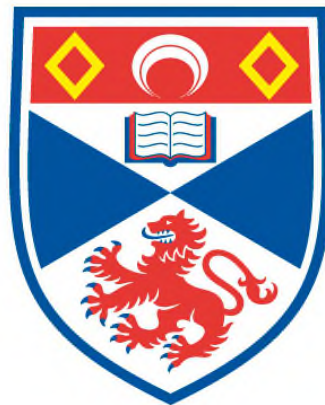


**MEN WITH CANCER:
PSYCHOSOCIAL ISSUES, HEALTH BEHAVIOURS,
COPING AND HELP SEEKING**

Hannah Dale

**A Thesis Submitted for the Degree of PhD
at the
University of St Andrews**



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Men with cancer:
Psychosocial issues, health behaviours, coping and
help seeking

Hannah Dale



University of
St Andrews

This thesis is submitted in partial fulfilment for the degree of PhD
at the
University of St Andrews

18th September 2015

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Abstract

Background: A range of factors contribute to men with cancer having worse mortality and morbidity rates than women. The research specifically focused on psychosocial issues and health behaviours in men with cancer, and factors affecting help seeking behaviour.

Methods: A mixed-methods study recruited adult men with cancer in the East of Scotland. The quantitative cross-sectional study explored psychosocial issues, health behaviours, and desire for support. Data from the Scottish Longitudinal Study were accessed to check sample representativeness. The qualitative study built on the preliminary findings of the quantitative study and used semi-structured interviews to explore factors affecting men's access to support. Inductive thematic analysis was undertaken.

Results: 127 men with cancer completed the questionnaire. Being separated or divorced, younger and living in a high deprivation area was associated with poor psychosocial outcomes and some lifestyle behaviours. Social support was also influential. Twenty participants were interviewed. Appraisal of, and coping with, cancer in addition to biopsychosocial antecedents, the role of masculinity, and service contexts impacted on help seeking. The findings support a modified model of the transactional model of stress and coping relevant to men with cancer, which is new and original since it specifically incorporates the role of masculinity, highlights feedback from coping to appraisal, and recognises important service context factors that impact men's service access choices.

Discussion: Legitimation of help seeking and the use of emotion-focused coping styles were needed by some men, particularly where ideas about masculinity played a strong role in men's appraisal of, and coping with cancer. Implications for practice and policy relate to the survivorship agenda given the ongoing support men with cancer may need. Related to this, there is a need to carefully tailor and advertise services to men, and for health professionals to help legitimise the use of certain coping strategies and services.

Statement on Collaborations and Publications

There was a formal collaboration with Dr Pauline Adair, Consultant Clinical Psychologist, NHS Fife during the first two years of the research. Dr Adair acted as an NHS supervisor and contributed to the design and undertaking of the systematic review and questionnaire study. Dr Adair also contributed to the write up of the systematic review for publication (Dale et al., 2010).

Declarations

1. Candidate's declarations:

I, Hannah Dale, hereby certify that this thesis, which is approximately 60,000 words in length, has been written by me, and that it is the record of work carried out by me, or principally by myself in collaboration with others as acknowledged, and that it has not been submitted in any previous application for a higher degree.

I was admitted as a research student in July 2008 and as a candidate for the degree of PhD in September 2008; the higher study for which this is a record was carried out in the University of St Andrews between 2008 and 2015.

I, Hannah Dale received assistance in the writing of this thesis in respect of spelling, punctuation and grammar, which was provided by Ms Clare Robinson

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I hereby certify that the candidate has fulfilled the conditions of the Resolution and Regulations appropriate for the degree of PhD in the University of St Andrews and that the candidate is qualified to submit this thesis in application for that degree.

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List of Abbreviations

7-DPARQ	7 day physical activity recall
AMOS	Analysis of Moment Structures
ANOVA	Analysis Of Variance
BMI	Body Mass Index
BP	Blood Pressure
BPI	Brief Pain Inventory
CBSM	Cognitive Behavioural Stress Management
CBT	Cognitive Behavioural Therapy
CES-D	Center for Epidemiologic Studies-Depression
CFI	Comparative Fit Index
CIS	Checklist Individual Strength
CONSORT	Consolidated Standards of Reporting Trials
DASS	Depression Anxiety Stress Scale
DT	Distress Thermometer
FACT-F	Functional Assessment of Cancer Therapy-Fatigue
FACT-G	Functional Assessment of Cancer Therapy-General
FACT-P	Functional Assessment of Cancer Therapy-Prostate
FSS	Fatigue Severity Scale
EORTC QLQ-C30	European Organization for the Research and Treatment of Cancer instrument
EPIC	Expanded Prostate Cancer Index Composite
GP	General Practitioner
HADS	Hospital Anxiety and Depression Scale
IES	Impact of Events Scale
MAX-PC	Memorial Anxiety Scale for Prostate Cancer
MIDUS	Midlife in the United States National Longitudinal Study of Health and Well-Being
MOCS	Measure Of Current Status

NHS	National Health Service
NRT	Nicotine Replacement Therapy
PCS-C	Positive Contributions Scale for Cancer
POMS-B	Profile of Mood States
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PSMS	Perceived Stress Management Skill
PSS	Perceived Stress Scale
QOL	Quality of Life
RCT	Randomised Controlled Trial
RMSEA	Root Mean Square Error of Approximation
RSCL	Rotterdam Symptom Checklist
SD	Standard Deviation
SEM	Structured Equation Modelling
SF	Short-Form Health Survey
SIMD	Scottish Index of Multiple Deprivation
SIP-8	Sickness Impact Profile-8
SLS	Scottish Longitudinal Study
SPSS	Statistical Package for the Social Sciences
STAI	State/Trait Anxiety Inventory
STROBE	Strengthening the Reporting of Observational Studies in Epidemiology
UK	United Kingdom
USA	United States of America

1. Introduction

1.1 Overview

This thesis is concerned with men with cancer, and the key challenges that they face around psychosocial issues (particularly anxiety, depression, distress) health behaviours (for example, exercise and smoking), coping (with and beyond cancer) and accessing services (such as psychological or dietary support). It is founded within the field of health psychology, that also engages with relevant literatures from gender studies, sociology and health services research. This thesis should be read as a piece of applied health psychology research employing a broadly critical realism approach. The findings contribute to important key debates around how best to engage men with cancer in improving their psychosocial and lifestyle health, what interventions may be effective in improving their health, the application of theories of stress and coping to men with cancer, and the key roles that health professionals can play in supporting men in relation to these areas. The introduction aims to map out the literature around mortality and morbidity in men with cancer and sub-groups of men with cancer, the influence of psychological, social and health behaviours, how the thesis has developed over time, and the assumptions underpinning the research. It then goes on to give a summary of the remaining chapters.

1.2 Key terms

Given that some of the terms used in this thesis are broad terms with multiple interpretations, the definitions that were used within the thesis are specified, as follows.

The term 'psychosocial' is a broad overarching term commonly used in psychological and other social sciences. There is no agreed definition of what is meant by 'psychosocial', however, it typically incorporates psychological factors (e.g., anxiety, wellbeing), and social factors (e.g., social support, which may be the support people receive from friends and family, health professionals or support groups; Fallowfield, 1995). Within the context of this thesis, 'psychosocial' is concerned with the psychological health and social support in men with cancer.

Although a range of psychological issues could be explored, there is a focus on the common psychological constructs of depression, anxiety, and distress given their reported prevalence in the cancer population (Massie, 2004). The measures used to assess these factors within the quantitative study are discussed in 4.4.3. It is, though, recognized that psychological issues go beyond these particular constructs. Within the qualitative research I conducted as part of this PhD (Chapters 6 and 7), the discussion of psychological issues is less governed by key boundaries. It is more focused on participants' perceptions of psychological issues and how having cancer has affected them psychologically, incorporating anxiety and depression, along with their broader wellbeing.

The 'social' part of 'psychosocial' here focuses on social support, which has been reported to be influential in individuals' psychological health and health

behaviours (Hann et al., 2002). Social support typically refers to the actions of others that are supportive to an individual; usually focused on emotional, informational or instrumental/practical support (Thoits, 2011). Social support measures explore a wide range of factors as discussed in 4.4.2. Here, I was interested in men's perceived support (how much support they believe they are receiving) given that perceptions of whether or not actions are supportive may be more important than actual or volume of support. Further, there is not necessarily a correlation between network size or number of close persons (which other measures explore; Antonucci and Akiyama, 1987). Therefore, social support in the context of this thesis aimed to examine men's perceived social support (more details of the measure used are in 4.4.2). Psychological issues and social issues are inter-related, therefore, the term 'psychosocial' here is used to indicate both psychological and social issues individually, as well as the inter-relatedness between these factors.

'Health behaviours' can refer to any aspect of a person's behaviour that may have an impact on their health. The term is most commonly used in relation to behaviours that may prevent ill health, or contribute to illness, when the healthy behaviour is not engaged in, for example diet, and excessive alcohol use (Kasl and Cobb, 1966). Therefore, within this thesis the term health behavior is used to refer to common lifestyle behaviours known to contribute to illness (for example, cancer, heart disease, diabetes), incorporating diet, exercise, smoking, and excessive alcohol use.

'Coping' can be considered as thoughts or behaviours that are utilized in response to events or stressors, which can lead to positive or negative outcomes such as engagement in healthy lifestyles or an improvement or deterioration in depression. Negative outcomes may occur when people perceive that they cannot adequately cope with the resources they have (Carver et al., 1989; Lazarus, 1966). Within this thesis, coping, therefore, refers to the behaviours and thoughts that people engage in as a result of a stressor (in this case, a diagnosis and experience of cancer, including its treatment). Incorporated into coping is people's appraisal of an event. Appraisal encompasses their perception of an event as stressful (or not), and their ability to make use of strategies to support them to cope (Carver et al., 1989).

'Help seeking' is generally considered as an action taken by a person to enable them to receive support that addresses their needs. It has been defined as an "intentional action to solve a problem that challenges personal abilities. The complex decision-making process begins with the recognition and definition of a problem, which leads to the decision to act, and this is influenced principally by social-cognitive factors. Once a behavioural intention is formed, the person moves to selecting a source of help, makes contact and discloses the problem in exchange for help." (Cornally & McCarthy, 2011, p286). The complexities of health seeking recognised within this definition are acknowledged within this thesis. In the context of health care, help seeking may, therefore, include seeking medical help for symptoms, support from other patients with a similar condition, phoning a helpline, or seeking psychological support, and it is affected by a range of factors.

Since this thesis is interested in psychosocial issues and health behaviours (as defined above), help seeking, here, is recognized as an intentional action to seek help from someone or something (e.g. it could be a self-help book or website support), to support them to have an improvement in psychosocial health or health behaviours in the context of cancer.

In the literature, different terms and definitions are used to discuss the concept of masculinity. This includes 'hegemonic masculinity' (Connell, 2005) which is often used within with the interdisciplinary field of Critical Men's Studies, and focuses on the social roles of men and women and how this influences attitudes, ideas, perceptions, and behaviour. Hegemonic masculinity supposes that men have a dominant place in society over women and men aspire to become more 'masculine' through embodying particular traits, such as courage, mastery, some forms of aggression and being tough in body and mind (Donaldson, 1993).

Whilst this thesis includes the need to understand ideas about masculinity and its influences, it does not attempt to take a Critical Men's Studies approach and therefore, does not specifically refer to hegemonic masculinity. The reason for this approach is that research has highlighted the limitations in using hegemonic masculinity to define the roles that masculinity plays in society (Coles, 2009). Reference to masculinity here draws instead on the notion that there are various 'masculinities' (Courtenay, 2002; Coles, 2009) rather than one form of 'hegemonic masculinity'. In effect, there is a range of ideas about what it means to be a man (which may vary from person to person, within a social context) but which are nevertheless culturally recognisable as being a form of masculinity.

In this thesis, the term 'ideas about masculinity' is used to capture the socially and culturally influenced perceptions of masculinity within men's discourse. Accordingly, I will later argue that it is not masculinity *per se* that is salient in men's accounts of coping, distress, and access to care, but rather their perceptions of masculinity that shape attitudes and behaviour. These perceptions may at times resonate with familiar understandings of masculinity that relate to the specific concept of 'hegemonic masculinity' (i.e., unemotional, aggressive, independent personalities) but more commonly reflect other ways of 'being a man' in the twenty-first century. In light of the discussion above, which highlights the different forms of masculinity men can adopt, here I chose to use the term 'gender' to describe traits recognised within the UK as masculine (or feminine). Following from this, I employ the word 'sex' to describe the physical state of being a man or a woman. In essence, I regard gender as a predominantly social construct, whereas I take sex to be a biological construct (Stoller, 1968).

1.3 Mortality, Men, Marital Status and Cancer

It is well established that in most areas of the world, men have greater mortality rates than women. This is true in general (Rajaratnam et al., 2010) and specifically for cancer (Micheli et al., 2009; Jemal et al., 2011). The gap closes in the older age groups, and is worse in some countries than others. More locally in Scotland, the same pattern of mortality rates from cancer is found, despite diagnoses of cancer being roughly equal between the sexes and is worse in Scotland than the rest of the UK (United Kingdom; NHS National Services

Scotland, 2014; Office for National Statistics, 2009). The factors impacting on these figures are complex, but focus on modifiable risk factors (Courtenay, 2003). This includes historically higher rates of smoking and alcohol consumption for men compared to women, poorer awareness of cancer symptoms, slower medical advice seeking and lower uptake to screening programmes (All Party Parliamentary Group on Cancer, 2009; National Cancer Intelligence Network, 2009, Weller et al., 2007).

More specifically, single men with cancer have been identified in the literature as a particularly vulnerable group with poorer survival rates than partnered men and single or partnered women (Abdollah et al., 2011; Aizer et al., 2013; Goodwin et al., 1987; Kogevinas, 1990; Kanski et al., 2006; Kravdal, 2001; Lai et al., 1999; Lai and Stotler, 2010; Newell et al., 1987; Pinquart et al., 2010; Saito-Nakaya et al., 2008). Some research in the general health literature – not cancer-specific – suggests that it is men’s living arrangements that are important. Accordingly, rather than marital status contributing to mortality, solo-living has a potential contribution to mortality rates and should be at least be investigated separately to marital status (Jamieson et al., 2009; Kandler et al., 2007; Koskinen et al., 2007; Nielsen et al., 2007; Udell et al., 2012). Research on the link between living arrangements and mortality specifically in men with cancer is lacking. Men who are not married and/or living alone represent an even more vulnerable group than men who are partnered/living with someone. In the field of cancer, marital status is particularly linked to mortality.

When exploring factors that may contribute to mortality in men with cancer on the whole, some research shows that poor psychosocial health, including depression, social support and hopelessness, can contribute to morbidity and mortality in some cancers (Berkman & Syme, 1979; Everson et al., 1996; Fawzy et al., 1993; Jayadevappa et al., 2011; Spiegel et al., 1989). Yet, the link between psychological health and mortality has been contested as being over stated by some (Coyne et al., 2007; Garssen, 2004). Research more convincingly suggests that lifestyle risk may contribute towards mortality in men with cancer, however, data on single men with cancer are lacking (Giovannucci et al., 2005; Hamer et al., 2009; Hastert et al., 2014; Kenfield et al., 2011; Lee et al., 2011; MacMillan Cancer Support, 2011; Meyerhardt et al., 2006). Some research also shows the link between lifestyle and an increased risk for other chronic diseases in cancer patients, and that a healthier lifestyle, particularly exercise, may assist in reducing comorbidities (Brown et al., 1993; Yabroff, 2004; Demark-Wahnefried et al., 2007). Therefore, the complex interactions between psychosocial health, health behaviours, and mortality are still being closely investigated and debated.

Despite the number of studies showing that single men with cancer have greater mortality risk than other groups, there is little research investigating whether factors such as symptom awareness, advice seeking and uptake for cancer screening or indeed whether psychosocial morbidity and health behaviours are worse in single men with cancer. In the general population, there is a small amount of research that suggests that men who live alone and/or are unmarried seek help less for physical health problems, have fewer primary care consultations,

and access fewer preventative services, including colorectal cancer screening, than those who are married (Atzema et al., 2011; Blumberg et al., 2014; Sandman et al., 2000; van Jaarsveld et al., 2006). Yet, even in the general population, this research is scarce. Consequently, it is unknown what specific factors may contribute to reported higher mortality rates in single men with cancer. Nevertheless, research in the general population, detailed above, does suggest the importance of marital status in affecting help seeking.

1.4 Morbidity, Men, Marital Status and Cancer

Although the direct effect of lifestyle and psychological health on mortality are not fully understood, psychosocial morbidity can still be highly problematic for individuals with cancer. This can include relationship difficulties, poor quality of life, difficulties adjusting to a diagnosis, as well as diagnosable conditions such as depression and other psychiatric disorders (Eton & Lepore, 2002; Grassi & Rosti, 1996; Kugaya et al., 2000; Polsky et al., 2005; Stam et al., 1986). It is generally accepted that living a healthy lifestyle, particularly exercise, can improve quality of life, psychosocial health and fatigue, along with reducing the risk of treatment complications and side effects of cancer (Blanchard et al., 2004; Galvão & Newton, 2005; Pinto and Trunzo, 2005; Thorsen et al., 2005).

In the general population, men who are not married can have poorer psychological health and health behaviours (Lewis et al., 2006; Sandman, 2000; Wilson & Oswald 2005). Living alone has been associated with worse psychosocial morbidity including quality of life, depression, general health problems, long-term

conditions, and poorer social functioning in men with prostate cancer (Boyle et al., 2011; Dieperink et al., 2012). Therefore, evidence suggests that it can be even more challenging for those who are single or living alone to live a healthy lifestyle and maintain good psychological health. These factors may be important to living well with cancer and, certainly in the case of lifestyle variables, living healthily may be important for reducing mortality. There may be links between living alone or being unmarried and poorer psychological health and engagement in poorer health behaviours compared to men living with someone.

1.5 Morbidity, Men, Other Demographic Factors and Cancer

Other demographic factors have been shown to affect morbidity in men with cancer or cancer patients more generally. Younger patients (generally defined as under 45 or 50 years of age) are more likely to experience distress, followed by the overlapping category of middle-aged (40-60/65 years of age) when compared to older men and women (Giese-Davis et al., 2012; Linden et al., 2012; Macefield et al., 2009; Step et al., 2013). Some research suggests that younger cancer patients may be more likely to engage in negative health behaviours including an unhealthy diet, smoking, and reduced exercise (Eakin et al., 2007; Hawkins et al., 2010; Humpel et al., 2007; Satia et al., 2004). However, engagement in healthy lifestyle behaviours varies between and within individuals for different health behaviours and most studies explore findings in men and women together (Hawkins et al., 2010). Consequently, the variability of health behaviours reported in men with cancer of different age groups is relatively high.

Deprivation is another key area that is linked to patient outcomes. Mortality rates in cancer are strongly linked to deprivation areas, with a gradient of increasing risk from low to high areas of deprivation for men and women (Information Services Division, 2011; Ou et al., 2008; Public Health England, 2014; Schrijvers et al., 2006). There have also been links found between living in areas of high deprivation, poor psychosocial health and engagement in poorer health behaviours in the general population (Allen et al., 2014; Mackenbach, 2006; Michie et al., 2008; The Scottish Government, 2008a). However, this has not attracted much attention in the cancer literature, nor has research explored links between deprivation and psychological health in cancer patients.

Living in rural locations - often distant from a cancer centre - has been linked to worse mortality from cancer but not specifically to psychosocial or health behaviour morbidity (Campbell et al., 2000; Sabesan & Piliouras 2009). Nevertheless, this is an important and neglected demographic characteristic in the literature.

1.6 Morbidity, Men, Disease Factors and Cancer

In addition to the link between demographic factors and morbidity in men with cancer, studies suggest that both men and women with particular cancer disease factors or certain types of cancer are more vulnerable to psychological difficulties. Cancers of the lung are often cited as having the highest levels of psychological problems, particularly distress, along with cancers of the head and neck, brain, and pancreas (Admiraal et al., 2012; Brintzenhofe-Szoc, et al., 2009;

Gao et al., 2010; Hopwood & Stephens, 2000; Keir et al., 2006; Linden et al., 2012; Nekolaichuk et al., 2011; Wells et al., 2015a; Zabora et al., 2001). Most studies found prostate cancer patients to have low levels of distress compared to men with cancer at other sites (Pirl et al., 2002; Sharpley & Christie, 2007a). Nevertheless, Gao and colleagues (2010) found that palliative care patients with prostate cancer suffered very high levels of distress.

Psychosocial problems may also be worse at certain time points in the cancer trajectory for men and women; most studies again examining both sexes together. Distress is generally higher at diagnosis and treatment then decreases with time. Yet, a proportion of patients (roughly 12-36%) report high levels of distress years after diagnosis (Carlson et al., 2013; Ciaramella et al., 2001; Dunn et al., 2013; Schroevers et al., 2006; Sharpley & Christie, 2007b). Those with multiple cancer diagnoses have been found to have poorer physical and mental health, including less positive health behaviours (Burriss and Andrykowski 2011). Accordingly, both cancer type and stage in the cancer journey may influence psychosocial morbidity.

1.7 Psychological, Social and Lifestyle Interactions

In addition to particular psychosocial factors and health behaviours being more problematic for certain groups, there can also be interactions among these factors. For example, distress is associated with a lower likelihood of behaviour change, especially for smoking (Berg et al., 2013; Pinto & Trunzo, 2005), therefore indicating some inter-linkages between psychological status and lifestyle. There

may also be interactions between social support and health behaviours, with greater social support being associated with positive health behaviours (Gritz et al., 1999; Harper et al., 2007; Park & Gaffey, 2007).

Psychological distress can also be affected by social factors. Social support, in its various guises, can impact on a person's ability to adapt following a cancer diagnosis. The term social support is used widely and usually refers to the support a person receives from anyone around them, from professional to informal sources, in emotional, informational, and practical levels (Cohen et al., 2000). Multiple studies have found correlations between social support and psychological factors, with longitudinal data suggesting that poor social support can result in worse psychological health. This includes studies that have explored different types of social support in a range of cancer areas (Karnell et al., 2007; Scroevers et al., 2006). Yet, a complex relationship exists among social support, distress, and quality of life. The difficulties in definition and assessment of social support adds to this complexity (de Groot, 2002). Further, most studies investigate men and women together, consequently potential differences by sex remain unknown. Consequently, the complex interactions of these factors in men with cancer requires further investigation.

1.8 Thesis Development and Evolution

As discussed above, men, and more specifically single men, with cancer are identified as a vulnerable group for cancer mortality. Moreover, a range of other demographic and disease factors may interact to lead to further morbidity.

Therefore, this led me to a desire to examine these issues further, and particularly explore interventions for improving psychosocial health and health behaviours in men and single men with cancer.

At this time, I was commencing my 'Stage 2' training in health psychology; a 2-year full time position with NHS Fife which led to Chartered status as a Health Psychologist through completion of the professional health psychology qualification with the British Psychological Society. Exploring interventions for men and single men with cancer was one of two primary projects to be undertaken as part of this training. Soon after commencing Stage 2 training, I also registered for a PhD at the University of St Andrews, with the view to expand further on the research undertaken as part of my NHS post. Accordingly, around one third of the research undertaken as part of my thesis presented here was conducted as part of my 2-year NHS post. The remainder has been undertaken fully in my own time and has been self-funded.

Since my PhD was undertaken part-time, the literature, policy and clinical practice that are relevant to this work have all evolved during this time. This is particularly so in relation to men's health, but also the broader cancer intervention literature and how behaviour change interventions are described. Regarding men's health, much literature around the time of PhD commencement highlighted the dearth of intervention studies in men's health, along with the worse status of men's health (in general and specific to cancer) compared to women's health (e.g., Kanski et al., 2006; Lai et al., 1999; O'Brien & White, 2003; White & Banks, 2004). Men's health, in and outwith the cancer field, has become more prominent

throughout the writing of the thesis, with the worse health status cited to a greater extent and factors affecting this (e.g., men's poorer help seeking) highlighted (e.g., All Party Parliamentary Group on Cancer, 2009; Banks, 2009; Berrino et al., 2009; National Cancer Intelligence Network, 2009; Oberoi et al., 2014).

Similarly, the development of interventions for men (including men with cancer) have developed further, in part as a result of the increasing literature and policy development on men's health (e.g., Gray et al., 2013; also see the update review, which found nine relevant interventions in the period from 2008-2015, compared to a total of 11 papers with a slightly broader inclusion criteria pre-2008 for the original systematic review). In relation to the update review undertaken in this thesis, the more recent men's cancer literature reflects the broader shift in intervention development around health behaviour change. This includes the greater specification of intervention components within behaviour change interventions, incorporating specifically defined behaviour change techniques (Bourke et al., 2014; Michie et al., 2013). Some more recent literature also suggests that particular modes of intervention are important, such as the tailoring of interventions to individuals targeting men with cancer (e.g., Anderson et al., 2010). Therefore, literature such as this has been incorporated into the discussion and recommendations.

Interventions targeting psychosocial issues in men with cancer, appear to have evolved to a lesser extent throughout the thesis, reflecting that the general psychosocial intervention literature has historically been more established than interventions targeting health behaviours. Yet, some intervention literature in

cancer patients in general has grown, for example, to include the recommendation for mindfulness interventions. As discussed under 8.5.2, however, caution is used when discussing these, since they are not aimed solely at men with cancer. The literature showing that lifestyle interventions can have positive effects on mental health and wellbeing has also grown, however, again, much of this is in the general population, or both male and female cancer patients. Therefore, there may be limited specific recommendations made around lifestyle interventions for mental wellbeing.

A further area of research that has grown is around 'gender-comparative' studies in the field of cancer. This area has largely emerged since the commencement of this thesis. This type of research can reveal important areas of difference (or not) between men and women, and may have been an option for consideration had this area been well known at the time of study design. Lastly, work around the health care system, including integrated model of care, has evolved and grown in publicity since 2008 (e.g., Graves, 2013).

The increasing focus on men's health, the shift around specifying the behaviour change content of lifestyle interventions and the development of integrated models of care did not specifically influence decisions made within the thesis. Yet, these factors have affected some of the discussion of findings and recommendations. For example, the recommendation around the use of behaviour change techniques (incorporated from the update review) is influenced by this shift in the reporting of, and evidence around interventions. Recommendations to embed psychological support within integrated models of care within cancer are

due to this emerging literature. More generally, the increased emphasis on the need to target men with cancer around psychosocial issues and health behaviours helps support the recommendations and could potentially assist in pushing these forward in practice.

In addition to the evolution of some relevant literature, Scottish Government policies around cancer have evolved throughout the time of undertaking the thesis. Better Cancer Care (The Scottish Government, 2008b) was part of a changed approach to cancer in recognising that more people are surviving cancer. More recently, The Scottish Government's Transforming Care After Treatment programme, in partnership with MacMillan Cancer Support, has built on Better Cancer Care to further develop services to support cancer patients who are surviving after treatment (NHS Scotland, 2013). The increasing shift towards acknowledging that cancer can be a long term condition is seen within these policy documents, which are part of the broader survivorship agenda in cancer, also reflected in policy throughout the UK (Department of Health, 2011; MacMillan Cancer Support, 2009). As such, the primary policy shift related to psychosocial issues and health behaviours has been towards recognising that cancer patients are living longer and many experience cancer as a long term condition, or consider themselves to be 'survivors' of cancer. Given the thesis focused on post-treatment interventions, the policy shift has not significantly impacted. However, it provides further support for the recommendations that are made here.

Clinically, in terms of psychosocial support in cancer, the modes of support have evolved, as have some of the available services to men with cancer. The

support discussed here focuses on what is available to men with cancer in the localities that the studies were undertaken in. However, it reflects similar patterns of increasing support provided elsewhere in Scotland and the UK. Psychosocial support had been relatively strong for cancer patients for several years prior to commencement of this thesis, for example, Maggie's centres were available in the three main Health Boards in the East of Scotland, MacMillan Cancer Support offered a range of face-to-face and telephone services, and the Health Boards had psychologists working in oncology. Since the commencement of this thesis, online support offered by charities including MacMillan and the Maggie's centres have developed, support groups (often facilitated by the NHS and/or Maggie's) have grown in number, and some Maggie's centres have offered groups for men. In addition, with the shifting understanding and acceptance around prevention and management of cancer, lifestyle support has been developed to support cancer patients to improve their health in the voluntary and NHS sectors, including through the Self Management Fund (Lee et al., 2015; the Scottish Government, 2010). Therefore, there is a recognition that support in a range of settings and modes is available to patients, however the challenges can lie more in assisting some men to access services when needed, which is reflected in the findings of, and recommendations from the thesis.

1.9 Assumptions and Underpinnings to the Research

A range of assumptions and approaches underpin the research in this thesis. The first is the disciplinary approach, which is predominantly situated within

health psychology. The discipline of health psychology uses a biopsychosocial approach to health and illness and focuses on the role of psychology in illness onset, adaptation and outcome, which encompasses constructs including beliefs, behaviours, coping, help seeking, and quality of life (Ogden, 2012). Health Psychologists use this knowledge to develop interventions to support individuals and populations to reduce or delay illness onset and promote more positive adaptations and outcomes.

This thesis, therefore, explores the adaptation to, and outcomes from, cancer in men, around psychosocial issues and health behaviours, with a view to informing the development of interventions. It could, therefore, be considered as being situated within an applied psycho-oncology (psychology in cancer) sub-discipline of health psychology. This area typically considers the psychosocial impacts of cancer, the factors affecting psychosocial health and health behaviours in the context of cancer, along with interventions with patients and health professionals, and system changes that may improve the health of cancer patients.

The thesis also draws on literature from other disciplines. Firstly, that of health services research through the focus on men with cancer within the health care setting and implications for the NHS in the UK. Secondly, sociological literature is relevant, through the acknowledgement of the nature of factors such as social construction and social influences on behaviour. Therefore, although the psychological approach is predominantly concerned with the individual, sociological approaches are relevant and incorporated since the social influence on behavior and outcomes is recognised. Lastly, the field of gender studies is drawn

upon, through the integration of men's health literature in informing the development and analysis of questions, and recommendations. This disciplinary approach has consequently influenced the research, from understandings of health and illness, development of research questions, methodologies utilised, analysis, and interpretation. For example, the integration of the transactional model of stress and coping is influenced by the health psychology disciplinary approach. The incorporation of knowledge and approaches from other disciplines has strengthened the thesis, since it has allowed a thorough consideration of issues such as masculinity and the influence of the social world on illness experience.

The philosophical approach to the research (incorporating perspectives on ontology and epistemology) is important since it defines how the researcher views and interprets knowledge, and therefore has a large impact on the methods used to address research questions and the interpretation of findings. Both ontology and epistemology typically inform the overall theoretical approach. Ontology is usually defined as how the researcher views the nature of reality, for example, whether it is made up of concrete entities, or whether its nature differs depending on who is viewing it (Guba & Lincoln, 1994). A positivist perspective would assume that knowledge produced through research reflects an objective reality. Conversely, interpretivism (often considered to be an opposing view to positivism) assumes that we are all under influence of the social world, and that our interpretations of events will be influenced by our own experiences and assumptions: as a result, research cannot produce definitive answers about the nature of reality that apply across all contexts. Related to ontology is epistemology, with a researcher's epistemological

approach reflecting their assumptions about how we can know about reality, and the relationships between the knower and object or construct that is the focus of knowledge generation within research. As such, a researcher's epistemological position has implications for their relationship with the data (Guba & Lincoln, 1994). For example, a positivist stance would assume that the researcher's subjectivity will not influence the interpretation of the data, whereas an interpretivist approach would assume that the researcher's prior knowledge and experiences will affect analysis and interpretation.

The ontological and epistemological approach taken here acknowledges that a reality exists that can be commonly understood throughout the world, but that this might nevertheless be interpreted somewhat differently by individuals in varied cultural contexts. Further, the approach taken considers that different methodological strategies are important in gaining insight into different aspects of reality (e.g., quantitative methods to understand how demographic factors affect health, and qualitative methods to understand how ill-health is experienced). Consequently, it is recognised that people's interpretations of reality will differ and that there are varied approaches to the gathering and interpretation of knowledge. In the context of research, the researcher will, at times, be influenced by their own ideas about reality when collecting and analysing data (reflexivity is discussed further in Chapter 6 detailing the qualitative methods).

Theoretical approaches to the understanding of knowledge generation within research, especially those within qualitative traditions, have evolved over the years to include a greater number of approaches, sometimes known as paradigms

(Morgan, 2007; Teddlie & Tashakkori, 2012). These include positivism, postpositivism, constructivism, critical realism, interpretivism, and pragmatism (Gray, 2014; Guba & Lincoln, 2005; Mertens, 2015). The ontological and epistemological perspective taken here, and described above, most closely aligns with the broad theoretical approach of critical realism (Bhaksar, 2010).

Critical realism recognises that natural and social events can be observed empirically, but that social events are more complicated to observe empirically since the 'rules' that underpin them are constantly changing (Bhaksar, 2010; Scott, 2007). Therefore, a more objective interpretation may be acceptable for natural events within a critical realist approach, whereas a greater element of subjectivity is accepted for social and psychological events. Regardless of the observed object, there is an acknowledgement that there may be differing interpretations of knowledge, and that factors including the object of study, the method of study, the interpretation, and analysis can impact on this knowledge generation (Maxwell, 2010). Since critical realism acknowledges the importance of objectivity and subjectivity, it is compatible with a range of research methods (e.g., quantitative and qualitative) and avoids the researcher switching paradigms for different methods (McEvoy and Richards, 2006). Critical realism, is an approach used in health psychology (and other branches of applied psychology), in part because of the diversity of what this profession investigates, and hence, the methodologies utilised (Rohleder, 2012; Usher, 1999).

As a consequence of the broadly critical realist approach taken in this thesis, for the quantitative research and systematic review, it is assumed that this

type of knowledge generation affords some objectivity and is hence methodologically appropriate to the kinds of knowledge that the researcher is seeking to produce. Yet, it is also acknowledged that the researcher is interpreting this data based on their world view. For the qualitative research, a greater element of subjectivity is assumed through the participants' interpretations of questions and their experiences, along with the researchers' assumptions being of influence too. Indeed, as will be discussed in Chapter 6 (qualitative methods), researcher subjectivity is an important research tool in itself, in order to contribute towards to production of knowledge about the experiences of others.

In addition to the assumptions and underpinnings to the research described above, the clinical dimension is the final key factor of importance in influencing the overarching approach to the research. The thesis is applied in nature since the questions, design, interpretation and recommendations are informed by my role as an applied Health Psychologist working in the NHS in Scotland. The research also recruited participants from the NHS and a voluntary organisation and, subsequently constitutes a sample of patients engaged with health services. These factors have influenced the thesis through increasing the clinical influences on the research, since current practices in the health service are considered, and a depth of understanding of the clinical population existed prior to the research commencing. There is also a strong applicability of the research to clinical practice in the NHS, given the applied nature of the recruitment, understanding, along with the associated recommendations.

1.10 Plan of the thesis

The structure of the thesis is as follows. Following this introductory Chapter, the thesis continues with a systematic review of psychosocial and behaviour change interventions (interventions aiming to modify health-related behaviours, such as diet and alcohol use) for men with cancer (Chapter 2). This was undertaken with the aim to explore and draw on the evidence to develop effective interventions for men with cancer, in order to improve lifestyle behaviours and psychosocial health. There was an intended focus on single men. The literature meeting the inclusion criteria was scarce and no studies focused on single men. Only 11 studies were included, leaving a limited number of studies that could be drawn on to inform the development of interventions for men with cancer. Thus, it was felt that there was insufficient information to develop interventions for men with cancer in the NHS and further research to understand psychosocial and lifestyle issues in men with cancer would be needed. This led to a shift in the focus of the thesis, to explore what psychosocial and health behaviour issues are relevant to men with cancer and, in particular, the demographic or disease factors that made them more vulnerable. Linked to this, the thesis also aimed to explore the barriers and facilitators to help-seeking in men with cancer. Therefore, the research was no longer aimed at developing interventions. The focus shifted to developing knowledge at the pre-intervention stage, whereby a better understanding of these issues in a broad sample of men with cancer was desired.

The new research focus was intended to build on the systematic review in informing and making recommendations for the development of interventions. The

studies included in the review were based on the state of the literature before 2009. For the purposes of the thesis, a rapid update review (Appendix 1) was undertaken in 2015 to explore findings emerging since the systematic review was undertaken and is discussed further in Chapter 8. The search criteria remained the same with the exception of only searching for studies with 100% male samples. The search was undertaken in February 2015 using Medline and found nine papers for inclusion. The findings revealed more evidence than in the original review for interventions targeting health behaviours. That is, studies drawing on a range of behaviour change techniques saw positive results. The lower-intensity interventions for psychosocial issues were often unsuccessful or had very small effects. Since only one intervention of the nine interventions included non-prostate cancer patients, this review revealed that there is still a need to identify effective interventions for men with all types of cancer.

Understanding the wider literature relevant to men with cancer was also important and was explored in Chapter 3. This includes the factors that may make men more vulnerable to psychological morbidity and help seeking behaviour in men with cancer, along with the effect of wider cultural factors such as masculinity. Chapter 3 sets out the aims, rationale and methodology of the research. A mixed-methods study design (Chapter 3) was chosen to enable relevant factors to be examined in a large broad sample of men with cancer through a quantitative questionnaire study (Chapters 4 and 5). A more in-depth approach was planned to expand on questionnaire findings through a qualitative interview study (Chapter 6 and 7).

