefit from support, and yet where they can feel abandoned after a reduction in the intensive support offered during treatment. It would be useful for all cancer services to monitor the emotional and psychological wellbeing of men post-treatment, in keeping with NICE (2004) recommendations. It may be possible to develop protocols or structures that provide post-treatment support for these men. This could include

clear signposting to information sources, such as cancer charities Orchid and Macmillan Cancer Support, to local support groups and online resources such as www.yourprivates.org.uk, a website dedicated to testicular cancer. Several of these men highlighted how meeting others affected by testicular cancer helped to reduce feelings of alienation and to normalise some of their difficulties.

I am committed to trying to disseminate the findings of this study in order to contribute to greater understandings of the lives and experiences of men after testicular cancer treatment. This is likely to include practical workshops and written information which will be disseminated through a male cancer charity. Furthermore, I hope to publish the findings of the study in a relevant academic journal in order to disseminate the findings to academic communities, and to make a contribution to the literature about men's health, masculinities and cancer.

4.5 Final reflections and conclusions

4.5.1 Epistemological and methodological reflexivity

The research question guiding this study was expressed as follows: how do men who complete treatment for testicular cancer manage life afterwards? This question acknowledges the possibility of there being real components of these men's experiences, and it hints at the possibility of their representation in language. By locating the study within a constructivist-interpretivist paradigm, I acknowledged the existence of multiple realities, and the possibility that language constructs, as well as represents these realities. Adopting an epistemological stance akin to contextual constructivist, a middle ground between naïve realist and radical constructivist, encouraged a focus on the interpersonal, social and cultural contexts in which these accounts were produced (Madill et al., 2000). Therefore, I see the end product of this research as a construction, by virtue of participants' attempts to represent their experiences in language and my role in its interpretation.

This stance is consistent with my therapeutic engagement with clients as a counselling psychologist. My approach involves respecting participants' and clients' experiences, trying hard to understand parts of the world as they feel to them, thus taking them at their word. I believe it would be invalidating and insulting to suggest to a client that their experiences are mere constructions (Bekerman & Tatar, 2005; Orlans & Van Scoyoc, 2009). Having said that, I often invite clients to reflect on the relational, social and cultural context in which we are both inevitably embedded, and the significance and meaning of particular words and phrases. This work also involves acknowledging

that uncertainty, complexity and contradiction are always present and that certain parts of their experiences remain unknown, or perhaps unknowable (Rafalin, 2010). Thus, I never assume to have the full 'picture' of a client's difficulties, or that such a position is even possible. This pluralistic approach, including an acceptance of tensions and ambiguities, is perhaps one of the hallmarks of counselling psychology (Orlans & Van Scoyoc, 2009).

Regarding my choice of methodology, it is possible that adopting a purer or more focused analytic approach may have facilitated the development of more in-depth analysis in a particular area. For example, a phenomenological study may have provided richer descriptions of the lived experiences of these participants. A discourse analysis might have facilitated a more skilful interpretation of how, why and to what effect these men used linguistic resources in the ways they did. Alternatively, a narrative analysis might have helped to shed more light on their processes of constructing meanings.

However, as previously discussed, GT is a label applied to a wide range of research, with diverse ontological and epistemological foundations. Indeed, there are many 'grey' areas in GT, including a lack of clarity about how constructivist GT theorises the role of language (Willig, 2008). I found this inherent flexibility of GT to be challenging but also helpful, because it compelled me to reflect on my own perspectives as a researcher-therapist, and facilitated a flexible and pluralistic approach to interpretation, which fit well with this particular study. Thus, my approach included both 'empathic' and 'suspicious' styles of interpretation (Willig, 2013). It involved examining the data in multiple ways: as a representation of real experiences, as ways of talking potentially shaped by discursive resources related to cancer and masculinities, and also as a social performance that may have been driven by a range of conscious and unconscious motivations. However, there was no manual or framework to guide this movement between realist, phenomenological or social constructionist positions. These ways of responding to the data were developed after deep engagement during the initial coding phases, a hallmark of GT. Insofar as possible, I tried to be guided by participants' data. For example, when social constructions of cancer or masculinities were referenced, either explicitly or implicitly, this prompted me to reflect on factors that might enable or constrain their ways of talking about an experience, and to what purposes they may be striving to use language at these moments.

I feel satisfied that this fluid approach was appropriate as a means of interpreting the data generated in this study, and represents an attempt to respect the diversity and multidimensional nature of the findings. It is also conducted in the spirit of recent arguments in favour of more flexible and pragmatic use of qualitative methodologies, and prioritising the construction of meaningful findings about human struggles (Chamberlain, 2012).

4.5.2 Personal reflexivity

Throughout the study, I have been aware of a relating to the subject matter, and to participants' experiences, in a number of different ways. Perhaps this can be summed up by saying that I occupied positions akin to more or less an insider, and an outsider, and the space in between the two (Corbin Dwyer & Buckle, 2009). At moments, I felt closer to that of an insider, particularly when they described experiencing a traumatic event at a young age, a confrontation with mortality, and their struggles with interpersonal difficulties and what it means to be a man. However, there was considerable fluidity and movement within these positions and at many other moments I felt closer to an outsider position.

I feel a deep sense of gratitude towards these men for being willing to take part in the study and for sharing of themselves so openly and generously. As with my clients, I am aware of the courage it takes to open up about difficult experiences, particularly when the outcome of such an activity is uncertain and offers no guarantees.

Deep engagement with the lives of others, whether as a researcher or therapist, can have a lasting impact. Engaging with these men's experiences had a significant effect on me and has changed some of the ways in which I think about my own life (Finlay, 2002; Kasket, 2013). I was surprised by what I understood to be their process of **searching for an enduring connection**. This prompted me to reflect more on my own needs and motivations related to training to be a counselling psychologist. I have come to believe that this training, and way of focusing my professional life, helps me to feel connected to my past history, and the ways in which I have changed as a result of my life experiences. It focused my mind more on the importance of remembering and not denying our past histories and traumatic events in our lives.

A lot has changed in my life since embarking on this training. I am now married and have a young son. Engaging with these men's experiences as I approach the next

major transition in my own life, finishing counselling psychology training, highlights how my own narratives and meaning-making processes are constantly evolving. Reaching this conclusion seems to have had an energising and liberating effect on me, despite the inevitable uncertainty about what is around the next corner.

4.5.3 In conclusion

Testicular cancer has been largely absent from academic, psychological and cultural sources. What focus it has received has generally related to its impacts on sexual functioning and satisfaction. Thus, it has been reasonably suggested that the psychological impacts of testicular cancer are poorly understood (Luckett, Butow, King, & Olver, 2008).

This study has provided an understanding of how some men experienced and managed their post-treatment lives. It disputes the idea that life after treatment is simple or unproblematic, and sheds light on the considerable disruptions and difficulties they experienced in how they felt about themselves, their identities and their relationships. It illustrates how initial attempts to manage life were predominantly solitary and silent, and seemed to be weighed down by dominant cultural discourses of cancer and masculinities. It emphasises the importance of meaning-making processes, and remembering trauma, as part of reducing post-treatment distress. Perhaps most significantly, it creates a more realistic and nuanced picture of life after testicular cancer treatment. Prior to the recent doping scandal, Lance Armstrong may have represented an idealised version, or perhaps expectation, of a testicular cancer 'survivor', who grabbed this 'opportunity' and excelled because of it. These participants emphasised the existence of what they consider to be post-treatment growth, which occurred alongside feelings of loss, change and vulnerability. Their identities and lives seemed to be simultaneously enhanced and challenged by their unique experiences of testicular cancer. In these ways, this study has contributed to creating space for seldom heard aspects of testicular cancer to be expressed. These findings highlight the importance of greater understanding of, and focus on, the emotional and psychological needs of men with testicular cancer. Counselling psychology, with its pluralistic, flexible and relational focus, can contribute to providing useful support for some of these men.

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Appendices

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Appendix 1: City University Ethics Release Form

Ethics Release Form for Student Research Projects

All students planning to undertake any research activity in the School of Arts and Social Sciences are required to complete this Ethics Release Form and to submit it to their Research Supervisor, **together with their research proposal clearly stating aims and methodology**, prior to commencing their research work. If you are proposing multiple studies within your research project, you are required to submit a separate ethical release form for each study.