The cross-sectional questionnaire study aimed to study psychological factors, social support, health behaviours, and desire for more help for these issues (Chapter 4). This revealed some interesting findings around the trends relating to demographic factors, psychosocial issues, social support, and health behaviours (Chapter 5). The development of a model to explain the interaction between social support, psychological factors, and desire for more support was proposed. Further questions were raised by this study which informed the qualitative research (see Chapter 3 for more details on this).

The exact focus of the interview study (Chapter 6) was decided following preliminary analysis on the questionnaire data. The qualitative study explored in-depth the factors that influence help seeking in men with cancer. The richness of the data from the interview study (Chapter 7) enabled an in-depth analysis of men's reactions to cancer and how this influences how they cope and in turn, their psychosocial health and engagement in health behaviours such as exercise. During the qualitative analysis (Chapter 7), it became apparent that much of the data fitted an extended version of the transactional model of stress and coping, so, the results reflect this. The data show that a range of individual, social, environmental and biological factors affect how men with cancer appraise and cope with cancer, which in turn affects their psychosocial outcomes (encompassing psychological and social issues for example, depression, wellbeing, feeling supported). Data also revealed the wider influence of contextual factors, such as location and time, and the strong cultural factors (common societal ideas and practices) relating to ideas about masculinity, within the social antecedents.

The discussion (Chapter 8) reflects on the findings from both the quantitative and qualitative Chapters, along with drawing together the systematic review, wider literature, and findings from throughout the thesis. Here, each research question is systematically answered and further research drawn on to help explain and inform findings. Key implications for the development of interventions for men with cancer include:

1. Services should ensure that they are screening men for psychosocial issues and health behaviours, while being aware of demographic factors that may make them more vulnerable
2. The use of CBT and behaviour change techniques incorporated into interventions may assist in their effectiveness
3. Services and health professionals may need to work to engage with men actively to enable services access through advertising, legitimisation and an informal approach to services.

Recommendations (Chapter 9) are proposed which have the potential to positively impact on psychosocial wellbeing and health behaviour change in men with cancer. In addition to the implications discussed above, recommendations centre on the role of services and health professionals in helping legitimise help-seeking in men with cancer. Recommendations for future research include that research on larger samples, and longitudinally, may help to confirm and elaborate on the thesis findings. Research exploring these factors in both men and women with cancer will help further elucidate which findings are specific to men.

This applied research has focused deliberately to have direct relevance to men with cancer in the UK and inform the development and delivery of services in the NHS. This thesis, therefore, intersects the areas of health behaviours, psychosocial issues, stress and coping, men's health and support seeking.

2. Systematic Review of Post-Treatment Psychosocial and Behaviour Change Interventions for Men with Cancer

This is partially based on the following published work: Dale, H., Adair, P., & Humphris, G. (2010). Systematic Review of Post-Treatment Psychosocial and Behaviour Change Interventions for Men with Cancer, *Psycho-Oncology*, 19(3), 227-237.

2.1 Background

As discussed in the introductory Chapter, men with cancer, and particularly those who are single, suffer worse mortality rates than women (e.g., Goodwin et al., 1987; Kanski et al., 2006; Lai et al., 1999; Reynolds & Kaplan, 1990; Saito-Nakaya et al., 2008). Poor psychological health and lifestyle behaviours are also problematic for men with cancer (e.g., Bellizzi et al., 2005; Demark-Wahnefried et al., 2000; Eton & Lepore, 2002; Grassi & Rosti, 1996). As a result, men with cancer, and single men with cancer in particular, are groups that may warrant specific attention to improve outcomes. Interventions to improve these outcomes will be explored in this systematic review Chapter.

Although some studies show an effect of psychosocial interventions on mortality in cancer patients, this link has been contested (Coyne et al., 2007; Edelman et al., 2000; Spiegel et al., 1989). What is more established is the ability of psychosocial interventions to reduce psychosocial morbidity in cancer patients. This is particularly so since the psychosocial impact of a cancer diagnosis can be

significant and includes poorer family and personal relationships, reduced quality of life, depression and other psychiatric disorders, distress, and adjustment difficulties (Berry, 1993; Clark et al., 2003; Eton & Lepore, 2002; Grassi & Rosti, 1996; Kugaya et al., 2000; Polsky et al., 2005; Stam et al., 1986; van't Spijker et al., 1997). Indeed, reviews of psychosocial intervention studies have repeatedly shown positive outcomes, including improved mood and quality of life, psychosocial function, reduced fatigue, and reduced symptoms of anxiety and distress (Andersen, 1992; Clark et al., 2003; Jacobsen et al., 2008; Kangas et al., 2008). However, reviews and individual studies are dominated by research that is focused on specific areas of cancer (often breast) and/or women or do not provide sufficient information on sex of the participants to draw conclusions for men with cancer (Andersen, 1992; Clark et al., 2003; Jacobsen et al., 2008; Kangas et al., 2008).

Interventions in the field of cancer promoting healthy lifestyle behaviours have been increasingly studied in the last decade. This has led to an evidence-base that suggests that engagement in healthy lifestyle behaviours can reduce risk of further cancers and mortality from cancer (Chlebowski et al., 2002; Day et al., 1994; Hastert et al., 2014; Holmes et al., 2005; Khuri et al., 2001; Laukkanen et al., 2010; Lee et al., 2011; Mohle-Boatani et al., 1988; Richardson et al., 1993), along with improving quality of life and reduce fatigue in cancer patients (Blanchard et al., 2004; Galvão & Newton, 2005; Penedo & Dahn, 2005). Again studies are dominated by those targeting women and often breast cancer (Galvão & Newton, 2005).

A review exploring what interventions may improve psychosocial and health behaviour outcomes for men with cancer was, therefore, warranted, in order to draw on the available evidence base for the development of interventions for men with cancer. The purpose of this systematic review was to examine the effectiveness of psychosocial and behaviour change interventions targeting men with cancer. The review sought to include studies exploring post-treatment psychosocial or behaviour change interventions for adults who have had a diagnosis of cancer, with a minimum of a 50% male sample. Participants post-treatment were sought to reflect the increasing rates of survival from cancer and discussions around cancer being a long-term condition. Therefore, the review aimed to focus on studies supporting cancer patients to make lifestyle changes or to reduce the risk of cancer recurrence or further cancer diagnoses, rather than to support them to manage treatment. This was along side supporting patients' long term psychosocial wellbeing, rather than supporting the difficulties patients can face during treatment. The challenges patients face during and after treatment have been reported as different (e.g., Gao et al. 2010), and the review here aimed to inform the development of interventions to support adult men with cancer post-treatment. Studies needed to report psychosocial or behavioural outcomes and be of a 1-3 level of evidence (Oxman, 1994). To improve specificity of the review, in line with research discussed above, there was an intention to focus particularly on men who are single.

2.2 Research Questions

1. Are interventions targeting psychosocial issues and health behaviours in men, and particularly single men, with cancer effective in improving outcomes?
2. What types of interventions are most effective in improving psychosocial issues and health behaviours in men, and particularly single men, with cancer?
3. What recommendations can be made for the development of psychosocial and health behaviour change interventions for men, and particularly single men, with cancer?

2.3 Methods

The procedure to undertake the review was guided by the Cochrane handbook for systematic reviews of interventions, but did not follow this fully. For example, due to time constraints, studies in a non-English language were excluded and the studies were not screened by two authors at all stages of review. Given that systematic reviews by nature aim to be objective, the broad critical realist approach taken to the research makes assumptions about the influence of researcher on the data. In the context of this review, it is assumed that the systematic methods of searching and screening papers in relation to inclusion and exclusion criteria are objective. However, the research questions, search criteria, and interpretation of the data will be influenced by the researcher, particularly in terms of disciplinary background and approach, along with the understanding of

interventions and the potential to apply them in health settings (Maxwell, 2010). The reporting of the review followed the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidance (Moher et al., 2009; Appendix 2). The inclusion and exclusion criteria aimed to enable the selection of relevant studies to inform the development of interventions for men with cancer in the NHS in the UK. See Table 1 for detailed inclusion and exclusion criteria

Table 1. The inclusion and exclusion criteria for studies in the systematic review

	Inclusion Criteria	Exclusion Criteria
Population	Samples with ≥50% men	Samples on >50% women
	Samples on only adult men aged ≥18	Samples including those <18 years old
	All participants must have a current or historical cancer diagnosis; at any stage of the disease Interventions targeting just the cancer patient	Those who have never been diagnosed with cancer Interventions targeting couples, carers, families or other interventions targeting not just the cancer patient
Interventions	Interventions that aimed to improve psychological health, lifestyle behaviours/behaviour change, social support and engagement by men in services to improve these factors	Medical/physiological interventions
	Any intervention format (e.g., group, individual/one-to-one/home or internet-based)	No exclusions on format

	Post-treatment (surgery, immunotherapy, chemotherapy or radiotherapy) and post-hospitalisation interventions	Interventions that are pre/during treatment or during hospitalisation (treatment defined as surgery, immunotherapy, chemotherapy or radiotherapy only; hormone therapy and other forms of more minor or longer term treatment included)
Comparisons/ study Design	Studies containing a Quantitative element which meets the level III level of evidence criteria (all RCTs and cohort studies with a concurrent comparison group)	Qualitative studies; quantitative studies at level IV or V level of evidence
Outcomes	Interventions measuring psychosocial and behavioural outcomes	Interventions not measuring psychosocial or behavioural outcomes
	Short or long term outcome measures	No exclusions on time/length of outcome measures
Other	N/A	Papers written in non-English languages were also excluded Full paper not available; only abstracts provided

2.3.1 Search strategy

Initially, scoping searches were conducted to explore and refine the search criteria to ensure that the terms entered produced relevant papers (Centre for Reviews and Dissemination, 2008). In particular, searches explored the use of the terms 'men' or 'male' and 'single' or 'divorced' or 'separated' to assist in generating relevant papers. Both sets of terms (men/male and single/divorced/separated) were designed to better identify interventions targeting single men. These did not generate sufficient relevant results and known papers that had at least 50% men

were not captured by the search. Therefore, an attempt to make the review search more specific was not possible and instead a broader search criteria that would capture more results, many of which would later be excluded, was necessary.

Similarly, a search that included terms to specify the format of interventions or the outcome measures was excluding of relevant papers in scoping searches. A range of terms were tested prior to finalising the search criteria to ensure successful generation of intervention studies that aimed to improve psychosocial health, improve lifestyle through behaviour change interventions and more generally engage men in service to improve these factors. The four terms used appeared broad enough to include a range of papers, but not so broad that tens of thousands of results were found. Since the desired outcome of the review was an evidence base that could inform the development of psychological and behaviour change interventions in practice, a balance was struck between considering inclusion of studies that only met the 'gold standard' randomised controlled trial protocols (Akobeng, 2005) versus studies considered less rigorous but that may have been undertaken in practice. It was decided that studies that met the 1-3 level of evidence would be included, encompassing RCTs (Randomised Controlled Trials), cohort studies and similar designs that had a comparison group (Oxman, 1994).

The terms (cancer* malignan* tumor*) AND intervention AND (Behavio* psycholog* engage* social support) were used in the final search (also see Table 2 for the factors included in the search and the terms inputted into databases).

Table 2. The factors targeted for database searches and the terms used in the searches in the systematic review

	Factors for inclusion in search	Terms inputted into search engine
Population	Cancer	Cancer* Malignan* Tumor*
Interventions	Intervention	Intervention
	Behaviour change, psychological health, engagement, social support	Behavio* psycholog* engage* social support

Note: The use of '*' denotes that any ending after the preceding letter will be captured by the search.

The following databases were searched via Ovid: Medline (1950-2008), Embase (1980-2008) Psychinfo (1806-08), Cochrane controlled trials, Cochrane systematic reviews and Cochrane methodological register (all to 2008), British Nursing index & archive (all to 2008), Social work abstracts (1977-end 2007; 2008 studies not yet available). Databases were also searched via Web of Knowledge: Science Citation Index Expanded (1986-2008) Social Sciences Citation Index (1986-2008). See Appendix 3 for an example of full search strategy within OVID.

2.3.2 Procedure for selection of studies

Following database searches, data were exported to Refworks, a reference management system. Studies were systematically screened by title and abstract. Full papers were then downloaded or requested and papers were further screened

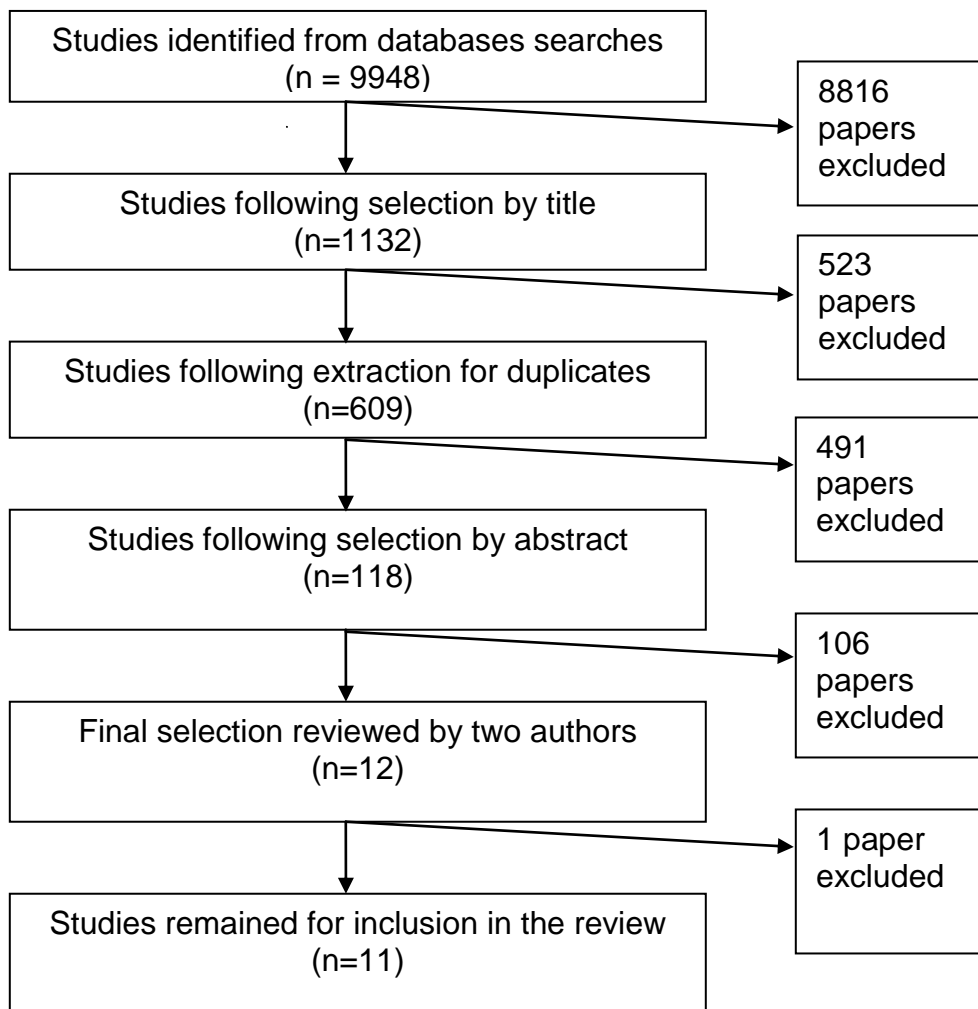
for inclusion until a final selection of papers was checked and agreed with a supervisor. Data were extracted from papers directly into the table of study characteristics (Table 3). Since outcome measures were homogenous, it was not possible to undertake a meta-analysis on these, nor provide summary data of outcome measures. No formal tools were used to assess risk of bias, in part due to poor reporting of intervention protocol making it difficult to assess and stringently compare. Bias, including selection and performance bias, was considered in the collation of findings.

2.4 Results

2.4.1 Selection of studies

9949 potentially relevant citations were identified (see Figure 1 for flow chart of study selection). 1132 relevant studies were then identified by title, which were further reduced to 609 following extraction for duplicates. From abstract selection, 118 studies were identified as being eligible or needing the full paper to confirm eligibility. The full papers were then examined and a further 107 papers were eliminated. Where papers did not indicate whether or not it met the inclusion criteria (for example, percentage male was not available), authors were contacted for clarification. The remaining 12 full papers assessed also by a supervisor and any disagreements discussed; one paper was excluded at this point since it was confirmed that some participants were still undergoing treatment.

Figure 1. Flow of papers through the systematic selection procedure



Throughout the study selection process, the predominant reasons for exclusion were:

- Was not a psychological or behavioural intervention
- Only had an abstract (e.g., from dissertation abstracts international)
- The study did not have a comparison group

- Less than 50% male participants
- Study taking place during cancer treatment

2.4.2 Study characteristics

The 11 papers included (Table 3) represent a range of intervention types. The majority of studies used group intervention approaches and report on a variety of outcome measures. Prostate (65%) and head and neck (18%) cancers dominate the populations targeted in interventions. Most studies employed psychoeducational (46%), or Cognitive Behaviour Therapy (CBT)-based (46%) techniques, with just one intervention implementing hypnosis (Lioffi & White, 2001a). Outcome measures centred on Quality of Life (QOL), functioning scores, distress, anxiety and depression, and, less frequently, healthy lifestyle behaviours. Baseline measures were always taken, but length of follow up varied across the trials from immediately following the intervention to 12 months follow-up. Whilst couple, carer and family interventions were excluded, no such interventions met all the other inclusion criteria.

No articles examined the possible differences of marital status on intervention outcome. It was, therefore, not possible to examine the effect of interventions on outcomes in single men. The interventions fall into three main intervention categories and are accordingly discussed as follows.

Table 3. Characteristics of included studies in the systematic review

Author & location	Participant demographics^a	Intervention length, content & groups	Measures & follow-up^b	Reported results^b	Author's conclusions
Allison et al., 2004 Canada	N = 66 79% male 49% over 55 years old 30% living alone Head and neck cancers Attrition: 24% Refusers: 49%; more older people refused participation	Four weeks. Psychoeducational NuCare coping strategies intervention; Three participant-chosen conditions: 1. Small group 2. One-to-one (both 2-3 2 hour sessions with a therapist over 4 weeks) 3. Home alone	EORTC QLQ-C30 (European Organisation for the Research and Treatment of Cancer instrument; measures Health Related Quality Of Life) & HADS (Hospital Anxiety and Depression Scale). Measured at baseline, 6 weeks and 3 months.	Different group formats affected different subscales: One-to-one/group (combined data) showed significant improvements in sleep, depression and global scores. Home format showed improvements in social and fatigue scores.	'...the intervention may have some beneficial effects...' (p482)
Carmack Taylor et al., 2006 USA	N = 134 100% male Mean age = 69 83% married or co-habiting Prostate cancer Attrition: 15% No data on refusers	Six months. 1. Group-based lifestyle physical activity programme 2. Group-based educational support (both 16 x 1.5 hour weekly then	SF-36 (Short-Form Health Survey); CES-D (Center for Epidemiologic Studies-Depression); STAI State scale (State/Trait Anxiety	No significant difference between groups on any of the measures. Moderator analyses* show participation in groups 1 & 2 benefited those	'Results suggest a lifestyle program focusing on cognitive-behavioral skills training alone is insufficient for promoting routine physical activity...' (p847)

		4 x 1.5 hour biweekly sessions) 3. Standard care	Inventory); BPI short form (Brief Pain Inventory); a six-minute walk test and BMI (Body Mass Index); 7-DPARQ (7 day physical activity recall). Measured at baseline, 6 months and 12 months.	who had greater baseline anxiety, depression, pain, and more limited physical role or social support. Benefits decreased by 12 months.	
Daubenmier et al., 2006 USA	N = 93 100% male Mean age = 66 71% living with spouse or partner Prostate cancer Attrition: 12% No data on refusers	One year. 1. Lifestyle intervention 'active surveillance'; plant-based diet, exercise and stress management plus weekly support group, following a one week retreat 2. Control group; usual care	Lifestyle Index (measures intervention adherence); SF-36; the Perceived Stress Scale (measures stressful situations in the past month); Sexual Function subscale of the UCLA Prostate Cancer Index. Measured at baseline and 12 months.	Significant improvements in group 1 compared to group 2 on lifestyle but not quality of life (QOL) at 12 months. Greater lifestyle scores in the whole sample were related to significant improvements in physical health-related QOL & perceived stress.	'... men choosing active surveillance should be encouraged to make changes in lifestyle that may slow the progression of their cancer and improve their HR-QOL.' (p126)

<p>Gielissen et al., 2006 The Netherlands</p>	<p>N = 98 52% male Mean age = 45 84% married or co-habiting Haematologic, testicular, breast cancers & other frequently diagnosed tumours Attrition: 16% Refusers: 23%; no demographic differences in attrition or refusers</p>	<p>Up to 6 months. 1. Individual Cognitive Behaviour Therapy (one-hour per sessions; sessions ranged from 5-26). 2. Waiting list control</p>	<p>Fatigue severity subscale of the CIS (Checklist Individual Strength); SIP-8 (Sickness Impact Profile-8, measures functional impairment); Symptom Checklist 90 (measures psychological distress). Measured at baseline and 6 months.</p>	<p>Group 1 reported significantly greater decrease in fatigue severity, functional impairment and in psychological distress.</p>	<p>‘Cognitive behaviour therapy has a clinically relevant effect in reducing fatigue and functional impairments in cancer survivors.’ (p4882)</p>
<p>Lepore & Helgeson, 1999 USA</p>	<p>N = 24 100% male No data on age or marital status Prostate cancer Attrition: 0% Refusers: 17%</p>	<p>Six weeks. 1. Psychoeducational support group. 40 minute lecture, 20 minute question & answer session, 45 minute facilitated discussion 2. Control group</p>	<p>SF-36; Lepore’s Social Conflict Scale (measures interpersonal conflict); IES (Impact of Events Scale, measures intrusive and avoidant thoughts); Self-efficacy scale developed by authors; Social</p>	<p>Group 1 showed significant positive effects on conflict with spouse and family/friends, self-efficacy, and ratings of distress by intrusive thoughts. Those in group 1 with low support from their wives and</p>	<p>‘This intervention can serve as a model for cost-effective, community-based interventions for men with prostate cancer’ ‘The intervention was especially beneficial to men with inadequate social support</p>

			support measure developed from the UCLA Social Support scale; Litwin's measure of prostate-specific problems. Measured at baseline and 9-10 weeks.	family/friends benefited most from the intervention.	resources...' (p81)
Lepore et al., 2003 USA	N = 250 100% male Mean age = 65 Range = 45-80 87% married Prostate cancer Attrition: 10% Refusers: 15% (those who refused to be contacted about the study)	Six weeks. 1. Group education. 1 hour lecture, 10 minute question & answer session 2. Group education (as above) plus 45 min facilitated group discussion 3. Control group	SF-36; CES-D modified to contain 15 items; UCLA Prostate Cancer Index (measures disease-specific QOL); health behaviour index. Measured at baseline, 8 weeks, 7.5 months and 13.5 months.	Groups 1 & 2 showed greater health behaviours than group 3; the effect was stronger for group 2. Better scores in physical function were found in those without a college degree. Group 2 maintained employment, and had reduced sexual bother compared to groups 1 and 3. Those with initial low prostate-specific self-	'...relatively brief group education interventions were successful in enhancing QOL in men treated for localized prostate cancer, especially if they had less formal education.' (p451)

				efficacy, global self esteem and high depression scores benefited most from groups 1 & 2 compared to controls#.	
Lioffi & White, 2001a# Greece	N = 50 54% male Age range = 35-74 No data on marital status Any palliative cancer No data on attrition rate Refusers: 36% (Those who refused or were ineligible)	Four weeks. 1. 4x30 min sessions of hypnosis. 2. Standard palliative care	RSCL (Rotterdam Symptom Checklist, measures physical and psychological distress, activity level and overall evaluation of life); HADS. Measured at baseline and at 4 weeks.	Significant decrease in anxiety and depression and psychological distress for group 1 when compared to group 2.	'...hypnosis is effective in the enhancement of quality of life in terminally ill cancer patients.' (p145)
Pendeo et al., 2003 USA	N = 92 100% male Mean age = 61 No data on marital status. Prostate cancer No data on attrition rate or refusers	Ten weeks. 1. Cognitive behavioural stress management (CBSM) group; 2hrs/wk 'didactic portion' of stress management & relaxation training	FACT-G (Functional Assessment of Cancer Therapy-General; measures QOL); MOCS (Measure Of Current Status, measures Perceived Stress	Group 1 participation was a significant predictor of post-intervention QOL.	'A 10-week cognitive-behavioral group intervention was effective in improving the QoL in men treated for PC [prostate cancer]...' (p192)

		2. 4 hour seminar control condition containing components of group 1 (met once around week 5-6 of the intervention group programme)	Management Skill, PSMS). Measured at Baseline and 12-13 weeks.		
Penedo et al., 2006 USA	N = 191 100% male Mean age = 65 75% married Prostate cancer Attrition: 22% Refusers: 30%	Ten weeks. 1. CBSM group 2. 4 hour seminar control condition (as above; Pendo et al., 2003)	FACT-G; MOCS; PCS-C (Positive Contributions Scale for Cancer, measures benefit finding, i.e. seeing positive impacts of cancer). Measured at Baseline and 12-13 weeks.	Group 1 participation was a significant predictor of post-intervention QOL and benefit finding.	'Results support the use of group based cognitive-behavioral interventions in promoting QoL and BF [benefit finding] in this population.' (p261)
Penedo et al., 2007 USA	N = 71 100% male Mean age = 65 No data on marital status Prostate cancer Attrition: 31% Refusers: 27%	Ten weeks. 1. CBSM group 2. 4 hour seminar control condition (as above; Pendo et al., 2003)	FACT-G; EPIC (Expanded Prostate Cancer Index Composite; measures sexual functioning). Measured at Baseline and 12-13 weeks.	Group 1 participation was a significant predictor of post-intervention total QOL, physical and emotional QOL, and sexual functioning.	'... participation in a culturally and linguistically adapted CBSM group intervention improved QoL in Hispanic monolingual men treated for localized PC

					[prostate cancer]' (p164)
Vilela et al., 2006 Canada	N = 131 72% male 62% over 55 years old 69% living with partner or relative Head and neck cancers Attrition: 23% Refusers: 43%; more older people refused participation.	Four weeks. 1. Psychoeducational NuCare intervention (as above; Allison et al., 2004); in a group, one-to-one or home alone. 2. Control group	EORTC; QLQ-C30; HADS. Measured at Baseline and 3-4 months.	Group 1 showed significant increases in several QOL and depression scores; no significant changes in control group. When mean change in scores were compared to control group, only global QOL showed a significantly greater increase in group 1 than group 2.	'...the NuCare programme may improve quality of life and reduce depressive symptoms in head and neck cancer patients.' (p88)

^aBaseline number of participants quoted; attrition and refuser rates were based on data available in papers; attrition rates represent participants for whom no outcome data were available. ^bPrimary measures and comparison results reported. ¥ a second paper Edgar et al. (2001) reports on the same sample and was drawn on for additional information. * Carmack Taylor et al. (2007) reports moderator analyses. #Helgeson et al. (2006) reports moderator analyses. #Also see Lioffi and White (2001b) for an erratum.

2.4.2.1 CBT-based interventions

Programmes based on CBT were tested in several studies. Gielissen and colleagues (2006) offered one-to-one CBT to severely fatigued cancer patients for up to six months. Improvements in the intervention group comprised a decrease in fatigue severity, functional impairment, and psychological distress. A CBT-based curriculum was also employed in three studies by one research team (Pendo et al., 2006; Pendo et al., 2003; Pendo et al., 2007). Two studies (2006, 2007) had a high proportion of men from ethnic-minority groups, enabling a test of the intervention for harder-to-reach populations. They examined the effectiveness of a Cognitive Behavioural Stress Management (CBSM) group intervention for men with prostate cancer, which met for two hours weekly over a period of 10 weeks. The 90 minute didactic portion followed by 30 minutes of relaxation training brought positive results in QOL in all three samples, when compared to a half- or full-day CBSM control condition, which involved a psycho-educational seminar focussing on stress-management and relaxation skills. Perceived Stress Management Skill (PSMS) mediated changes in QOL in two of the studies (Pendo et al., 2006; Pendo et al., 2003), and there were additional intervention group benefits of improved sexual functioning (Pendo et al., 2007) and benefit finding - a construct to examine perceived benefits of participant's diagnosis and treatment (Pendo et al., 2006).

Carmack Taylor and colleagues. (2006) also used a cognitive behavioural-based curriculum in their lifestyle physical activity group programme targeting those with prostate cancer. They had a control condition as well as two intervention groups, which aimed to improve QOL, depression, and anxiety and ran over six

months. An education support programme comprised a facilitated discussion. A cognitive-behavioural-based lifestyle physical activity group focused on increasing physical activity to encourage moderate physical activity on most days of each week and further impact on psychosocial outcomes. The last half hour of the 1.5 hour sessions in both groups were matched by providing either a facilitated discussion or an expert speaker on relevant topics. Results showed that there were no significant differences between any of the groups on the psychosocial or physical activity measures (body composition and endurance) at six or 12 months. Mediating variables of cognitive and behavioural skill and stage of change improved in the lifestyle physical activity group only. Moderator analyses (Carmack Taylor et al., 2007) did show some psychosocial and physical functioning benefits of participation in both groups, when compared to controls, for those who had greater anxiety, depression, pain and more limited physical role and social support. Effects were greater at six months.

2.4.2.2 Hypnosis interventions

Just one intervention that met the inclusion criteria used hypnosis and aimed to improve depression, anxiety, and QOL in palliative care patients. It improved outcomes for depression, anxiety and psychological distress, when compared to the standard palliative care controls (Lioffi & White, 2001a). This was based on four 30-minute weekly hypnosis sessions with a four-week follow-up.

2.4.2.3 Psychoeducational interventions

Various successes in achieving psychosocial outcomes were accomplished using psychoeducational approaches. Lepore and colleagues (Lepore & Helgeson,

1999; Lepore et al., 2003) examined the effectiveness of psychoeducational support groups for men with prostate cancer. Their first study (Lepore & Helgeson, 1999) examined a support group comprising a lecture, question time, and a facilitated discussion. Improved outcomes, including self-efficacy, conflict and distress resulted, when compared to controls. Those with baseline low levels of support benefited particularly so. Their second study (Lepore et al., 2003) explored the strength of the discussion group component, by running an educational group, containing a lecture, alongside a group which had a facilitated discussion in addition to the lecture. Results were compared to a control group. There were some positive effects of the intervention on health behaviours; these were enhanced for the education plus discussion group. No significant effects were reported at the 12-month follow-up. Other positive effects included greater physical functioning in both intervention groups, but only for those without a college degree. Employment stability improved for the education plus discussion group when compared to the education and control groups. Better outcomes around sexual bother were seen for the education plus discussion group compared to controls. Moderator analyses showed that those with lower self-efficacy, self esteem and higher depression scores benefited the most from intervention (Helgeson et al., 2006).

Psychosocial and health behaviour changes were targeted simultaneously in a diet, exercise, and stress management intervention for men with prostate cancer (Daubenmier et al., 2006). This ran over 12 months and was preceded by a one-week retreat to familiarise participants with the intervention. It comprised a

weekly support group and instructions to adhere to guidelines of a plant-based vegan diet with 10% of total calories from fat, three hours per week of moderate exercise and one hour of stress management practice each day. At 12 months, the intervention group had made significant improvements in lifestyle, measured by adherence to the intervention guidelines, compared to the control group. No significant between group differences were found for QOL due to ceiling effects. For the whole sample, greater lifestyle scores at baseline were related to greater physical and mental QOL, and greater sexual function. Within the intervention group, at 12 months, greater lifestyle scores were related to physical measures of QOL and a reduction in perceived stress.

The final two studies implemented a psycho-educational programme called Nucare, for head and neck cancer patients, which provided a resource pack and aimed to teach participants how to cope with their cancer. Allison and colleague's (2004) feasibility study offered a choice of three psycho-educational formats of the Nucare programme to participants: small group, one-to-one, or home alone. Since there were only three participants choosing the small group intervention, their data were combined with the 27 one-to-one-condition participants for analysis. A number of significant results were observed in social and fatigue scores for the home format, and sleep, depression, and global health status scores for the one-to-one/group formats combined. Vilela and colleagues (2006) employed the same Nucare programme with head and neck cancer patients, though combined all intervention formats together to compare findings to a control group, participants chose which format they received. Results showed significant improvements in

depression and the physical, social, global, fatigue, and sleep disturbance subscales for the intervention group, with no significant changes for the control group. However, when mean change in scores was examined, between group analyses showed only global QOL had significantly greater increases in the intervention group compared to controls.

2.5 Discussion

2.5.1 CBT-based interventions

The five studies that utilised CBT-based techniques collectively improved QOL, depression, anxiety, and pain outcomes in some intervention conditions, along with sexual function, fatigue, psychological distress, and physical impairment, though were less successful in eliciting physical activity improvements (Carmack Taylor et al., 2006; Gielissen et al., 2006; Pendo et al., 2003; Pendo et al., 2006; Pendo et al., 2007). It is worth noting that in the trial by Carmack Taylor and colleagues, stage of change for participants and their cognitive-behavioural skill had both improved, yet, not to the extent that it impacted on behaviour and QOL, since these outcome measures did not improve. The authors acknowledge that it is possible that these skills are not conducive to changes in physical activity levels. However, the intervention may have succeeded in part by being somewhat motivational as it may have resulted in movement towards change, through the improved stage of change scores. The study also indicates that those with the lowest functioning acquire greater benefits from the intervention. Reasons for the differential success of using cognitive-behavioural approaches to improve

psychosocial outcomes may lie in the application of CBT-based techniques in the specific intervention delivered. The use of CBT-based techniques appeared to vary, however, due to lack of reporting of intervention detail, exploration of the specific components of CBT utilised becomes problematic.

The varied findings may also be in part due to the strengths and weaknesses of the differing methodologies used. The studies by Pendo and colleagues (2003, 2006, 2007) and Gielissen and colleagues (2006) show strengths since they employed intention-to-treat analyses; the former also controlled for heterogeneity in their analyses, though the latter did not. Both studies are weakened by their lack of long-term follow up and the studies by Pendo and colleagues (2003, 2006, 2007) use a comparison rather than a control group. Nevertheless, the generation of significant effects when evaluated against the comparison group, is perhaps indicative of the intervention's effectiveness. Carmack Taylor and colleagues (2006) measured longer-term outcomes and used a control group in addition to a comparison group indicating robustness. However, group attendance in all studies showed either large variations which were not controlled for, or the data were not reported in the article. Despite this heterogeneity, the strong significant results for the Gielissen study, the consistency of the Pendo trials across three multi-cultural samples, and some benefits of the Carmack Taylor study, support the effectiveness of CBT-based techniques in improving psychosocial outcomes. Disappointingly, no significant improvements in any condition for the physical activity measures arose, hence CBT-based techniques alone may not be sufficient to elicit lifestyle behaviour change.

2.5.2 Hypnosis interventions

The single hypnosis intervention was successful in achieving highly significant improvements for anxiety, depression, and psychological distress (Lioffi & White, 2001a). However, there was no long-term follow up. The authors also note that their sample did not reflect the range of palliative patients, since those too unwell were not included. A robust methodology was employed with randomised group assignment, and homogeneous baseline and demographic values across groups. Interestingly, like Carmack Taylor and colleagues, the greatest improvements in psychological distress featured in those with the worst baseline scores, suggesting that interventions targeting the most psychologically disadvantaged are more likely to show positive outcomes.

2.5.3 Psychoeducational interventions

Improvements in psychosocial and/or behavioural outcomes arose from the five studies, though the degree of consistency varied (Allison et al., 2004; Daubenmier et al., 2006; Lepore & Helgeson, 1999; Lepore et al., 2003; Vilela et al., 2006). This may partly be due to the generally large number of outcome measures explored, or may be representative of weaker interventions. These studies could all be classed as psycho-educational partly since they were self-defining, but also because of their use of information and support-giving. However, their mode of delivery and intervention content varied widely. As with studies detailed earlier, reporting of intervention detail was generally not extensive enough for replication. When probing psychosocial outcomes, educational lectures, particularly when followed by a facilitated discussion appear to be an effective

method in eliciting positive psychosocial outcomes, especially for those with lower psychosocial functioning, and also resulted in positive health behaviour outcomes (Helgeson et al., 2006; Lepore & Helgeson, 1999; Lepore et al., 2003). Instructions to adhere to a healthy lifestyle and weekly support to encourage adherence shows successes in eliciting positive health behaviour change. Its value in improving QOL is promising for those who adhere to the healthy behaviours prescribed (Daubenmier et al., 2006). The NuCare intervention delivered in varied formats may bring psychosocial benefits, though the combining of formats for analyses makes it difficult to reach firm conclusions about the benefits of each intervention component (Allison et al., 2004).

As with the CBT-based studies, the psycho-educational studies varied in their design quality. Methodologically, Daubenmier and colleagues (2006) present a strong and well-controlled study. Yet, there were no long-term follow-ups and the measures of lifestyle adherence were by self-report; a method questionable due to issues of reliability (Adams et al., 1999). The NuCare interventions had substantial limitations, particularly with the small sample size and drop-out rate of the first study (Allison et al., 2004). Vilela and colleagues' matched control and intervention participants by time since cancer diagnosis and stage of cancer, though, significant differences between groups by sex and age appear not to be controlled for. This, coupled with the lack of intention-to-treat analyses for both studies, indicates weaker methodologies. The long follow-up time, intention-to-treat analyses, homogeneity in group attendance, and much larger sample size for the Lepore and colleagues (2003) study, represents a more robust intervention than the other

psycho-educational studies. Since limitations remain both methodologically and in the reporting of studies, further rigorous trials are needed to tease out the most effective elements and formats. Lepore and colleagues (2003) suggest that more 'intensive and tailored one-to-one interventions may be required to improve these [disease-specific QOL] outcomes' (p451).

2.5.4 General Discussion

Whilst these studies may appear effective, their lack of long-term follow-up means their effectiveness over time is unknown. Perhaps their omission of a follow-up over a longer time period is one reason for their apparent success. Furthermore, due to the mixed success of the two studies aiming to change behaviour (Carmack Taylor et al., 2006; Daubenmier et al., 2006), this perhaps suggests that a cancer diagnosis does not necessarily assure a 'teachable moment' for behaviour change (Demark-Wahnefried et al., 2005). Alternatively, it may be evidence that the intervention approaches used are not sufficient to bring about behaviour change or that the window of opportunity for a 'teachable moment' is at a distinct point in an individual's cancer journey, or indeed that some patients require a highly-skilled facilitated conversation by a health professional to enable them to capitalise on a teachable moment. Therefore, when answering research question 1, it appears that interventions targeting men with cancer can be effective in improving health behaviour and psychosocial outcomes, however mixed results remain.

A substantive finding is embedded within the first NuCare intervention (Allison et al., 2004), which demonstrates a large preference by participants

towards individual interventions since only three of the 66 participants chose the group format. This suggests that cancer patients – particularly men, since the sample was 79% male – may be more resistant to group approaches than individual interventions. Also noteworthy is that sub-groups of populations appear to respond differently to interventions. A common theme emerged from several studies indicating a stronger improvement in outcomes for those with worse baseline psychosocial scores (Carmack Taylor et al., 2006; Lepore & Helgeson, 1999; Lepore et al., 2003; Lioffi & White, 2001a). This suggests that those most in need of psychological or behavioural intervention are more likely to show positive outcomes, and interventions targeting these groups may be more likely to demonstrate positive outcomes.

The interventions meeting the inclusion criteria tend to focus on psychosocial outcomes. The lack of interventions that target healthy lifestyle behaviours suggests that whilst these studies may be in existence, in the field of cancer research they have historically tended to focus on women, intervene during treatment, or do not use comparison groups (the three primary reasons for intervention exclusion in this review). As can be seen in Table 3, the attrition and refuser rates varied, as did the reporting of this. The characteristics of participants who refused to engage in the study and those who dropped out is unclear, though older people may be a particularly hard group to recruit (Allison et al., 2004; Vilela et al., 2006). There was also a lack of reporting of the effects of social class in results; although several studies measured it, few controlled for this. The lack of range of cancer types included (prostate and head and neck dominated, making up

82% of included studies) may limit the generalisability of the findings to other cancer sites. The reasons for this occurrence may be explained by several factors, discussed further below. Although cancer incidence is generally higher in males (World Health Organisation, 2005), difficulties in recruiting men with cancer to participate in interventions may result in the majority of participants being female (Berglund et al., 1997; Bui et al., 2002).

It is not then surprising that many prostate cancer studies remained in the review, since the greatest factor responsible for eliminating papers - <50% male participants - will not restrict prostate cancer papers from inclusion. The predominance of prostate cancer in the review may also be attributable to it being one of the most prevalent cancers worldwide (Ferlay et al., 2004; NHS Scotland, 2008). Head and neck cancer sites are typically dominated by men; of those studies on head and neck cancer patients excluded, none were for a low percentage of male participants. Conversely, melanoma cancers are one of the few cancers (that affect both men and women) where incidence is often greater among women (Ferlay et al., 2004; Office for National Statistics, 2006). Low number of males accounts for the majority of melanoma studies being excluded from the review. The two papers included in the review that included several cancers only just met the majority male criteria with 52% and 54% of participants being male (Gielissen et al., 2006; Lioffi & White, 2001a).

Accordingly, because studies rarely focus on men *per se*, any review exploring interventions for majority male populations will be skewed by the oncology areas which are dominated by males. One explanation for the evident

gap in research into men with cancer is that due to long-standing campaigns for women's health issues (perhaps particularly in the area of cancer), men's health issues have arguably been sidelined until recently (Doyal, 2001; O'Brien & White, 2003). The need to research the effectiveness of interventions for men, from all oncology areas, not merely the male-only cancers is imperative.

With so few studies focusing on men, it is not hugely surprising that single men, as a sub-group, are also neglected in the literature, despite evidence to suggest that single men do have poorer outcomes, including worse mortality rates (Goodwin et al., 1987; Konski et al., 2006; Lai et al., 1999; Reynolds & Kaplan, 1990; Saito-Nakaya et al., 2008). Reasons for this may include the difficulties in recruiting men, making researchers reluctant to further narrow down their criteria, particularly for a potentially more vulnerable population that would lack the encouragement of a partner. Researchers may also avoid selecting a sub-population for fear of discrimination or rejection of proposals by ethical committee, or may be based on a lack of awareness of the apparent greater need of single men. Since many of the studies showing greater mortality rates for single men are recent, the findings may not have yet translated into the trialling or funding of interventions for single men. However, this does not explain why researchers fail to analyse data for variations based on marital status. Consequently, none of the research questions could be answered for the sub-population of single men with cancer. There remains a great need for more research, and perhaps associated funding, to focus on developing psychosocial and behavioural interventions for both male and single male populations.

As discussed earlier, the range of intervention types, heterogeneity among studies, lack of follow-up and detail in reporting, and varying methodologies makes rigorous comparisons problematic (Stevinson et al., 2004). The need for improved reporting of intervention content and results, in line with CONSORT (Consolidated Standards of Reporting Trials) guidelines, is increasingly stated, and guidance for the reporting behaviour change techniques used in behavioural interventions has been developed (Davidson et al., 2003; Michie et al., 2013; Schmitz et al., 2005; Schulz et al., 2010). Whilst this is often considered in relation to RCTs, improved reporting is also clearly important for non-RCT interventions and whilst not available to authors of the papers reported here, the STROBE (Strengthening the Reporting of Observational Studies in Epidemiology) statement aims to support authors to improve reporting for cohort, cross-sectional and other observational studies (von Elm, 2007). Further limitations include that most studies were not RCTs. Most studies were, therefore, subject to a potentially high level of bias. Lack of detail in the reporting of study protocols meant that this could not be fully scrutinised.

There were strengths and limitations in the methodology for the systematic review. The inclusion criteria aimed to capture relevant intervention studies exploring psychosocial issues and health behaviours. Since studies meeting the I-III level of evidence were included, this resulted in studies without a control group, which are considered less robust than RCTs. Although this resulted in the inclusion of studies arguably more relevant to practice (Green, 2008), it also represents a limitation, especially in relation to the quality of the studies.

A further limitation when drawing inferences for effective interventions for men with cancer, is the inclusion of studies targeting both men and women. Whilst the reason for this (to include a wider range of studies) is warranted, it does mean that some findings may be less specifically relevant to men. Similarly, the decision to include studies with both short and long outcome measures was due to scoping searches that found few studies with long term (above 6 months) outcome measures. Therefore, to enable a greater number of studies to be included, any length of follow-up was accepted. As discussed above, most studies lacked a long-term follow-up, therefore it is unknown whether the interventions were successful in improving psychosocial health and health behaviours long-term.

The search strategy attempted to reflect the inclusion criteria, yet also has some limitations. Whilst in many fields, the term 'intervention' may typically be used to describe studies that deliver an intervention to a participant, there may be other times when different terms are used. Studies may use the terms 'therapy', 'treatment', 'education', or specific type of intervention, such as, 'cognitive behaviour therapy'. More recent published reviews have accounted for this within the search strategy, for example Semple et al. (2013) used a range of terms, not simply 'intervention'. There may have been advantages of including a broader range of search terms for 'intervention' or not using that specific term at all. Scoping searches were undertaken prior to the finalisation of search criteria, and the inclusion of the term 'intervention' captured all known studies that met the inclusion criteria, hence its justification. Still, it may have been possible to search

for other terms that reflect 'intervention', just like multiple terms were used to search for 'cancer'.

The intervention search criteria included interventions on behaviour change, psychological health, engagement, and social support. Similar to the discussion of limitations around the use of the term 'intervention', it is possible that these terms did not fully capture all possible studies around psychosocial issues and health behaviours. Other inclusion criteria (including the study type, outcomes used, and the desire to explore post-treatment interventions) were not included in the search criteria. This was to avoid inadvertently excluding papers. For example, searching for 'post-treatment' may have accidentally excluded some post-treatment interventions if they did not specifically define the study using those terms. Both the study type and outcomes included were broad and specifying these in the search terms may have again accidentally excluded papers. In spite of these limitations around inclusion criteria and search strategy, the search did capture known intervention studies, it resulted in a high yield of papers, along with a high number of duplicates. This may indicate a thorough search, yet the limitations are acknowledged above.

With respect to the selection of studies, it is desirable to have two reviewers screen all studies. Unfortunately, this was only possible at the latter stages of study selection. Therefore, there is potentially the limitation of human error and interpretive error (error relating to the interpretation of how a study fit or did not fit the inclusion criteria) in the selection of studies, which could have accidentally

have resulted in studies being excluded, either accidentally, or through the mistaken interpretation of a study description.

As discussed above, the studies on the whole lacked quality around several factors, including lack of a control group (which was a deliberate, as discussed above), the potential for selection bias, and potential internal biases around allocation and blinding (which were often unknown). Predominantly due to their lack of reporting of detailed intervention protocols, no formal quality appraisal was undertaken. Further, at the time of undertaking the review, this was not a mandatory part of systematic review protocols and publication.

Lastly, the critical realist approach recognises the potential for the researcher to influence some of the (selection of knowledge, knowledge generation and interpretation of the data). Whilst this may be seen as a strength given my applied psychology background, it may also be seen as a weakness by some researchers, since it may reduce the presumed objective nature of a systematic review.

2.6 Conclusions

The multiple problems in drawing comparisons among studies makes it difficult to arrive at conclusions on what makes an effective intervention for men with cancer. Therefore, research questions 2 and 3 can only be answered in part. Indeed, it is not possible to draw any conclusions around effective interventions for single men with cancer. Factors including the content and length of intervention and follow-up time influence effectiveness and help to explain the varied findings.

Psycho-educational interventions often bring mixed results, with those implementing CBT-based interventions being more consistently effective in eliciting psychosocial outcomes. Hypnosis also appeared effective, however, is limited to a single small (N=50) study with only slightly more men than women. In eliciting behaviour change, a psycho-educational year-long weekly support (Daubenmier et al., 2006) to assist adherence to a healthy lifestyle regime brought the most promising improvements. The findings demonstrate that there may be effective components in the interventions and approaches used, and some positive findings were apparent from all studies. Rigorous methodologies, longer-term follow-ups and detailed reporting of interventions, along with a greater focus on men and single men, are essential in future studies to allow better generalisation, replication, and informing of effective interventions for men with cancer in practice.

It is problematic to recommend specific intervention approaches based on these findings for improving the psychosocial health and health behaviours in men with cancer, and indeed single men with cancer. As such, more research, particularly on single men with cancer, may be needed before such interventions can be developed and implemented in the NHS. A greater understanding of these factors may help shape the type and content of interventions. The aim of undertaking the systematic review was to use the findings for the development of interventions for (single) men with cancer in the NHS. However it appears that further research may be needed in order to broaden our understanding of men with cancer and in turn help inform the development of interventions for this group. The broader literature around psychosocial issues and health behaviours in men with

cancer may also need to be examined, as well as a greater understanding of help-seeking and desire for help in men with cancer. This literature will be discussed in Chapter 3, followed by the methodology and results of the primary research studies in Chapters 4-7.

3. Literature Review and Development of Research Questions

3.1 Introduction to Literature Review

The introduction established that men with cancer, and particularly single men, have worse mortality rates than women, and that a range of factors may contribute to men with cancer being more vulnerable for morbidity and mortality. The systematic review identified a dearth of reported interventions targeting men with cancer and a focus on men who had prostate cancer. For many areas, data from men with cancer is not well established, either because research in cancer focuses on women, or mixed-sex research does not analyse data by sex. A better understanding of psychosocial issues and health behaviours in men with cancer may assist in informing the development of interventions.

This Chapter aims to discuss the available literature on the prevalence of psychosocial issues and health behaviours in men with cancer, along with men's health seeking behaviour and barriers and facilitators to men utilising available support. This review aims to further inform the research questions, methodology, interpretation of findings, and discussion of the major research studies in this thesis. Following on from the literature review, the aims, rationale and overall methods used to answer the aims will be presented.

3.2 Prevalence of Psychosocial Issues in Men with Cancer

As discussed in Chapter 1, within this thesis, psychosocial issues focus on common psychological problems (e.g., depression), and wellbeing, along with perceived support. Mixed reports are found for the relationship between distress and a cancer diagnosis. Crucially, different measures are used; therefore, it is difficult to derive exact prevalence. Massie's (2004) review exemplifies this, highlighting that reported rates of depression in cancer patients can range from 0-58%. Anxiety levels have been reported in around one-quarter of the cancer population, however, there is a proportion of patients who have both depression and anxiety symptoms (Brintzenhofe-Szoc et al., 2009). Often the term distress is used to encompass depression and anxiety, with levels of around one-third of cancer patients experiencing distress being typically reported (Howell and Olsen, 2011) and prevalence often found to be slightly higher than the general population (Burris and Andrykowski, 2011).

The person's stage in the cancer trajectory can affect distress. Some research has found distress to be highest in palliative stages followed by treatment period (Gao et al. 2010), others indicating that distress is less than 10% in palliative stages (Rabkin et al., 2009) and some suggesting that it is only higher than the general population shortly following diagnosis (Scroevers et al., 2006). There are also findings that suggest that cancer site is linked to distress; men with prostate cancer sometimes reported to have the lowest levels of distress in several studies and lung cancer among the highest (Admiraal et al., 2013; Zabora et al., 2001). There is little research specifically on men with cancer. Most studies in the

area of prostate cancer, similarly show rates of anxiety, depression or distress can vary from 12%-47% (Bloch et al., 2007; Pirl et al., 2002; Saini et al., 2013; Sharpley & Christie, 2007b). This research is limited given its focus on prostate cancer and lack of comparison with other cancers. Research on a broader sample of men with cancer would elicit more relevant information.

When inspecting social support in cancer patients, it has also been found to be associated with lowered depressive symptoms in male and female cancer patients (Hann et al., 2002). Yet, others have found weak associations between low levels of social support (and self-esteem) and depressive symptoms (Scroevers et al., 2003). Yet, a review of studies examining the association between social support and adjustment to cancer found that not only is emotional support most desired by patients, but also that emotional support has the strongest associations with adjustment (Helgeson & Cohen, 1996). Others have found similar strong relationships between social support and adjustment in men with cancer and better quality of life (Hoyt & Stanton, 2011; Zhou et al., 2010). However, de Groot (2002) discusses several methodological issues in assessing social support in cancer patients, particularly that social support is measured differently between studies. Social support measures may explore perceived support, adequacy of support, or network size, which all represent different aspects of support. Perhaps due to this reason, rates of social support are not typically cited and compared; rather their relationships to other variables tend to be the focus of investigation. It is also highlighted by de Groot that men are more focused on instrumental goals, and therefore, the type of support men seek and need may be different from women.

Consequently, despite some research presented here, the association between cancer-specific factors and psychosocial issues is not fully understood.

When looking specifically at men, some research in the general population suggests that men suffer from mental health problems less than women, particularly anxiety (Martin, 2003; Mclean et al., 2011; Piccinelli and Wilkinson 2000). Despite this, rates of substance abuse and suicide, which are both higher in men, question whether men indeed suffer from mental health problems less than women (Kilmartin, 2005). Kilmartin (2005) suggests that these problems manifest differently in men than women, and pressures around masculinity influence this. Further, investigations also suggest that distress may take on a different meaning to men than it does women, therefore, comparing rates between both sexes is not viable (Keller & Henrich, 1999). Keller and Henrich (1999) suggest that it is the perceived psychological impact of the illness, or men's adjustment that explains psychological ill health. More recent research also suggests that it is adjustment to having cancer that predicts psychological difficulties (Rand et al., 2012). Accordingly, psychological factors may be important in men with cancer.

3.3 Prevalence of Health Behaviours in Men with Cancer

A range of studies have found variations in the prevalence of healthy lifestyle behaviours in cancer patients, with the rates of some health behaviours being as high as those without a cancer diagnosis (Bellizzi et al., 2005; Demark-Wahnefried et al., 2000; McBride et al., 2000; Pinto & Trunzo, 2005). Typically, research does not specifically study men. Some existing research does show that

among cancer patients, advice not to smoke is adhered to by the majority of patients, and there is often a reduction in alcohol consumption after diagnosis (Hackshaw-McGeagh et al., 2015; Hawkins et al., 2010; Karlsen et al., 2013; Parsons et al., 2010; Westmaas et al., 2015). Healthy eating and regular exercise are adhered to somewhat less; often less than 50% of patients are adhering to guidance around these behaviours (Blanchard et al., 2008; Broderik et al., 2014; Stevinson et al., 2013; Williams et al., 2013). The large variations in healthy lifestyle behaviours in patients with cancer suggest that targeted interventions may be required to improve effectiveness of behaviour change. Researchers have indeed emphasised the need to intervene following a diagnosis of cancer to make use of ‘teachable moments’ which may be utilised to assist behaviour change (e.g., Denmark-Wahnefried et al., 2005). Nevertheless, it may be problematic to know precisely when this critical period occurs in each cancer patient, since it may vary between individuals (Dale et al., 2010). Further, there are barriers to health professionals discussing lifestyle change with cancer patients (Anderson et al., 2013; Coa et al., 2014).

There may be sub-groups of men with cancer who are less likely to engage in healthier behaviours. As for psychological health, there are associations between social factors and lifestyle. Associations in the general cancer population have been found between social support and a healthy lifestyle in a review by Park and Gaffey (2007). Another study found that it was being part of a support group, rather than perceived social support, that was associated with health behaviours (Brunet et al., 2014). Little other research has explicitly explored the role of social

support and lifestyle. It appears that there is huge potential for lifestyle modification in men (and women) with cancer, and that perceived or actual support may assist lifestyle change.

3.4 Men and Help Seeking

Research varies in its identification of men being more vulnerable than women around psychosocial issues and health behaviours. Similarly, the extent to which men and women with cancer differ around utilising support to improve their health may vary. Typically, though, it is found that men seek less help than women (Addis & Mahalik, 2003). This includes poorer symptom awareness and slower medical advice seeking, which can lead to late diagnoses (All Party Parliamentary Group on Cancer, 2009; Galdas et al., 2005; National Cancer Intelligence Network, 2009; Oberoi et al., 2014; White & Banks, 2004); poorer uptake to cancer screening programmes (Steele et al., 2010; Weller et al., 2007); and fewer men accessing support for psychological issues or making preventative lifestyle changes such as losing weight (Lee & Owens, 2002; Wilkins et al., 2008).

Help seeking behaviour in relation to health behaviour change and distress has multiple influences, including gender, social support, and psychological factors. For example, in the general and oncology populations, men seek help for mental health problems less than women, independent to the severity of distress (Nekolaichuk et al., 2011; Oliver et al., 2005). This would indicate that distress alone does not trigger help-seeking in men with cancer; a possibility that requires further testing. Men also have been found to seek help less for a range of physical

health issues and preventative lifestyle factors, such as losing weight (Wilkins et al., 2008). Psychological barriers, which may be influenced by social norms, pressures around masculinity (acknowledged by men), and wider cultural norms may also contribute to less help seeking (O'Brien et al., 2005; Robertson, 2007; Smith et al., 2005). Stigma around mental health problems may too influence help seeking for such issues (Clement et al., 2014).

Therefore, based on the general literature, it appears that seeking help at all stages of the cancer journey may consign men to a more disadvantageous position compared to women around their physical, psychosocial health, and lifestyle behaviours. The relationship among the range of factors influencing help seeking has yet to be established but these factors are clearly important for developing appropriate support services that adequately target the needs of men with cancer.

Within the cancer literature, the influence of gender on help seeking is not fully understood. Research focuses on help seeking for symptoms prior to diagnosis, rather than help seeking for distress, support or to make lifestyle changes once a diagnosis of cancer has been given. For example, the cancer patient who considers changing their lifestyle may find such a change easier with support from others (Park & Gaffey, 2007). However, the pathway of how social support influences help seeking is not fully explored.

Another factor likely to be influencing men's behaviour around help seeking compared to women in the area of cancer is the multitude of campaigns for women's health issues (O'Brien & White, 2003). Whilst this has assisted in raising the profile of cancer in women, it may have done so at the detriment to men's

health. In addition, there is a greater number of charities for cancer in women, and in the UK, there is less expenditure on cancer in men than in women, possibly impacting on treatment and then mortality rates (Berrino et al., 2009). Banks (2009) also highlights that health services in the UK are often unaware of how to engage men, since they do not explore the barriers that men face nor do they attempt to overcome barriers specific to localities or groups (for example, the interactions between being male with social class, ethnicity or other factors). Furthermore, health care services are generally female dominated and may not relate as effectively to men to encourage participation (Smith et al., 2006), or there may be a perception that this is the case, which then acts as a barrier. So, a large number of factors may contribute to help seeking and possibly the greater mortality rates seen for men than in women.

3.5 Aim and research questions

Building on the systematic review and literature discussed here, the overall aim of the primary research was to understand the psychosocial and health behaviour factors that affect men with cancer, influences on and between these factors and the factors that affect desire for support and help-seeking for these issues. Lastly, the research aimed to bring together the findings to inform implications for the development of interventions for men with cancer.

3.5.1 Research questions

Specific questions were:

1. Which demographic and disease factors, including marital/relationship status, affect psychosocial issues and health behaviours in men with cancer?
2. What is the relationship among psychological issues, social factors, health behaviours and desire for more help in men with cancer?
3. What, if any, additional support do men with cancer desire for improving psychosocial issues and health behaviours?
4. What are the barriers and facilitators to men with cancer seeking support, including the influence of masculinity?
5. What are the implications of findings for the development of interventions within health services (e.g., the NHS), including how services can reduce any barriers of access for men with cancer?

Given the broad scope of the questions, and the scarcity of research on men with cancer, the research aimed to study all adult men with a diagnosis of cancer. The broad criteria enabled a wide-ranging sample of men with cancer to be studied. This is especially important given the dearth of literature currently focussing on these questions. The desire to recruit a broad sample of men with cancer for the questionnaire study, led to an exploration of the representativeness of this sample. This was done through gaining comparative data on disease and

demographic characteristics of men with cancer in the same demographic area in which recruitment took place (discussed further in Chapter 4).

3.5.2 Rationale for research questions

Research question 1 was developed based on the studies showing that men who are not married are more vulnerable to mortality in cancer. It is not known what factors influence this, though it is possible that psychosocial issues and/or health behaviours may act as mediators in this relationship. Therefore, by exploring the effect of marital/relationship status on these factors, it may help reveal whether they play a part in explaining why men with cancer who are not married fare worse. There are multiple demographic factors in addition to marital status, some of which (in particular age and deprivation) that have been shown to correlate with psychosocial and health behaviour factors. Similarly, some disease factors (time since diagnosis and some types of cancer diagnoses) also correlate. It was, thus, deemed appropriate to explore the effect of a range of demographic and disease variables. This would also enable the research to identify, more broadly, whether particular demographic characteristics or disease factors make men more vulnerable to psychosocial and health behaviour morbidity.

Research question 2 was posed since there are known relationships in the general population between some psychosocial factors and health behaviours. As such, when attempting to identify indicators of vulnerability in men with cancer and how these factors interlink, it is necessary to investigate interactions among factors and indeed whether these relationships are true for men with cancer. There may

also be links between psychosocial issues and health behaviours and wanting help for those issues, which has not previously been explored in men with cancer. This should build on the answers to question 1 in forming a better understanding of key indicators of vulnerability in men with cancer around psychosocial issues and health behaviours, and how variables interact.

Research question 3 was developed since research has typically shown that men in general access support less than women. The review in Chapter 2 also highlighted that men may be less likely to take part in interventions than women. Therefore, exploring what men may want from support, will help inform the development of interventions for men with cancer.

Linked to research question 3, research question 4 seeks to understand what may affect the seeking and acceptance of support for men with cancer. In the general population there are often a range of barriers and facilitators that can affect help seeking and support access, and some research suggest that men seek help less than women. Exploring this in men with cancer will help inform the future development of interventions, particularly what they look like and how they engage men with cancer.

Research question 5 aims bring together the findings from questions 1 to 4 and explore the implications for the development and delivery of services in health services for men with cancer.

3.6 Study Design

A mixed-methods study design was chosen, combining a quantitative questionnaire study and a qualitative interview study. This approach was taken since it was felt it would enable a breadth and depth of understanding of a seldom-studied area, enabling greater clinical relevance than a single methodology (Creswell et al., 2011; Johnson & Onwuegbuzie, 2004; Sale et al., 2002). The mixed-methods nature of the research enables the development of methodology to 'fit' the question(s), and the approach to the interpretation of what is meant by reality (critical realism), allows for both some objectivity and subjectivity, which is common within the discipline of health psychology. A mixed-methods design utilising both quantitative and qualitative methodologies, thus enables the results of both arms considered both separately and then together in the discussion. Accordingly, by examining the results of both methodological approaches together, it enables a richer understanding of the topic (Creswell & Clark, 2011).

As discussed in Chapter 1, the overall theoretical approach to the research is situated within critical realism (Bhaksar, 2010; Maxwell, 2010; Scott, 2007). There is much discussion in the literature about how critical realism lends itself well to mixed-methods research, since it recognises both objectivity and subjectivity in qualitative and quantitative methodologies and addresses some of the discussed challenges in combining methods (Lipscomb, 2011; Maxwell, 2010; McEvoy and Richards, 2006; Scott, 2007; Zachariadis et al., 2010). This approach aims to help reconcile some of the recognised debates and acknowledged challenges in the literature that suggest that it can be problematic to bring together the two

approaches in research. This is since quantitative research is typically assumed to be more objective (positivist approach; Guba & Lincoln, 1994) and qualitative research assumed to be more subjective (interpretivist approach; Bryman, 2007).

Within the mixed-methods literature, a range of approaches are discussed and there are debates around what type of design is most useful and when (Creswell & Clark, 2011). Indeed, there are further debates about what 'mixed-methods' refers to, along with what term best reflects the type of research undertaken. As Tashakkori and Creswell (2007) discuss, there are a range of definitions of mixed-methods research, recognising that, often, it incorporates qualitative and quantitative research, yet the specifics of how they are used and incorporated can differ immensely. Others discuss how the epistemological approach can differ, and a distinction among multi-methods, mixed-methods and mixed-model research (Brannen, 1992; Bryman, 1992; Creswell et al., 2003; Denscombe, 2008; Johnson et al., 2007; Leech and Onwuegbuzie, 2009). Although there are not fully agreed definitions of mixed- or multi-methods studies, in general, multi-methods studies involve two independent pieces of research, the results of which are interpreted together, often through triangulation (Brannen, 1992; Morse, 2003). Mixed-methods research typically involved quantitative and qualitative research and there may be many ways to integrate and interpret findings, with no single definition (Creswell et al., 2003). Accordingly, there are different ways to integrate quantitative and qualitative research.

Since this research aimed to utilise a quantitative and a qualitative study, it is defined broadly as 'mixed-methods'. Nevertheless, the research presented in

this thesis may by some people be considered to be multi-methods research, since the boundaries between mixed- and multi-methods research are blurred (Johnson et al., 2007).

Further to the definitional and philosophical debates around mixed-methods, there are discussions around how methods can be mixed. The way that mixed-methods research can be combined focuses on which type of research is undertaken first, where the integration of methods occurs (e.g., data analysis, interpretation) and the theoretical perspective (Creswell, 2003; Leech & Onwuegbuzie, 2009).

The approach within mixed-methods taken here most fits the 'explanatory sequential design' whereby quantitative research is first collected and analysed and the findings then influence qualitative data collection and analysis, after which, the body of findings are considered together for an overarching interpretation (Cameron 2009; Creswell, 2003; Creswell et al., 2011; Rauscher and Greenfield, 2009). This approach fits both the need to gather a breadth and depth of data, and aligns with the overall theoretical approach to the research (i.e., critical realism). Some researchers combining quantitative and qualitative research assume triangulation (which this research does not, as discussed below), may collect both sets of data concurrently or lead with qualitative research (e.g., concurrent triangulation, sequential exploratory, concurrent nested; Creswell, 2003; Mays and Pope, 2000).

As fitting with the explanatory sequential design, the exact focus and aims of the qualitative study were decided upon once findings the quantitative study had

been analysed. There was some overlap in the recruitment periods since the quantitative study suffered from slow recruitment, and was, therefore, analysed for preliminary findings in January 2010 on a sample of 75 participants. This led to decisions to be made about the focus of the interview study, and ethical approval was then sought, and recruitment commenced alongside the recruitment of the quantitative study. Therefore, the mixed-methods approach taken (explanatory sequential design) had implications for the design – with the quantitative research informing the qualitative research, so the latter could give more explanation to the findings of the former. Although the explanatory sequential design did not presume a particular focus or method for analysis of either study, this approach meant that the qualitative findings were, in part, attempting to answer questions that could not be answered through quantitative approaches (particularly around barriers and facilitators to men accessing support services). The interpretation of findings, based on the research questions are discussed concurrently in Chapter 8, as is typical of this type of mixed-methods research.

Some mixed-methods research assumes that data can be ‘triangulated’. This term is used to describe that a greater confidence in, and generalisability of, findings that can be assumed when the findings from two or more types of research on the same topic are examined together. For example, some researchers discuss how mixed methods research can enable triangulation of data and therefore, increase validity and make triangulation more comprehensive (Cameron, 2009). Others suggest that triangulation is either not possible or does not increase validity, whilst acknowledging that triangulation within mixed methods

can enable the generation of more knowledge (Moran-Ellis et al., 2006; Sale et al., 2002). Here, it is not specifically assumed that triangulation will be achieved, more that a mixed-methods design will enable a richness of understanding and will enable both a breadth and depth of data for analysis and interpretation. This is done through a mixed-methods approach with the two study designs answering the research questions. Research questions 1, 2, and 5 are answered by the quantitative study and are the main focus of this study. Research questions 3 and 4 are answered in part in the quantitative study through brief questions. The qualitative study focuses on answering questions 3, 4, and 5, along with building on findings of the questionnaire study to further shape the focus of these questions. The systematic review and the broader literature will also be drawn on to answer question 5.

First, a cross-sectional questionnaire study primarily looking at psychosocial issues and health behaviours in men with cancer, and their desire for more support for these issues was undertaken. Second, a semi-structured interview study exploring the support needs of men with cancer, and the barriers and facilitators to them seeking support, was conducted.

4. Methodology of Questionnaire Study Exploring Psychosocial Issues and Health Behaviours in Men with Cancer, along with Desire for Support

As discussed in Chapter 3, a mixed-methods design, combining quantitative and qualitative approaches, was used to examine the research questions detailed below. The quantitative arm was a cross-sectional questionnaire study exploring anxiety, depression, distress, social support, health behaviours (exercise, fruit and vegetable consumption, alcohol intake, and smoking), and desire for more support to improve these areas (see appendix 4 for questionnaire). As detailed in Chapters 1 and 3, the research takes an overall theoretical approach of critical realism. This means that although it is assumed that there is objectivity in the collection and analysis of the data, there is an element of subjectivity in influencing research questions, study design and interpretation. This is also the case when participants are interpreting the questions, since they will do this through their own understandings of concepts and realities. Subjectivity also comes into play in the study design and interpretation of the findings, the emphasis placed on findings and the perceived implications for practice, which are influenced by my own ideas about concepts, and the way that health psychology is embedded in practice.

4.1 Study Design

A cross-sectional design was chosen since it would enable a greater understanding of the difficulties men with cancer face, along with relationships among these factors. This was considered appropriate particularly due to the dearth of such evidence in populations of men with cancer. The quantitative study would not only give indications of important factors that are prevalent in men with cancer and their associations, but also recommendations for further research. The final reason for the design choice was pragmatic. Due to the mixed-methods design and the need to use findings from the quantitative study to influence the qualitative study, a need for quantitative results in a relatively short amount of time required a cross-sectional study.

4.2 Aim

The aim of the quantitative study was to explore the effect of demographic factors on psychosocial issues and health behaviours in men with cancer, the inter-linkages between these and whether or not men desire further support in these areas.

4.2.1 Research questions

1. Which demographic and disease factors, including marital/relationship status, affect psychosocial issues and health behaviours in men with cancer?
2. What is the relationship among psychological issues, social factors, health behaviours and desire for more help in men with cancer?

3. What, if any, additional support do men with cancer desire for improving psychosocial issues and health behaviours?
4. What are the barriers and facilitators to men with cancer seeking support, including the influence of masculinity?
5. What are the implications of findings for the development of interventions within health services (e.g., the NHS), including how services can reduce any barriers of access for men with cancer?

The intention of the quantitative study was to focus mainly on research questions 1, 2, and 5 (as discussed in Chapter 3) and cover aspects of questions 3 and 4 through single-item questions to enable findings to be built on for the qualitative study.

4.3 Participants

The inclusion and exclusion criteria for participant inclusion in the study were as follows (Table 4):

Table 4. Inclusion and exclusion criteria for the quantitative study

Inclusion criteria	Exclusion criteria
Male	Female
Aged 18 or over	Aged under 18
Has had a diagnosis of cancer	Has not had a diagnosis of cancer

The inclusion criteria were deliberately broad to include all adult men with a cancer diagnosis at any time point in the cancer trajectory given the current dearth

of literature in this area. By targeting all adult men who had received a diagnosis of cancer, it enabled a broad population to be studied. Disadvantages of this approach are that the sample may be so broad that generalisations could be problematic, since not enough representation from sub-groups is achieved. However, given the lack of literature exploring all men with cancer, it was felt that this breadth of approach was preferable. As discussed in Chapter 3, and detailed later in this Chapter, to test the representativeness of the sample, demographic characteristics of cancer patients in the study area were obtained from the Scottish Longitudinal Study.

There was a broad focus within this thesis on men with cancer post-treatment. This is because of the increasing numbers of men (and women) surviving cancer, which links to additional care considerations around psychosocial issues and health behaviours, that may be different from cancer patients undergoing intensive treatments, such as surgery, chemotherapy and radiotherapy (Gao et al. 2010). This was not, however, a strict part of the inclusion criteria for several reasons. It was recognised that recruitment for a non-clinical trial could be difficult, therefore, restricting the participants to post-treatment only may reduce the number of potential participants too much. Further, definitions of post-treatment can vary, and the types of treatment available across cancers can differ with new treatments emerging too. For example, prostate cancer patients on hormone therapy may be considered to be on treatment, however, they may have completed all their major treatment, such as radiotherapy. Patients post-major treatment were the desired focus of the thesis, given the potential care needs of this group.

Because of the difficulties in defining treatment, ensuring that all participants were post-major treatment (the definition used for the systematic review) would be problematic to identify either from staff involved in the recruitment of participants, or participants themselves. As such, staff involved in recruitment were advised not to actively recruit any men who were at the point of diagnosis, making treatment decisions, or those who were undergoing palliative care. Although this could not ensure that all men were 'post-major treatment', it would assist in enabling the key target sample (men with cancer post-major treatment) to be recruited.

The initial aim for recruitment was 100 men. This was in part due to a power calculation which suggested that the minimum sample size needed for an approximate effect size of 0.15 and a power level of 0.8 would be 54 for 1 predictor, 67 for 2 predictors and 76 for 3 predictors, 84 for 4 predictors and 91 for 5 predictors in multiple analyses. Planned multiple regressions would be based on first exploring individual effects. Given not all potential predictors have previously been explored in men with cancer, it was unknown how many predictors would likely be significant and therefore be entered into analyses. As such, if only two demographic factors were significantly associated with health behaviours, a lower number of participants would be sufficient to reach power. To allow for tests on multiple predictors, and any possible variations in assumptions made in the power calculation, a sample of 100 was deemed sufficient. Given the structured equation modelling was exploratory, a power calculation was not warranted, however, a larger sample is recognised as desirable.

4.4 Measures

As discussed in Chapter 1, the philosophical approach to the research predominantly lies within critical realism. It is, therefore, assumed that the measures used within the questionnaire study will give an indication of realities for participants, rather than represent the whole truths. The nature of psychological difficulties is assumed to have elements that can be objectively rated, however these are through the subjective realities of patients. Therefore, a high score on a depression scale will be interpreted as an indication of depression, rather than assumed that the participant *is* experiencing depression. This is in keeping with the purpose of measures of psychological issues in particular, which were designed as screening test to indicate issues such as depression, rather than to be diagnostic (e.g. Zigmond & Snaith, 1983).

4.4.1 Demographic and disease factors

Relationship status (single, married, civil partnership, separated, divorced, widowed, partnered/in a relationship), living arrangements (live alone, live with partner or spouse, live with parents or relatives, live with friends, live with children, other (please state)), and age were all measured using forced answer choices in response to single-item questions. Type of cancer(s) diagnosed, date of diagnosis, stage of cancer or prognosis, and treatments received were assessed using open answer questions in order to avoid forced answers, particularly given the differences among cancer types and their treatments. Participants' postcodes were taken in order to gain both a measure of deprivation through the SIMD (Scottish Index of Multiple Deprivation, The Scottish Government, 2009) and a measure of

rurality (Scottish Government Urban Rural Classification, The Scottish Government, 2012). The SIMD ranks postcode areas from high to low deprivation. The Urban Rural Classification provides each postcode with one of six categories ranging from large urban areas (settlements of over 125,000 people) to remote rural areas (areas with a population of less than 3,000 people, and with a drive time of over 30 minutes to a Settlement of 10,000 or more).