This form should be completed in the context of the following information:

- An understanding of ethical considerations is central to planning and conducting research.
- Approval to carry out research by the Department or the Schools does not exempt you from Ethics Committee approval from institutions within which you may be planning to conduct the research, e.g.: Hospitals, NHS Trusts, HM Prisons Service, etc.
- The published ethical guidelines of the British Psychological Society (2009) Guidelines for minimum standards of ethical approval in psychological research (BPS: Leicester) should be referred to when planning your research.
- **Students are not permitted to begin their research work until approval has been received and this form has been signed by Research Supervisor and the Department's Ethics Representative.**

Section A: To be completed by the student

Please indicate the degree that the proposed research project pertains to:

BSc

M.Phil

M.Sc

D.Psych

n/a

Please answer all of the following questions, circling yes or no where appropriate:

1. Title of project

An exploration of how young adult men manage life after completing treatment for testicular cancer

2. Name of student researcher (please include contact address and telephone number)

Brian Garvey
(Address and phone number removed)

3. Name of research supervisor

Dr. Don Rawson
Subsequently changed to Dr. Karen Ciclitira

4. Is a research proposal appended to this ethics release form? **Yes** No

5. Does the research involve the use of human subjects/participants? **Yes** No

If yes,

a. Approximately how many are planned to be involved?

Up to 12 participants

b. How will you recruit them?

I intend to encourage voluntary participation in this study through a recruitment flyer distributed through existing voluntary sector cancer networks such as those run by Macmillan Cancer Support, Everyman and Orchid. I intend to seek external ethical approval to recruit through treatment centres such as The Royal Marsden (Surrey) and similar centres in Ireland. I may also consider recruiting participants through media outlets aimed at young adult men, including magazines and radio programmes. Depending on the success of these measures, I may also use snowballing to find additional participants.

c. What are your recruitment criteria?

(Please append your recruitment material/advertisement/flyer)

See appendix A for recruitment flyer to be used in this study.

Males aged between 18 and 35 who completed treatment (surgery, chemotherapy and/or radiotherapy) for testicular cancer at least 12 but no more than 36 months prior to agreeing to participate in this study.

d. Will the research involve the participation of minors (under 18 years of age) or vulnerable adults or those unable to give informed consent? Yes **No**

d1. If yes, will signed parental/carers consent be obtained? Yes No
Not applicable

d2. If yes, has a CRB check been obtained?
Yes No **Not applicable**

(Please append a copy of your CRB check)

6. What will be required of each subject/participant (e.g. time commitment, task/activity)? (If psychometric instruments are to be employed, please state who will be supervising their use and their relevant qualification).

Participants will be asked to take part in a research interview lasting up to 90 minutes. These interviews will take place in private rooms booked at City University to ensure the safety of participant and researcher. The interviews will be audio recorded. Prior to taking part in the interview, participants will be asked to complete a short questionnaire asking about demographic and health factors (see appendix B for the short questionnaire to be used in this study).

I may seek participant permission to conduct a follow-up interview to clarify or further elaborate on the content of the first interview. If this is the case I will go through the full briefing and debriefing process for each interview.

Towards the end of this study, participants will be offered the opportunity to attend a focus group where I seek to cross-validate the findings from the interviews. This focus group will also act as part of the debriefing process aimed at ensuring participant wellbeing.

7. Is there any risk of physical or psychological harm to the subjects/participants?

Yes

No

If yes,

a. Please detail the possible harm?

I recognise the possibility that, in talking about their personal experiences of testicular cancer, participants may experience emotional distress or upheaval.

b. How can this be justified?

The purpose of this study is to contribute to health and social care practitioners' understanding of the lives and experiences of testicular cancer survivors. It is hoped that this understanding will clarify potential support needs of this group. This study can be located as part of efforts to understand and meet the support needs of this group.

c. What precautions are you taking to address the risks posed?

Participants will be thoroughly briefed and debriefed about this research. This will include explicit discussion of psychological wellbeing and any support they may need. The debriefing process will include the provision of written and verbal information about sources of support (see appendix C for written information sheet about sources of support). It will also include a telephone contact with participants two weeks after each interview to discuss these topics again.

I intend to use my professional experiences as a trainee counselling psychologist to ensure that participant wellbeing is a central focus throughout. I will actively look out for any signs of distress and to provide the participant with opportunities to take breaks or indeed end an interview at any stage. I will use my training in the hope of providing a positive and beneficial experience for all participants who have the opportunity to share their experiences in a supportive and encouraging environment.

8. Will all subjects/participants and/or their parents/carers receive an information sheet describing the aims, procedure and possible risks of the research, as well as providing researcher and supervisor contact details?

Yes

No

(Please append the information sheet which should be written in terms which are accessible to your subjects/participants and/or their parents/carers). **See appendix D for information sheet for participants.**

9. Will any person's treatment/care be in any way be compromised if they choose not to participate in the research?

Yes

No

10. Will all subjects/participants be required to sign a consent form, stating that they fully understand the purpose, procedure and possible risks of the research?

Yes

No

If no, please justify

Not applicable.

If yes please append the informed consent form which should be written in terms which are accessible to your subjects/participants and/or their parents/carers). **See appendix E for informed consent form.**

11. What records will you be keeping of your subjects/participants? (e.g. research notes, computer records, tape/video recordings)?

Audio recordings and paper transcripts of research interviews.

12. What provision will there be for the safe-keeping of these records?

In order to maintain confidentiality, the digital and paper files will be numerically coded using a system only known to the researcher. They will not contain personally identifying information such as names or addresses. The digital files will be stored on an encrypted USB stick (SafeStick) and paper files will be kept in a locked cupboard at the researcher's home. Apart from the researcher, no one will have access to these files and all personally identifying materials such as names, addresses and the completed short questionnaires will be kept in a secure place separate from the audio recordings and paper transcripts.

13. What will happen to the records at the end of the project?

The files will be kept for up 3 months after the completion of this study and qualification on the Professional Doctorate in Counselling Psychology. They will then be securely destroyed or shredded.

14. How will you protect the anonymity of the subjects/participants?

In order to maintain confidentiality, the digital and paper files will be numerically coded using a system only known to the researcher. They will not contain personally identifying information such as names or addresses.

Apart from the researcher, no one will have access to these files and all personally identifying materials such as names, addresses and the completed short questionnaires will be kept in a secure place separate from the audio recordings and paper transcripts.

15. What provision for post research de-brief or psychological support will be available should subjects/participants require?

I will provide all participants with written and verbal information about psychological support services. At the end of each interview I will discuss how the participant is feeling and ask about any potential support they may need. I will contact each participant two weeks after an interview to explore these topics again. Participants will also have the opportunity to attend a focus group towards the end of the study. After the focus group, I will again go through the debriefing process outlined above and to explore any psychological support needs.

I may also need to facilitate access to these services for participants who wish to access psychological support. This may include providing and potentially part- funding a small number of sessions with a psychologist who has been made aware of the research and the possibility that participants may contact them directly.

If you have circled an item in **underlined bold** print or wish to provide additional details of the research please provide further explanation here:

Signature of student researcher ----- Date -----

CHECKLIST: the following forms should be appended unless justified otherwise

Research Proposal

Recruitment Material

Information Sheet

Consent Form

De-brief Information

Section B: Risks to the Researcher

1. Is there any risk of physical or psychological harm to yourself? Yes **No**

If yes,

a. Please detail possible harm?

I do not anticipate suffering any harm as a result of this research study. The interviews will take place in a private room within a social sciences building at City University. In the unlikely event that I become distressed while engaging in this research study, I will discuss it further with my research supervisor and have the option to explore it in personal therapy if needs be.

Not applicable

c. What precautions are to be taken to address the risks posed?

Not applicable

Section C: To be completed by the research supervisor

(Please pay particular attention to any suggested research activity involving minors or vulnerable adults. Approval requires a currently valid CRB check to be appended to this form. If in any doubt, please refer to the Research Committee.)

Please mark the appropriate box below:

Ethical approval granted

Refer to the Department's Research and Ethics Committee

Refer

Signature

PhD

Date

13/08/2014

Section D: To be completed by the 2nd Departmental staff member

(Please read this ethics release form fully and pay particular attention to any answers on the form where underlined bold items have been circled and any relevant appendices.)

I agree with the decision of the research supervisor as indicated above

Signature

Date

5/8/14

Appendix 2: List of amendments to recruitment criteria

Recruitment for this study commenced in April 2012. A male cancer charity has been raising awareness of the study and encouraging participation through its website, Twitter, Facebook and by distributing leaflets at meetings. 5 people have so far expressed an interest in taking part. Several of these potential participants meet some but not all of the initial recruitment criteria. For example, two individuals are aged 37 and 39. One potential participant finished treatment 7 years ago.

Having reflected on the core of the study – young men’s experiences of life after testicular cancer treatment finishes – I am requesting permission to make slight amendments to the recruitment criteria. I believe these changes strike the balance between remaining focused on the core question while also responding flexibly to participants who come forward. I propose to make two amendments and these are noted under question 5c of the ethics form:

- Change the age range to 18 to 40 (from 18 to 35).
- Change the treatment completion dates to between 1 and 10 years post treatment (from 1 to 5 years). Common wisdom suggests that being 5+ years post cancer treatment is a significant date. It is possible that the experience of life after this point may differ in important ways from life in the first five years after treatment. I would like the option to include some participants who were more than 5 (but not more than 10) years post-treatment.

These changes will enable me to start the interview process and to include the participants who came forward.

Appendix 3: Recruitment flyer

Have you
finished
treatment
for testicular
cancer?

Are you
willing to
share your
experiences
of life since
treatment
finished?

About this research study

There is a real need to understand more about the experiences of men who survive testicular cancer, particularly what life is like after treatment finishes. Most research in this field relies on surveys or questionnaires. This study is different in that it offers participants the chance to share their experiences in their own words.

Who can participate?

The study is focused on men aged 18 to 40, who finished treatment for testicular cancer at least 1 year ago but not more than 10 years ago. If this description applies to you, I would genuinely like to hear about your experiences. I hope that taking part in this study will be an interesting and worthwhile process for you.

What's involved?

You will be invited to attend an informal one-on-one interview where I will ask you about your experiences since treatment finished. You will only be asked to talk about topics with which you feel comfortable. The interview will last around 90 minutes and will take place in central London at a time that suits you. It will be tape recorded but everything you say will be treated anonymously and your confidentiality will be protected.

How to participate or find out more

If you are interested in participating or would like more information then please contact me, I would be happy to answer any questions you may have.

T 07786 464 314

E brian.garvey.1@city.ac.uk

W www.lifeaftertreatment.com

About the researcher

My name is Brian Garvey and I'm studying for a doctorate in Counselling Psychology at City University in London. The study is being supervised by an experienced researcher and psychotherapist, Dr. Karen Ciclitira, who can be contacted at k.ciclitira@mdx.ac.uk



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Appendix 4: Pre-interview information sheet

Pre-interview information sheet for participants

Thank you for agreeing to be interviewed today. My name is Brian Garvey and this research study is being conducted as part of a doctorate in Counselling Psychology at City University. The purpose of the study is to understand more about the lives of young adult men after treatment for testicular cancer finishes. It is being supervised by Dr. Karen Ciclitira (k.ciclitira@mdx.ac.uk).

What will happen today?

To start with, you will have the opportunity to ask any questions you might have about the research, the purpose of the study and what will be involved for you as a participant. I will ask you to sign a consent form to take part and to complete a brief questionnaire. We will then spend up to 90 minutes talking about your experiences and life after your treatment finished. Once the interview is completed, there will be a chance to discuss your experience of the interview, how you are feeling and to answer any further questions you might have.

What will happen after today?

I will contact you by telephone in approximately one month to give you the chance to discuss your experiences further and any thoughts that occurred to you after our conversation today. Towards the end of the project, you will also have the opportunity to attend a focus group with other research participants, where I will share some of the research findings with you and hear your point of view about what I have learned.

Do I have to take part and what if I change my mind?

You have the right to not answer particular questions if you do not feel comfortable or to take a break during the interview at any stage. You also have the right to withdraw from the study at any point during the interview or even up to one calendar month after the date of your interview. If you decide to withdraw, all of the information related to your interview and participation in the study will be securely deleted and will not be used in the study.

Will my information be kept confidential?

All of your information will remain anonymous. Apart from the researcher, no one else will know that you are taking part in the study. The stories or experiences you might choose to share will remain confidential. The digital files containing the recordings of the interview sessions will be encrypted and paper transcripts will not contain your name or other personally identifying information. The write up of the research may include some of the words you use during the interview but they will not be attributed to you and so will remain anonymous. At the start of the focus group, we will discuss and agree on confidentiality between participants.



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Appendix 5: Informed consent form

Informed consent form

Research Study: 'An exploration of how young adult men who complete treatment for testicular cancer manage life afterwards'.

Researcher: Brian Garvey (Research Supervisor: Dr. Karen Ciclitira).

Participant consent

I confirm that I have been given sufficient information about the purpose of this research study and what is expected of me as a participant. On the basis of this information I consent to being interviewed for this study and to take part in a follow-up telephone interview to be conducted approximately one month after this date. I also consent to the interviews being audio-taped and to direct quotes being used in the write-up and reporting of the study.

I understand that the data collected for this study will remain anonymous, that I will not be personally identified in any way. I also understand that the data will be stored in a secure manner and will be deleted 3 months after the project is finished.

I understand that I have the right to ask questions about the study and will be given a written information sheet before and after the interview. I know that I have the right to refuse to answer any questions with which I do not feel comfortable, can ask to take a break during the interview and have the right to withdraw from this study at any stage, including up to one calendar month after the interview takes place.

Name

Signature

Date

.....

.....

.....

Researcher statement

I have informed the above named participant of the nature and purpose of this study and have sought to answer their questions to the best of my ability. I agree to adhere to the British Psychological Society (2010) Code of Human Research Ethics in carrying out this study.

Signed

Date

.....

.....



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Appendix 6: Pre-interview questionnaire

Pre-interview questionnaire

Strictly confidential

Participant background info

Age:

Occupation:

Marital status:

Dependants:

Testicular cancer diagnosis and treatment

Date of diagnosis:

Treatment received:

Date treatment completed:

Any other information?

.....

.....

.....



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Appendix 7: Post-interview debrief sheet

Post-interview debrief and information sheet

Thank you for taking part in this research interview today and for sharing your experiences with me. This sheet has information about questions people sometimes have after taking part in an interview.

What should I do if I have questions or concerns after the research interview?

Please do not hesitate to contact me, Brian Garvey, either by telephone on 07786 464314 or by email at brian.garvey.1@city.ac.uk. I will do my best to answer any questions you have or to help if I can. If you have concerns about the research that you would like to discuss with my research supervisor, her name is Dr. Karen Ciclitira and she can be contacted by email at k.ciclitira@mdx.ac.uk. I will contact you to arrange a follow-up telephone conversation in approximately one month. This will provide a further opportunity for you to ask questions or discuss any concerns.

Will my information be kept confidential and how will the information be used?

Your information will remain anonymous; this means that unless you choose to discuss it with others, no one will know who you are or that you have taken part in the research. I will transcribe the information from the recordings myself. Some of what you say, your stories and the actual words you use, may be included in the report of the findings and in published material such as academic journals. If this is the case, it will be done anonymously, meaning your name or personally identifying details will not be used or will be changed to preserve your anonymity.

What should I do if I feel distressed after taking part in this research?

I hope taking part in this research will be a positive experience for you. However, sometimes talking about personal experiences can be difficult and some people can feel distressed by this. If this is the case you may wish to talk to someone about this. Below are the details of some organisations you can contact if you think you would benefit from emotional support. I will contact you by telephone approximately one month after the interview to discuss how you are feeling since the research and if you think you need any additional support. In the event that you would like to access psychological support, I will try to help you to find the right person or service for your needs. Please do not hesitate to contact me if you have any questions or concerns before then.

Macmillan Cancer Support
0808 808 0000
www.macmillan.org.uk

Samaritans
08457 909090
www.samaritans.org

British Psychological Society*
www.bps.org.uk

British Association for Counselling and Psychotherapy*
www.bacp.co.uk

*These organisations provide help to find counsellors, therapists or psychologists in your area.

If you need urgent assistance please contact your GP, NHS Direct on 0845 46 47 or visit Accident & Emergency at your local hospital.



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Appendix 8: Initial interview schedule

Can you tell me why you are interested in taking part in this research?

Can you tell me about your life since treatment finished?

Knowing what you know now, if a friend had just finished treatment for testicular cancer and was wondering what life would be like afterwards, what would be important to tell them?

If a book was being written about your personal experience of life after testicular cancer treatment finished, what would it be called? And what would the main chapters be?

Or

If a film was being made about your personal experience of life after testicular cancer treatment finished, what would it be called? And what would the main themes be?