4.4.2 Social support

Social support was measured using the Social Provisions Scale (Cutrona, & Russell, 1987). This standardised, validated, 24-item measure examines perceived support and has been used previously in the field of oncology (Evans et al., 1995; Karnell et al., 2006; Roberts et al., 2006). It was felt that perceived support rather than actual support would better assess additional needs around social support. It was also felt that this measure was preferable over a range of other cancer-specific and general social support questionnaires; sometimes these made assumptions about who someone should be receiving support from, and that people should be receiving support regardless of need (e.g., Lehto-Järnstedt, 2004; Sherbourne & Stewart, 1991; Stansfield & Marmot, 1992). The Social Provisions Scale was worded in a way that asked if people would receive support if they needed it.

4.4.3 Psychological factors

Two measures of psychological factors were utilised. These explore the common mental health problems seen in cancer patients, as discussed in Chapter 1). The Hospital Anxiety and Depression Scale (HADS) was used since it is a well-validated measure of anxiety and depression (Wilkinson & Barczak, 1988; Zigmond

& Snaith, 1983). A measure of distress was also taken using the Distress Thermometer (DT; Akizuki et al., 2003; Roth et al., 1998). The DT has been developed for use with cancer patients and measures level (0-10) and sources of distress for the patient in the last week. It is a validated scale and is being increasingly used in cancer services. However, there are questions about its validity as a screening tool so it was felt important to examine both the DT and the HADS (Mitchell, 2007). More recently, the validity of the HADS has been questioned. This is particularly in relation to its ability to examine anxiety and depression as independent constructs (Cosco et al., 2012; Coyne & van Sonderen, 2012). A pragmatic decision was made to analyse anxiety and depression in the HADS as separate (but related) constructs, given the clinical levels (20% for depression and 29% for anxiety, and there was only some overlap of cases).

4.4.4 Health behaviours

Health behaviours (as defined in Chapter 1) were measured using questions assessing self-reported smoking, alcohol, fruit and vegetable intake, and exercise. Although there are other health behaviours, such as drug use, that could have been investigated, it was felt that the four areas explored here captured the key lifestyle issues, without over burdening participants with too many questions. Health behaviour questions were developed based on UK government targets around the behaviours, in order to generate data around numbers meeting guidelines, where possible. Questions also assessed their desire to improve their health, through a fixed answer question (yes/no/haven't thought about it), and self-

efficacy which was measured following each health behaviour question using a 5-point Likert scale.

4.4.5 Support needs

Support needs were defined here as the perceived support needed around a given issue (Helgeson & Cohen, 2006). It was measured throughout the questionnaire following each section, therefore, gathering information on desire for further support around all the issues measured (anxiety and depression, distress, social support, and each health behaviour). Participants were also asked whether or not they were aware of the support available to them (yes/no), if they have accessed support services (yes/no) and details of barriers to attending services or whether or not they felt that any accessed services had helped them (both open answer questions). The last section of the questionnaire sought information about accessing services, including factors that may encourage them to access support services, their confidence in accessing services and whether they feel they need more help to access services.

4.5 Procedure

The study aimed to recruit a representative sample of adult men with a diagnosis of cancer. Whilst an opportunity sampling method was utilised, it was hoped that participants would remain to be fairly representative of the adult male cancer population, due to the range of professionals from each cancer specialty in the NHS Board area(s) involved in recruitment.

Following NHS ethics approval, oncology staff members from statutory and voluntary (e.g. Maggie's Centres, MacMillan) agencies in Fife were approached for assistance with recruitment. Recruitment initially targeted patients who resided in Fife, through the cancer services. This was later expanded to include men from NHS Tayside and Lothian to increase recruitment rate. An ethical amendment was submitted to and approved by both the NHS and University of St Andrews ethical committees.

Once staff members from NHS and voluntary cancer services agreed to assist with recruitment, they were provided with "research packs" and guidelines for giving out the packs. This included, not approaching men to take part who were at the point of diagnosis, treatment decisions or palliative stages of cancer. Oncology staff members were asked to introduce the study to potential participants who attend their services, if they felt it was appropriate to do so. It was stressed that the research should not be discussed with those who were very distressed at the time. The research pack included a letter introducing the project and giving instructions on what to do to take part. It also contained an information sheet providing full details of the study, the questionnaire, and a stamped-addressed envelope to return the questionnaire. A contact sheet of cancer support organisations available to cancer patients in their area (Fife, Tayside, or Lothian) was also included. The questionnaires were printed on coloured paper in three different colours: green, yellow, and blue. Pale colours (rather than bold colours or white) were chosen as it may assist anyone with mild learning difficulties (e.g., dyslexia) in completing the questionnaire, and make it more attractive. Since there

are three main places of work for oncology staff in Fife (Victoria Hospital, Kirkcaldy, Queen Margaret Hospital, Dunfermline and the Maggie's Centre, Kirkcaldy), a different colour of questionnaire was used for each of the three sites. This was done to monitor the rough numbers that were returned from the different sites, since oncology staff members in Fife stated they wished for feedback on the numbers of questionnaires returned. Regular contact was maintained with all staff assisting with recruitment. For questionnaires sent to Tayside and Lothian, the board area was written on the questionnaire so records could be kept around how many were returned from each health board. Several of the procedures described were chosen in part because they have been shown to increase response rates of questionnaires: use of colour; booklet format; including a stamped addressed envelope (Edwards et al., 2002).

The action of completing and returning the questionnaires was implied consent (this was made clear in the information sheet). This helped ensure anonymity. Completed questionnaires were kept in a locked cupboard in the NHS Fife Department of Psychology for two years before being destroyed.

4.6 Scottish Longitudinal Study

The study aimed to recruit a sample of men with cancer that was roughly representative of the general population of cancer patients in the same geographical area by demographic and disease factors. In addition to the primary study, data were accessed from the Scottish Longitudinal Study (SLS; Hattersley & Boyle, 2007). The SLS holds longitudinal data taken from the Census taken each

decade for a 5.3% random sample of the Scottish population, which is presumed to be a high enough sample to be representative of the population as a whole.

Cancer data can be linked, enabling the identification of cancer diagnoses for anyone within the SLS. Data from the SLS were accessed during 2012 and linked to the cancer data for male cancer patients in the East of Scotland, encompassing the Fife, Tayside and Lothian regions (N = 2669; varies due to missing data). From this, simple descriptive statistics were calculated to provide comparative demographic data for male adult cancer patients from the same region, enabling sample representativeness in the current study to be examined.

4.7 Missing Data

Whilst 127 questionnaires were returned, some had missing or unclear data. These were addressed as follows:

Date of diagnosis was not always clearly given. Therefore, when this was not given as month and year as requested, rules that attempted to gather the average of their answer were applied. For example “mid 2008” would be interpreted as “June 08”, “2005” would be interpreted as “June 2005”, and “early this year” would be interpreted as “February 2009” (being the mid-month of the first three months). Whilst this may not be a wholly accurate representation of when they were diagnosed, it was consistently applied to all missing data regarding the date of diagnosis. Where there was more than one cancer diagnosed, the date of the first diagnosis was taken. Only one person did not enter a date of diagnosis, and the SPSS (Statistical Package for the Social Sciences) software package that

was used would not allow missing data to be marked when it is in date format, as such, the average data of diagnosis for all participants was entered.

The specific type of cancer was translated into the categories of cancer used in NHS Fife, Tayside, and Lothian, as follows, with examples of specific cancers in brackets: Urology (prostate), Head and Neck (larynx, throat, mouth), Haematology (myeloma, lymphoma), Upper GI (stomach, upper gastric tract), Colorectal (bowel), Lung (non small cell lung cancer, right lung), Skin (basal cell carcinoma, melanoma), and Brain (right frontal brain lobe).

Where postcode data were missing, a score for deprivation or rurality was not computed, since there was no consistent and accurate way to compute this.

Within the HADS and the Social Provisions Scale, where data were missing, the average score for that sub-scale for that individual was imputed, including rounding up or down to the nearest whole number. Within the DT, where a score on the thermometer was missing, the average score for the whole sample was imputed on most occasions. There were some cases where a DT score out of 10 had been given for each cause of distress, instead of one score for the thermometer. Where this was the case an average of these scores was entered. When re-calculating the means for these scales following imputation of missing values, the means changed by less than 0.1, therefore, this was considered an acceptable method of modifying the means.

For health behaviours, if participants did not enter a single whole number, an average of the numbers they had given was taken. For example, if they indicated they exercised for '3-5 hours' a week "4 hours" was entered. For those

who put “only drink occasionally”, a zero was entered since it was assumed that when the participant chose not to enter a figure for weekly alcohol consumption, on average, they would typically drink less than one unit per week. Further, a number of participants had left the health behaviour questions blank. It was decided not to input the average scores for health behaviours since there was no accurate way of calculating this. The same decision was made for other questions around support needed and preferences for support services. For all missing data not imputed, missing values were highlighted within SPSS (by using the code ‘999’) to enable identification within the spreadsheet and in analyses.

4.7.1 Reliability of scales

The internal consistency reliability (Cronbach’s Alpha) were calculated for the Social Provisions Scale (0.78), the HADS total score (0.89) and the two sub-scales within the HADS (anxiety 0.83 and depression 0.81). All showed good internal consistency reliability.

4.8 Data Analysis

Data were analysed using SPSS (versions 18 & 22), utilising a number of analyses, including regression, multiple regression and logistic regression, ANOVA (Analysis of Variance), *t*-test, and chi square (χ^2). Data were checked for assumptions of parametric data, including outliers (through Z-scores), skewness, and kurtosis. Where data did not meet the assumptions of parametric data, non-

parametric tests were used. Answers to open questions were collated into themes or represented by the numbers of participants giving the same answer. For multiple regression analyses, bootstrapping was used to calculate critical ratios (i.e., significance values). This approach enabled greater confidence to be placed on the effects identified by smaller samples especially when the distribution is not close to normal distribution. The software repeatedly (2000 times) re-sampled cases from the raw data simulating random sampling from the population (Rodgers, 1999). Whilst assumptions about the representativeness of the sample are assumed, this seemed appropriate given the representativeness of the sample by demographic factors when compared with the sample in the Scottish Longitudinal Study (Efron, 1979).

Inter-relationships among the major constructs (social support, distress, health behaviours, and desire for help) were further tested using Structured Equation Modelling (SEM). The 6 basic steps of SEM were followed (Kline, 2011). The outcome of desire for help was the major interest, especially given the variable nature of the relationship of some constructs with desire for help. Due to the limited sample size, there was a need to restrict the number of variables entered into the model. Given the variability of the effect of demographics on a range of psychosocial and health behaviour factors (discussed in the next Chapter), and the large number of demographic and disease factors, it was decided to exclude these from the Structured Equation Model analysis.

Latent variables of the major constructs discussed above were created from the variables relevant to that overarching construct. Latent variables summated a

number of factors within the modelling analysis. This was beneficial since it allowed for the psychological variables to be grouped, assisting model development. A similar approach was adopted, with desire for support and the two health behaviours (exercise and diet). The construction of latent variables, therefore, allows for commonalities among different indicators to be recognised. For small samples, the grouping of indicators into constructs takes into account a greater range of data whilst reducing the network of variables. Latent variable structured regression modelling was conducted using AMOS (Analysis of Moment Structures) v19. The specified model, therefore, used latent variables that represented the observed variables for which associations had already been established through previous analyses and is supported by previous research discussed in earlier Chapters. For social support, where there was one single variable, the reliability of that item was estimated and it was adjusted for reliability to disattenuate the association between social support and other latent variables. Accordingly, social support was used as a 'psuedo'-latent variable. Data for smoking and alcohol use were omitted from analyses due to very small numbers, e.g., only one individual wanted help for reducing alcohol intake.

All variables entered into the structural equation model were inspected for large variations in normality and bootstrapping of standard errors was conducted to reduce biased interpretation of effect sizes. Maximum Likelihood estimation was employed given that this is a requirement of most SEM analyses. This enables the derivation of parameter estimates and is robust to deviations to variable normality (Kline, 2011). All tests were two-tailed with alpha set to 0.05. Conventional fit

indices were used including chi square, Comparative Fit Index (CFI) and Root Mean Square Error of Approximation (RMSEA; Hu & Bentler, 1999). Values of chi square were not approaching significance and CFI and RMSEA above 0.95 and below 0.05, respectively, were adopted to indicate close fit of raw data to the specified model.

4.9 Summary

The cross-sectional questionnaire study used a combination of validated measures and questions developed for the purposes of the study. The study aimed to explore psychosocial issues and health behaviours in men with cancer, desire for, and barriers to, accessing support services. The results are considered in Chapter 5.

5. Results of Questionnaire Study Exploring Psychosocial Issues and Health Behaviours in Men with Cancer, along with Desire for Support

This Chapter presents the results of the quantitative cross-sectional questionnaire study with men with cancer, as part of the mixed-methods study. It examines key data around psychosocial issues and health behaviours in men with cancer, along with their desire for more support for these issues. It also reports on what services men have accessed and any perceived barriers to accessing services. The findings discussed in this Chapter, along with the findings of the qualitative study later examined, hope to elucidate implications for support services for men with cancer. The key questions it addresses are:

1. Which demographic and disease factors, including marital/relationship status, affect psychosocial issues and health behaviours in men with cancer?
2. What is the relationship among psychological issues, social factors, health behaviours, and desire for more help in men with cancer?
3. What, if any, additional support do men with cancer desire for improving psychosocial issues and health behaviours?
4. What are the barriers and facilitators to men with cancer seeking support, including the influence of masculinity?

5. What are the implications of findings for the development of interventions within health services (e.g., the NHS), including how services can reduce any barriers of access for men with cancer?

There is a focus on addressing questions 1, 2 and 5, with questions 3 and 4 partially focused on, to be expanded upon through the qualitative research.

5.1 Demographic Characteristics

127 men with cancer participated in the questionnaire study described in Chapter 4. Table 5 shows the demographic characteristics of the participants in this study compared to male cancer patients within the SLS (Scottish Longitudinal Study) in the same geographical areas as the recruited sample to determine the sample representativeness. The data suggest that the study sample is comparable for age, relationship status, living arrangements, deprivation, and rurality.

Exceptions included that study participants had more recent diagnoses of cancer and fewer people with multiple cancer diagnoses. Finally, the site of primary cancer diagnosis in this study was over-represented by male genital organs and under-represented by skin and urinary tract cancers. Therefore, the sample in the current study is representative of the general cancer population of the same geographic area by demographic factors however, it may not be representative by disease factors.

Table 5. Demographic characteristics of the study sample and men with cancer from the East of Scotland in the Scottish Longitudinal Study (SLS)

Demographic variable		Study Sample N (%)	SLS
Age at Diagnosis	Mean	62 (11.5)	65.9 (14%)
	Range	23-86	Not permitted to report
Relationship Status	Single/divorced/separated	16 (13%)	452 (17%)
	Married	97 (76%)	1868 (71%)
	Widowed	7 (5%)	321 (12%)
	In a relationship/living with partner	6 (5%)	N/A
Living arrangements	Lives alone	21 (17%)	536 (20%)
	Lives with someone	106 (83%)	2092 (80%)
Primary cancer diagnosis	Lip, oral cavity and pharynx	6 (5%)	65 (2.5%)
	Digestive organs	17 (13%)	475 (18%)
	Respiratory and intrathoracic organs	22 (17%)	286 (11%)
	Bone and articular cartilage	0 (0%)	<10 (<0.4%)
	Skin (including non-melanoma)	15 (12%)	901 (34%)
	Mesothelial and soft tissue	0 (0%)	27 (1%)
	Breast	0 (0%)	9 (0.3%)
	Male genital organs	43 (34%)	461 (17%)
	Urinary tract	1 (1%)	176 (6.5%)
	Eye, brain and other parts of the CNS	4 (3%)	33 (1%)
	Thyroid and other endocrine glands	0 (0%)	<10 (<0.4%)
	Ill-defined, secondary and unspecified sites	0 (0%)	42 (1.5%)
	Lymphoid, haematopoietic and related tissue	19 (15%)	177 (6.5%)
Number of cancer diagnoses	One cancer	116 (91%)	2195 (82%)
	More than one cancer	11 (9%)	474 (18%)
Years since diagnosis	Mean	5	10
	Range	0-33	1-31
Deprivation level (Scottish Index of Multiple	0-25% quartile (worst deprived areas)	25 (20%)	470 (18%)
	26-50% quartile	24 (19%)	614 (23%)
	51-75% quartile	41 (32%)	644 (24%)

Deprivation)	76-100% quartile (least deprived areas)	33 (26%)	947 (35%)
Rurality (Scottish Government Urban Rural Classification)	1&2 Urban areas	83 (68%)	1927 (72%)
	3&4 Small towns	17 (13.5%)	339 (13%)
	5&6 Rural areas	23 (18.5%)	403 (15%)

5.2 Descriptive Statistics

Table 6. Descriptive statistics for psychosocial and health behaviour measures

Measure		Mean (percentage meeting government guidelines in brackets)	SD	Range (total possible score in brackets)
Social Provisions Scale	Social support score (N=116)	79.3	8.3	58-93 (96)
Hospital Anxiety and Depression Scale	Anxiety (N=117)	5.5	4	0-20 (21)
	Depression (N=118)	4.3	3.6	0-16 (21)
	Total score (N=117)	9.8	6.9	0-36 (42)
Distress Thermometer (DT)	DT score (N=103)	2.4	2.4	0-10 (10)
Health Behaviours	No of cigarettes smoked/day (N=10; all smokers)	13 (91% of sample non-smokers)	5.4	5-20
	No of units of alcohol/week (N=87; all alcohol drinkers)	13 (90%)	18	0-144
	Fruit and vegetable intake/day (N=114)	3.5 (24%)	1.9	0-15
	Hours of exercise/week (N=122)	6 (67%)	6.3	0-35

The descriptive statistics in Table 6 show the mean, SD (standard deviation) and range of the key data. Given the mean time since diagnosis was 5 years, it suggests that most participants were post-major treatment. Scores on the Social Provisions Scale indicated that many participants had good levels of support. The majority of people were meeting government guidelines for not smoking and drinking a maximum of 21 units of alcohol per week, though fewer participants met the guidelines for exercise and fruit and vegetable intake.

Table 7. Clinical cut off rates for participants around anxiety, depression and distress

Scale	N (percentage)
HADS Anxiety (N=117)	
Non-clinical 0-7	82 (70.1%)
Clinical mild 8-10	22 (18%)
Clinical Moderate 11-14	9 (7.7%)
Clinical Severe 15-21	4 (3.4%)
HADS Depression (N=118)	
Non-clinical 0-7	95 (80.5%)
Clinical mild 8-10	16 (13.6%)
Clinical Moderate 11-14	5 (4.2%)
Clinical Severe 15-21	2 (1.7%)
Distress Thermometer (N=103)	
Non-clinical 0-3	74 (71.8%)
Clinical 4-10	29 (28.2%)
Non-clinical 0-4	84 (81.6%)
Clinical 5-10	219 (18.4%)

Table 7 shows that when using the HADS as an indicator for possible anxiety and/or depression, 18%, 8% and 3% fell into the mild, moderate, and severe categories for anxiety, respectively and 14%, 4%, and 2% for depression.

Two clinical cut-offs for the Distress Thermometer (DT) were used to examine the data since there is not an agreed cut-off yet and ≥ 4 or ≥ 5 is most commonly found in literature (Grassi et al., 2009). Depending on the cut-off used for the DT (4 or 5), the scores indicate that 28%, or 18% of the sample reported distress.

The number of people who expressed that they were experiencing distress in areas identified in the DT is detailed in Table 8.

Table 8. Frequencies and percentages of participants identifying particular areas that were causing them distress from the DT

Practical Problems	N (%)	Physical Problems	N (%)
Housing	8 (6%)	Pain	41 (32%)
Insurance	9 (7%)	Nausea	13 (10%)
Work/school	16 (13%)	Fatigue	71 (56%)
Transportation	14 (11%)	Sleep	50 (39%)
Child care	2 (2%)	Getting around	26 (28%)
		Bathing/dressing	19 (15%)
Family Problems		Breathing	23 (18%)
Dealing with partner	17 (13%)	Mouth sores	13 (10%)
Dealing with children	6 (5%)	Eating	22 (17%)
		Indigestion	24 (19%)
Emotional Problems		Constipation	24 (19%)
Worry	40 (32%)	Diarrhoea	18 (14%)
Fears	32 (25%)	Changes in urination	30 (24%)
Sadness	31 (24%)	Fevers	1 (1%)
Depression	24 (19%)	Skin dry/itchy	40 (32%)
Nervousness	25 (20%)	Nose dry/congested	26 (21%)
Loss of interest in usual activities	31 (24%)	Tingling in hands/feet	37 (29%)
		Feeling swollen	20 (16%)
Spiritual/Religious Concerns	7 (6%)	Sexual	41 (32%)
		Appearance	17 (13%)
		Memory/Concentration	55 (43%)

The scores were generally low for practical and spiritual/religious problems and were higher for emotional problems and highest for some physical problems, especially pain, fatigue, sleep, skin being dry or itchy, and memory/concentration.

5.3 Statistical Analysis

5.3.1 The effect of demographic and disease variables on psychosocial factors and health behaviours

The effect of relationship status on psychosocial health was explored using ANOVAs. There were significant effects on social support ($F(3,112) = 3.426, p < .01, R^2 = 0.29$) and depression ($F(3,114) = 3.568, p < .05, R^2 = 0.29$). Yet, this was the case when using the categories of married/living with a partner, single, separated/divorced and widowed and no post hoc tests were significant. The category of separated/divorced had the poorest scores, in line with some of the literature discussed earlier. Therefore, when grouping all other categories together compared to separated/divorced, using *t*-tests, the effect of relationship status on social support was significant ($t(114) = 2.146, p < .05, R^2 = 0.20$) and likewise for depression ($t(116) = -3.127, p < .01, R^2 = 0.28$). This indicated that those who were separated/divorced had lower social support and higher depression scores. There were no effects on anxiety or distress. The effect of relationship status on health behaviours using chi square (χ^2) analyses was undertaken. There were no statistically significant results.

The effect of age on psychosocial issues was explored using regression analyses. Age was significantly associated with anxiety ($\beta = -.376$, $SE = 0.03$, $p < .000$, $R^2 = 0.14$) and distress ($\beta = -.073$, $SE = 0.018$, $p < .000$, $R^2 = 0.14$). Specifically, younger people (scale data, rather than categories of age) typically experienced worse psychosocial health in terms of anxiety and distress but not social support or depression. The effect of age on health behaviours was also explored using logistic regression analyses ('0' score for not meeting UK government recommendations, '1' for meeting recommendations). There was one significant result showing that younger patients were more likely to be smokers ($B = -0.72$, $SE = 0.24$ (Constant $B = 2.03$, $SE = 1.43$), odds ratio = 0.93 (lower = 0.89, upper = 0.98), R^2 Nagelkerke = 0.16, $p < .01$).

Analyses using *t*-tests revealed that living in an area of high deprivation compared to low deprivation resulted in greater scores of depression ($t(112) = -2.77$, $p < .01$, $R^2 = 0.25$), anxiety ($t(112) = -2.94$, $p < .01$, $R^2 = 0.27$) and distress ($t(98) = -3.46$, $p < .001$, $R^2 = 0.33$). There was no effect on social support. The effect of deprivation on health behaviours was tested through a series of logistic regression analyses. Living in an area of high deprivation was associated with lower levels of exercise ($\chi^2(1) = 4.90$, $p < .05$).

The effect of rural-urban status on psychosocial factors (ANOVA) and health behaviours (χ^2) was explored and there were no effects of rurality on any variables.

ANOVAs were used to explore the effect of cancer category on psychosocial health. This was significantly associated with social support ($F(7,108)$

= 2.52, $p < .05$) and depression ($F(7,110) = 2.39, p < .05$), but not anxiety or distress. When exploring the post hoc tests, no cancer categories were significantly associated with psychosocial health. As a result, the use of cancer category at this stage was eliminated. The lack of significant post hoc tests is likely due to relatively low numbers of participants in some of the cancer categories, therefore meaningful conclusions could not be made due to lack of power.

The effect of recency of diagnosis on psychosocial issues was examined using regression analyses. None of the analyses were significant.

The effect of multiple diagnoses on psychosocial health was explored using t -tests with no results being significant. The effect of having more than one cancer diagnosis on health behaviours was tested using χ^2 . There were no significant results.

Given there were multiple predictors of some variables, multiple regression analyses with bootstrap were conducted. Upper and lower confidence intervals are reported. Visual inspection showed little change between standard and bootstrapping analyses in significance values and bias was low (≤ 0.15).

In multiple regression analyses, social support, relationship status, and deprivation were entered stepwise to examine their ability to predict depressive symptoms. As seen in table 9, all remained significantly associated with depression.

Table 9. Multiple regression analyses of the effect of social support, relationship status and deprivation category on depression

Step	Variable	B	SE B	β	R ²
Step 1	Constant	20.47	2.92		
	Social Support	-0.20	0.04	-0.47 ($p < 0.001$)	0.22
Step 2	Constant	18.87	2.94		
	Social Support	-0.19	0.04	-0.43 ($p < 0.001$)	
	Relationship status	3.02	1.25	0.20 ($p < 0.05$)	0.26
Step 3	Constant	17.59	2.92		
	Social Support	-0.17	0.04	-0.39 ($p < 0.001$)	
	Relationship status	3.06	1.23	0.21 ($p < 0.05$)	
	Deprivation	2.08	0.86	0.20 ($p < 0.05$)	0.30

Bootstrapping 95%CI, Social Support: 77.87, 80.94; Relationship Status: 0.02, 0.11; Deprivation: 0.07, 0.20.

In addition to the statistical analysis presented above, the clinical significance of findings are explored since it is important to investigate whether the findings are likely to represent meaningful differences between groups of patients, in addition to statistical difference (Jacobsen et al., 1984). Sometimes effect size is used as an indication of clinical significance, however this approach has been critiqued, since even large effects sizes can mean there is no clinical significance (Jacobsen et al, 1999). There is not one single definition of clinical significance, and standardised approaches typically focus on the difference between pre- and post-intervention scores; in psychology, this often involves participants moving out

of clinical diagnostic categories (Fisher and Wells, 2005; Jacobsen et al, 1999; Jacobson and Truax, 1991; Kazdin, 1999). However, it is recognised that the requirement for participants to fall within the a different diagnostic category may be too stringent a criterion for clinical significance, and it is suggested that much smaller changes may still be clinically significant (Jacobsen et al, 1999; Kazdin, 1999). Other methods for measuring clinical significance include a criterion relating to patients falling within half to 2 standard deviations of the mean or a normative sample, 10% change or difference in scores and using a combination of methods (Jacobsen et al, 1999; Man-Son-Hing et al., 2002; Page, 2014; Sloan et al., 2005). As a consequence, there are no agreed methods, particularly for exploring clinical significance in cross-sectional data.

Here, the comparison of two groups to examine clinical significance is explored in two ways. Firstly, where the mean of one group falls within the normal range and another within a clinical diagnostic range, a clinically significant difference will be recognised (Fisher and Wells, 2005; Jacobsen et al., 1984; Jacobsen et al., 1999). However, given that smaller differences may still be classed as clinically significant (Jacobsen et al, 1999; Kazdin, 1999), where the means of the two groups fall at least 10% points apart on a scale, this will be classed as a small clinical significance (sometimes known as the minimally detectable difference; Man-Son-Hing et al., 2002; Page, 2014). For example, with a 10-point scale, a difference in score of 1 may reasonably be expected to result in a noticeably different experience between participants.

In order to explore clinical significance relating to the regression analysis in Table 9, the mean depression score for the independent variables was calculated so that between-group differences could be examined. Relationship status and deprivation were dichotomous, therefore means for the two categories within each of these were able to be gathered. For social support, which is a continuous variable, a dichotomous split was created through creating one category of low social support for those who fell below the median score, and a second category for those with higher social support for those falling above the median score.

Table 10 shows the mean depression scores for the two categories in each of the three variables in the multiple regression analyses in Table 9. For relationship status, the mean depression score falls within the mild clinical range (8-10) for those who are separated and divorced, compared with all other relationship categories falling outwith the clinical range. This clearly represents a clinically significant difference, in addition to the statistical significance seen in table 9. For those with lower levels of social support and people living in areas of higher deprivation, these participants on average experienced at least 10% higher scores on the depression scale than those who had higher levels of social support or were not living in the areas of highest deprivation. Although the mean score for both these categories always fell outside the clinical range for depression, a difference of 2.5 within a scale out of 21 may represent a small clinical significant difference.

Table 10. Mean depression score for the dichotomous categories within social support, relationship status and deprivation category

Variable	Category	Mean depression score
Social Support	Low levels of social support (score of 80 or below)	5.55
	High levels of social support (score of 81 or above)	2.87
Relationship Status	Separated or divorced	8.29
	All other relationship status categories	4.01
Deprivation	Living in the 20% most deprived areas	6.60
	Living in the 80% least deprived areas	3.92

In multiple regression analyses, age, social support, and deprivation were entered stepwise. All stayed significantly associated with anxiety (Table 11). As for the previous multiple regression analysis, the mean anxiety scores for different groups were explored for clinical significance. As undertaken for social support, a dichotomous split was created for the continuous variable age through creating one category of younger age for those who fell below the median score, and a second category of older age for those falling above the median score. The median score was within 0.6 of the mean and ensured enabled the use of whole numbers for the dichotomous split.

Table 11. Multiple regression analyses of the effect of social support, age and deprivation category on anxiety

Step	Variable	B	SE B	β	R ²
Step 1	Constant	13.61	2.00		
	Age	-0.13	0.03	-0.37 ($p < 0.001$)	0.14
Step 2	Constant	25.35	3.52		
	Age	-0.12	0.03	-0.32 ($p < 0.001$)	
	Social Support	-0.16	0.04	-0.33 ($p < 0.001$)	0.24
Step 3	Constant	23.67	3.5		
	Age	-0.10	0.03	-0.30 ($p < 0.001$)	
	Social Support	-0.15	0.04	-0.31 ($p < 0.001$)	
	Deprivation	2.40	0.98	0.20 ($p < 0.05$)	0.28

Bootstrapping 95%CI, Age: 63.08, 67.51; Social Support: 77.85, 80.94;

Deprivation: 0.07, 0.20.

Table 12 shows the mean anxiety scores for the two categories in each of the three variables in the multiple regression analyses in Table 11. Living in an area of high deprivation resulted in participants, on average, falling within the mild clinical range for anxiety, compared with people living in less deprived areas who were not in the clinical range. This represents clinical, in addition to statistical, significance. For younger participants and those who had lower levels of perceived support, anxiety scores were on average 2 points higher than older participants and those who had greater levels of perceived support. Therefore, there are

detectable small clinically significant differences for these two areas, in addition to the strong clinical significant difference for deprivation.

Table 12. Mean anxiety score for the dichotomous categories within social support, age and deprivation category

Variable	Category	Mean anxiety score
Age	Ages 65 and below	6.91
	Aged 66 and above	4.15
Social Support	Low levels of social support (score of 80 or below)	6.52
	High levels of social support (score of 81 or above)	4.29
Deprivation	Living in the 20% most deprived areas	8.27
	Living in the 80% least deprived areas	5.06

Age, social support, and deprivation all were shown to influence distress. When examining these factors together, age, and social support were statistically significantly linked to distress, as seen in Table 13.

Table 13. Multiple regression analyses of the effect of social support and age on distress

Step	Variable	B	SE B	β	R ²
Step 1	Constant	6.27	1.22		
	Age	-0.61	0.02	-0.33 ($p < 0.001$)	0.11
Step 2	Constant	12.47	2.26		
	Age	-0.054	0.02	-0.29 ($p < 0.01$)	
	Social Support	-0.08	0.03	-0.31 ($p < 0.01$)	0.20

Bootstrapping 95%CI, Age: 62.73, 67.59; Social Support: 78.46, 81.75.

Table 14 shows the mean distress scores for the two categories for both statistically significant variables in the multiple regression analyses in Table 13. Mean scores in all categories fell below the suggested clinical cut offs for the DT. Mean distress scores for the whole sample (when not exploring sub-categories) were 1.6 below the lowest cut off of 4. Therefore, it is not entirely surprising that the mean scores here also fell below that range. Nevertheless, for those who were younger and had poorer perceived levels of support, anxiety levels on average were at least 10% higher than for older patients and those with higher levels of support. Therefore, this represents a small clinical significance, meaning that experiences may differ between these groups.

Table 14. Mean distress score for the dichotomous categories within age and social support

Variable	Category	Mean anxiety score
Age	Ages 65 and below	3.06
	Aged 66 and above	1.70
Social Support	Low levels of social support (score of 80 or below)	2.89
	High levels of social support (score of 81 or above)	1.82

Multiple logistic regression analyses explored the effect of social support and age, on smoking and found that both remained statistically significantly associated with smoking (Table 15).

Table 15. Multiple logistic regression analyses of the effect of age and social support on smoking

Step	Variable	B	SE B	β	95% Bootstrapping CI Lower	95% Bootstrapping CI Upper	Nagelkerke R ²
Step 1	Constant	2.56	1.57		-1.05	7.98	
	Age	-0.08	0.03	0.92	-0.17	-0.03	0.17
Step 2	Constant	8.44	3.16		3.57	15.57	
	Age	-0.07	0.03	0.93	-0.16	-0.00	
	Social Support	-0.08	0.04	0.92	-0.17	-0.02	0.25

As for the previous multiple regression analyses, the clinical significance of the results presented here were explored. Given the low number of smokers in some categories, the mean number of cigarettes was not a meaningful way to explore smoking difference within categories. Instead, the number of smokers by age and social support has been presented. Table 16 shows the number of smokers for the two categories for both variables in the multiple regression analyses in Table 15.

Table 16. Smoking status for the dichotomous categories within age and social support

Variable	Category	Numbers of smokers
Age	Ages 65 and below	9 smokers
	Aged 66 and above	2 smokers
Social Support	Low levels of social support (score of 80 or below)	10 smokers
	High levels of social support (score of 81 or above)	1 smoker

Greater numbers of smokers among younger patients and those with lower levels of social support are clearly seen. Although there is no agreed way of calculating clinical significance for raw scores, the clear differences seen below, which represent a much larger than 10% difference, is likely clinically significant.

5.3.2 The effect of social support on psychological health and health behaviours

The effect of social support and psychological health and health behaviours were explored. Lower levels of social support were associated with poorer anxiety scores ($\beta = -0.18$, $SE = .41$, $p < 0.001$, $R^2 = .13$), depression ($\beta = -0.19$, $SE = .04$, $p < .001$, $R^2 = .20$), and distress scores ($\beta = -0.09$, $SE = .03$, $p < .01$, $R^2 = .02$).

Logistic regression analyses showed that lower social support was linked to a person being a smoker ($B = -0.83$ $SE = 0.30$, $p < .01$, R^2 Nagelkerke 0.13). There were no other significant effects of social support upon lifestyle factors.

5.3.3 Inter-relationships between social factors, psychological issues and health behaviour factors

Previous research suggests that there are relationships among psychosocial issues and health behaviours. Therefore, a series of correlation analyses exploring these relationships were conducted. Whilst these cannot show the direction of prediction, it indicates where relationships exist. The correlation analyses showed that higher levels of anxiety ($r = 0.30$, $p = < 0.01$), depression ($r = 0.36$, $p = < 0.01$), and distress ($r = 0.21$, $p = < 0.05$) were related to smoking. Higher depression

levels also correlated with lower fruit and vegetable consumption ($r = -0.31, p < 0.01$). No other significant results were found. This series of analyses indicates that there are some relationships among psychosocial and health behaviour factors.

Since different measures were used to assess anxiety, depression and distress, the relationship among them was also explored. Firstly, the correlation between scores on the HADS and the distress thermometer was conducted. The HADS anxiety scale ($r = .57, p < 0.01$), depression scale ($r = .64, p < 0.01$) and HADS total scale ($r = .66, p < 0.01$) were all highly correlated with scores on the distress thermometer. This indicates that all three measures are examining similar constructs. When exploring correlations between different health behaviours, none were found to be significant.

5.4 Desire for More Support and the Factors of Influence

5.4.1 Support for psychosocial issues

The desire for more support around psychosocial factors was examined. The frequency of people desiring additional support, along with types of support desired around these factors is listed in Table 17.

Table 17. Frequency of desire for additional support around social support, depression and anxiety, and distress

Desire for more support for:		
Social Support (N=114)	Anxiety and Depression (N=116)	Distress (N=112)
Yes = 16 (14%)	Yes = 14 (12%)	Yes = 16 (14%)

The relationship between psychosocial factors and desire for more support was examined. There was a significant relationship between wanting more help to feel more supported and a low score on social support (B = -0.084, SE = 0.03 (Constant B = 4.68, SE = 2.48), odds ratio = 0.92 (lower = 0.86, upper = 0.98), R² Nagelkerke = 0.11, $p < .01$). There was a significant relationship between wanting more support to improve one's feelings and a high score on the HADS (B = 0.13, SE = 0.04 (Constant B = -3.52, SE = 0.65), odds ratio = 1.14 (lower = 1.05, upper = 1.24), R² Nagelkerke = 0.18, $p < .01$). When looking at the relationship between score on the DT and wanting more support, the result was significant (B = 0.48, SE = 0.34 (Constant B = -3.45, SE = 0.65), odds ratio = 1.61 (lower = 1.23, upper = 2.11), R² Nagelkerke = 0.27, $p < .001$), showing that those who were in more distress were more likely to want help to reduce it.

5.4.2 Support for health behaviours

Table 18 shows the frequencies and percentages of people wanting to improve their health.