Was there anything we spoke about today that surprised you?

Are there parts of your life since treatment finished that we have not spoken about today?

Appendix 9: Revised interview schedule

Can you tell me why you were interested in taking part in this research?

Intrapersonal

Thinking about life since treatment finished, can you describe how you **feel about yourself**?

Can you describe yourself as a person **before** being diagnosed with testicular cancer?

Since treatment finished, are there ways in which you have **changed**?

What **decisions** have you had to make as part of managing yourself, your thoughts, feelings etc. during this time?

Interpersonal

What have you noticed about your relationships with others since treatment finished?

What **decisions or choices** have you made regarding your relationships with others?

To what extent have you **shared your experiences** of life after treatment with others?

Have these experiences had any impact on what it means to you to be a man?

- Prompt if necessary: What masculinity means? How people think about you as a man? How you feel about yourself as a man?

Meaning of cancer

How would you describe what cancer means to you personally today?

Has that changed at all over time?

How have you managed this over time?

Is there anything else about life after treatment that you would like to tell me about?

Appendix 10: Transcription key

The following forms of notation as used for the transcription of interviews were adapted from Gail Jefferson's version in Potter and Wetherell (1994). The interviewer is indicated by the letters BG and the participant is indicated by their pseudonym.

Brackets indicate an overlap by the other speaker between utterances e.g.:

I: What do you k (of Women & Health) about Women and Health?=
A: Yes

An 'equals' sign at the end of a speaker's utterance indicates the absence of a discernible gap between speakers e.g.:

I: Did you=
A: Yes

Pauses longer than 5 seconds are indicated by number of seconds in brackets, e.g. a 7-second pause: (7)

Words which are underlined were spoken with emphasis. Words in uppercase were uttered noticeably louder than the surrounding words e.g.:

A: I REALLY, REALLY don't like it. It makes me so unhappy.

A sigh or a loud intake of breath are indicated in the text by ..hh.

A colon indicates an extension of the preceding vowel sound, or phoneme, e.g.:

A: Yeah:h, I see:

Words which could not be heard/understood during transcription are indicated by a lower case x per word e.g.: xx

An uppercase X indicates a name of a person or place which cannot be given for the sake of confidentiality. A description of the relationship of the person, or the type of place (e.g. country) is indicated in curly brackets e.g.: X {current male partner} said

Feelings such as anger, or a distinct tone of voice, are described in curly brackets, e.g. {sounded unhappy}

Appendix 11: Extract of transcription and coding

not confident/
imagine could find support
if needed it

imagine that speak to other
to survive my nightmare
Dwell more on it
Wanna try to dwell less
"Try to take mind off it
not focus on it"

feeling alone with experience
No one to relate to
feeling others interest / care
NOT want to tell others
Too personal to tell / speak
Anticipate being judged by
others
NOT want to complain?
Only so much one can

BG: And it sounds like you feel confident that you could find your way to support if you needed it actually?

Dean: Yeah I mean especially with the internet and things nowadays, I think that there is... I mean there were other people obviously out there going through the same thing and I'm sure that if I'd looked online or if I'd sort of asked the hospital and if I'd wanted to sort of contact people that I could sort of chat to about it (hm:m) then I'm sure there would have been people but I was of more of the other opinion where I kind of spent enough of my own time sort of dwelling on it that I didn't want to find other people to talk about how they felt about it. I would rather talk to my friends and brothers and stuff about other things (hm:m) because more than anything as I say you have that nagging thing where even though you don't want it to it's sort of constantly coming up and I think that in the other sense, I actually wanted to TAKE MY MIND OFF IT rather than FOCUS MY MIND ON IT (hm:m) and em:m I wanted to fill my time with other stuff rather than, spend my time thinking about how I was feeling (hm:m) if that makes any sense

BG: So you were... there was a couple of things that I picked up on and again I'll check whether it... One is it seemed like you at moments you felt quite alone although some of that was by choice it sounds like (yeah) but also it sounds like it was very quick, which had good parts to it but was also all of a sudden you were being told OK we'll see you in 3 months and then you're being left to it kind of

Dean: Yeah I mean it is quite alone in a sense that you're the only person going through it and em:m and it is... and although people ask about it and they... People want to know about and people want to be there for you eh they don't know what you're going through and you kind of don't want to tell them because you don't... not you don't want to bring them down but a lot of it is very personal (hm:m) and it's about your own body and sort of a lot of it you kind of think well, not it's no-one else's business but it sounds a bit sort of when you think about it like you're complaining too much. Like the more you... like you talk about it a lot and there's only so much I've always felt that people could listen to (hm:m) because you start to talk about the same things over and over again and back to the sort of girlfriend analogue thing about

Trying NOT to dwell
on thoughts + feelings
LOOK for distractions

memo ⑤
feeling alone

keeping others at distance

memo ⑥
Anticipate social rejection
or criticism

"sounds like... you're
complaining too much"

Initial open support
 Waning over time
 feeling that others will have
 heard it before
 keeping some part of his
 experience to himself
 feeling restricted by knowing
 others - NOT want to speak
 to close friends/family
 about center part
 CHOICE to go through some
 parts alone

when you break up with someone (hm:m) like when that happens and your
 mate talks about it ALL THE TIME, at first you sort of you're there and you
listen and it's all good and you're kind of like yeah yeah she wasn't that great
 whatever. But then after awhile you kind of go, you've told me all this (hm:m)
 and you kind of hit that point with it and you don't wanna talk because
 everything you've thought you've told them or everything you wanna tell them
 you've told them so you end up just sort of saying the same stuff again and
 then it's like, he knows how I feel in that sense (hm:m) and then anything
 that you haven't told people it's because it's personal and you don't want to
 tell them (hm:m) so em:m... it's a bit like what we were saying earlier on
 when we first came in about sort of doing the psychological, doing this and I
 said it's easy to chat to you because I don't know you (hm:m) em:m where as
 if I did know you it would be different because there's certain things you don't
 necessarily want to share. I think that that's (hm:m) that's kind of how that is,
 you SHARE the things you want to and the other part you don't share so.
 You're lonely... the bits that you go through alone are more because you want
 to go through them alone em:m... (yeah) and in a sense a sounding board
 that you don't know could be easier for you to talk to people about things you
 don't... but I never looked for that so em:m

BG: *But that... is also really interesting that thing that you described where it
 sounds like internally there's this thing of... part of you is trying to some of the
 time, you're trying to put this out of your mind, to not think about it but
 you're also finding that it that that that that for whatever reason it is coming
 up and coming up into your mind it sounds like in the early part a fair bit
 (yeah) but that externally when you're engaging with people that you care
 about when you're talking to them there's a feeling that actually maybe
 you're... although things don't feel that they are resolved internally you you
 think that you've kind of exhausted your=*

Dean: Yeah... your kind of... I mean people will always listen because people
 are nice and they're your family and stuff but yeah you do get to a point
 where you thought you you you do kind of feel I've exhausted this especially
 after a few months when you're still going through it but medically you're fine
 (hm:m) so you've kind of hit your quota* where you can't complain anymore
 because they know you're fine and it's it's hard to kind of go oh yeah I'm...
 and most of the stuff as I say is the silly stuff that you don't want to tell

Imagining criticism from
 others

Hiding the "personal" from
 others - keeps the
 personal private?
 Memo @ ASD
 Dudson

will get
 Imagining others are tired
 listening to him
 Contrasting idea of
 medically fine with internal
 worry + fear
 Having a quota on support

NOT Having the right to
 speak - "medically fine"

Rationalising why he
 kept others in the dark.

Imagining others NOT understanding
 "Be's judged in a hard
 Need to hide his deepest
 fear
 TRY to find distractions
 won't to have fun
 Anticipating further isolation
 - others not finding him fun
 Not speaking as way to engage
 with other topics
 Worries + fears especially
 when spent time by himself
 Internal process beyond
 his control
 Mind 'spirally'
 "Dwelling" + feels lonely
 find distraction easier
 when in social situation

people that you're dealing with internally, like the... cos it I mean if I turned to
 someone and went I'm more worried about losing a testicle than getting
cancer again you it it's hard to voice that because it sounds so irrational that
 it seems easier not to tell anyone because it sounds crazy (hm:m) and then
 there's a load of really stupid things like that and em... I dunno em:m I spent
 a lot of time sort of going out and trying to have fun and just trying not to
 think about it (hm:m) and that's kind of how I kind of got over it (hm:m) by
 just kind of slowly over time trying to just not think about I but you also... it's
 not just about sort of having exhausted your people to talk to... it's about you
 want to spend time around people and you get the feeling that if you do just
 talk about it all the time they won't want to spend time with you (ok) so and
 also then it's kind of ALL you talk about so you... if you... as I say you're trying
 to keep your mind off it so if you talk to someone about it they'll talk back to
 it about you, whereas if you don't bring it up they'll talk about something else
 and if they are talking about something else then it can take your mind off of
 it (hm:m) so it it's more the kind of when you're by yourself that... I mean
 when you're surrounded by people you feel less like talking about it in a way
 because you talk about other things where as it's more in bed at night when
 you're low or when you're just sort of walking to the shops or when you're
 sitting watching tele your mind starts to kind of spiral and you just... it's when
your mind is active by itself that you start to think about things (hm:m) and
 that's also why I think it's quite lonely because it's it's kind of the times you
 are alone when you start to kind of dwell on it (hm:m) and when you're
 around people or at the pub or stuff you've got other things going on so
 although it does click up in your head em:m you can kind of push it down and
 think of other things (hm:m) rather than just kind of constantly dwelling on it
 so=

BG: That makes sense and I and I understand what you mean about in some
 ways that helps with your goal at some of those moments to try and stop
 thinking about it actually (hm:m) if you are talking to other people and there's
 other stuff going on and you're alive in the moment kind of (yeah) with
 whatever's happening.... Em:mm do do you... can you tell me a bit more
 about what those moments were like when you were on your own? I'm
 particularly interested in what you felt actually, what were the feelings that
 you had?

memo 30 B sequential.

Imagining others
 judging him
 criticizing himself.
 Gets over it by not
 thinking about it
 Imagining further isolation

Memo 10 + 11

Has NO control over
 thoughts

find distraction
 (+ enjoyment) in social
 context

Describe internal psychological
process: fear of loss
Listed fears - loss
of testicle, B-6, guy with
no testicles, death/mortality,
can't recurrence

Constant nagging
constant anxiety
(contrasted with when not
constant)

Going through different
phases - "Want more fun
- 'being what I want to do"
Disinhibited? unrestrained
by who "should" be?

Making a dick out of himself

- Mind of constantly at
odds - conflicted

Contrasts Rational Mind
with other parts on mind

Hidden mood swings

Internal battle and
struggle
uncertainty

Dean: Em:m it was... I mean it's a constant sort of feeling of fear em:m for ALL SORTS OF REASONS em:m that sort of... once again back to the sort of FEAR of losing the other TESTICLE, the fear of not being able to have a FAMILY, the fear of that sort of side of things, the fear of sort of being the guy with no testicles {spoken quietly} em:m and there's that sort of fear and there's... there is the fear of death and the fear that it could sort of come back (hm:m) em:m and there's there is just sort of a constant sort of nagging at you that there's... this could happen again and that it might not be over and that just goes away with time because the longer it all goes on and the further it gets and the more you're told you're healthy (hm:m) that's all good but especially the first 6 months is a constant kind of em:m anxiety and fear that and there's also the feeling that like I I went through kind of a stage of NOT NOTHING MATTERS but kind of .hh not IMMORTALITY either but you go through a stage of kind of I wanna have MORE FUN in the sense there's sort of... .hh if THIS IS IT I've spent ALL my life at school and at university and I spent so much time doing what I don't want to do (hm:m) for a future that I may not have (laughs) so there's also a sort of side of that as well that you kind of think I'm gonna be more who I want to be not who I am and then you go out and you do stupid things and you make a dick of yourself and then you go oh god I've done that again em:m so it's kind of... there's lots of sides that kind of that you're constantly... but you you your MIND'S constantly at ODDS to each other that like you your mind's sort of... your rational mind is going you're fine, you're going to be fine, just get back to a normal life, go back to uni, study, kind of do all that and then the other half of you is going no no this could be it, go out, like studying doesn't matter (hm:m) like if you do die in six months of cancer then you've WASTED ALL THIS TIME and (hm:m) and your... it's not kind of one thought it's just it's the fact that from MOMENT TO MOMENT your mind just JUMPS ABOUT and you you constantly depending on your mood... and your mood constantly changes (hm:m) em:m and sometimes you can be very rational and everything is very simple and focused and everything falls into place and then other times your mind jumps to something else and well what am I doing with my life kind of (hm:m) and you kind of have that on top of this fear that it could all come back and I think you kind of... I wouldn't say that you're mood swings... I mean mood swings may sound like externally you're mood swings but I think it's more of an internal mood that your mind kind of swings from place to place em:m and it's HARD to kind of FOCUS on anything because you're constantly your opinion is

memo 12 feels scared

feeling deeply afraid
fear of loss of other
testicle - health,
mortality

finding reassurance
over time

feeling disinhibited?

memo 17
Internally is turned
having lots of sides on you

feeling uncertain
uncertain priorities?

Grappling with chaos
memo 4 feeling uncertain

Swinging Moods
Experiences

Mind jumping + Mood
Change sort of how to
improvise over time
NOT struggling like he is
today.

Mind is out of control
- jumping, skidding about
IN FLUX
contrast between what he
'should' do vs. what he really
wants to do
Part of mind encourages
him to 'cut loose'
NOT as concerned with
pleasing people
questioning self + others
Right to pressure him / shape him
Moments of a nasty look
Multiple moods + parts of
personality
overthinking

changing from sort of day to... well not even day to day but hour to hour
really (hm:m) you can't kind of focus on what you should be doing because
you're constantly, there's just something constantly in you ragging and it's get
easier and easier and as I say now I don't even think about it because it's
been years but at the time I remember it being=

BG: = Well I'd like to ask you more about that in a second actually {spoken
quietly}. Did you... so you... the... that sounds really confusing, the the
(hm:m) for you. I'm imagining what would you feel at that moment, so you're
going from a certain moment where you're being very rational, very focused,
you might think about statistics and likelihood and it's fine and then on the
other hand you're you're kind of .hh really fundamental parts of how you're
living your life and who you are are being questioned then at the next
moment. Is that right?

Dean: YEAH em:m that that is pretty right em:m but it it's more JUMPY than
that as well. Your brain is kind of... so you don't.... looking back now that's
probably the best way of putting it but at the time it was sort of you you
you're not... it wasn't as U as that (hm:m) it's just kind of more... YOUR MIND
is just kind of SKIDDING ABOUT and.... I can't think of the best way to put
it.... Em:m... .hh you have kind of what you should do and what everyone tells
you you should do and then you have kind of what you want to do (hm:m)
and you know that sort of that's how it should be and then sort of part of you
just goes no let's CUT LOOSE and you've got this little voice in you that goes
'no just do what you want' and I've spent my whole life kind of... because of
the way I was brought up trying to please people (hm:m) and kind of be the
person that I should be and then like it... not lowered my inhibitions but it
made me think kind of WHY... WHY be who everyone WANTS me to be, why
not be who I wanna be? (hm:m) So I could be a lot more snide, sort of
meaner to people because I thought well screw it like (hm:m) but that would
be like a two minute mood swing and I'd be sort of... I'd make a sort of
dickish comment to someone and then sort of I'd be like nah and then the
real me would come back and I'd be like that's a horrible thing to do so then
I'd be very apologetic (hm:m) and my mind was sort of constantly in FLUX
(hm:m) of how I'd be feeling and you can't really... I mean most of the time
you're just kind of going through the motions but when you sort of, sort of
start to think about things then you OVERTHINK them (hm:m) just you... it's

Perpetually changing

memo @ F11
Mind skidding ABOUT
Bf out of control.
feeling conflicted
Questioning himself
Questioning others
SEARCHING for
ways to feel happy?