Table 18. Frequencies and percentages of people wanting to improve their health around smoking, alcohol, diet and exercise

Lifestyle area	Yes, want to improve health	No, do not want to improve health	Haven't thought about it
Quit smoking (N=10)	7 (70%)	2 (20%)	1 (10%)
Reduce alcohol intake (N=89)	5 (6%)	67 (75%)	17 (19%)
Improve diet (N=123)	44 (36%)	53 (43%)	26 (21%)
Increase exercise (N=73)	53 (43%)	51 (42%)	19 (15%)

Between 10% and 19% of people had not thought about changing their health behaviours, highlighting that there may have been missed opportunities by professionals involved in their care to promote health around these factors. Very few wished to reduce their alcohol intake, with the percentages wanting to improve their health increasing through diet, then exercise to smoking, which was a high percentage at 70%.

When looking at desire for support to improve health, table 19 demonstrates that support is not always desired, with just one person wishing for more support to reduce alcohol intake, and low percentages desiring support around diet and exercise.

Table 19. Frequencies and percentages of people wanting additional support to improve their health around smoking, alcohol, diet and exercise

Lifestyle area	Yes (support desired)	No (support not desired)
Quit smoking (N=10)	6 (60%)	4 (40%)
Reduce alcohol intake (N=88)	1 (1%)	87 (99%)
Improve diet (N=125)	13 (10%)	112 (90%)
Increase exercise (N=124)	15 (12%)	109 (88%)

Also examined was whether there was a relationship between people wanting to improve their health and those who are not meeting government guidelines. This relationship was significant for alcohol ($\chi^2 (2) = 11.20, p = < 0.01$), with a medium effect size (Cramer's V = 0.36), showing that those who drink above

the recommended guidelines are more likely to want to reduce their intake. This was insignificant for diet ($\chi^2 (2) = 5.86, p = > 0.05$), though was approaching significance, and was insignificant for exercise ($\chi^2 (2) = 3.37, p = > 0.05$). This could not be computed for smoking due to low numbers of smokers (N=10). Therefore, desire to improve health does not necessarily relate to existing engagement in healthy behaviours.

The relationship between desire to improve health and desire for support to improve health was also examined for diet and exercise. This could not be calculated for smoking due to low numbers of smokers. The χ^2 analysis revealed that those who wanted to improve their diet were more likely to desire support to improve it ($\chi^2 (1) = 26.10, p = < 0.001$). Cramer's V effect size was high (0.46). The same analysis was significant for exercise ($\chi^2 (1) = 7.16, p = < 0.05$, effect size 0.24) and non-significant for alcohol ($\chi^2 (1) = 0.34, p = > 0.05$).

Table 20. Participants' confidence levels in changing lifestyle behaviours

	Very confident	A little confident	Neither confident or unconfident	A little unconfident	Very unconfident
Quit smoking (N=10)	1 (10%)	3 (30%)	3 (30%)	1 (10%)	2 (20%)
Reduce alcohol intake (N=89)	70 (79%)	10 (11%)	7 (8%)	0	2 (2%)
Improve diet (N=74)	65 (52.5%)	34 (27.5%)	17 (14%)	4 (3%)	4 (3%)
Increase exercise (N=73)	55 (44%)	29 (23%)	27 (22%)	7 (6%)	6 (5%)

The confidence levels of participants in improving their health were assessed and the frequencies and percentages are shown in table 20. Analyses of any relationship between confidence and desire for support could not be calculated due to the low values in each cell. However, Table 16 indicates that there are higher confidence levels for improving alcohol intake and diet, followed by increasing exercise, and a low confidence for stopping smoking.

5.4.3 Awareness of and preferences for services

The majority of people (94%) were aware of support services available to them, yet, only just over half of these (55%) had accessed services. Participants were asked to select any preferences they had for services. Answers for which are shown in Table 21 (N=124).

Table 21. Frequencies and percentages of people desiring particular service preferences

Service delivery mode	Yes (would like this mode)	Service delivery mode	Yes (would like this mode)
One-to-one appointments	37 (30%)	A referral to a service	22 (18%)
Same-sex groups	12 (10%)	Being able to self refer	23 (19%)
Mixed-sex groups	14 (11%)	A service in a community venue	10 (8%)
Evening appointments	13 (11%)	A service in a hospital	26 (21%)
Weekend appointments	4 (4%)	A service in a local health centre/GP surgery	30 (24%)
Drop-in service	40 (32%)	Home visits	19 (15%)
Other	11 (9%)		

Details of other service preferences
"Happy with the NHS"
"I currently have all the support I need. I know how to access support if required"
"I get all the support that I need at the Maggie's centre"
"My lifestyle suits me & is what I choose. Lucky me I have a choice"
"Any of which available"
"I need encouragement"
"No problems so far"
"None"
"Not really applicable as I do not feel I need additional support"
"Prostate cancer (male) groups meeting. I am already aware of"

The most popular preferences were one-to-one appointments, a drop-in service, receiving a referral to a service, but also being able to self-refer, and services in a range of settings, including community venues, hospitals and local health centre or GP (General Practitioner) centre. Those who commented in the 'other' box mostly indicated that they were happy with the support and choices they have. However, a few suggested that they needed more encouragement or that they wished to access any available service.

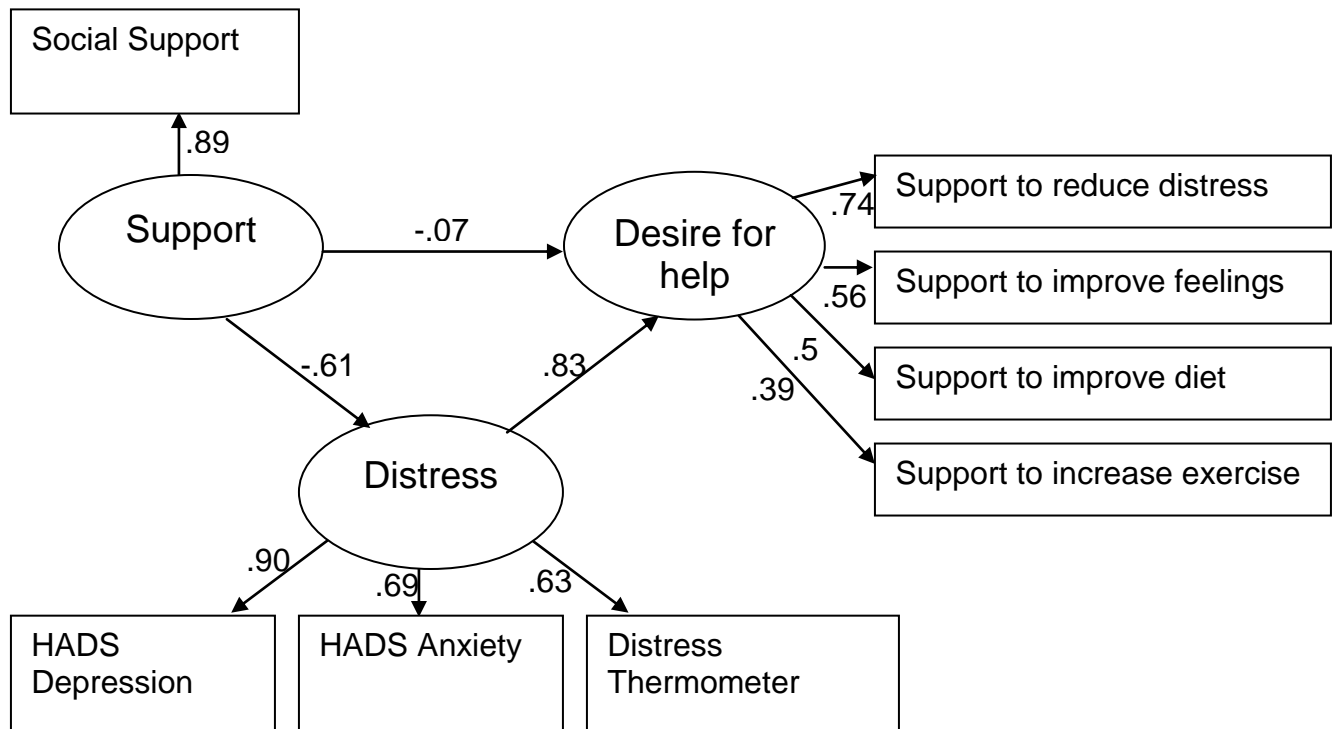
Participants were also asked about their confidence in accessing support services. The majority of participants who responded to this question (N=68) felt confident in accessing services (54% very confident; 12% a little confident), a large proportion remained 'neither confident or unconfident' (22%) and several were a little (9%) or very (3%) unconfident. When asked about whether they would like support to access further services, only 10 (9%, N=113) felt they would like further support.

5.5 Modelling Analysis: Social Support, Distress and Desire for Help

The exploratory mediational model which is specified in Figure 2 summarises the interactive effects of the variables entered. The latent variable structural regression model was tested to provide associations between Support and Distress (specified by the three indicators: HADS depression, HADS anxiety, DT) and Desire for Help (defined by ratings of desired support on four health concerns; distress, feelings, diet, exercise). The direction and size of all parameter estimates were theoretically consistent to expectation. There were no significant correlated errors.

The Bollen and Stine (1992) bootstrap for small samples was performed and gave a p value of 0.965 demonstrating close approximation to the robust χ^2 to show excellent model fit (Nevitt & Hancock, 2001). The conventional fit statistics confirmed the adequacy of this fair fit: $\chi^2 = 12.05$, $df = 18$, $p = 0.85$, CFI = 1.00, RMSEA (Root Mean Square Error of Approximation) = 0.0001 (95%CIs: 0.001, 0.06, Hu & Bentler, 1999). The total standardised effects of support on Desire for Help was -0.54, $p = 0.0039$. The direct effect was not significant: -0.07, $p = 0.63$. Figure 2 shows that desire for help for psychological issues and health behaviours is influenced by social support but mediated by distress. Error terms are excluded for clarity.

Figure 2. Structural mediational model demonstrating the effects of social support and distress on desire for help (standardised coefficients)



5.6 Qualitative Data

A series of open-ended questions were also posed within the questionnaire with space for participants to write their own responses. For psychosocial issues, participants were asked to describe in their own words what support they would like to improve their perceived social support, distress and feelings of depression and anxiety. Table 22 summarises the key themes identified.

Table 22. Themes of support people desired to feel more supported, improve feelings, and reducing distress

Support desired around increasing perceived social support	Support desired around improving feelings	Support desired around reducing distress
Type of support		
<u>Problem-focused:</u> “Domestic help; garden help” “Nutrition, exercise, finance” “If my condition deteriorates my disabled wife would need help” “Somewhere to go to give my partner a break”	<u>Problem-focused:</u> “Relaxation & exercise” “People visiting me, take me places”	<u>Problem-focused:</u> “Financial support, housing support” “Help in overcoming urination problems” “Help with disability caused by progressive MS” “Sexual, indigestion” “Viagra” “Somewhere to go close to where I live to give my worried partner a break”
<u>Emotion-focused:</u> “Regular close emotional support”	<u>Emotion-focused:</u> “As before, I would welcome close emotional support” “Just more time for me” “Concentration, restlessness, panic” “Talking to people, help and support”	<u>Emotion-focused:</u> “Company” “1 to 1 in the early days” “Depressions” “Space for me”
<u>Meaning-focused:</u> “Spiritual”	<u>Meaning-focused:</u> N/A	<u>Meaning-focused:</u> “Would like to see more activity making people aware that spiritual support is available”
Support to come from		
<u>Professionals:</u> “A GP with interest and expertise in PCA [prostate cancer]” “More home visits” “Anyone who could help, welfare, dist nurse etc.” “Talking at support group”	<u>Professionals:</u> “GP” “Anyone who could help, welfare, dist nurse etc.” “Therapy classes”	<u>Professionals:</u> “Counselling”

<u>Friends/family:</u> “Just relatives that listen and don't comment. I have newborn twins and just some time for me would be helpful. But is tough for my wife” “Friends to talk in DETAIL about cancer”	<u>Friends/family:</u> “Maybe from a support group”	<u>Friends/family:</u> N/A
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Table 23 reveals the type of support people desire for each health behaviour.

Table 23. Support desired by participants for stopping smoking, improving diet and increasing exercise

Support desired around quitting smoking	Support desired around reducing alcohol	Support desired around improving diet	Support desired around increasing exercise
<u>Problem-focused:</u> “NRT” (nicotine replacement therapy) “Tablets”	<u>Problem-focused:</u> “At the moment I am off alcohol because of my medication”	<u>Problem-focused:</u> “Correct diet for me” “Any” “Everything” “More pre-prepared salads in shops. Too much hassle otherwise” “Nutritional info and recipes” “Professional advice, cooking classes” “More info on how nutrition could be improved/changed to support the body better whilst undergoing chemotherapy”	<u>Problem-focused:</u> “Any help that alleviates lethargy and weakness to exercise possibly vitamin tablets or such like” “Exercise for cancer patients” “Swimming safely” “Stronger legs” “Help at a gym and access. group sessions - a varied programme” “help in working out a balanced exercise regime” “Perhaps someone to take me to gym or swimming in case

		“Support talking to a dietician about food intake”	I got into difficulty”
<u>Emotion-focused:</u> “Psychological”	<u>Emotion-focused:</u> N/A	<u>Emotion-focused:</u> “Perhaps relaxation or cognitive therapy would help - I sometimes panic at the thought of eating”	<u>Emotion-focused:</u> “Space to have time for me” “Someone to walk with me, to encourage me” “someone to motivate me” “Home encouragement”
<u>Support not required:</u> N/A	<u>Support not required:</u> “None” “When first diagnosed I went tee total for 2 years. Could do the same again if I had to”	<u>Support not required:</u> N/A	<u>Support not required:</u> N/A

The support desired for reducing smoking focused on psychological and pharmacological support. Support was not desired for changing alcohol consumption. For diet, participants would welcome assistance from a dietician, support to find the correct diet, more nutritional information, more convenient healthy food, more time to prepare meals, and a better understanding of how eating particular foods may help their particular condition or treatment. For exercise, participants highlighted a lack of energy but others also wanted support to help them alleviate lethargy, along with someone to help motivate them, having a balanced exercise programme, and specific ways to strengthen muscle groups, or know how to swim safely with their condition.

Table 24 shows a collation of the answers to open-ended questions around what support people had accessed and if there were any barriers to accessing support, if they had not accessed any. The data show that many felt that there was no need for them to access support service or that there were no barriers stopping them. A minority, however, felt that many factors represented barriers, that others with more severe symptoms should be prioritised, or that they were too busy receiving medical treatments to get psychosocial support. Of those who had accessed services, this was often from the Maggie's centres (voluntary sector organisation offering information, advice, counselling and support to cancer patients) or support groups, along with the medical team, other NHS professionals, MacMillan Cancer Support, and other cancer support organisations. It appears that a significant number of people were already accessing support and other people felt there was no need or no barriers.

Table 24. Summary of the responses to questions around support service access and any barriers felt by participants

Support services accessed	Barriers to accessing support services
Maggie's Centre (N=48)	Don't feel the need to access support (N=17)
Cancer Support Group (N=19)	No barriers (N=7)
Cancer Medical Team (N=14)	Not good at talking (N=1)
MacMillan Cancer Support (N=13)	Everything (N=1)
Other Support Organisation (N=7)	No time due to cancer treatment (N=1)
Other Health Professionals (N=5)	People with more severe symptoms should be prioritised (N=1)

5.7 Brief Discussion

This brief discussion will be expanded upon in Chapter 8 where results of both primary studies are considered. Descriptive statistics show that participants largely had good levels of social support and low levels of distress. They met guidelines for not smoking and drinking only in moderation though did not meet guidelines for exercise and fruit and vegetable intake. Roughly 30% of people met criteria for anxiety and 20% of people for depression. Since prevalence rates in cancer patients vary enormously (Massie, 2004) this profile falls within rates previously found. Any distress experienced tended to focus on emotional problems and some physical problems including pain and fatigue, which have all been commonly found in cancer patients, and often represent areas of unmet need (Carlson et al., 2004; van den Beuken-van Everdingen, 2007; Wells et al., 2015a). The results suggest that the sample of men with cancer recruited is largely comparative to men with cancer in the East of Scotland by demographic factors, however, was less representative around disease factors.

Some key factors that indicated worse psychosocial health or poorer lifestyle, were lower levels of social support, being separated or divorced, being younger and living in an area of high deprivation, which largely confirms some previous findings (Eakin et al., 2007; Linden et al., 2012; Mackenbach, 2006). Desire for more support for psychosocial issues, alcohol use, diet, and exercise was low (1-14%). The only area for which it was high was for smoking (60%). Looking at services overall, 94% of people said that they were aware of support services available to them. Little research has previously studied cancer patients'

awareness of support services. A study by Eakin and Strycker in 2001, found that awareness of services in the USA may be up to 90%, though awareness was lower for community (33%) or internet-based (10-14%) services. Naturally, the services available in the UK may differ from that in the USA and awareness may have changed over the years given the increasing use of electronic media. Just over half of participants stated that they were very confident in accessing support services. Modelling analysis showed that desire for help for psychological issues and health behaviours is influenced by social support but mediated by distress.

The data presented here, therefore provides answers to some of the research questions and discussions will be expanded upon in Chapter 8. The qualitative study (Chapters 6 and 7) aims to build on this research to explore in-depth the types of support that men with cancer may desire and the factors affecting whether or not they seek support. Thus, building on findings here that desire for support can be low and that complex factors around support and psychological health may influence this.

6. Methodology of Interview Study Exploring the Factors Affecting Whether or Not Men with Cancer Utilise Support Services

Chapter 3 discussed the overall aims of the primary research studies and the mixed-methods approach employed to answer the research questions. Chapters 4 and 5 detailed the quantitative study, which showed that some demographic characteristics make men vulnerable to psychosocial issues and health behaviours. It also showed that social support, mediated by distress influences desire for more support. The qualitative study aimed to build on the quantitative study to explore through a semi-structured interview design, in depth what support men with cancer utilise, what, if any, extra support they may desire around psychosocial issues and health behaviours, and the barriers and the facilitators to accessing support.

As discussed in Chapters 1 and 3, the research takes an overall theoretical approach of critical realism, and this approach allows for fluidity in the understanding of knowledge, so that questions, design and interpretation between studies may be influenced by an understanding that there can be both objectivity and subjectivity in knowledge generation and interpretation. This recognises that people may have different perspectives of the same reality and there may be multiple influences on this (Bhaksar, 2010; Maxwell, 2010; Scott, 2007). In the design of questions, attempts are made to gather from participants what their interpretation of terms are, for example 'support', therefore, accounting for the fact

that different participants may have differing views on what support means. It is also, therefore, recognised that as a researcher, my own views influence the analysis and interpretation of data. This is detailed further when discussing reflexivity, within the section on rigour (6.7).

6.1 Study Design

An interview study design was chosen for the qualitative study since it allows engagement with participants on an individual basis and should enable an openness and honesty about a sensitive subject, which may not be afforded by approaches such as focus groups (Gill et al., 2008). Semi-structured interviews were considered optimal since they pose a number of open questions based on the aims. They also allow the interview to follow the participant to other relevant areas not previously anticipated so gain a balance between depth and breadth of data (Britten, 1995). This approach recognises the different realities that participants may perceive. Further, in keeping with the critical realist approach adopted in the thesis, critical realism recognises that there are multiple realities and that the knowledge gained in the interviews is influenced by the dialogue and relationship between the interviewer and interviewee (Maxwell, 2010).

The development of, and rationale for, the research questions is discussed in Chapter 3. Interview questions aiming to address the research questions were informed by the preliminary findings of the questionnaire data. For example, asking about desire for more support in the quantitative study, generated findings around men not feeling the need to access support, potentially highlighting barriers to

support, which could be explored further in the qualitative research. Desire for more support may, thus, grow out of a number of factors including service availability and a lack of support from others, as well as psychological barriers to accessing services that are available. Therefore, it was felt that the qualitative interview questions should include a range of questions around what factors affect barriers and facilitators to seeking help, and indeed whether or not men desire more support, along with ways that services may further reduce barriers to men's service access. Consequently, such in-depth data from the qualitative interviews should reveal further insights into how best to support men with cancer through tailored interventions.

6.2 Aim

The interviews aimed to provide an in-depth understanding of the factors affecting psychosocial issues and health behaviours in the context of help seeking in men with cancer, and whether services may need to adapt to support help seeking.

6.2.1 Research questions

3. What, if any, additional support do men with cancer desire for improving psychosocial issues and health behaviours?
4. What are the barriers and facilitators to men with cancer seeking support, including the influence of masculinity?
5. What are the implications of findings for the development of interventions within health services (e.g., the NHS), including how services can reduce any barriers of access for men with cancer?

6.3 Participants

Men with a diagnosis of cancer in the East of Scotland (Fife, Tayside and The Lothians) were recruited between July 2010 and February 2012. Inclusion criteria remained the same as for the questionnaire study (Chapter 4, Table 4) and included any adult male who had received a diagnosis of cancer. Similar to the questionnaire study, the interview study was predominantly interested in recruiting participants who are in post-major treatment phase. However, the interviews were interested in finding out about past and current access to support, along with barriers and facilitators. Therefore, the interview study was more flexible than the questionnaire study in the recruitment of participants, yet there remained a desire to predominantly recruit participants post-major treatment. This would allow for current perceived needs to be identified in those post-major treatment, as well as reflections on their desire for and actual support seeking earlier in their cancer journey.

6.4 Interview Questions

An interview schedule (Appendix 5) was developed based on a combination of the preliminary results of the quantitative data undertaken on a sample of 75 men in January 2010, and the growing emergent literature around men's health, particularly around help seeking. As discussed in Chapter 3, an explanatory sequential design approach to the mixed-methods research was taken. This means that the qualitative data collection and analysis follows that of the quantitative data

(Cameron 2009; Creswell, 2003; Creswell et al., 2011; Rauscher and Greenfield, 2009). Therefore, drawing on the preliminary results of the quantitative research fits this broad mixed-methods approach.

The aim of interview questions included a desire to seek information around support received, support service access, influences on help seeking and acceptance of support and factors that may better enable men to feel able to utilise support services. For example:

- Tell me about any support you've received since being diagnosed with cancer.
- Are there any reasons why you don't access support services?
- In your experience, do you think men access support to the same extent that women do?
- Are there things that could be done to help you access services more?

Additional questions were added to the schedule as the interviews developed. The additional questions were appended according to data gathered in earlier interviews. The purpose was to provide detail in key areas for exploration in relation to the overall aims of the qualitative study, ensuring that a breadth and depth of answers to each question were attained.

6.5 Procedure

As with the quantitative study, an opportunity sampling method was undertaken. This was done by asking all cancer services within the selected NHS

Scotland Health Boards, along with individuals from the voluntary sector, to enable a representative sample to be recruited.

Potential participants were identified and approached by NHS oncology staff - primarily nurses - during routine appointments, as well as by local cancer charities (e.g., Maggie's Cancer Charity Centres in the three Health Boards and MacMillan Cancer Support). Similar to the questionnaire study, staff involved in recruiting were advised to not actively recruit men at the point of diagnosis, treatment decisions or palliative care. Participants were given an information sheet with a slip to tear off and return with their details should they be interested, along with a stamped addressed envelope. They could also get in contact directly by phone or email if they wished to take part. Interested participants were then contacted and an interview arranged at a place convenient to them. This was most usually their home, a health centre or a Maggie's centre. Written consent was taken prior to starting the interview (see Appendix 6 for consent form).

The following demographic and disease characteristics were asked of participants prior to commencing the interview: age, relationship status, living arrangements, cancer(s) diagnosed, date of first diagnosis, and postcode. Cancer diagnosis was collated into the same larger categories described in methods Chapter 4. Participants' postcodes were used to gain the measures of deprivation and rurality as described in Chapter 4 (p86-87). The first name participants would like to be referred to in publications was gathered – sometimes this was their own name and other times it was a pseudonym. This flexibility allowed participants a greater degree of confidentiality (through the use of a pseudonym) should they

wish, and respects that some participants may prefer their voice to be heard by potentially being identifiable (through the use of their real name; Kaiser, 2006; Wiles et al., 2006). Ethics approval was granted from the NHS Tayside ethics committee and the University of St Andrews, which was via an amendment to the original application made for carrying out the quantitative study.

6.6 Analysis

Following transcription by the Research and Development department in NHS Fife (funding received from the Alison Scott Memorial Award, NHS Fife), analysis commenced, roughly following Braun and Clarke's (2006) six phases (as detailed below). Predominantly inductive data-driven thematic analysis was primarily undertaken, with theories and previous research drawn on to assist with articulating and organising themes (Boyatziz, 1998). Additional work was undertaken in some phases based on other literature, such as the use of memos and feedback from supervisors on themes and coded transcripts (see table 25 for a comparison of Braun and Clark's described phases and the analyses carried out in this research study). As is commonly used in thematic analysis, themes, refer to the highest-level of coding and codes refer to lower-levels of coding that are sub-categories of themes (Braun and Clark, 2006).

Phase 1: The transcripts were examined along with the corresponding audio recording. This was to re-engage with and become more familiar with the data, highlight important passages, make initial notes, check the accuracy of transcripts and ensure all required parts of the transcription were appropriately anonymised

(Saldaña, 2009; Braun & Clarke, 2006). At this point, information that could be identifiable was removed, including names of people and places referred to during the interviews (Kaiser, 2009).

Phase 2: The data were then transferred to QSR NVivo 8 in order to organise the data. The decision to use NVivo to organise the data rather than analyse the data by hand was based on the need to undertake in-depth analysis over a large number of hours, and NVivo's facilitation of efficiency in qualitative research (Auld et al., 2007; Hoover and Koweber, 2011). Initial codes were developed through reading the transcripts and developing codes in NVivo. A coding framework (Appendix 7) was developed during the process of analysis (rather than pre-developed) that included a code name, description, further details of how to 'flag' the theme from the interview transcripts, along with examples from the text (Auld et al., 2007, Boyatziz, 1998; Guest, 2013).

Phase 3: High-level themes and re-organisation of codes was undertaken and a hierarchy developed, which reflected latent and manifest content (Braun & Clarke, 2006). Any data for which there was no obvious code was initially coded as unclear data and re-visited later to explore whether it may fit into a code or theme or whether it remained separate (Guest, 2013).

Phase 4: Themes and codes were then reviewed across the interviews and in the context of the whole data set to ensure accuracy and consistency, and some were collapsed into one code or separated into multiple codes (Braun & Clarke, 2006). Themes and codes were also examined for their labels and modified to ensure they matched the sense of the theme and any relevance to theory and

existing literature (Braun & Clarke, 2006). Memos (Appendix 8 presents an example) were also kept throughout to promote analytic reflexivity (6.7.8), and particularly revisited in phase 4 of analysis (Saldaña, 2009).

Phase 5: The data were further explored for the fit of the theme names, re-defining themes, and re-organising data evidence to enable the drawing out of key findings from the data.

Phase 6: The writing and re-writing of the analysis was undertaken, to tell the story of the data relating to the themes, codes and relevant theory and evidence. Verbatim quotes were used in order to help ensure that the data were accurately represented (Corden & Sainsbury, 2006). Further discussion of the evolution of codes through the six phases of analysis are detailed in Appendix 9.

Table 25. Titles and descriptions the 6 phases of thematic analysis as described by Braun and Clark (2006) along with a description of the phases undertaken in this study

Phase titles of thematic analysis (Braun and Clark, 2006)	Description of phases taken directly from Braun and Clark (2006)	Description of phases undertaken in this analysis
1. Familiarising yourself with your data:	Transcribing data (if necessary), reading and rereading the data, noting down initial ideas.	Transcripts (transcribing undertaken by others) checked for accuracy with audio recording; re-engagement with data, initial ideas noted.
2. Generating initial codes:	Coding interesting features of the data in a systematic fashion across the entire data set,	Data transferred to NVivo, initial codes developed through examining each transcript. Coding

	collating data relevant to each code.	framework developed during process. Supervisors examined 2 transcripts along with codes; provided feedback.
3. Searching for themes:	Collating codes into potential themes, gathering all data relevant to each potential theme.	Hierarchy of codes further developed and higher-level themes identified and defined. Primarily inductive data-driven analysis undertaken (Boyatzis, 1998). Unclear data coded as such and re-visited later (Guest, 2013)
4. Reviewing themes:	Checking in the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic “map” of the analysis.	Themes/codes reviewed across all transcripts, checking accuracy/consistency. Memos revisited. Supervisors examined 2 coded transcripts which were discussed and codes further refined.
5. Defining and naming themes:	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells; generating clear definitions and names for each theme.	Codes and themes further refined to reflect the overall story of the data.
6. Producing the report:	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.	Analysis written and re-written, identifying relevant text to reflect the data, whilst reflecting on whole transcripts, themes and codes in relation to literature.

6.7 Rigour

Rigour in qualitative analysis typically includes a range of factors including a clear account of methodology and analysis of data, reflexivity and an audit trail, (Long and Johnson, 2000; Mays and Pope, 1995). Further, reliability and validity in qualitative research are too discussed and are encompassed in the broader category of rigour (Mays and Pope, 1995). It is acknowledged within the critical realist approach that it is not possible to ensure objectivity in qualitative research, nor was that the intention here. Rather, rigour aims to ensure the research is as reliable and valid as possible within the context of qualitative research. The following sub-sections detail the key areas of rigour that were considered in analysis.

6.7.1 Audit trail

The development of codes inductively throughout the analysis is an important area requiring transparency, through an audit trail. The structure of the qualitative results (Chapter 7) shows and discusses the development of codes during the inductive analysis and presents the final coding framework diagrammatically. Section 7.3.1, details clearly a comparison of initial and final codes, along with an account of how several codes evolved over the process of analysis, giving further transparency (Long and Johnson, 2000; Murphy et al., 1998).

6.7.2 Use of memos

In order to further increase analytic rigour, memos were kept, capturing key decisions, queries and questions about the data throughout analysis (Appendix 8).

These were revisited later in the analysis when reviewing themes, to promote further reflections (Koch, 1994; Long and Johnson, 2000).

6.7.3 Constant Comparison

The constant comparison method of analysis, combines coding and analysis, re-visiting whether, and how much, cases are described well by the coding framework that is developed, to eventually reach a final theory or themes following much iteration (Boeije, 2002; Glaser, 1965; Murphy et al., 1998). Although constant comparison is often discussed in relation to developing a theory (especially in grounded theory methods), it has relevance to other methods of qualitative analysis, though may not be explicitly labelled in that way (Boeije, 2002). Constant comparison was used within the broader Braun and Clark (2006) framework for thematic analysis used in this thesis. This iterative approach, described earlier, involves the development of a coding framework, simultaneous to the analysis, with both informing each other, along with comparing the findings between participants. Although there are some frameworks for undertaking constant comparison in the context of a grounded theory approach, these were not specifically taken, since they were not wholly compatible with the thematic analysis framework followed (Boeije, 2002; Braun and Clark, 2006).

6.7.4 Inter-coder reliability

When analysing qualitative research, there are mixed views in particular on inter-coder reliability (Cohen & Crabtree, 2008). Some report inter-coder reliability as useful or necessary for qualitative analysis (Boyatzis, 1998; Rust & Cooil, 1994), whilst others are more critical of this approach (Barbour, 2001). Given the inductive

nature of analysis, the assumed element of subjectivity and the expertise developed by the researcher, it was felt unrealistic to expect any inter-coder reliability tests to be high and unnecessary given the philosophical approach to the research. This falls within the critical realist approach to the whole thesis, described in Chapters 1 and 3, and earlier in this Chapter, which assumes that the analyst of data will influence the findings through their own understanding of the world and the topic discussed (Bhaksar, 2010; Maxwell, 2010; Scott, 2007). Inter-coder reliability was, therefore, not undertaken. It was, nevertheless, felt useful for supervisors to examine the data and associated codes at different points in analysis to enable discussion and refinement (Barbour, 2001). During the second phase of analysis, supervisors examined two transcripts to get a general sense of the codes emerging. These were discussed, which further enhanced the analysis. During the fourth phase, supervisors again examined two transcripts, which this time were coded. This enabled further discussion, deliberation, and refinement of codes and code names.

6.7.5 Negative cases

Attention to negative cases is a further area for consideration in analysis. Most commonly, this refers to the identification and discussion of cases that deviate from the norms found in the data (Morse et al., 2002; Murphy et al., 1998). Therefore, 'negative cases' are not considered pejorative; more, it is a way of describing examples of the variety of responses that may not represent the majority of participants' narratives. Within analyses, negative cases, where participants' narratives did not fit the themes discussed, are highlighted within the

qualitative results Chapter (7), and in the discussion. This represents ‘fair dealing’, where the data balances individual’s narratives with presenting results that are collectively robust (Murphy et al, 1998). Therefore, where themes or codes are only expressed by a very small number of individuals, they may not be representative of men with cancer on the whole, and may be expressed as a negative case, rather than fully integrated into the key findings.

6.7.6 Respondent validation

A further approach that can be used to increase rigour in analysis is respondent validation (sometimes known as member checking; Long and Johnson, 2000; Mays and Pope, 1995; Murphy et al., 1998). This most commonly involves the researcher feeding back findings to participants and gathering views on the perceived accuracy of findings. Potential difficulties with member checking arise since it relies on participants’ reading the results in detail, that they will be unbiased in their assessment, and, crucially, understand and relate to the results as representing collective findings of multiple participants, not them as an individual (Morse et al., 2002; Murphy et al., 1998). Since the final results would include the collective data from multiple participants, it was felt that member checking would not effectively increase the rigour of analysis of this work, since the collective results would not fully represent individual’s stories.

6.7.7 Triangulation

As discussed in Chapter 3, triangulation of the quantitative and qualitative research was not attempted. This is because, although some schools of thought suggest that triangulation can increase the validity of research, critiques of

this approach suggest that it is not possible to triangulate research, or that it does not contribute to validity (Cameron, 2009; Moran-Ellis et al., 2006; Murphy et al., 1998; Sale et al., 2002). Rather than attempting triangulation, and assuming a greater validity through the research, it was instead assumed that the mixed-methods approach employed enabled a breadth and depth to findings.

6.7.8 Reflexivity

As demonstrated in Chapter 7, a large amount of data were acquired from the interviews. Reflexivity is usually defined as the influence that a researcher has on the findings, acknowledging that qualitative research has an element of subjectivity (Jootun, 2009; Mays and Pope, 2000; Murphy et al., 1998). Here, I reflect on various factors that may have influenced the design and interpretation of the qualitative research, recognising that my own interpretation of ideas, concepts and the data will influence the results presented, in line with the critical realist approach discussed above (Bhaksar, 2010; Maxwell, 2010; Scott, 2007). Firstly, I was developing the interview questions and analysing the interview data as a Health Psychologist, who had worked in practice with oncology patients. This naturally helped shape the focus of questions, and influenced the analysis, both around the particular code names ascribed to data, and the interpretation of the data. Therefore, it is likely that someone from another discipline, and perhaps a Health Psychologist with purely research experience, would have developed questions and interpreted men's narratives differently. Further, my training in applied psychology will have influenced how I prompted and probed for details within men's stories. This, too, was influenced by my qualitative research training,

however, the use of reflections in particular is an approach I use in practice and was not part of my research training. Indeed, I feel this was a useful approach to help men elaborate on points. At other times, I did probe more deeply than I would or could have done had I been working with these men in applied practice. My role as a researcher both enabled me to do this, since I was there to discover, and helped facilitate men to talk about their stories, since they had entered into the conversation as willing research participants, and they saw their role to respond to questions (naturally knowing that they also were not under pressure to do so). There were times when men either did not know an answer off the top of their head, gave very short answers, or perhaps did not see the point of a question asked during the interviews. These were occasions when I asked them to elaborate. Often, this resulted in insights that I would not have achieved otherwise, nor would I have gain such insights had I been working with these patients in my role as a Health Psychologist working in practice.

The analysis was clearly shaped by my understanding of health and illness, as part of my disciplinary training. This includes the knowledge of models of illness, stress and coping, which informed the analysis and results presented in Chapter 7. Due to part of the interview questions investigating the role of masculinity, I feel that being a woman may have assisted men to open up, since there was no need to 'prove' their masculinity to another man. Similarly, being younger than all the participants meant that I could have been seen as being different to them. This may have helped facilitate them to open up, since there is no obvious 'competition' and due to the perceived differences, there is more legitimacy to the questions

asked and more detail given in answers. Men were also aware that they were speaking to a psychologist. It is possible that they did use this as an opportunity to talk in detail about things that they would not have done otherwise. Some men commented that they had not discussed some things with anyone before. As such, although I was not there to offer therapy, knowing that I was a psychologist may have increased their confidence that they would not be judged and that I may understand any difficulties that they had experienced may have also helped facilitate them opening up. Therefore, a range of factors may have influenced the development of interview questions, how I asked questions, how men responded and how I analysed the data. This is an accepted part of qualitative research and is acknowledged in the discussion as both a strength and limitation.

6.8 Summary

The semi-structured interview study aimed to elucidate from men insights into the use of support, help seeking, and the factors that affect this. Thematic analysis followed the six phases of analysis detailed by Braun and Clark (2006). Analysis included the development of a coding framework and an inductive iterative approach. The results are detailed in Chapter 7.

7. Appraisal, Coping and Support: Factors Affecting Psychosocial and Health Behaviour Outcomes in Men with Cancer

This Chapter presents the results of qualitative interviews with men with cancer, as part of the mixed-methods study. It aims to expand on the quantitative research by providing an in-depth understanding of the desire for support in men with cancer, the factors influencing this, and implications for services. The key thesis research questions that the interview study specifically addresses are:

3. What, if any, additional support do men with cancer desire for improving psychosocial issues and health behaviours?
4. What are the barriers and facilitators to men with cancer seeking support, including the influence of masculinity?
5. What are the implications of findings for the development of interventions within health services (e.g., the NHS), including how services can reduce any barriers of access for men with cancer?