Not unhappy that will make him happy - turmoil?
 Feels unsure about what he's changed on that he wanted to change
 Had an excuse to behave badly
 Drinking a lot
 Acting on spur of the moment - doing whatever he felt like going out too much
 Regrets not saving compensation money
 Judging his actions as irrational
 NOT BE open to being challenged by others - other NOT BE able to question him
 Trying to take his mind off by ill
 Had an excuse to be stupid or behave stupidly
 Never had a settled mind
 Mind settling down over 4-6 years?

very volatile in the sense that you can only really make your mind up on where you're standing and (hm:m) you just sort of swing about and part of you kind of says yeah do what you want and then sort of you start to do what you want and you realise that that doesn't make you happy either so (hm:m) so you kind of... I dunno it's a WEIRD TIME and I think you also know that you have the EXCUSE that you can do what you want (hm:m) so that makes it easier to be... like oh he's having a rough time... and then you start to use that because you know that people don't care because he's going through a tough time and then you do something stupid and it's like... no now I'm just being THAT GUY and em:m... it's things like you start to go out... because I was at uni and stuff and started to go out quite a lot and sort of drink a lot, not stupidly, I didn't sort of suffer from alcoholism or anything ANYWHERE NEAR THAT (hm:m) but em:m I got compensation for from life insurance because of it so I was given a large chunk of that. One half of it went into medical care in case I was sick again and the other half went into my bank and that meant when anybody said do you want to go out I had money to go out so I went out FAR more than I should have and when I should have been in studying (hm:m) I didn't... I sort of went out like not sort of drinking heavily but just kind of to the pub (hm:m) or just just... if em:m... like looking back now I should have saved that money or invested it or it would have been very useful but one of my mates one weekend went do you wanna go skiing? And I just went YEAH I WANNA GO SKIING. It was a stupid thing to spend money on. I had to buy ski gear, had to buy ski passes, had to buy... it cost an absolute fortune but NO-ONE COULD TELL ME NOT TO because I'd never been skiing and looking back now if I suddenly turned around now and went I'm gonna go skiing this weekend everyone would go (name) don't be a dick, you can't afford to go skiing but NO-ONE can tell you stuff like that (hm:m) because YOU'VE BEEN ILL and LET HIM ENJOY IT sort of... so you kind of have this excuse to be stupid and you use it and then you feel bad about using it and then... but then also as I say you're trying to take your mind off of being ill (hm:m) so it is a good excuse to be stupid because when I went away you think a lot less about it because you're off having fun, you're skiing, you're drinking and I dunno your mind's just never settled and you just... it's CONSTANTLY JUMPING so and I I I haven't felt like that in the last couple of years (hm:m) I'm a lot more settled, it was something about that that keeps your mind jumping but it's weird=

Having Privileges
 OR Excuses - Licence

Memo (18) made or had for
 future
 Living for the moment

Memo (11)
 Bef in Turmoil

Never having a
 settled mind

Had a specific date when
this changed / improved
Not thinking about being ill as
sign of change

Believe this was felt
better / improved - NOT A
process he was necessarily
in control of?

'See light at end of tunnel'
Cancer still on his mind
- Weekly, NOT every minute
- NOT as anxiously
more as recognition or
acknowledgement

feels relieved - believe
his mind might settle down

feels at peace, relaxed
Acknowledges without overly
worry about cancer because
identifying vulnerability / weak
point - worry can

BG: = When did when did it when do you think it changed?

Dean: Em:m (8)... I have the date written down somewhere em:m... it's... there was... I think it was about a year and a half in and it was the day after that I actively thought "YOU DIDN'T THINK ABOUT BEING ILL YESTERDAY" and I actually wrote the date down because it was a big change, like every day it would come up at least once (hm:m) and then there was just... and on that day I might have thought about it and then forgot about thinking about it but when you're trying not to think about it so it's constantly there because you're trying not to think about it... and then there was probably about a year, year and a half in, after treatment, maybe even longer than that, there was just a day when I was sitting there the day after that day and I've thought, you didn't think about being ill yesterday. And I went... and that's when I sort of thought YOU'RE GETTING BETTER, you're coming out the other end of this (hm:m) sort of... you're not thinking about it all the time (hm:m) and on the build up to that it was probably le... I mean it gets LESS AND LESS AND LESS and then nowadays I... I mean I still think about it, I mean it comes up definitely once a week but only in the sense that something will get brought up about cancer not about me having cancer and then you kind of go ah:h but it's not thought of in the same way because in that sort of first year it's brought up as a WORRY (hm:m) whereas now when it's brought up it's not brought up as a WORRY or a concern, it's just brought up as a FACT and a MENTION and you kind of go ah and your mind goes 'ah:h cancer' (hm:m) whereas back then every time it's mentioned it's... you get a kind of ball in your stomach and there's a fear and a worry, whereas yeah and the fact that I hadn't thought about it em:m made me kind of think I'm coming out the other end of this and I'm gonna be all right (smiles).

BG: What did you... what did that feel like that day when you thought my god I didn't think about it yesterday?

Dean: .hh It felt em:m... it felt really good... i i it felt sort of you're, you're settling back into life and like it was only sort of a quick realisation so, it wasn't sort of an overly thought thing but it was just a GREAT FEELING of yeah this is, it's going to be ok (hm:m) and it was kind of like it might come back but it wasn't the worry it had been (hm:m)... it was... and I mean still now if I think about it too much I can worry about it but I chose not to. That

Return to a normality
Not think ABOUT being ill
See light at end of tunnel

memo (14)
Being chased or
going back?

feels less raw

Believe he would
survive the experience

Reach an epiphany
 - "don't dwell on it"
 Acknowledging that he was
 (+ Accepts) NOT IN CONTROL
 Won't let "have yourself
 sick"
 Belief "I'm going to be
 all right"
 (Reach the point of
 belief)

Cancer as lens for the
 world / daily life
 By totally preoccupied with
 Cancer
 Relates to all things cancer
 Contrast how he relates
 to portrayals of cancer

was the first step of not worrying about it because it was kind of the epiphany of don't dwell on this (hm:m) nothing... if you get it you get it, if you don't you don't, like... you could go 50 YEARS and never have another problem or you could get it again tomorrow and worrying about it does NOTHING about it (hm:m) and it was kind of that 'don't think about it because it doesn't help to think about it' like... well not it doesn't help to think about it, it helps to be prepared but it doesn't help to SIT and DWELL and WORRY and just like make yourself sick about it, it just em:m.... It was a first step towards that so it felt... it was a good feeling of kind of I'm going to be all right

BG: Incredible. It's funny that you can that you can picture a... that there is a particular day

Dean: Yeah there was a particular day, weird. I've never told anyone that before (laughs) yeah em:m=

BG: =And I suppose what I understood about the worry in your mind is that i is the difference between you know I suppose while treatment was still going on or in the immediate year or year and a half afterwards it sounded to me like you felt... there was a part of you that felt very And again I'm trying to understand, not put words into your mouth (hm:m) but felt very raw so that when something like cancer might be mentioned that it was there and it was very=

Dean: =YEAH IT DOES em:m and also I think that... and this is the case with everything em:m but I think that the mind floats to whatever, like you you... WHATEVER PROBLEM YOU HAVE, YOU NOTICE (hm:m) so if you're in debt and you're worrying about debt, everything on TV seems to be about debt, if you're going through a bad breakup every song or thing on TV seems to be about that (hm:m). And I think it's not that there's anything more it's just that if you're not in debt then things on TV about debt don't worry you because so they're just things on TV and if you're not going through a breakup then it doesn't worry you because it's just someone else on TV going through a breakup (hm:m) whereas I think you think more about it and like you relate more to the things you're going through so that's why they seem more raw when you see them on tele... so now when I see cancer on tele there are elements of it that I sort of agree with and sort of see myself in but not in the

Left 90
 Memo (13)
 Develop Acceptance

Seen the world
 through Cancer

Desperately want to relate
to cancer in past - to
understand myself? to feel
less alone / crazy?

Want help to explain on
understand how he felt.
feeling raw + need to relate

Cancer as two outcomes
- survival or death?

Look to TV portrayals
to help him understand process
eg source on life

Wondering if he was prepared
himself

same way as then because every element of it when you see it or mentioned
DRIVES HOME... I think you you you LOOK TO RELATE so you do (hm:m) like
now it's sort of... not more clinical but it's more I went through that, it's more
kind of like... you'll see something about cancer on TV and you'll go that's
wrong, that's not what happens, whereas in those days like you kind of go...
or they'll sort of saw something and like... they'll make one comment and
you'll... or you'll disagree with the way they are acting it or something (hm:m)
and then there'll be one thing where you kind of go no I do agree with that,
whereas when you're ill, that one comment... it could all be completely wrong
from how you feel but then there could be that one good comment and you
sort of LATCH ON you go 'THAT'S EXACTLY HOW I FEEL' (hm:m)... and I think
YOU WANT TO RELATE TO IT, so it's a lot more raw and you change your
moods to match what you see and you kind of focus on it cos it's always in
your mind so as soon as you hear it you kinda go 'YEAH THAT'S ME' (hm:m)
and you kind of you look for it although you're not looking for it=

BG: =Do you do you... I know that you wouldn't have necessarily thought
about it like this at the time because we're probably we're not as mechanical
or whatever but... I wonder what you were doing at those moments back
then... so if when you said you'd see a portrayal of it, even though loads of it
might be wrong you'd see a part that you could relate to (hm:m) that felt true
to you and you'd go yes that's exactly it. It almost sounds like you'd be really
relieved and maybe that part of your experience would become dominant
almost for that moment. What do you think and this might sound like a weird
question... what do you think you were doing... what was the process that was
happening... what were you doing by doing that?