7.1 Characteristics of Participants

Twenty men with cancer participated in the interviews. Table 26 shows the characteristics of the sample, which had a wide age range and representation of patients across most variables explored. Half of the participants were separated, divorced, or widowed; accordingly, the sample captured men who were less likely to have high levels of support.

Table 26. Demographic and disease characteristics of interview study

participants

Demographic or disease factor	N (unless otherwise stated)
Age at interview	Mean = 66 Range = 43-92
Relationship status	
Married/in a relationship	10
Single/Separated/divorced	7
Widower	3
Living arrangements	
Lives with wife/partner	9
Lives alone	9
Lives with another relative or children	2
Cancer diagnoses (N=> 20 due to multiple diagnoses)	
Digestive organs	3
Respiratory and intrathoracic organs	1
Skin (including non-melanoma)	3
Male genital organs	7
Urinary tract	5
Eye, brain and other parts of the CNS	2
Number of cancer diagnoses	
1	18
More than 1	2
Years since diagnosis	(range = 0.5-18 years)
0-2	9
3-5	7
More than 5	4
Palliative (self-report of non-curative/palliative treatment/aggressive cancer)	
Yes	6
No	6
Unknown	8
Deprivation¹	
Lives in 20% most deprived areas	4
Lives in 80% more affluent areas	16
Urban-rural area²	
Urban areas	12
Small towns	4
Rural areas	4

¹ Scottish Index of Multiple Deprivation ² Scottish Government Urban Rural

Classification

7.2 Evolution of themes

As discussed in Chapter 6, the iterative coding cycle enabled codes to be developed, revisited and modified as analysis deepened. This included the merging of codes, the elimination of codes and the development of new codes. A wealth of data were gained from the interviews, the key themes from which are detailed below. As discussed in the methods Chapter (6.6), a predominantly inductive thematic analysis was undertaken using Braun and Clarke's framework. In the 3rd and 4th iterative phase of analysis and re-coding, common higher-level codes were evident around appraisal of cancer, coping, and their relationship with social support.

Here, the comparison of initial to final themes and codes is detailed, with examples demonstrating the evolution of codes. Further discussion of the final themes and how they relate to the stories of individual participants will follow in section 7.6.

7.2.1 A comparison of initial and final codes

To demonstrate the comparison of the themes and codes between the initial and final coding, the top two levels of codes are presented in Table 27. The final codes are presented in column 2. The initial code that relates to the final code is presented in column 1. It is indicated where any codes included in the final model were not initially coded. In the table. Only the higher-level theme/code and first sub-codes are represented to help facilitate a succinct presentation that is aimed at being readily comprehensible.

Table 27. Demonstration of how initial themes/codes relate to the final coding framework for the two highest levels of codes

Representation of themes/codes after initial coding	Representation of themes/codes after final coding
<ul style="list-style-type: none"> • Barriers and facilitators to support <ul style="list-style-type: none"> ○ Psychological/Individual ○ Cultural ○ Environmental (Biological was not specifically coded but was captured within the broader discussions of coping) 	<ul style="list-style-type: none"> • Antecedents <ul style="list-style-type: none"> ○ Psychological/Individual ○ Social ○ Environmental ○ Biological
<ul style="list-style-type: none"> • Reactions and difficulties <ul style="list-style-type: none"> ○ Initial reactions • Barriers and facilitators to support <ul style="list-style-type: none"> ○ Past coping behaviour ○ Self-efficacy 	<ul style="list-style-type: none"> • Appraisal <ul style="list-style-type: none"> ○ Primary ○ Secondary (including past coping behaviour and self-efficacy)
<ul style="list-style-type: none"> • Coping <ul style="list-style-type: none"> ○ Emotion-focused ○ Problem-focused ○ Meaning-focused • Support <ul style="list-style-type: none"> ○ Emotional ○ Practical ○ Informational ○ Help-seeking 	<ul style="list-style-type: none"> • Coping <ul style="list-style-type: none"> ○ Emotion-focused ○ Problem-focused ○ Meaning-focused • Support <ul style="list-style-type: none"> ○ Emotional ○ Practical ○ Informational ○ Help-seeking
<p>These were not initially specifically coded. Rather, they were represented within quotes representing other themes.</p>	<ul style="list-style-type: none"> • Outcomes/adaptation <ul style="list-style-type: none"> ○ Positive or negative feelings ○ Health/illness (including health behaviours) ○ Wellbeing ○ Social Functioning
<ul style="list-style-type: none"> • Barriers and facilitators to support <ul style="list-style-type: none"> ○ Practicalities ○ Time ○ Advertising or approachability; accurate perception of service; good advertising ○ Service aligned to 	<ul style="list-style-type: none"> • Contextual factors of services <ul style="list-style-type: none"> ○ Practicalities ○ Time ○ Advertising/accessibility of services ○ Content of support

<ul style="list-style-type: none"> ○ Facilitated or structured service; informal/indirect support ○ Gatekeepers ○ Female dominated 	<ul style="list-style-type: none"> ○ Mode of support ○ Gatekeepers to support ○ Sex of professionals delivering support
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To further exemplify the development of themes/codes, several quotes are presented in Table 28 below, demonstrating the initial and final code(s) associated with that quote. Here the full code path including theme, sub-code and further sub-code is detailed. The quotes and coding patterns in Table 28 demonstrate that some codes shifted during the process of analysis to ‘belong’ to a different highest-level code/theme. For example, although anger was initially categorised under reactions and difficulties, upon re-evaluation/re-coding, it was considered to align more closely with emotion-focused coping. This is because anger is more of an active behaviour, rather than a purely a cognitive appraisal of the cancer. Some codes were initially identified as ‘barriers and facilitators’ to healthy lifestyles or to support. Although the term ‘barriers and facilitators’ did fit, it was a very broad category that lacked specificity. When re-coding, therefore, the factors represented by ‘barriers and facilitators’ were subsumed within other more specific categories (for example, ‘appraisal’ or ‘antecedents’). This provided a greater level of specificity in the coding hierarchy. Others were subsumed under other higher-level codes, or the higher-level code name changed to better reflect the sub-codes.

Table 28. Initial and final codes associated with several quotes

Quote	Initial code path	Final code path
Kyle: "I was very, very angry, really angry and I'm no different to a lot of other people I've spoken to that have been very angry [...]"	<ul style="list-style-type: none"> • Reactions and difficulties <ul style="list-style-type: none"> ○ Initial reactions <ul style="list-style-type: none"> ▪ Anger 	<ul style="list-style-type: none"> • Coping <ul style="list-style-type: none"> ○ Emotion-focused <ul style="list-style-type: none"> ▪ Anger
Chris: "[...] whereas with the fitness side of things I think, no if things get, you know, if I get too out of breath doing normal things that I never have been in the past or the weight has increased dramatically then I'll go back out and start walking and running and things like that so. That's within my control."	<ul style="list-style-type: none"> • Barriers and facilitators to healthy lifestyles <ul style="list-style-type: none"> ○ Past coping behaviour • Barriers and facilitators to healthy lifestyles <ul style="list-style-type: none"> ○ Self-efficacy 	<ul style="list-style-type: none"> • Appraisal <ul style="list-style-type: none"> ○ Secondary <ul style="list-style-type: none"> ▪ Past coping behaviour ▪ Self-efficacy
Jimmy: "I was, I used to be frightened of it at first but not now"	<ul style="list-style-type: none"> • Reactions and difficulties <ul style="list-style-type: none"> ○ Initial reactions <ul style="list-style-type: none"> ▪ Stress (in relation to cancer) 	<ul style="list-style-type: none"> • Appraisal <ul style="list-style-type: none"> ○ Primary <ul style="list-style-type: none"> ▪ Stressful
Ian1: "...it's very prevalent, this macho image em, and you don't want to show your vulnerabilities you don't want to show that you're not coping."	<ul style="list-style-type: none"> • Barriers and facilitators to support <ul style="list-style-type: none"> ○ Cultural <ul style="list-style-type: none"> ▪ Masculinity 	<ul style="list-style-type: none"> • Antecedents <ul style="list-style-type: none"> ○ Social <ul style="list-style-type: none"> ▪ Cultural template • Masculinity

An example of this is the term 'reactions and difficulties', which was later substituted with 'appraisal'. Such a substitution related to the fact that 'appraisal' represented the data better since it referred to how men interpreted the cancer diagnosis and their ability to cope with it. Similarly, 'masculinity' was initially coded

as a barrier and facilitator to support. Upon further analysis, however, masculinity could be seen to impact on appraisal and coping, in addition to help-seeking behaviour. As such, this code did not fit well under barriers and facilitators to support. The final code representation of masculinity was under cultural templates.

7.2.2 An example of an evolution of a single code

In order to demonstrate the evolution of a single code, the code 'denial' is used to demonstrate how a code can evolve (Table 29). Examples of quotes demonstrating the code 'denial' are as follows:

- Fred: “even now I still think oh they’ve got it wrong. I still wake up every morning and think oh they’re gonna phone us and say they’ve got it wrong, ken what I mean. No, I find it very hard to accept like.”
- Kyle: “The whole thing yeah. I think there’s probably a denial that well I don’t know actually probably ‘it didn’t affect me that much’ ‘I’m all right’, you know [...]”

Table 29. Phase, title and descriptions of analysis with the example of a single code, ‘denial’ and how it evolved during analysis

Phase titles of thematic analysis (Braun and Clark, 2006)	Description of phases undertaken in this analysis	Example of an evolution of a code: ‘denial’
1. Familiarising yourself with your data:	Transcripts (transcribing undertaken by others) checked for accuracy with audio recording; re-engagement with data,	N/A; no codes yet generated

	initial ideas noted.	
2. Generating initial codes:	Data transferred to NVivo, initial codes developed through examining each transcript. Coding framework developed during process. Supervisors examined transcripts along with codes, and provided feedback.	'Denial' coded as part of initial framework
3. Searching for themes:	Hierarchy of codes further developed and higher-level themes identified and defined. Primarily inductive data-driven analysis undertaken (Boyatziz, 1998). Unclear data coded as such and re-visited later (Guest, 2013)	Initially coded within the hierarchy: <ul style="list-style-type: none"> • Reactions and difficulties <ul style="list-style-type: none"> ○ Initial reactions <ul style="list-style-type: none"> ▪ Denial
4. Reviewing themes:	Themes/codes reviewed across all transcripts, checking accuracy/consistency. Memos revisited. Supervisors examined 2 coded transcripts which were discussed and codes further refined.	After further analysis, this was amended to: <ul style="list-style-type: none"> • Appraisal <ul style="list-style-type: none"> ○ Primary appraisal <ul style="list-style-type: none"> ▪ Denial
5. Defining and naming themes:	Codes and themes further refined to reflect the overall story of the data.	No further changes to 'denial'
6. Producing the report:	Analysis written and re-written, identifying relevant text to reflect the data, whilst reflecting on whole transcripts, themes and codes in relation to literature (Murphy et al., 1998)	

7.3 Key themes

This section presents the key themes emerging from the data. A comprehensive coding framework is located in Appendix 7; this details each theme, including sub-codes (sometimes known as parent and child nodes), definitions, and examples of data that represent that code. Where '[...]' appears within the text, this represents where text has been omitted from the quote presented. For example, where several sentences that do not reveal anything new are omitted to assist in providing a succinct quote. At times, words are entered in square brackets to help clarify the topic of discussion, to indicate something not apparent in the text alone, or to provide some description where parts of the text have been anonymised. Round brackets are used to indicate where sounds (e.g., laughter, sighing) appeared or where the audio recording was inaudible. Since interviews were transcribed verbatim, any miss-spellings within the interview text are due to the way individuals pronounced words. Names of participants (either their own name or a pseudonym as discussed in Chapter 6) for each quote are indicated at the beginning of the quote to clarify to whom it relates.

The key themes (highest level coding assigned) found in the data are:

1. Individual/psychological antecedents
2. Social antecedents
3. Environmental antecedents
4. Biological antecedents
5. Primary appraisal
6. Secondary appraisal

7. Emotion-focused coping
8. Problem-focused coping
9. Meaning-focused coping
10. Social support
11. Contextual factors of services
12. Outcomes/adaptation

Each of these will be discussed in turn in more detail below.

7.3.1 Psychological antecedents

A range of individual or psychological factors emerged from the interviews as being important in influencing participants' appraisal of, and coping with cancer. Psychological (along with other) factors are referred to as antecedents, since they typically occur prior to and influence the appraisal of, and coping with, cancer.

Values (and their relationship to cancer experience)

Values are defined here as the subjective importance that individuals ascribe to ideas and entities in their lives. A number of participants expressed that ideas or entities that they valued gave them a different perspective on their cancer, and supported their coping efforts. For example, as Ian1 noted:

Ian1: "Know what's important and what's not and it's not things or possessions its people and relationships [after cancer diagnosis]."

Here, Ian is suggesting that the people and relationships he previously valued came to be more salient following his cancer, encouraging further focus on these which supported his wellbeing.

Beliefs and assumptions (attitude towards methods of coping and help seeking)

Beliefs and assumptions that impacted on coping with cancer focused particularly on attitude. Attitude is a personal idea about, or evaluation of an object, person or activity, and overlaps with people's beliefs and assumptions (Wood, 2000). For example, where there are beliefs and assumptions about an object, person or activity, this can influence people's attitudes. Attitude towards engaging in methods of coping, particularly talking and seeking out help, were evidently important across many interviews. Prominent within the data was the experience that a positive attitude (based on existing beliefs and assumptions) influenced some people to engage in coping strategies (e.g. talking and accessing services):

Leonard: "Well I, at first I thought oh well am I going to gain anything by going [to the Maggie's Centre]. I thought, oh well I might go along in February and just see what it's like so I went along in February just to see what it was like."

Jim: "The only person that had mentioned it [The Maggie's Centre] was [name of nurse specialist]. Anyway this sort of switched on a wee light bulb in my head and I thought here this sounds the sort of thing that I might enjoy, because I like interacting with people [...]"

For Leonard and Jim, a positive attitude specifically towards attending support services (at the Maggie's Centres) was a factor that helped facilitate attendance.

Box 1. Brief description of the Maggie's Centres

Many participants refer to the Maggie's Centres as part of the services they have accessed. This box aims to give an overview of the Centres. More information on the charity can be found here: www.maggiescentres.org. The Maggie's Centres aim to provide practical, emotional, and social support to anyone affected by cancer. Their buildings are designed by leading architects and aim to provide a calm space for individuals to enjoy. Their ethos is that anyone can make use of the Centre at any time (within opening hours – usually Monday-Friday 9-5); people are encouraged to 'drop-in' to the centre and have a cup of tea and a chat. The layout of buildings helps facilitate this, usually having an open kitchen, communal (and sometime private) seating areas, as well as rooms and larger spaces for the classes and courses that they run. These include Tai Chi, nutrition classes, managing stress classes, art groups, and coping with life after cancer. The first Maggie's Centre was in Edinburgh, and there has been subsequent expansion throughout Scotland, the rest of the UK. Some are now based internationally. The centres are typically situated on hospital sites, which enable them to be accessible to those attending hospital. They are, however, independent of the Health Service. Everything they offer is free.

However, on occasion, beliefs and assumptions could contribute to a lack of health behaviour change:

Drew: *"I must admit in spite of all the leaflets about diet and the rest of it the cancers I have never changed my eating habits one little bit because I just felt well if I get a problem, I'll get it, if I don't, well, I'll be okay. And, and that's just it, so why should I change?"*

Drew's attitude toward health behaviour change such as changing his diet, particularly that he has never modified it previously, influenced his belief that he should not change now.

Optimism (relating to cancer)

Optimism has been described as an “individual difference variable that reflects the extent to which people hold generalized favourable expectancies for their future” (Carver et al., 2010, p879). Holding positive expectations (cognitions) about their ability to cope with cancer was typically supportive of patients' wellbeing and appeared to be influenced by a historic optimistic disposition:

Mike: *“We've [my wife and I], had similar attitude, to get on with life, make the best of it and that's what we did [when diagnosed with cancer]. I would say I've always been that way [...].”*

Robert: *“Just my own self and thinking positive and eh not necessarily being frightened of something like that [cancer].”*

It is likely that being of an optimistic disposition in general assisted participants to experience optimism in relation to their cancer and ability to cope.

Introversion/extraversion

The personality traits of introversion and extraversion were influential in peoples' utilisation of certain coping methods, particularly help seeking through support services:

Robert: *"With feeling that that's a, adequate and I'm not the type to venture out to meetings and things with loads of people that have got psychiatric problems or cancer problems or what whatever [...]"*

John: *"Pff, that's a, I don't honesty think [that anything has influenced lack of support seeking] so but probably if I was probably, oh god how would you describe, say that there was, intro, introverted, not an outgoing person"*

Therefore, John and Robert who either implicitly (Robert referring to himself as not the 'type' to venture out), or explicitly identified as introverted, were disinclined from engaging with services that involved other people, regardless of the focus of the meetings/support. This appeared to be a key factor in influencing participants' desire to not engage with such services and was always related to help seeking in participants' narratives.

7.3.2 Social/cultural antecedents

A range of themes relating to social and cultural antecedents/factors influenced appraisal of, and coping with, cancer. These are described below.

Socio-economic status

Difficulties relating to socio-economic status could lead to added pressures on the experience of cancer for a number of men, such as Ian1:

Ian1: *"I was homeless for a short time I was then declared bankrupt and I then had cancer [...]."*

Fred: *"I've got a pension, but I'm struggling and it stops me getting other benefits and people go oh you'll get this and you'll get that, but no me."*

Financial difficulties impacted on experiences of cancer for some participants and had a knock on effect around their ability to cope with cancer. This highlights how factors not related to cancer can be significant in influencing an individual's experience.

Ideas about masculinity (cultural templates)

Of particular prominence within the antecedents were British cultural templates (i.e., commonly shared ideas in society), which played a part in shaping men's appraisal and coping with cancer. The predominant cultural factor discussed by men as affecting their appraisal of, and coping with, cancer was common cultural ideas about masculinity. This was discussed by over half of men

interviewed and included the notion that men and women are different in their approach to utilising coping methods, such as talking and asking for further help:

Ian2: *"I would think [men] probably less so than women would [access services], em, women tend to be a more social animal than us men you know."*

John: *"I think, em on my side, obviously my side I haven't needed it but I think men tend to hide things a, a lot more than women eh, ladies are always together, ladies like to have a chit chat over coffee whatever you know even with problems, you know. It's sort of I don't know if it's a ladies social thing, whatever problems you've got with kids, husbands, whatever the case may be I think they all seem to want to be together. Men: 'how are you doing today Jim?' 'Fine', okay then. You know that's it, you know more that the men possibly, I don't know if that's what you call a macho image that men have, I'm fine, I don't need any help, maybe some do maybe some don't."*

Ian1: *"I suppose the first thing that might happen they don't want to show themselves vulnerable to a man so it's a, we're a complicated breed. We really are. Cos women are obviously much more eh kind of forward thinking and will go out and seek support and even support from their friends and their peer groups where men just don't so yeah it's probably seen more that women will do it."*

Fred: *“They’re [men] scared of showing their emotion, they’re no as confident as they make oot ken they’re no in an environment where it’s, a lot of men that I meet go to the pub a couple of days at the weekend and that’s their environment, their enjoyment or go to the football or, something.”*

Commonly discussed in the above quotes is an assumption that men find it more difficult than women to communicate, and that there is a pressure on men to avoid showing their feelings in order to maintain a particular image of masculinity. However, one person felt that the distinction between men and women was not so well defined:

Rom: *“I don’t know, um quite candidly I, um, I can imagine quite a lot of men don’t communicate on it, but and women, women I wouldn’t know, women are a law unto themselves. There are so many women who are women’s women and there are women who are very tough guys in themselves so I just don’t know really. I would’ve thought women in some cases are more able to cope with this than men.”*

Some participants rationalised discussion of emotions by reaffirming that they were men and that they had negotiated that crying was an acceptable masculine action:

Fred: *“A lot of men as well ken the culture, you dinnae speak about your problems, you dinnae dae this, that’s wi a lot of men. I mean I was, I was a bit like, ken I’m a*

man's man type thing ken, never show emotion and stuff like that ken, but I tell people I ken a guy, I use to go to school wi him and he's no well and I says look you dinnae have to go doon there and burst into tears, there's nothing to stop you from speaking to them. I says if you burst into tears they're no going to think anything less of you because he sits there day efter day and he's gave up and I'm like dinnae gie up. I think a lot of men are scared of showing their emotions, that's what it is."

Consequently, there are factors (for example acceptability of crying) that challenge men's ideas about masculinity, sometimes so much that it may stop them being able to do something to help their rehabilitation. For others, they can re-negotiate the masculinity ideal and still engage with a helpful coping strategy, such as showing emotion to others in order to receive support.

Ideas about age and generation (cultural templates)

Age and generational factors, within the higher-level theme of cultural templates, were perceived to impact on the desire to utilise talking or seeking help. Similar to the discourse on masculinity, in keeping with the critical realist approach to this research, age and generation are discussed in terms of people's 'ideas about age' and 'ideas about generation', which are of course also influenced by wider social and cultural factors, as well as actual bodily experience. Thus, it is people's ideas rather than a concrete concept of age or generation that is

influential in coping. Exemplified in the quote from Mike are the linkages between ideas about generation and cultural norms about the roles of women and men:

Mike: *"It's a generational thing too, I think, I'd like to think that my generation were maybe a bit more amenable and happy to (inaudible). My father died of cancer, eh; he would never discuss things with mother. And neither would my grandfather, it was just women were at home to look after the kids, look after the house and we went out to work."* Mike

Harry specifically discusses the idea that historically cancer wasn't spoken about, and that, generally, people can be more open about cancer now:

Harry: *"I mean years ago the Big C you never spoke about the Big C you ken it was kept under the carpet sort of thing you know but noo it's, folks open and talking about it you know."*

Being of an older age was also perceived to impact on coping and therefore a reduced need to access services:

Rom: *"No, no not at all no. I'm quite, em as far as I'm concerned and I think probably it's an age thing. If I were thirty-two or forty-two instead of ninety-two I would probably approach it differently, but as far as I'm concerned I think I'm jolly*

lucky to have got to where I have got age-wise and so you know pinprick things which I might latch on to.”

Age also may have influenced service access since some services either were not set up for people of certain ages (younger adults) or that services were dominated by older men:

Fred: “The thing I found as well was age. See for when you’re sort of younger and you’re ill there’s no a lot out there, there’s no a lot of, see most the guys that go to [palliative care unit] and that they’re all older ken. There’s only there’s no many gets things like this ken what I mean, there is nothing. I would say if you’re no well between the ages of sort of 20 and 50 there’s no a lot there ken [...] it’s like sitting with your dad and all his mates, ken what I mean, they’re like that” Fred

Social network

Having a good social network made up of friends and family could be supportive to men with cancer, both through the provision of social support, and network members supporting them to access other services. A network may be facilitative of social support, though social support can be provided through a range of professional and non-professional sources, hence their distinction:

Interviewer: “And being a man yourself have you got any ideas as to how what can help men overcome that [low utilisation of services by men]?”

Bill 1: *“I mean let’s face it half the men that come to Maggie’s their wives are pushing, pushing, pushing, they don’t come of their own free will.”*

David: *“I was just travelling every day which kind of took it out of you, but luckily friends and neighbours they took a turn.”*

Support given by participants’ social networks, which included partners as well as wider network of friends and neighbours, enabled men to access services and facilitated practical support, positively impacting on their wellbeing.

7.3.3 Environmental antecedents

A range of factors relating to the environment or situation impacted on men’s experience of cancer, in particular their appraisal of cancer.

Situational variables

Often participants were experiencing other events that added to the difficulties of coping with cancer. This has some overlap with socio-economic status, since participants’ financial difficulties were often triggered by other situations and/or were exacerbated by having cancer and being unable to work. Situational variables were often related to the death of significant others, either before or after a cancer diagnosis:

Bill1: *"I'm still here but since my wife died I've become even more complacent. I used to think that life was everything and I don't think life is everything, I think that marriage is everything. And since my wife died I've sort of gone down."*

Timing (of the cancer diagnosis)

The timing of receiving a cancer diagnosis was particularly problematic for a number of people who had other difficult experiences affecting them at the time, which again has links to situational variables and socio-economic status and the quote below exemplifies:

Ian1: "I had a whole load of things going on in my life at the time em, that all sort of, I'd separated from my wife em, I was homeless for a short time I was then declared bankrupt and I then had cancer all within a 6 month period."

Therefore, the timing of a diagnosis can be particularly impactful when significant other events are occurring. The relevance of the quote above also exemplifies that there can be blurred boundaries between themes, since elements of this represent the theme of socio-economic status. The quote above specifically reflects the timing of cancer, on top of relevant difficulties around relationships and socio-economic status.

Ambiguity

Ambiguity or uncertainty relating to participants' situations and diagnoses seemed to add to the stress they felt relating to having cancer:

Mike: *"As I was told, the, eh, what the future is full of ifs and buts, and I could understand that, nobody can, nobody has an x-ray vision not could they predict the future so until they'd carried out the tests that they had in the programme, they couldn't give me an answer so it was pointless me asking the question before there was a need to."*

Clark: *"I don't know whether I've got 6 months or 5 years or 10 years and it could be any of them; I don't like the uncertainty of it em."*

In the cancer context where ambiguity can remain for some patients for the rest of their lives, this can significantly impact their quality of life and ability to cope with having cancer.

Social and material resources

Having resources to support men in their experiences with cancer, whether these be concrete or something less tangible, relieved some of the difficulties experienced (which links to social support):

Jim: *"So my brother was supportive that way in that he brought my wife down one night and his wife drove his car home and he took my car home, and it's amazing that in the depths of this physical unwellness it was good to know that my car had been taken home, so I think that these wee practical things can be very helpful as well [...]"*

Where individual patients lack resources that may support some of their cancer-related difficulties, it may make living with cancer particularly challenging for them.

7.3.4 Cancer-specific antecedents (biological)

In the context of this research, biological antecedents were always related to cancer diagnosis, treatment, and side-effects. Disease status factors were influential in how people employed coping strategies; with some participants only feeling that they would ask for support if their condition or prognosis was worse. The influence of side effects was also important.

Rom: *"Ah well it [formal support] would only appeal to me I think if circumstances [specific diagnosis and prognosis] altered so much I thought, I might think well I wonder how so and so or this person or that person gets along with it and they might be able to tell me how they get round it, but at the moment [...] I don't need any kind of help in that way [...]"*

John: *“Em, I think maybe we had a look at it [Maggie’s centre] when they first, first opened up, em my wife was still alive at the time, yeah she was. So went and had wee look inside but eh but it was nice, new. The folk were obviously make you, you know very welcome. But I have so far not had any reason to ask for help.”*

For Rom and John, their cancer diagnosis was not severe enough to be impacting significantly on their lives. As a result, they felt no need to seek further support. For others, particular symptoms and side effects evidently affected their appraisal of cancer:

Fred: *“No, I find it very hard to accept like, people’s perception of cancer I think 99% of people just think well that’s it then ken, you get a tumour and well that’s it, I do self-catheterisation for my bowel and my bladder and that takes a long time to get my head round then ken [...]”*

Sometimes, utilising certain coping strategies enabled them to experience better wellbeing in spite of the limitations imposed by particular biological aspects of their condition:

David: *“Yeah, aye cos I read, I’m going through books like nothing on earth. I just read quite a lot now, just to pass the time cos it does get a bit frustrating at times, not being able to do things cos I do some things [...]”*

The biological consequences of having cancer were, therefore, significant for Fred and David, and could result in psychological challenges. However, they found ways of adapting, to an extent, to their specific challenges.

7.3.5 Appraisal of cancer diagnosis

Appraisal of cancer is the interpretation of a stressor (in this case a cancer diagnosis) as threatening or non-threatening (primary appraisal), and appraisal of one's ability to cope with the stressor (secondary appraisal; Lazarus & Folkman, 1984). This was revealed through the stories of diagnoses that most participants chose to tell at the start of the interviews. It was evident that cancer was mostly perceived as a stressor and a number of sub-themes within primary and secondary appraisal emerged as follows:

(Appraisal of the experience as) Stressful (primary appraisal)

For many, a cancer diagnosis was appraised as a stressful event, which is perhaps influenced by common ideas in society about what it means to have cancer:

Fred: *"I got diagnosed on the Friday, operated on the Monday and my life had totally changed. It was upside down it wasnae, I didnae even have a clue I had cancer."*

Ian2: *“When I was first diagnosed, well your mind just sort of goes: boom! Boom! Boom!”*

The initial cancer diagnosis often left participants in a state of shock or numbness, prior to any psychological adjustments that they subsequently made.

(Appraisal of the experience as) Manageable (primary appraisal)

A minority of individuals indicated that it was not a huge shock or difficulty getting a diagnosis of cancer, discussing it pragmatically and suggesting that although it may have been stressful, it was manageable:

Ian2: *“I’ve sort of dealt with cancer in the family before – my mother and father they both died of cancer so, it wasn’t a word that frightened me really”*

The quote above shows that sometimes past experiences may assist in enabling people to appraise cancer as manageable. The other factors that was protective against participants’ perceiving that cancer was a threat was a lack of severity of disease status and the type of treatment required:

Chris: *“Again, I didn’t, em I’m trying to think back. It didn’t really strike me as being all shock and awe, it was just sort of well this is what it was, it was a, a mole there that had to be removed and then tested, it came back positive. It was just like following a process and I’ve been used to that all my life.”*

It, therefore, appears that the specific diagnosis and an understanding or experience of cancer were key factors in influencing some individuals to appraise cancer as manageable.

(Appraisal of the experience as) Fearful (primary appraisal)

Being fearful of cancer and particularly of its consequences were evidently factors that can result from a cancer diagnosis:

Jimmy: *"I was, I used to be frightened of it at first but not now"*

Leonard: *"Some of it was a wee bit frightening but eh I was just concentrating on the treatment that I was getting so that seems to be alright and I think it's quite eh."*

Although fear may be experienced by some, typically this reduced over time as men developed increased understanding of their specific cancer and associated treatments. This led to a shift towards them feeling that their cancer was more manageable than originally perceived.

Denial (of the diagnosis; primary appraisal)

Since a cancer diagnosis often came as a shock to participants, this led to denial for some people in relation to their diagnosis:

Fred: *“Even now I still think oh they’ve got it wrong. I still wake up every morning and think oh they’re gonna phone us and say they’ve got it wrong, ken [you know] what I mean No, I find it very hard to accept like.”*

Mike: *“And when I was asked, em, had I any questions, me in my old insensitive way said “yes will I still be able to sing?” you know and my wife was in tears, the chap, the young doctor even he was emotional. And I thought Oh what a plonker you know it was me just, and later on I thought, was that just me dealing with that question, that diagnosis. I’ve often wondered if it was that psychologically I came out with that because I didn’t feel emotional and all the way home.”*

For Mike, denial appeared to be part of the process of diagnosis. Yet, for Fred, denial was still experienced years after diagnosis. This impacted his psychological health, through a difficulty in accepting his diagnosis and prognosis.

Fatalistic (attitudes towards cancer; primary appraisal)

For some, fear went further and could be described as fatalistic, with some participants appraising their diagnosis as a death sentence:

Leonard: *“Well the first day I was diagnosed that was in the morning eh, in the afternoon I went up and got the price of cremation you know I was that, the way my brain was going round and then within a week or so I made a will [...]”*

Clark: *“Yeah I to start with em no not very easily em I went through that whole panicking that people go through of Hell I’ve got cancer I’m going to die.”*

Most commonly, the fatalistic appraisal was concentrated at the time of diagnosis, and reduced once participants’ understood more about their likely prognoses (even if these remained ambiguous).

Controllability (primary appraisal)

Many spoke of cancer as being out of their control, perhaps understandably given that this was an illness that they were experiencing and did not have the expertise themselves to treat:

Clark: *“I’m quite a black and white person and I em operate better in knowing the facts the uncertainty of is it a month is it 5 years is it 10 years doesn’t sit well with me.”*

Leonard, however, expressed that once he understood the prostate cancer markers and test results, he felt more in control:

Leonard: *“I mean whatever the PSA reading is or if they think it’s getting worse the consultant sees it and then decides because I got a letter once when the PSA was going up eh to take another tablet, so I got that and then the PSA came down a bit.*

But it's rising just a wee bit now but I go again next week for another injection so everything's more or less under control you know."

This suggests that the specific cancer context and treatments may influence the perceived controllability, even if this stems from medical intervention. This is perhaps in addition to individual factors around what it means to be in control or not in control.

Self-efficacy (secondary appraisal)

Self-efficacy is defined as a belief in one's ability to undertake a task (Bandura, 1977). In the context of this thesis, self-efficacy refers to the belief by participants that they can engage in activities to help them cope with having cancer. This was evident within the interviews:

Bill1: "Aye, I took up gliding when I was 60, flying an aircraft without an engine and I was pushing and pulling gliders across the airfield and what not, and to have a sort of, an iron curtain put down, 'Oh ye won't be able to do this, you won't be able to do that, you won't be able to do the next thing' [...] And yet I felt within myself yes I can [keep active around the ward]."

In some circumstances like for Bill1, his self-efficacy had to be strong to counter the perceptions by health care professionals about his ability to keep active

in hospital. This supported him to engage in helpful coping strategies and have better physical health and recovery.

Past coping behaviour (secondary appraisal)

Past coping behaviour, voiced by a number of men, suggested it was influential in appraising their ability to utilise helpful methods of coping with cancer, including through help seeking and engagement in health behaviours:

Kyle: "I really needed somebody to talk to. And that was the start of it. But I've done this kind of thing before, I went to counselling for a while there for about six months or so and that helped, just to get talking about it and trying to come to terms with it"

Chris: "If I get too out of breath doing normal things that I never have been in the past or the weight has increased dramatically then I'll go back out and start walking and running and things like that"

Past coping behaviour may also be linked to self-efficacy, since where men had previously engaged in helpful coping strategies, this may have increased their self-efficacy for engaging in this strategy again.

7.3.6 Coping

Coping represents the strategies or behaviours that people adopt in response to their primary and secondary appraisals of cancer (Carver et al., 1989; Lazarus, 1966). In the literature, these are typically divided into emotion- problem- and meaning-focused coping strategies; these were evident in the interviews too (Glanz, 2008; Park, 2005). Emotion-focused strategies define coping strategies that may include venting feelings, avoiding emotions (which may be related to denial) and social support. Problem-focused coping includes active coping (a behaviour), problem solving, and information seeking. Meaning-focused coping involves utilising religion, spirituality, or a broader acceptance and finding meaning to support coping efforts. The first group of strategies described here utilise emotion-focused coping.

Distraction (emotion-focused coping)

Several men used distraction as a way to help them manage their diagnosis and feelings associated with it:

Fred: "Maggie's Centre is great for support and for trying to keep you busy, trying to keep your mind active ken. Just: and they're good I ken I can go in there any day. Somewhere like the Maggie Centre is a good place to go and forget about it."

One person spoke of how they've "kept myself busy and kept you know not really needing any support" (John). Therefore, by using coping strategies helpful to

them, participants were better able to feel supported. Alternatively, they felt that they did not need further support to manage any difficult feelings associated with their diagnosis.

Anger (emotion-focused coping)

Several people spoke of experiencing anger which was sometimes uncontrollable. Some described having moved past this, while others appeared to be holding onto some of that anger in ways that could be unhelpful:

David: *“Cos it does get a bit frustrating at times, not being able to do things, cos I do some things then I start getting tired then I start shaking and things like that so it kind of, make you, grrr, I’m no saying angry, just kind of aggravated”*

Kyle: *“I was very, very angry, really angry and I’m no different to a lot of other people I’ve spoken to that have been very angry, but then you have this thing of why me and all this and it’s quite normal you know.”*

Clark: *“But there are times that it just it feels like I’m not in control I’m completely gone I’m, I’m and then I somehow come out of it and I’m like - God! Shouting and screaming and swearing like a complete arse hole [...]”*

Anger was, consequently, part of coping for some men with cancer. Anger was sometimes experienced and acted upon more at the time of diagnosis. For others, it was experienced periodically.

Relaxation (emotion-focused coping)

A number of people found ways to relax that helped them cope with the uncertainties and loss of control due to a diagnosis of cancer:

Mike: *“There was, if I felt down which I did on a number of occasions I would excuse myself, go upstairs and I was very fortunate I would apply self-hypnosis, for about 30 years I studied martial arts and stuff and it gave me that insight. I can calm myself down [...]”*

Fred: *“Like I say they’re good for that and the Maggie Centre are good for, what I liked about it, it was a good place to go and relax in their room up the stair you could just sit up there, it was good for that.”*

Ian2: *“Em, well you tend to deal with sort of things that bother you when you go fishing and you sit down on the bank out there in the wide open spaces and the trees and the birds and everything; a way of relaxing and you know relax your mind and relax your body too and concentrate on catching these fish. I would recommend fishing to anybody that’s bothered by [trails off].”*

Relaxation took a different form for each participant, however the common theme was that they did something that facilitated them to relax and, as a result, cope better with having cancer.

Talking (emotion-focused coping)

Talking to others enabled respondents to express their emotions. It may also be considered a form of social support, both about cancer and other things, and was seen by men predominantly as a positive way of coping with cancer:

Bill1: *“Oh one of, my ulterior motives in coming here [Maggie’s Centre] is to get someone to talk to, it doesn’t matter about what.”*

The diagnosis may legitimise men talking to others, when they may not have done previously:

Harry: *“[...] whenever you go in if they’re not engaged with somebody they sit and blether to you, you know, they get a cup of coffee for you if you want a cup of coffee and they’ll sit and blether to you. Then you maybe get someone else coming in and they sit and blether tae you, you know, you dinnae ken them fae Adam but it disnae matter they’re needing somebody to speak to. I’d no inhibitions or anything you know, normally before this carry on I’d never have dreamt tae talking to a stranger the way I’ve been talking to you aboot doon here, no way you know but, I don’t know Maggie’s just makes you alright, you know?”*

Turning to alcohol or cigarettes (emotion-focused coping)

Turning to alcohol and cigarettes supported two men to cope with their difficult emotions:

Robert: *“But it’s been a wee bit of a co comfort having a fag. You know it’s eh it relieves boredom as such and I know if you’ve never smoked you would never miss it because you’ve never had it to miss.”*

Rom: *“But if you’ve got cancer there is just the thought oh well you know I’ll take a chance. Maybe there’s something there, I just don’t, it’s, I think terribly easy to uh, not only have a drink with cancer, but also to seek solace in having a drink with cancer (laughs) it’s only an excuse [...]”*

Having cancer may have helped justify engagement with current and future unhealthy behaviours, since the difficulties experienced from having cancer meant that there could be more reason to engage in drinking or smoking to support coping.

Humour (emotion-focused coping)

The use of humour was implicitly evident in several interviews, both within the discourse in interviews and participants’ accounts of how they cope with cancer and treatments:

Mike: *“My family and friends, they would have to deal with the, my loss you know it would have been a big loss but (laughs).”*

Drew: *“I’ve been told I can either wear a pouch for the rest of my life or die so I thought bugger it I’ll wear a pouch and that’s it and my sons they say do you think about it if you wanted when you were emptying it you could put water in it mix it all up put it in bottles instead of baby bio. You’d have baby (inaudible) sell it in the shops (laughs). Fertilizer. (laughs)”*

Humour seemed to ease the difficulties of having cancer and the associated side effects or treatments. At times, it was utilised and supported by friends and family, and thus was not just a coping strategy for participants but also for their close ones.

Dissonance (emotion-focused coping)

Dissonance typically refers to when a person holds two or more opposing beliefs or values. The difficulty reconciling these, leads to people behaving in a way consistent with one belief or value and often discounting, or minimising the other (Festinger, 1962). Dissonance was evident both in terms of participants’ ideas about what caused their cancer and what they could do to improve their lifestyle. It enabled them to regulate their emotions and perhaps to avoid any self-blame. Participants’ explanations or ideas about what could have caused their cancer

were sometimes risk factors that were minimised or discredited by themselves, perhaps helping them to cope with their cancer:

Gary: "I havenae stopped smoking which I should have; I've cut down. But you'll think I'm daft, but I've got this wee thing here, I used to take sweetex instead of sugar. I took it for three or four years and I remember hearing that there was a thing about it could cause cancer so I got that stuck in my head that that's what caused it, it's no the fags so that's probably me just saying, trying to blame something else, it's no the alcohol or the cigarettes it's that bloody Sweetex you know so that's how I think [...] Another part of the reason I don't stop smoking is I'm scared that I'll put on loads of weight so [...]"

When asked about lifestyle change, there was often a focus on smoking and alcohol, particularly for those who considered that they did not smoke or drink to excess. Participants, therefore, projected an internal impression that they were healthy because of avoiding drinking and smoking and avoided discussion of exercise and diet. This dissonance may be a further way of coping with any potential lifestyle contribution to their cancer, whilst also acting as additional barrier around areas where change could be beneficial:

Interviewer: "I was just saying about services that might help you improve your health like smoking, diet, exercise, alcohol"

David: "Eh, I don't know I've never, well I don't smoke, I drink, but I don't drink to excess."

Interviewer: "And in addition to those there's sometimes services available to help people in view of their health like around stopping smoking, reducing alcohol intake, healthy eating and exercise, how would you feel about going to one of those services if someone suggested it?"

Bill2: "No, I don't drink and I don't smoke so, (laughs), no I don't drink and I don't smoke. Aye, that's about everything I think."

The seven coping-focused approaches utilised above all fall into the broader category of emotion-focused coping.

In addition, a range of problem-focused coping methods were utilised, and typically are practical ways of coping with a stressor. These are detailed as follows.

(Engaging in) Enjoyable activities (problem-focused coping)

Engagement with enjoyable activities was an active and direct problem-focused coping that some men utilised:

Robert: "I'm getting invited to parties and things you know eh, I play the gui, the gui, the guitar and that so there's a party coming up with a friend of mine eh whose

step-daughter is having a birthday party and there's a live band that they're hiring the whole pub for them so they want me to come to that, so that's all a boost for you to think positive eh..."

Bill2: "No I like, I play the accordion, I've got a key accordion and I sit through there in the bedroom and play it at night you know, maybe once a week, sometimes twice a week you know I go through for about half an hour and sit and play that and that keeps me happy"

Enjoyable activities were usually engaged with prior to men having cancer. Continuation or re-engagement with activities that brought them pleasure was one of the important ways that participants coped with having cancer.

Problem solving (problem-focused coping)

Seeing aspects of cancer and its treatment as controllable enabled some participants to solve difficulties they may be facing within the cancer journey. Equally, some people utilised methods of solving problems to help them see their cancer as more controllable:

Mike: "Now in my profession again I was, when I look upon job I had, I used what was sequential organisation, stick it into the box, deal with the box, don't move to the next one until you've completed that. Everything was combated with medication as long as I stuck to the medication and the order of the sequence, I had it fixed in

my mind, right that's day 1, that's day 2, that's 3, that's day 4, only another couple of days to go and I got it down to 5 days."

Chris: *"It was just like following a process and I've been used to that all my life. So they says right it's positive and we'll have to remove it, right okay and through the dyes and nuclear stuff they done it had traced so that they went for the lymph nodes and so."*

Similar to some of the coping strategies discussed above, problem solving was usually utilised in the same way that participants had done prior to having cancer. The strategies were simply adapted to having cancer and the particular related challenges.

Information seeking (problem-focused coping)

Several participants found that seeking out and using information was a helpful way of understanding more and therefore coping with their diagnosis:

Leonard: *"I got some information from the specialist nurse and some information from Maggie's and eh that helped. Well I think mainly, going to the group and talking to people that had had the experience of cancer and reading more information on it and as I said eh realising that it wasn't as dangerous as some of the other cancers, you know once I sort of calmed down a bit and after a few months I didn't feel any worse."*

Drew: *“But while I thought that I wasn’t prepared to read the bad things but you do read things that does stick in your mind and if you get the leaflets, more books, leaflets then you could look at them and you could make up your mind whether [opens leaflet] oh it says if you’ve got a stoma don’t eat orange pips, oh I’ll remember that.”*

Information was supportive of participants gaining more realistic, and sometimes less fatalistic perspectives on their particular diagnosis. It was also informative and supported them to make helpful choices in relation to managing their treatment and side effects.

The last broad theme around coping with cancer was meaning-based coping, ranging from a re-interpretation of the ‘threat’ of cancer through religious and spiritual coping methods to acceptance methods.

Spiritual/religious coping (meaning-focused coping)

Participants who stated that they were religious, as well as those who did not, found ways of coping that were grounded in ideas about religion and spirituality:

Mike: *“I have a very strong faith, there is a superior being looking after us on this earth and I’ve had that faith for many, many years.”*

Interviewer: "And what difference do you think that's made to you?"

Mike: "A whole massive difference, I know that there's, I can, there's many things going in, in the world that are much worse than the trauma that I experienced."

Ian2: "I'm not religious and I just feel you know if it's your time to go it's your time to go and there's nothing much you can do about it"

As is commonly discussed in the literature, spirituality goes beyond religion, for example, to encompass more general ideas around life and death; spirituality can, though, can be encompassed within religious coping at times (McSherry & Draper, 1998)

Acceptance (meaning-focused coping)

Some men discussed their ability to accept a diagnosis of cancer, symptoms or treatments, which sometimes seemed to develop after some time:

Mike: "As I was told, the, eh, what the future is full of ifs and buts, and I could understand that, nobody can, nobody has an x-ray vision not could they predict the future so until they'd carried out the tests that they had in the programme, they couldn't give me an answer so it was pointless me asking the question before there was a need to. And that's how I went through it."

Bruce: *“And this thing this cancer that I have it doesn’t really upset me any. I can’t say I like it; whatever happens is inevitable, what will happen and I’m not unduly worried about what’s going to happen.”*

Such reflections contrast with the denial and stress of cancer that was so often initially experienced. Through engaging with a process of acceptance, participants were supported to feel that they could cope better, even in adversity and uncertainty.

Finding purpose/meaning (meaning-focused coping)

The importance in developing and maintaining a purpose in life was sometimes evident:

Clark: *“Em so it’s better I think for all that I do what I want to do which is just take my time, I can still do some things I can do voluntary work and things like that em and still have a purpose in life. I might go back to university next year not for a not for any learning to do with the job just for learning to do with something that I want to do”.*

Through seeking out new interests and re-engaging with existing ones, participants were enabled to re-evaluate their priorities (which links to ‘values’ discussed earlier).

7.3.7 Social support

Receiving support from others was influential in helping to buffer the effects of cancer as a stressor, and help support men with cancer to engage in coping strategies, including help-seeking behaviour, along with improving their lifestyle (Kessler et al., 1995). Although social support may function as a coping strategy for cancer-related challenges, it is conceptualised as distinct enough to warrant its own theme. This is because support is a very specific factor that may buffer the effects of stressful events, and relies on relationships between people (Coyne & Downey, 1991). Social support was also facilitative of men utilising other coping strategies, so fed into how they coped with cancer in general. Discussion of social support fitted easily into the commonly known categories of emotional, practical, and informational support, along with help-seeking.

Emotional support

Emotional support typically involved a supportive empathetic environment that enabled the participants to feel supported:

Mike: “[name of friend] and I sat down and we shared eh feelings on it and em we’ve a had similar attitude, to get on with life, make the best of it and that’s what we did and that’s what [name of friend] certainly did eh, and up until the week before he passed away in fact 2 days before he passed away eh he was still sitting down having a cigarette and eh joking.”

When this type of support was received, it enabled an emotional connection, often involved empathy and resulted in improved psychological health and wellbeing among participants.

Practical support

Practical support centered on others doing something physical for the participants:

Robert: *“The the woman that does my cleaning and that, I’m getting my vegetables every day beautifully cooked food, she’s a basic ordinary rough and tough type of fe, female oh aye she is but she’s got a heart of gold once you get to know her and she’s making sure I’m getting fed well and I’m happy with that.”*

Harry: *“She said eh, have you ever thought to go to Macmillan’s, eh no Macmillan’s, Maggie’s, I says No, she says weel if ye like I’ll go wi ye, you an um on Wednesday night. I says fine so, took us up and I met eh the woman that runs it, I canny mind her name; when my daughter took me, that was, I wouldnae have went myself I don’t think.”*

Due to the physical limitations of cancer, practical support was invaluable. For Harry, this practical support was facilitative of further emotional support.

Informational support

Receiving information from others was a further way that a minority of men with cancer felt supported. Sometimes this was actively sought, and other times it was provided in regular appointments:

Fred: *"I got a lot of, see Macmillan Welfare they're great for money advice and for welfare advice and filling in forms and stuff [...]"*

Help seeking

Help seeking featured in many of the interviews, with most people valuing the help that was available to them, and that they could (and did) seek help on occasions. This was from a range of sources, such as family and friends:

David: *"Em then if I did have any problems well I had their phone numbers, I could phone up and they arranged whether to see Dr [name of doctor] or whether it was worthwhile seeing her or just changing my medication or something like that."*

Jimmy: *"Eh and [name of worker] comes in when I phone him. He just sits and talks to you; after we had this oper this blether in the hospital I don't know I just felt uplifted kind of thing just I felt a lot lot better."*

The availability of support when it was desired was a key feature in the above quotes.

7.3.8 Contextual factors of services

A range of contextual factors were key themes that were more external to the individual experience of cancer, which influenced men's decisions around whether or not to access services.

Practicalities

Practicalities around getting to services, including their location, impacted on the ability of men to utilise these as a coping method:

David: *"I think probably if it had been closer at hand I might've used it, but it's just that it's so far away you know, it's an hour and a quarter or an hour and a half depending on the times and you know, I believe it could have been. I probably would've used it if it had been closer to hand, but em."*

Ian2: *"I suppose it would be handier if it was nearer my home, or in the Medical Centre at [name of area] something like that, but em even if it was just round the corner from me the chances of me going would probably be quite slim"*

This may be an important consideration in the development and delivery of services; ensuring that services are not too impractical for patients to access.

Time

Time was both a barrier and facilitator to accessing support:

John: *“Being honest I actually haven’t really gone for any support em, I, I’ve found my life has, I’ve been busy enough during my life as it is. So, in some respects I’ve probably kept myself busy and kept you know not really needing any support”*

Leonard: *“Yes, I go there on the Wednesday and Thursday for the Tai Chi, there’s nothing else better to do sort of thing, so I, I find that if I keep myself occupied you know it’s not so bad you’re not sitting in the house sort of thinking about it.”*

Leonard describes how having time enabled to utilisation of some coping strategies, which ties into themes of ‘distraction’ and ‘enjoyable activities’ explained above.

Advertising/accessibility of services

Sometimes there were difficulties in participants accessing services to rehabilitate after oncology treatment and improve their lifestyle:

Bill1: *“Aye, so I went to my doc and I said ‘if they won’t let me in the gym, if they won’t let me in the pool, there’s nothing there’s no arrangements made for people who have had the operation to get them back their life really’ I said ‘ I am stagnating’ [...] And eh that’s when I started thinking about stamina and things like that, but I’m disappointed that convalescing at the [name of hospital], there was no, no physiotherapy, whatsoever.”*

The participants' preconceptions about both psychosocial support and services to improve lifestyle behaviours also influenced their views about accessing services:

Drew: "I don't, I don't think, I don't know but eh aye as I say I possibly people that have, it's impressions, what people's impressions are, now just Maggie's in [name of town], an awful lot of people mistake Maggie's for the hospice and things like that and I suppose if that's the case people have an idea in their head that eh Maggie's is for women and they won't go and think it's for people that's dying and they won't go, you know eh, I suppose it's what people think of things you know but that's it."

Interviewer: "So can I ask what you think they might involve – that sort of the stop smoking services; what's your idea [pause]?"

Chris: "Em, what these counselling, the sessions"

Interviewer: "Yeah the stop smoking sessions yeah"

Chris : "I really, I wouldn't like to think, I would hate to think it's everybody sat round and telling about their experiences and how many they smoke a day and that sort of goes back to Alcoholics Anonymous and stand up and 'I am, and I smoke forty a day'. Probably it's been imposed on to my mind without having any

read knowledge or anything like that about it so probably misguided in that aspect I suppose”

It appears that judgments are being made about services, based on wider cultural representations of support (e.g., Alcoholics Anonymous), that might not be accurate and can act as barriers for access.

Content of support

What is offered within the context of support can affect the desire to engage with it:

Fred: “I did go to the Maggie Centre and I’m thinking of going back again because they’ve got like a Writer’s Club on a Friday and one of the people one of the volunteers in the Palliative Care Unit she does the Reiki stuff and that for you ken.”

There was also the suggestion that by having more formal events or services with a specific purpose, other than just to talk, men might be more inclined to attend (potentially by removing a barrier or perception that attendees must talk openly about their emotions and cancer-related experiences):

Jim: “I mean when you look at things like the local projects like bums off seats where local people are encouraged to join sort of rambling groups etc. So I think that something that’s a wee bit more active because I think that we’ve all got sort of

different attitudes, different skills and different likes you know. I know a lot of people who come here who only come if there's a formal event on or a formal group. You know they're not interested in coming for a cup of coffee and a chat, they've got to come for a reason so maybe that's what we're talking about here that if there was a specific purpose something that really appealed to me I would go but not just the generic, you know, just having a wee blether."

Some men who were interviewed suggested that they would need a clear purpose to attend a service, and that the content of the service was important and would have to align with their specific interests.

Mode of support

Desire and motivation to attend services is affected by the mode of support delivery, its degree of formality, and its flexibility:

David: *"Yeah it's like you're not forced, every Wednesday at ten o'clock you've got to go somewhere whereas this you could, right enough I suppose there's some places you'd have to be kinda [...] but as long as you didn't have to go every week, you know, just pop along when you needed it sort of thing then you weren't put up or down whether you went, a couple of times I made arrangements to see a, to go to a clinic just because I wasn't em, just you know, cos they were quite good at drawing it out of you (laughs), em, but no as I say apart from that I just worked away.*

Jim: "I'd registered to go to Maggie's and it made the point that all you need to do is just drop in, I didn't believe that I thought well how do you just drop into place like that? I said 'I'm really phoning to find out about what's this concept of drop in, do you just, well drop in?' 'Of course there's always somebody here, anytime at all you know during opening hours just drop in eh somebody will will meet you and hopefully you'll eh eh you know just sort of come into the fold and sit and have a coffee or something.' Totally non threatening you don't need appointments etc."

In order for men to access support more generally, there was a clear preference among participants interested in support for more informal services, which allowed them access when was convenient to them.

Gatekeepers

Gatekeepers, in the form of professionals who may make decisions to inform and support service access or refrain from doing so, were influential in whether men knew about and subsequently accessed services:

Interviewer: "And have you been told about any other support services that you could access if you wanted to?"

Leonard: Eh, no but I've never asked and I'm no interested so [trails off]"

Jim: *“After that I phoned [name of worker] and said ‘I’ve been to Maggie’s and it was great’ and [name of worker] said to me ‘Jim of all my patients you’re the one person I knew would gain a lot from it’ she said ‘a lot of people, it’s not for them’ she says ‘bit I was sure that em with your nature and your approach to these things that you would enjoy it”*”.

Harry: *“Aye I would have [benefitted from going to Maggie’s earlier]. Definitely, if eh I mean naebody ever says to me ‘Maggie’s you can go to Maggie’s’ and eh fur anything you know, not a not a dickey bird you know [...] but eh no I never heard of onybody mentioning it till my daughter mentioned it you know”*

Through discussing relevant services, gatekeepers helped legitimise men seeking help, in addition to informing them of specific services.

Sex of professionals delivering support

There were mixed views on preferences for the sex of professionals in supportive roles. However, it was clear that whatever the preference, this may influence men’s desire to access services and their experience of services:

Ian1: *“Especially if it is something like just a testicular because then you then they have all sorts of questions as I did about sex and all the rest of it and that it’s difficult for men to ask a stranger especially a woman so yeah I think that’s a big barrier.”*

Fred *“The one thing I did think about the Maggie Centre, it is a great place right and they have got groups for men, but 85-90% of it is for women so you’re kind of like oh, well you can only do this one because. Same wi [palliative care unit] it was only a Friday the men went, the rest of the week it was for women ...Dinnae get us wrong the nurses and a’ that up there, they’re great ken they really do. And the volunteers ken the women that go in there they’re baking all day and ken they really are nice like ken...I think if there was – I think if there was mair [more] male volunteers it might help...”*

Yet, even when there is an idea that more male volunteers may help, a pervading idea that female volunteers may be preferable is strong:

Fred: *“[...] and ken cos I would say 99% of the volunteers are women for these things. I’ve only come across two guys, three guys for volunteering, most of them are women like, which is better as well because women are mair understanding, mair compassionate, mair patient, I find anyway, ken what I mean. A lot of women are, its mair natural for a woman to be like that, mair understanding, mair compassionate ken a lot of men would go what are you telling me for, ken what I mean? I mean like.”*

Even the name of services may be perceived as being focused on women and be off-putting; although Drew makes a joke in the extract below, the humour relies on a perceived gendered nature of Maggie’s centres:

Interviewer: Em, do you think there's any reasons why men might be less willing to go along [to the Maggie's Centre] than women?

Drew: (laughs) Maybe it's the name. Maybe if it was Jimmy's Centre they would go (laughs)

The sex of professionals delivering support, as with other contextual factors, can be seen to influence men's ideas about services, their desire to use them, and, ultimately, their help seeking behaviour. These motivations and behaviours relate to wider themes around coping with cancer and men's individual and collective ideas about masculinity.

7.3.9 Outcomes/adaptations

The reported psychosocial and health behaviour outcomes of men with cancer following processes of appraisal and coping were also influenced by psychosocial, environmental, cancer specific, and service specific factors. This section is intended to demonstrate the outcomes and adaptations that result from the appraisal of, and coping with, cancer. Accordingly, the quotes used to demonstrate such outcomes and adaptations include elements of appraisal and coping that have previously been discussed. Adaptations are related to biopsychosocial factors as follows.

Positive or negative feelings (in relation to cancer)

Men with cancer discussed how their feelings and mood had been influenced by having cancer and/or their coping efforts. Typically, men described how they had adapted through coping strategies, including service use, which had helped them to feel more positive:

Kyle: "I went down quite a bit but then eventually I did go there [Maggie's] and I've been going there for a few months now and that has made such a difference to my life. The support and the kindness and the laughs you know. I went to counselling for a while there for about six months or so and that helped, just to get talking about it and trying to come to terms with it [...]"

Harry: "But oh it's [Maggie's] been a godsend to me and I mean [name of wife] and I goes that Wednesday night you know."

These quotes exemplify how the use of help seeking to engage with coping strategies has supported the development of more positive feelings around having cancer.

Health and illness

For the majority of men, outcomes focused on psychological health and wellbeing. There were also some important adjustments to physical health status, which focused on lifestyle changes:

Gary: *“Having the diagnosis has made me cut down [on cigarettes].”*

Clark: *“I was trying to exercise to keep myself as fit as I could [...].”*

Wellbeing

In the literature, wellbeing encompasses a broad range of emotions, experiences and outcomes relating to the physical, mental and social (Naci & Loannidis, 2015). In addition to feelings or mood discussed above, men discussed outcomes of coping that resulted in a sense of wellbeing:

Bill1: *Maggie’s simply provides a spirit of wellbeing, I mean it’s not as if the[y] can operate and take out a tumour or whatever and there’s a lot of men think this is eh what should be done, Maggie’s is not a surger, I mean I turned up at 10 o’clock this morning, worked my way through traffic when it was light, first thing. I got up to make myself a mug of coffee, you just, I’m home!”*

Men who were interviewed generally discussed a greater sense of wellbeing as a direct result of accessing support services, which helped them to engage in useful coping strategies.

Social functioning

Adaptations were also made socially (i.e., in how men socialised and gained support from others). Such adaptations typically involved engagement with supportive services, such as support groups:

Mike: *“I was approached by one of the MacMillan nurses, 'look [name of surgeon] has been talking about forming a support group.' I thought it was great because you meet people like yourself and eh others within the departments who'll come along and who can fire the questions.”*

The above four codes represent some of the positive biopsychosocial factors that were evident from the interviews regarding how men adjusted to and coped with cancer. The next section goes onto explore the development of the analysis further, and introduces a model employed to help explain the interview data.

7.4 The use of a Model to Help Explain the Data

Due to the inductive nature of the analysis, it was felt important to stay true to the data, acknowledging differing interpretations of questions, knowledge, and experiences across participants. The findings presented above, in some way align with existing models of stress and coping (attribution theory; Heider, 1958, self-regulation theory; Leventhal, 1980, transactional model of stress and coping;

Lazarus & Folkman, 1984), especially around the appraisal of cancer as a stressor and subsequent coping.

There are a range of models used within the stress and coping literature that the data may align with. I was familiar with these models through my health psychology training. Therefore, when the emerging themes around appraisal and coping were evident, I revisited this literature to explore areas of overlap. Attribution theory is one such model, since it helps give an understanding of patients with cancer around why they are appraising the diagnosis as stressful and consider factors such as locus of control and emotions (Heider, 1958). However, it does not go beyond these explanations to explore antecedents, coping and outcome, which are seen in the data. Leventhal's (1980) self-regulation theory recognises a greater number of components than attribution theory. Specifically, the assumption that after a diagnosis of cancer, there is an interpretation of the illness (appraisal), including its consequences for that person and the controllability. Self-regulation theory also proposes that coping strategies may then be adopted, in this case to cope with cancer as a stressor, and finally adaptation/appraisal of that outcome is the final stage in the model. Therefore, there is more alignment between the data and self-regulation theory than attribution theory. Yet, self-regulation theory omits several factors seen in the data such as the biopsychosocial influences on appraisal and coping.

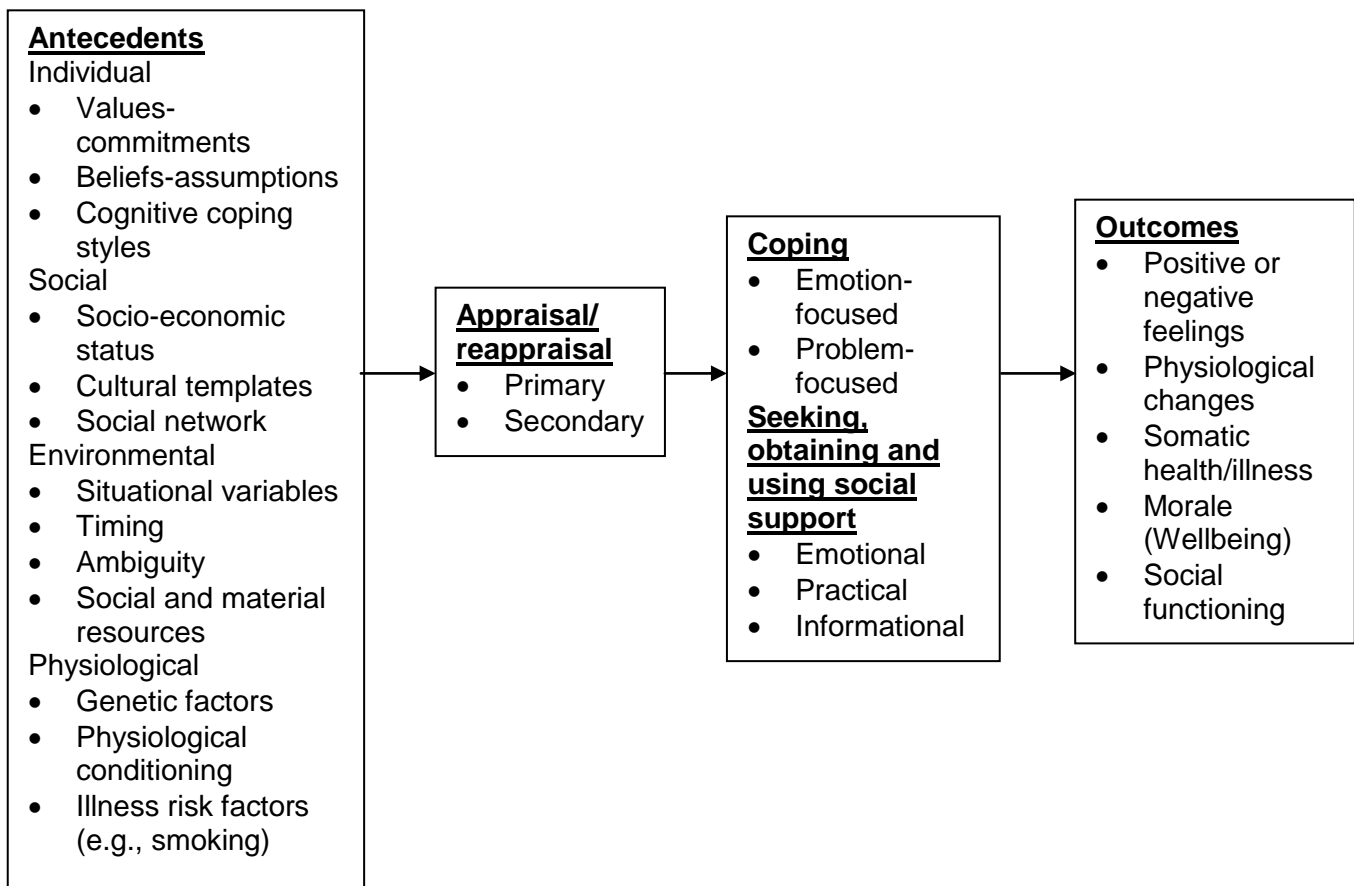
The transactional model of stress and coping incorporates the biopsychosocial influences, specifying these as antecedents (Lazarus & Folkman, 1984; Lazarus, 1999). It also focuses on appraisal of cancer, and coping utilised,

leading to outcomes or adaptations. When exploring the structure of this model, there were striking parallels with the themes from the interview data. This included the biopsychosocial antecedents; primary and secondary appraisal; emotion-, problem-, and meaning-focused coping, and social support. As such, self-regulation theory has significant overlap with the transactional model of stress and coping, however, self-regulation theory does not directly incorporate the important social, environmental (including cultural) and individual antecedents, which are very evident in the data presented here and are represented by the transactional model of stress and coping. In addition, the transactional model of stress and coping captures better some of the wider factors emerging from the data, including the effect of established coping styles (e.g. emotion and problem-focused), and the specific diagnosis and treatments under biological antecedents.

The original transactional model of stress and coping detailed in figure 3 has been adapted from the three models that represent the stress-coping pathways presented in Lazarus and Folkman (1984) and the additional updated figure presented in Lazarus (1999). In his 1999 book, Lazarus discussed how he had struggled to represent the theory in a single figure. Others have since done this, for instance, Glanz (2008), which I have used to assist in representing the model below. Lazarus also acknowledges that although the arrows indicate direction, they may feed back into each other and may not fully represent the complexity of relationships and processes; his caution reflects an attempt to avoid oversimplifying the processes involved. Lazarus discusses how the context of coping is important, as is the person doing the coping. In this thesis, the common context is

a diagnosis of cancer, however, additional multiple contexts for each individual naturally vary, for example, their social and family situation, whether or not they are working, and their beliefs about illness. There are further commonalities through all participants being male; yet, the differences in antecedents, appraisal, coping and outcomes will also be represented.

Figure 3. Original transactional model of stress and coping adapted from Lazarus and Folkman, 1984 and Lazarus, 1999



7.5 A Modified Transactional Model of Stress and Coping for a Population of Men with Cancer

The transactional model of stress and coping is used as a framework to discuss the findings that emerged, given the relative fit between the data and the model. Therefore, using the model to help represent the data when presenting the final results seemed appropriate. There was not a full overlap between the data and the model in figure 3, with some elements of the data not specifically represented by the model. For that reason, it was felt that a modified version of the transactional model of stress and coping would be needed to better represent the data. Therefore, whilst the study had intended to focus more specifically on perceived support, help-seeking, and barriers and facilitators to men accessing support services, the findings reflected a more complex picture, incorporating antecedents, appraisal and coping responses. It was, therefore, felt appropriate to draw on this model in the discussion of findings, adapting it for men with cancer.

The only higher-order code evident in the data that is not captured by this model is the contextual factors of health and voluntary services. These are the factors specific to services that are impacting on service uptake, detailed further below. Consequently, the data emerging from the interviews appear to fit a modified version of the Transaction Model of Stress and Coping.

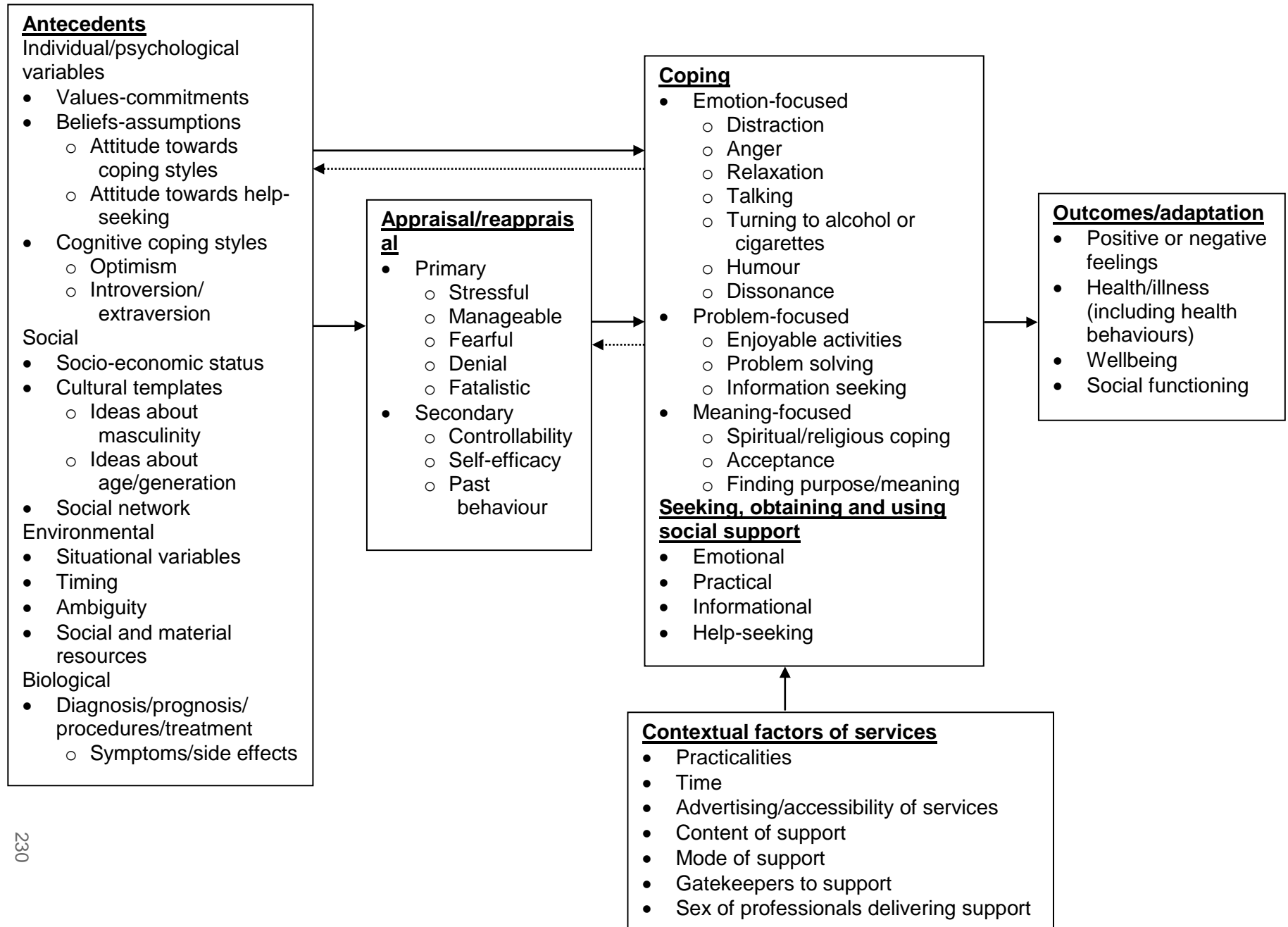
Much of the diagram representing the data (see Figure 4) remains the same as the original model represented by Figure 3. However, there are some differences. The adapted model differs from the original model especially under antecedents. Under the headings of personal, social, environmental, and biological

factors, emerging themes from the interviews are detailed. Although these antecedents generally vary across participants, the diagnosis of cancer is the common biological antecedent among all participants. Specific details of antecedents relevant to men with cancer are represented as codes under the original headings in order to give more specificity.

Unlike the original model, detail of specific codes emerging under relevant headings in the figure below is provided. For example, under 'coping', details of what type of emotion-focused coping are included (e.g., distraction or relaxation). In addition, 'meaning-focused coping' is added under 'coping', given this was apparent in the interviews and has become an accepted type of coping within the literature (Glanz, 2008; Park, 2005). Outcomes and adaptations in the modified model remain roughly the same as the original model, with biological changes omitted since these were not captured by the data, and the addition of health behaviours specifically referenced.

There is a further addition to the model of contextual factors. This relates specifically to the context that support services are offered and therefore, affecting whether or not men seek and use support. These contextual factors were prominent in the data but were not captured by the original transactional model of stress and coping. Lastly, Lazarus and Folkman (1984) do acknowledge that the transactional model of stress and coping is not unidirectional, however, this is not evident in their diagrams. In Figure 4, feedback from appraisal and coping back to antecedents is represented (by a dotted arrow) since this is apparent in the data. Antecedents impacted directly on coping style, and is, therefore, too represented.