Dean: Em:m (does that make sense as a question?) yeah that that does...
em:m... I think that the first thing you're doing is like cos I think on TV and
stuff and when you hear these things like quite often the stories go two
ways... they go... they only sort of focus on... I mean there are only two
sides... either the WORST or the BEST... I mean cos a lot of it's on tele there
the two things people focus on (hm:m)... em:m so you either focus on it and
you relate to it because it's the best and that's the outcome you want so you
kinda latch onto it because it's like well he was WORSE THAN ME AND HE
PULLED THROUGH so you kind of latch on it (hm:m) because of that or I
think also you want to prepare yourself for it so... or not prepare yourself for

Feel desperate to
relate, understand

search for
understand

CANCER AS LIFE
OR DEATH.

Memorandum
stung it with
doland
in back

Appendix 12: Sample memo - “Not talking about it”

Not talking about it

Memo 3(v2) (03/12/2013)

(Content of memos 9 (finding a way to talk) 25 (having trouble in a sensitive area) and 26 (experiencing others’ discomfort) merged here)

Related codes

“Let’s not talk about it” (Dean, 33)

Hiding the personal parts (Dean, 32).

Carrying the burden (Phil, 35)

Finding a way to talk (Dean, 37)

Feeling disapproved of – told to look on positives (Alan, 6)

Being “tip-toed around” (Dave, 24)

Finding humour in life and developing funny stories/anecdotes (Dean, 34; Dave 48; Phil, 25)

Perceiving others’ discomfort (Phil, 22 / Stephen, 11)

Being excluded from conversation – not being spoken to directly (Dave, 25)

There were several moments where participants kept their experiences, fears, and struggles to themselves. It seems to relate mostly to challenging, upsetting or worrying aspects of their experiences. This meant not only delaying or not speaking about cancer, but also hiding parts of their emotional or psychological or physical experiences – so avoiding disclosure in a broad sense, not just related to cancer status.

The extent, the content and the context of what was kept hidden from others varied depending on the participant. For some it meant that most of the troubling parts of their experiences were kept to themselves... or at least kept to themselves until they felt somewhat less troubling, and could then perhaps be shared with others. Phil seemed to share little of his worries or troubles with others and carried “the burden” (Phil, 35). This was perhaps related to trying to reduce the impact on others*. But it’s quite hard to be sure about this or to separate out the different components. I say this because I remember that for Phil, others being affected or showing the impact on them seemed to threaten or compromise his strategy of trying to carry on as normal. Speaking about or acknowledging worries or fears might make it difficult to maintain a sense of carrying on as normal.

Some of the other participants seemed to mainly keep the personal and intimate elements to themselves – perhaps partly out of feeling embarrassed or ashamed? I wonder if this might also have been a way of avoiding something else ‘bad’ from happening. Perhaps it was also a way to avoid feeling further fragility/vulnerability/rejection?

- Dean tried to hide the truly the “personal” or the “deeper, darker parts” from others (Dean, 32) e.g. fears of losing second testicle or anxieties about imagined sexual relationships with girls in the future.
- Alan felt upset by the changes in his body but found it difficult to speak to people about these, partly because they related to a sensitive topic (6).
- Stephen avoiding speaking about emotional upheaval to his colleagues or his manager at work because he felt vulnerable in his job and was worried about losing it. Two months before being diagnosed he had bought a new house and so felt under financial pressure (11).
- Stephen also felt unsure about who was genuinely interested in speaking to him, who would help if he opened up about his difficulties.

The location of the cancer in the testicles/genitals (“sensitive area” / “personal cancer”) seemed to create difficult feelings and social difficulties. In particular, some participants had difficulties speaking to women about it for fear of being seen as diminished, flawed or less manly (Phil, 29/30/31). Also, potential complications regarding fertility were seen as something difficult to negotiate with potential future partners – when to bring it up, how to speak about it, how others might react?

I find myself wondering if it is possible that not speaking might be a way to retain a feeling of control? Perhaps sometimes not speaking could be a means of keeping others at a distance and it may mean they don’t get to have a say in what is being worried about.

Dave said that he had shared many open discussions with his wife but kept back his fears about work. He did not want to tell her that he was afraid of losing his job (Dave, 30). Perhaps because he was trying to hold onto some feelings of being in control or making active decisions in one sphere of his life.**

For some participants this was contrasted with an ability to speak about difficulties related to cancer in general during treatment time. This was widely understood by others and in this was a sort of social permission? But after treatment finished it was felt less likely to be understood by others (Stephen, 16). Several mentioned a sense that they did not have this social permission to speak about emotional or personal difficulties as men*** (Alan, 7/47). Some found that when they described troubles that were not life and death they were essentially told to look on the bright side (Alan, 6).

For others, perhaps it related more to perceiving others’ discomfort and interpreting this as signals not to speak about their experiences. Some participants spoke about awkward interactions where others seemed hyperconscious of TC but did not speak directly e.g. “losing a ball” comment (Phil). Several felt that others tiptoed around

them or walked on egg shells (Phil, 22; Dave, 18/16). Perhaps this acts as a reminder of what sets them apart? Or makes them feel in a weaker or more vulnerable position? It also made me wonder about other social faux pas and Freudian slips or unconscious responses from other men. Perhaps this is a taboo subject or multiple taboo subjects.

Links to other memos

- * Thinking about the impact on others (25)
- ** Feeling powerless (17)
- *** Feeling less manly (7)

Appendix 13: List of initial and revised memo titles

Based on initial and focused codes and incorporating detailed notes about processes prepared from each interview, I wrote an initial set of 32 memos or analytic notes which represented the starting point for making the analysis more conceptual.

1. Wishing for more support after treatment finished
2. Experiencing delayed impacts
3. Avoiding disclosure
4. Feeling uncertain
5. Feeling isolated
6. Anticipating social disapproval
7. Feeling less manly
8. Feeling self-conscious
9. Finding a way to talk about it (and using humour)
10. Constantly thinking and worrying
11. Being in turmoil
12. Feeling scared
13. Developing acceptance
14. Being changed or going back
15. Being 'in the dark'
16. Carrying on as normal
17. Feeling powerless
18. Imagining or living for the future
19. Feeling less attractive
20. Experiencing loss
21. Finding signs of recovery
22. Making up for lost time
23. Enjoying or appreciating life
24. Thinking about the impact on others
25. Having trouble in a "sensitive area"
26. Experiencing others' discomfort
27. Experiencing side effects
28. Having good and bad luck
29. Being disrupted
30. Criticising or blaming self
31. Feeling frustrated with others
32. Feeling anxious about check-ups

These memos were then further developed by exploring areas of commonality and starting to try to synthesise larger sections of data. In some cases the title of memos was reconsidered in order to reflect how they had changed. Below is a list of the revised of 17 memos:

1. Feeling abandoned when treatment finished
2. Troubling realisations and impacts
 - Incorporating experiencing side effects
3. Not talking about it
 - Incorporating finding a way to talk about it; having trouble in a “sensitive area” and experiencing others’ discomfort
4. Facing uncertainty
 - Incorporating constantly thinking and worrying; being in turmoil – internal conflict; feeling scared and feeling anxious about check-ups
5. Being set apart
6. Anticipating criticism or judgement
7. Negotiating masculinities
14. Struggling between going back or being changed
 - Incorporating carrying on as normal
15. Being ‘in the dark’
18. Imagining or focusing on the future
19. Feeling less attractive
 - Incorporating feeling self-conscious
20. Experiencing loss
 - Incorporating feeling powerless; being disrupted
21. Finding signs of recovery
 - Incorporating developing acceptance
23. Appreciating and making the most of life
 - Incorporating making up for lost time; having good and bad luck
24. Struggling with the impact on others
25. Criticising or blaming self
26. Feeling frustrated with others

Appendix 14: Attempts to develop categories

This section includes some of my 'workings', documenting initial attempts to identify major categories and sub-categories that synthesised large amounts of data, captured the significance of the data and contributed to answering the research question. This involved moving back and forth between the revised list of memos, notes about processes from each interview and the transcript data. Below is a list of the initial four categories that I explored and the aspects of these potential categories that sprang to mind:

Living with uncertainties and anxieties

- Health
- Delayed impacts creating further uncertainty – what's next?
- What can I do after treatment? What 'should' I do? What do I want to do?
- Real relationships and imagined future relationships... sex life and fertility
- Ways of responding to feeling that the world was out of control?
- "Dwelling" vs. not thinking – establishing a feeling of (sufficient) control?
Accepting lack of control?
- Imagining or living for the future

Negotiating relationships

- Current (partner, children, parents, siblings, close friends, acquaintances) and potential or imagined future relationships (mainly partner)
- Not talking, keeping others in the dark, not being (more of) a burden?
- Feeling self-conscious... Not talking about "sensitive areas"
- Feeling guilty/responsible – having regrets for impact on others – self-criticism
- Feeling isolated, set apart, made different
- Experiencing others' discomfort – feeling without 'permission' to talk
- Anticipating others' disapproval – feeling judged/watched, imagining being criticised/rejected
- Feeling frustrated with or angry towards others

Negotiating masculinities

- Losing a testicle, potential fertility difficulties
- Emotional upheaval and distress – not talking about it
- Experiencing others' discomfort

- Imagining being seen as flawed or deficient by potential partners or having difficulty explaining possible fertility/stored sperm

Losses and gains

- Experiencing and processing loss and change
- Having good and bad luck
- Being changed or going back?
- Having a changed mind-set
- Finding signs of recovery
- Enjoying or appreciating life – making up for lost time
- Developing acceptance... over time?

Below is a table detailing a subsequent stage of category development. These tentative categories acted as the basis for the theoretical sampling of two additional participants who could help to further develop and refine the categories.

Negotiating relationship with self (intrapersonal) - Impact on trust and confidence in self - Touching upon control, agency, responsibility - Self-reflection... questioning self - Changing attitudes or mind-set - Complex and sometimes overwhelming emotions - Keeping it to themselves – not talking - Avoidance? Seeking to retain some feeling of control? - Negotiating internal conflicts (different parts of self) - Blaming or criticising self - Doing too much, too soon - Processing change and loss - Finding signs of recovery - Appreciating or making most of life (post-trauma growth?)	Negotiating relationships with others (interpersonal) - Current partner or potential future partner(s); children; other family; close friends; acquaintances; healthcare professionals - Being set apart from others - Keeping others in the dark – not talking - 'Personal'/intimate 'secrets' - Having less 'permission' to be affected after treatment finished - Worry about the impact on others - Feeling watched – an object of scrutiny? - Interpersonal experiences impacting on intrapersonal e.g. noticing others' shock/fear makes it hard to 'carry on as normal' - Anticipating criticism or judgement from real or imagined others - Negotiating masculinities - Perceiving others' discomfort - Experiencing others' tip-toeing around them
Negotiating relationship to cancer (after treatment) - A disruptive and dangerous intruder? - A threat to life - Needing support to cope - Delayed impacts/realisations - Feeling anxious about health... what ifs... - Living with the uncertainty - Imagining or living for the future (looking beyond cancer) - Living with long-term side effects - Taking part in interview as sign of progress/movement/recovery?	Negotiating relationship to past and future - Awakening of consciousness of mortality - Uncertainty of future - Desire for sense of control - Struggling between moving back (pre-cancer) and moving forward (accepting or embracing change)

Appendix 15: Connecting categories and codes

Category/Sub-category	Associated Codes
After <i>"the whirlwind"</i>	Unprepared for long-term impacts Being <i>"in the dark"</i> Experiencing delayed impacts
Living in uncertainty	What if's Feeling scared Never having a settled mind Being unable to relax
Internal conflict	Having different parts or <i>"sides"</i> of self Feeling <i>"in flux"</i> Difficulty making decisions Not trusting self
Overwhelming emotions	Experiencing emotional upheaval Having no control over feelings Not knowing what to feel
Feeling isolated	Being <i>"out of the loop"</i> Feeling set apart Perceiving others' discomfort Losing important friends
Facing the impact on significant others	Being <i>"a burden"</i> Wanting <i>"to protect"</i> others Feeling responsible for impact on others Feeling guilty
Struggling with others' silence and discomfort	Being <i>"tip-toed around"</i> Struggling to understand others Not being asked about cancer Living with a taboo
Anticipating social disapproval	Worrying about what others are thinking Feeling confused about others Imagining being disapproved of or rejected
Desirability, sex life and fertility	<i>"Less of a man"</i> Having sexual difficulties Worrying about disclosure Feeling less attractive
Ways of coping and being changed	Feeling restricted as a man Not having permission to talk Struggling with expectations of men Not breaking down
Managing by thinking or doing	Self-reflection Trying to make sense of it Just getting on with it – not thinking Carrying on as normal
Framing techniques	Focusing on life after cancer Seeing difficulties as 'tests' Describing cancer as a learning experience Adopting a positive attitude

Demanding more from self	Blaming myself Feeling inadequate The <i>"self beat-up"</i>
Keeping quiet	<i>"Let's not talk about it"</i> Not telling others Carrying <i>"the burden"</i>
Processing losses and gains	Having <i>"pivotal moments"</i> Finding signs of improvement or recovery Reflecting on being changed Acceptance of losses Acknowledging positive changes Finding positives and negatives
Breaking the silence	Finding ways to talk Seeing the funny side Using humour
Searching for an enduring connection	Wanting to remember, not to forget Wanting to stay connected

Appendix 16: Excerpts from researcher's reflexive diary

Interviewing and initial coding phase

From the pilot onwards, it became clear that the participants had a lot to say about their experiences of life after testicular cancer treatment finished. I had mixed feelings about this – at moments taking it as a sign that they felt comfortable, that sufficient rapport had been established and that the topic was rich. At other times, I felt overwhelmed, lost in the sheer volume of data, and concerned that I would struggle to do justice to the breadth and depth of what they shared with me, within the constraints of the doctorate.

After transcribing the first few interviews, I wondered if I was somehow reluctant to take a strong authoritative position in guiding the interviews. I wondered if this might relate to a fear of emasculating participants based on some underlying idea about what they might already have lost. Also I wondered if I was struggling to maintain a researcher-participant relationship rather than letting it morph into a client-therapist relationship. I seem to be asking myself if I should have controlled the interviews more? However, my priority was to share power with the participants and to try to get as much rich data as possible while being mindful of their wellbeing. While the amount of data generated is undoubtedly overwhelming, participants exerted considerable influence over how long the interview lasted and the directions it took. I don't feel that I was in fully in control of the interviews and I'm pleased to be able to say that.

During the analytic process

At times during this analysis, I felt drawn towards a more positivist position of wanting "the truth" about life after testicular cancer treatment to emerge from the data. Perhaps the idea of producing a theory is weighing heavily. Perhaps this is also due to anxieties about how to make my role in the research process visible and how this might be judged by others (Etherington, 2004). However, given the number of different ways I could imagine constructing this data, and the likelihood that another researcher would create alternative constructions, I recognise that I have shaped this analysis. I see it as one possible account of managing life after treatment. Acknowledging these components of my work helps me to feel more comfortable, as if the task is more manageable within these boundaries.

Writing the analysis chapter

Writing this chapter has been the most emotionally challenging and draining part of the research process so far. I felt overwhelmed by a sense of how important it was to me and the study and was afraid of not getting it 'right'. I struggled to try to find a way of doing justice to what participants shared with me, while adding a conceptual reading of these stories, but remaining grounded in the data. On reflection, I can see this in several different ways. This feels like the challenge of qualitative research and sitting with the inevitable ambiguities and uncertainties, which are perhaps exacerbated on a solitary research exercise of this kind. I wonder also about parallel process, whether being so deeply immersed in participants' stories allowed me to gain some direct and painful experience of what life was like for them at particular moments. I can see how I found it unbearable at certain moments and reached for the 'thinking', 'doing' or demanding more of myself approaches. I noticed a repetition of the patterns of how many of these participants coped with difficulties. It may also be that this deep engagement with their experiences has been so personally demanding because I can identify having shared some similar experiences, disruptions and relational problems. Perhaps this work is bringing these memories back into mind and that may also be why it has felt so draining at times.