Figure 4. Transactional model of stress and coping adapted to represent the data relevant to men with cancer from the interviews conducted



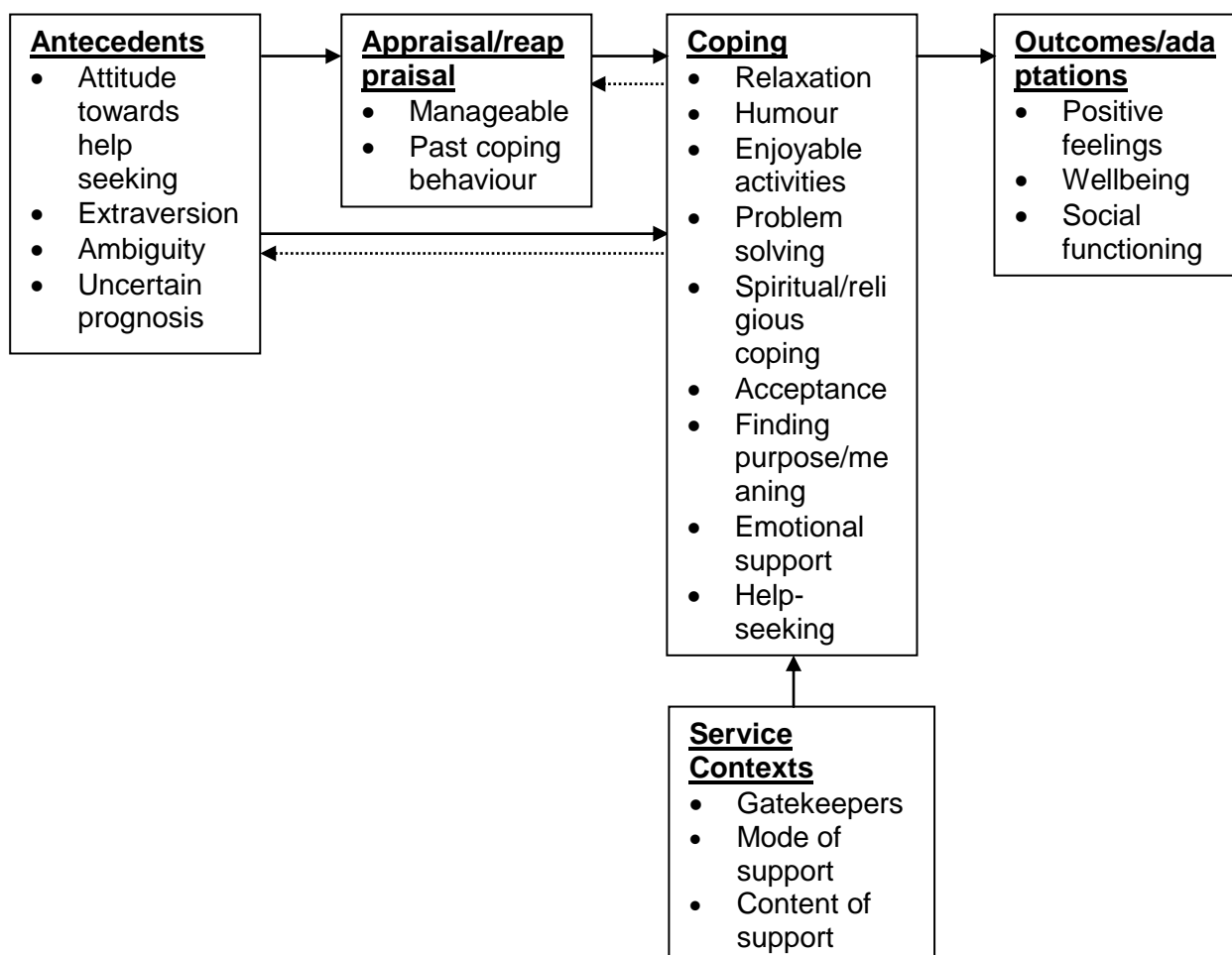
7.6 The Link among Antecedents, Appraisal, Coping, and Outcomes in the Transactional Model of Stress and Coping

Data across the interviews exemplify the transactional model of stress and coping. The key themes that emerged from the data were presented earlier (7.2). Here, linkages between each part of the model are drawn out within the individual stories from participants. The data presented here show the linkages between some or all four stages discussed in the transactional model of stress and coping that are represented in Figure 4. Whilst the specific details of each man with cancer differ, the common processes relating to the model are evident.

An interpretation of the quote or group of quotes is often given. Such discussion may also break up the quote to assist in explaining the linkages between points in the data. Basic demographic information is also given to provide further context, which consists of their age category (over or under 70) and their broad category of cancer. In the introduction or discussion of quotes, the specific code or higher-level theme is sometimes entered in round brackets to help clarify which part of the model the data relates to. Similarly, for each series of quotes from one participant, the parts of the model that the text relates to is presented diagrammatically.

As discussed, the data presented below from a selection of men interviewed aim to demonstrate the codes discussed and how they relate to the transactional model of stress and coping, and how they may extend or refute the model. In the quotes below, Mike (under 70, digestive organ cancer) discusses the factors that have affected his appraisal and coping with cancer.

The following diagram represents how Mike’s data reflects certain parts of the transactional model of stress and coping. As seen in the diagram, compared to the original model (figure 3), Mike’s data extends the model through the influence of contextual factors of services, which impacted on help seeking and, therefore, coping. Mike also utilised meaning-focused coping strategies, which were not represented by the original transactional model of stress and coping. Lastly, the specific sub-codes under the headings of antecedents, appraisal and coping gave more specificity than the original model, yet still fit with its broad categories. The diagram below therefore represents well the modified transactional model of stress and coping for men with cancer, which differs from and extends the original model.



Mike: "I was never in fear of it [cancer], eh, now in my profession again I was, when I look upon job I had, I used what was sequential organisation, stick it into the box, deal with the box, don't move to the next one until you've completed that. As I was told, the, eh, what the future is full of ifs and buts, and I could understand that, nobody can, nobody has an x-ray vision nor could they predict the future, so until they'd carried out the tests that they had in the programme, they couldn't give me an answer. So it was pointless me asking the question before there was a need to. And that's how I went through it."

Here, Mike discusses how despite the ambiguity or uncertainty with the situation, he appraised the cancer as manageable. In particular, he drew on a past problem-focused coping style of problem solving (e.g., sequential organisation) to assist him with this, showing that coping can also link back to affect appraisal. Although there was acknowledgement in the original model that factors could feedback, this was not made explicit, therefore this represents another extension of the original model. He went on to say:

Mike: "I could imagine what the ifs and buts may have been and if I wasn't going to be here to deal with it, it would have been her. My family and friends, they would have to deal with the, my loss, you know, it would have been a big loss but (laughs). Eh you know what, I'm not trying to be facetious but eh everything was being done for me so it was up to me to go with the flow. Does that give you a rough [fades off] [...] There was, if I felt down, which I did on a number of occasions, I would excuse myself, go upstairs and I was very fortunate I would

apply self-hypnosis. For about 30 years I studied martial arts and stuff and it gave me that insight. I can calm myself down without, I could put myself to sleep at the drop of my hat and that was of great benefit. Also I study reiki so I was able to give myself a, a psyche if you like. Parts of it upset my wife, 'I'll be down in an hour' and almost to the minute I'll be here, refreshed and good and, without going into it I have a very strong faith, there is a superior being looking after us on this earth and I've had that faith for many, many years.

Although Mike could imagine the 'worst case scenario', he used a range of strategies to help him cope. This included drawing on his faith, engaging in enjoyable, relaxing activities, an acceptance of his cancer and any uncertainty, along with the use of humour to cope. Mike then confirmed the impact that his faith made in assisting him adapt psychosocially to having cancer:

Interviewer: "And what difference do you think that's made to you?"

Mike: "A whole massive difference, I know that there's, I can, there's many things going in, in the world that are much worse than the trauma that I experienced. Had there been as I said to you at the beginning, I had no fear so had the future been black, I would have prepared myself and those close to me for the inevitable."

Mike sought further support to help him cope. This was influenced by a range of factors, particularly gatekeepers (for example, nurses, surgeon etc).

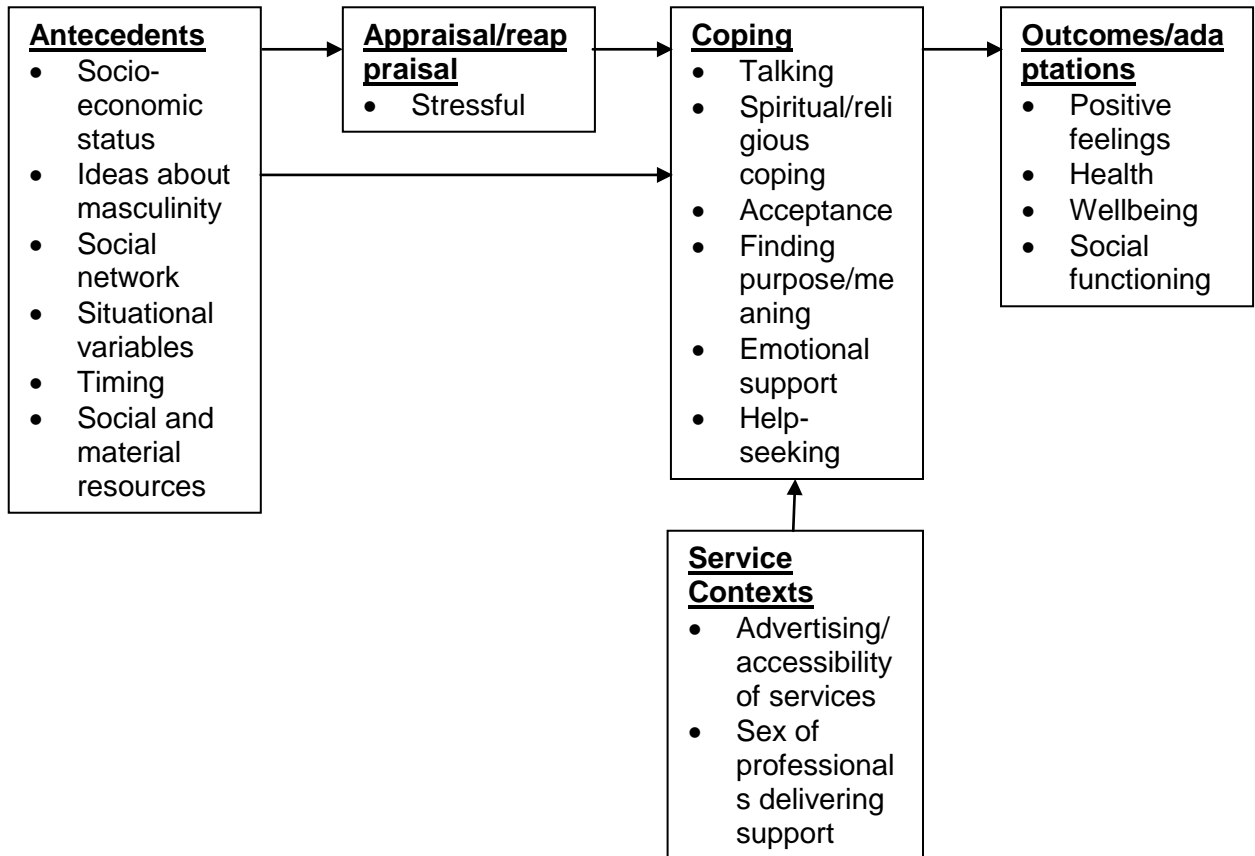
Support from Mike's existing social network - his wife - and the content and mode of support consisting of an informal support group enabled him to take a leadership role and find purpose/meaning. His positive attitude towards help seeking was influenced by others, and his extraversion enabled him to act on this, getting support, as well as giving it.

Mike: "My wife would say 'look you phone and, and make contact tell them that this has happened that that's happened' which I eventually did do, and realised very quickly look this is silly not wanting to lift the phone [...] I was approached by one of the MacMillan nurses, 'look [name of surgeon] has been talking about forming a support group.' I thought it was great because you meet people like yourself and eh others within the departments who'll come along and who can fire the questions and I'm sure the feedback's positive from both sides, I would get a call from the Macmillan team to say 'look we have Mr Bloggs, eh could I give her your name, number and can they call you up for to question you?' 'by all means' [I'd say] and when they do, I just wait on the call [...] I've never been inhibited but then again it goes back again to the jobs I've had, so I've always been fairly outgoing and I take people as I see them."

For Ian1 (Under 70, male genital organ cancer), the wider social and environmental factors made dealing with his cancer even more problematic, as seen in the diagram below. This included a reduced social network, having recently separated from his wife, his difficult financial situation and the broader timing of his diagnosis being when many difficult experiences were going on for

him. Similar to Mike’s narrative, the data from Ian1 represents the modified transactional model of stress and coping well, and extends it in a similar way. For example, through the addition of contextual factors, meaning-focused coping, and some of the specific sub-codes.

Ian1: *“I was separated at the time so I was pretty much on my own em. I suppose the only support I really got was from my, I lived in a bedsit, was from my flatmate who was a recovering alcoholic. He was fantastic, you know, he’d been through so much that he was a great help [...] I had a whole load of things going on in my life at the time em, that all sort of, I’d separated from my wife em, I was homeless for a short time I was then declared bankrupt and I then had cancer all within a 6 month period em.”*



The support Ian1 received from his flatmate (through talking) was particularly helpful, given there was not a huge amount of support from health or voluntary services available at the time (accessibility of services), with his diagnosis being in the early 1990's. The generational factor of friends and family not wanting to speak about it was also apparent, making his coping efforts more problematic:

Ian1: "Em I had a Macmillan nurse em who was, who was great and I also used the, em Backup [cancer charity] the telephone support system but em, that was pretty much it. There wasn't much else [in the 1990s]. There was no internet, I don't think, I can't remember [...] The professional support was excellent it was ach, the, the Macmillan nurse and Backup were fantastic and the telephone helpline I could phone any time day or night I could as I did cr, cry down the phone and they were just excellent, I, really they were fantastic [...] Yeah it was the kind of only support I had because, friends and family because they didn't want to speak about it really. They didn't know what to say you know and I didn't want to burden them with how I felt so it was easier going to the [trails off]."

There was also a sense of abandonment after treatment and a lack of support, medically, which added to Ian1 appraising the situation and having cancer as stressful. However, in addition to benefiting from help sought from one of the only available supports at the time - a telephone help line, he also drew upon religious coping:

Ian1: "I think sort of I got through the maybe a month after I finished radiotherapy em, yeah I don't think it was any longer than that. Em, although strangely once you've kind of been through treatment and then you know you're fine and they almost cut you lose you feel a bit I felt a bit lost [...] I know I definitely felt a bit abandoned em I think because you have all these support mechanisms and I mean they were still there I'm not saying they withdrew, you know [...] For me it was it was God and my faith has got stronger as time has gone on, em and you know I, people I suppose that was my main support but it's nice to speak to another person about it as well."

He sought a sense of purpose and meaning through raising awareness of testicular cancer, as well as the broader difficulties that can be occurring for patients co-currently with their cancer. He also gained a sense of acceptance and changed his approach to life and work – being less focused on a career and wealth – all of which contributed to his better psychosocial health:

Ian1: "[...] when I share that [my story] with staff, it's to try and, it's not just about the cancer there could be a whole lot of things going on in somebody's life and it's to be aware that if they are angry and emotional well it might not be purely driven by their disease it could be a whole number of issues. So it's just trying to share my experiences and eh, at some point they might if they are dealing with a patient they might think 'Oh I remember he said that'. Anything, it may or may not help. I used to go along to men's groups and speak about it particularly testicular examination [...] So, yeah it changed me hugely and I, I know what's

important and what's not and it's not things or possessions its people and relationships [...] I mean then it was you know the pursuing a career and pursuing things and wealth and all the rest of it but that kind of changed for the, it actually it didn't, it actually is not important. And it's also em, I don't let things bother me eh, I forgive very, very quickly there's no point in holding onto a grudge. It doesn't do any diff, you know it makes no difference."

Although Ian1 accessed services and felt no major barriers to doing so, he discussed a broader pressure in society relating to ideas about masculinity. He discussed how this can be a barrier preventing men from asking for help or showing they are not coping. Related to this, he also suggested that the sex of professionals delivering support being predominantly women may also be linked in putting men off from seeking support. However, he also recognised that not all men would open up to another man because it may reveal vulnerabilities:

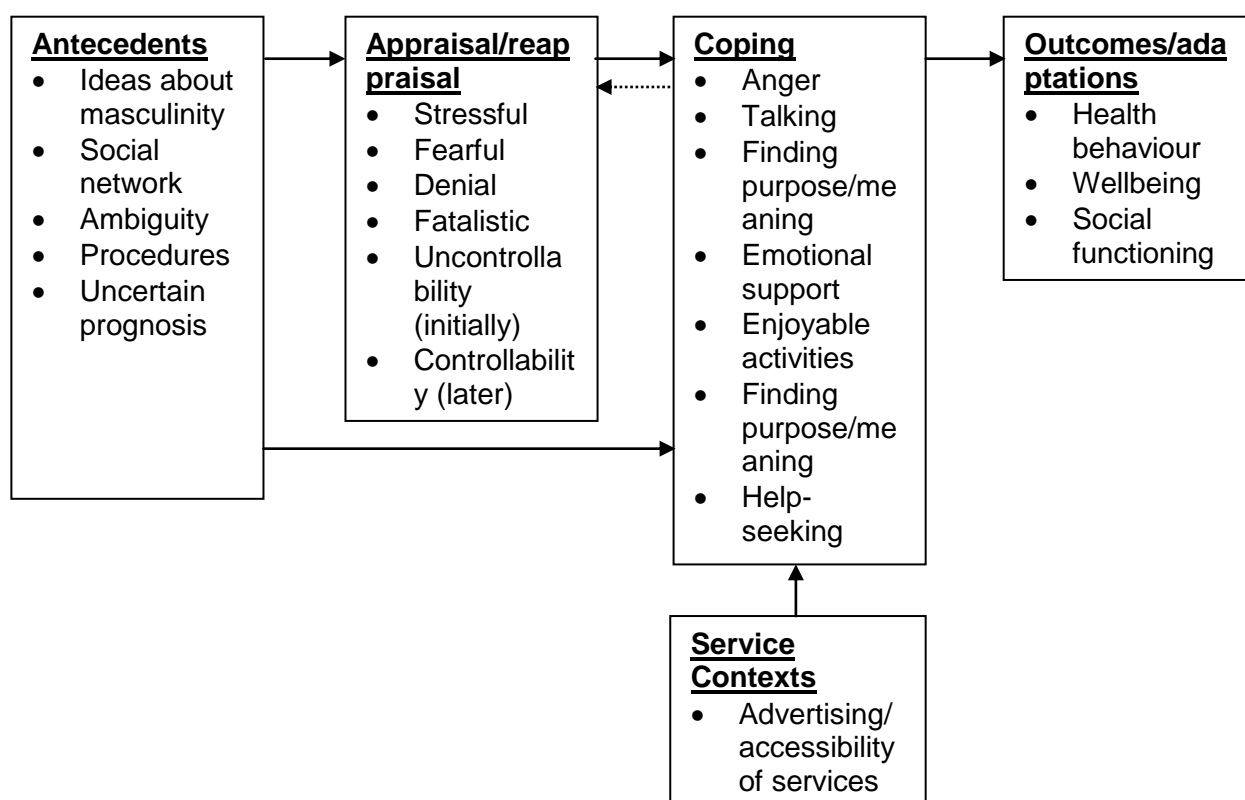
Ian1: "[...] it's very prevalent, this macho image em, and you don't want to show your vulnerabilities you don't want to show that you're not coping [...] I think because the support predominantly tends to be women I think they [men] might be bit more reluctant [...] especially if it is something like just a testicular because then you then they have all sorts of questions as I did about sex and all the rest of it and that it's difficult for men to ask a stranger, especially a woman, so yeah I think that's a big barrier. Em because again they always have to show themselves then to be vulnerable. I suppose the first thing that might happen they don't want to show themselves vulnerable to a man so it's a, we're

a complicated breed [...] Cos women are obviously much more eh kind of forward thinking and will go out and seek support and even support from their friends and their peer groups where men just don't so yeah it's probably seen more that women will do it."

For another participant, Clark (under 70, male genital organ cancer), the stressful procedures associated with his cancer, and the fact that the diagnosis was a shock, contributed to him feeling scared and somewhat fatalistic, in assuming he would die. He attributes the assumption that he would not get cancer to being influenced by ideas about men being invincible, which may be due a lack of awareness in the public about the cancer. Clark's narrative extends the original transactional model of stress and coping through the importance of contextual factors, meaning-focused coping, the utilisation of coping strategies feeding back to a reappraisal of cancer as having a greater element of controllability, and the specific sub-codes. As with Mike and Ian1, Clark's narrative supports this modified transactional model of stress and coping.

Clark: "Em in regards to support for me as a person, mentally, em, very little em, and em in, in that regard I would say I was completely unprepared em, the, the even on the first day that I, I, went and had a rectal examination. I, I, can't even think what I thought I was going for. But I didn't think it would be so excruciatingly painful and awful and degrading and that I would feel so bad about it and from that point onwards that that changed me quite a lot. Because I

was quite scared about it all em, I guess like em I, I, many other men you think you're somewhat invincible and that nothing's going to really harm you or touch you or you know bad things happen to other people. But bad things happen to everybody em or can happen to anybody [...] I went through that whole panicking that people go through of 'Hell I've got cancer I'm going to die'."



This was coupled with people commenting on how well he looked since he used exercise as a coping strategy, contributing further to feelings around people in his social network not understanding his difficulties (being misunderstood), non-specific feelings of anger, trying not to think about his cancer and its implications (avoidance or denial):

Clark: "But again what I do is just do what most people do: avoidance is a great technique to deal with thing you don't want to deal with. Just, just don't deal with it avoid it completely and you won't feel bad about it [...] I don't express that anger against other people I don't think or I try not to and just, just I'm just angry, I'm not sure who I'm angry at, I'm just angry [...] I think that when I em was treated with chemotherapy then there's more sympathy somehow. Well, your hair falls out, you start looking a bit gray and em cancer-like. But when I had my, my hair and I was trying to exercise to keep myself as fit as I could to get myself through it, the people you people and they still do it em would say 'Och you look awful fit'. It's almost like an accusation of you 'are you pretending that you have cancer?'"

He also had the experience of asking for help from staff on the cancer ward, which never came, perhaps because they were not available at that time on the ward; something he remembers two years on. Later he sought out help from the Maggie's centre, which has helped him to utilise talking as a coping strategy:

Clark: "In the cancer ward there they asked me if I needed any help I went through a, a summary that someone came round and took and I said yeah I do need help and that was 2 years ago and I've still never received any help.. I would say the only person that I tell I've told most of the truth to is my psychologist [at the Maggie's Centre] em because it feels safe because they're not going to judge you."

The uncertainty surrounding prognosis, in addition to not receiving additional support he had asked for as described above, added to his difficulties.

Clark: "I don't know whether I've got 6 months or 5 years or 10 years and it could be any of them [...] I don't like the uncertainty of it em [...]"

Yet, he has drawn on more helpful coping methods through engagement with enjoyable activities, and finding new meaning and purpose through re-appraising what is important in life, what it means to be him, and starting a new educational course. This has helped him to manage the perceived uncontrollability of his cancer and his reflections on himself as a changed person has helped him to re-gain a sense of control over the coping strategies he utilises:

Clark: "[...] and in being retired and at least that's, that is something that I feel as if I'm in control of em, I there will be things that I'll do for example I like talking and try and raise awareness about cancer and that's within my control, it's within my control if I do things with my kids or I take them on holiday now [...] Cancer definitely em for me em made me feel out of control made me feel as if I was cancer not [name of participant] [...] I've applied for Master in film studies because I like films em and I'm not, I don't plan on going to Hollywood or anything but it would be great and it would be an enjoyable thing to do and it

would be for me as opposed for anybody else [...] I'm trying to find me again but it's not the me and I think cancer does this to you: I'm not the same me as I was before cancer, I'm a completely different person em the, the sort of altruistic type things the helping other people that I do now I, I had no real, I mean I wouldn't if somebody had needed help I'd have helped them before but I had no real desire to do that in a regular basis whereas I do now. Em things look different in that for me the, the whole reason for living is really about my children now em and who cares if I don't have a car who cares if I've got an old TV, I it doesn't you know it doesn't matter not really."

The role of masculinity, particularly in the adoption of certain coping strategies and help seeking, is discussed further by Clark. Sometimes the barriers may lie with other men. He perceives that the culturally embedded ideas about masculinity are acting strongly against men discussing any difficulties arising from cancer, or indeed discussing the fact that they have cancer. For Clark, he re-frames ideas about masculinity as encompassing talking about difficulties and crying, which may have helped him legitimise his help seeking:

Clark: "I mean men will not talk about anything below the waist they just refuse to do it and I've been, I've been with at least one of my mates who's come to the hospital with me on one of my visits and he still doesn't want to talk about it [...] guys don't read magazines, guys when they go to the pub, I mean it's quite common that guys grunt at each other in the pub they don't really have a

conversation about anything they mention the football. They grunt at each other 'would you like another pint', 'I hate my wife', that's about it. And that 3 hours has now passed but you know trying to introduce into that that somebody's got testicular cancer or cancer of the penis or rectal cancer or something like that! Oh my god it would be like you could just see them running out the pub it would be like 'I need to leave now!' It just won't, it just doesn't happen like that [...] guys need help just as much as women need help whether they like to admit it or not em, yeah I think that a lot of guys do need help that the whole em mentality of 'you've got to be strong don't cry', that's sort of built into people from an early age but it is slowly changing and I think it it's a little bit like em that sort of I think sort of 70s or 80s thing of real men do cry. There's also probably a sort of extension to that of real men do go and talk about things em as opposed to you know real men stand at the bar and get completely drunk smoking cigarettes and don't tell anyone about it em [...] it's getting over that barrier of masculinity the, the I'm, I'm, a man and you know I shouldn't be worrying about things like that. Men don't get that sort of thing real men real men smoke Marlboro and ride horses across the prairie (laughs). But emm you know real men do get cancer and lots of them lots and lots and lots of them [...]"

However, like some other men, although there is a perception of barriers for men talking about cancer or seeking help, they themselves have sought help. This suggests that the perception of the strength of masculinity as a barrier may be greater than how it acts as a barrier in day-to-day life for these men with cancer. There also seems to be a role for legitimising help-seeking

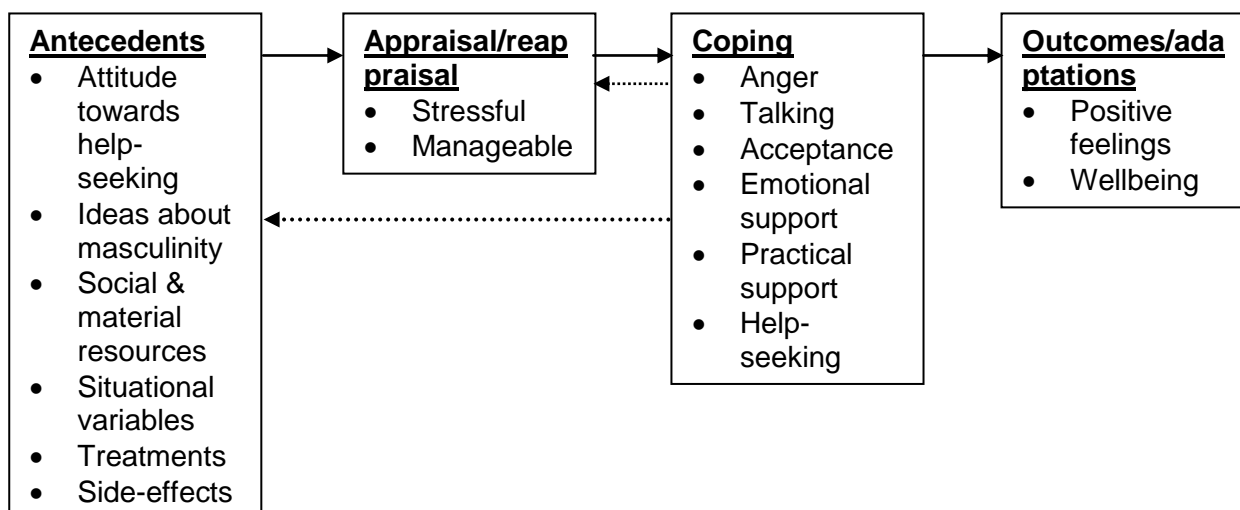
through a re-framing of what is 'masculine', and a possible distancing of men from the common social norms held about masculinity.

The data drawn from the interviews with Mike, Ian1 and Clark all demonstrate the gradual adaptations people have made following a diagnosis of cancer. Despite often feeling that it was stressful and unmanageable, each participant has gone through a process of adjusting to having cancer through finding ways to cope that are helpful to them. This feedback (represented by the dotted arrows) is an important explicitly acknowledged addition to the original transactional model of stress and coping. This has enabled them to function better psychosocially, often with the help of support around them, or support sought out. One man (Clark) also coped through engaging in exercise, demonstrating a change in health behaviour outcome, in addition to psychosocial wellbeing.

For others, like Kyle (70 or over, male genital organ cancer), there can be a delayed struggle with cancer, finding he was seeing cancer as manageable initially, then, following treatment, the difficulties started. Reflecting back on what he had gone through, he found it stressful and felt very angry, leading to low mood:

Kyle: "I was very, very angry, really angry and I'm no different to a lot of other people I've spoken to that have been very angry, but then you have this thing of 'why me and all this' and it's quite normal you know. But it didn't hit me until. It

was round about November last year. October or November I was all, I thought oh this is great I'm fine I'm fully recovered, but you're not and I didn't. I had no idea what was gonna hit me.”



A combination of treatment side effects and his partner not coping with the loss of sexual function leading to their break up, along with him no longer feeling like a man (ideas about masculinity) led to Kyle feeling 'not like a man' and worse psychological wellbeing:

Kyle: “And I had met somebody last August and it's been a, it's finished now and it's finished because she can't cope with it and that hurt because there's nothing wrong. You know I may not be fully functional, but I'm, you know, I'm ninety per cent there and that's not bad for a man of seventy years of age and she knew what she was getting into, but I respect her decision so that's hard. That's you know, it's not easy. So that is the part that um that you know the thing was to do with feeling not like a man and that hurt because you feel as if,

well somebody had taken something [the full use of my penis] away from me.”

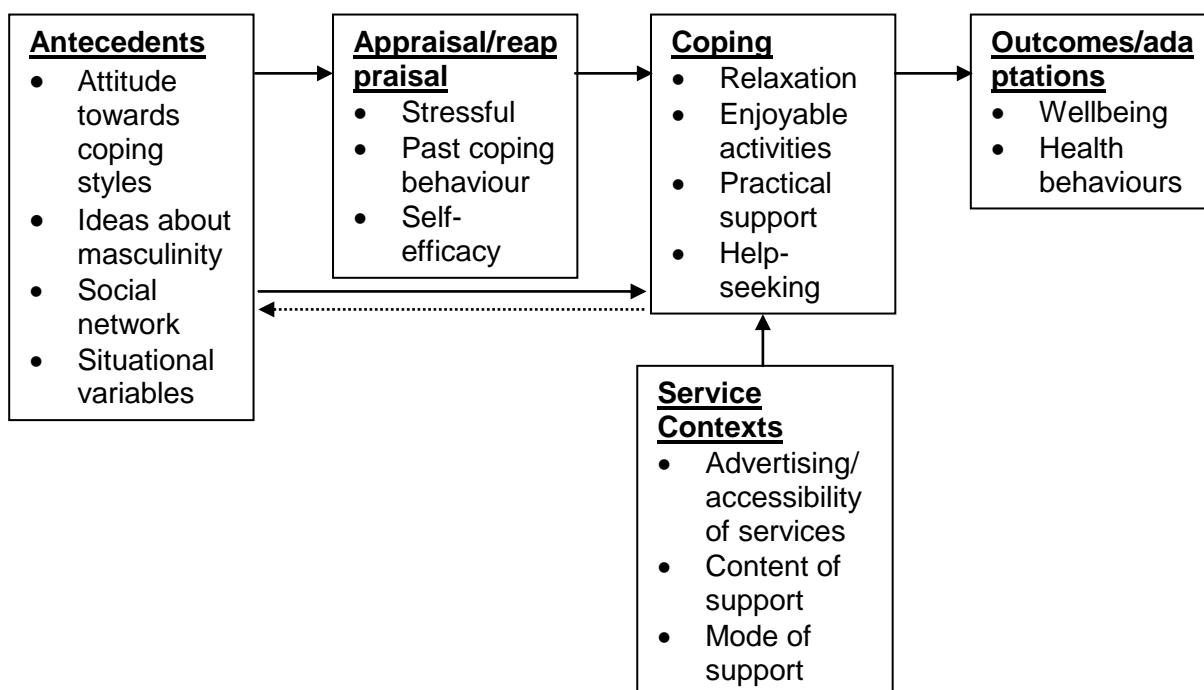
Kyle

Later Kyle engaged with voluntary services. A combination of factors helped him to access emotional support: his low mood, his past behaviour of accessing support, and practical encouragement from a female friend influenced his attitude towards doing so. Thus showing how elements of the model can feed back on each other: in this case support influencing antecedent (attitude towards help seeking). Through seeking support, he has experienced an acceptance and subsequent psychosocial improvements. Unlike the previous narratives presented, for Kyle, contextual factors of services did not influence his engagement with them, representing a contradiction of the modified model.

Kyle: “I went down quite a bit but then eventually I did go there [Maggie’s] and I’ve been going there for a few months now and that has made such a difference to my life. The support and the kindness and the laughs you know. I went to counselling for a while there for about six months or so and that helped, just to get talking about it and trying to come to terms with it but that’s, what’s that, thirteen years ago or something it’s a long time ago! [...] I was a bit reluctant to go [to Maggie’s] but then this particular consultant lady, I’ve known [name of friend] a long time, she lives in Northern Ireland, retired now, but no she said come on now you’ve got to go cos it’ll be good for you because she knows me well. I think I’ve come to terms with that now and that’s been a really

big change by talking about it and some of the questions that the counsellors asked me and got me talking about things so that's. I think that's been a big step forward coming to terms with that."

Although for many participants, their difficulties were related directly to their cancer, the difficulties experienced by some people was relating to wider situational variables. For Bill1 (70 or over, Respiratory and intrathoracic organ cancer), this was bereavement since his wife had died:



Bill1: "I'm still here but since my wife died I've become even more complacent. I used to think that life was everything and I don't think life is everything, I think that marriage is everything. And since my wife died I've sort of gone down. Stress [...] I've got a, you've got to forgive me for this, on the cancer side I am okay. On the other side, on the bereavement side I am not okay."

Even when asking for services that were available, Bill1 found barriers to accessing them. Bill1 experienced a lot of difficulty in gaining access to the services he wanted firstly to help rehabilitate him when he was in hospital:

Bill1: "Eh I asked for the, I asked to see the physiotherapist and I said to the girl that came round I said eh I want to get back some of the stamina that I used to have eh, I used to be able t do the 100 yards in 12 seconds [...] the day that I was leaving the [name of hospital], I was actually waiting for my medication eh the physiotherapist turned up and said that they'd booked me some physiotherapy , I said 'now stop, ye've had a fortnight, nobody's come near me'."

Then, Bill1 faced further difficulties in accessing services once he was out of hospital, which got in the way of him coping through exercise. His attitude towards how helpful exercise would be to help him cope with his difficulties enabled him not to give up. His past behaviour of being physically active, and his self-efficacy in his abilities, enabled him to pursue finding the right supportive exercises (practical support), and become fitter (health behaviour outcome):

Bill1: I wanted to do some general exercises [in a private gym] just to get my stamina back I said I used to do gymnastics and things so the gymnasium is no stranger to me, and I said I'm off to get onto the pool, 'oh you'd have to get clearance from your doctor to go in the gym' [said the gym company] and they

did not have a pool attendant at the swimming pool so they wouldn't let me in there either [...] so this is this young doctor, I'd never met her before, she said 'I've heard of something called Pulmonary rehabilitation' I said 'What's that?' 'Oh it's for people who have asthma and respiratory problems, it's a series of exercises' [said the doctor] [...] So I went there twice a week for an hour. An hour each time and it was the treadmill, it was the exercise bike, the rowing machine various different physical activities involving weights and things. So I did that and I was getting some of my stamina back, feeling fit, I had 2 dogs that I started taking them for a walk."

Bill1 also accessed psychosocial help. He was able to initially attend the Maggie's voluntary sector services because his wife went along with him. He proposes that wives play a key role in helping men access service, perhaps by legitimising service access for men by being able to 'blame' their wives for their attendance (ideas about masculinity). Through the support from his social network (his wife), he has been able to benefit from talking to others at the Maggie's centre, and the mode of support being informal and relaxed has contributed to him both attending and feeling a sense of wellbeing from attending:

Bill1: "I mean let's face it half the men that come to Maggie's their wives are pushing, pushing, pushing, they don't come of their own free will as I say I decided to try it because the consultant's assistant at the Royal suggested it and I came along here with my wife and I got tied up with [name of worker] and

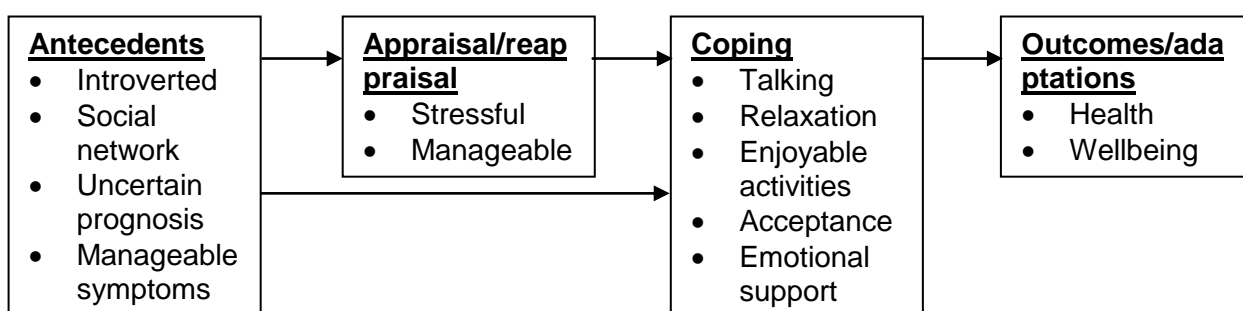
that 12 week class. I sometimes wonder if the wives aren't doing enough [...] To push their men into coming, do the wives understand about Maggie's what it's for? [...] Maggie's simply provides a spirit of wellbeing, I mean it's not as if the can operate and takeout a tumour or whatever and there's a lot of men think this is eh what should be done, Maggie's is not a surgery [...] I mean I turned up at 10 o'clock this morning, worked my way through traffic when it was light, first thing. I got up to make myself a mug of coffee, you just, I'm home!"

Bill1 adds that the way that services advertise themselves can have an influence on attitudes towards help-seeking and there may be opportunities for services to better tailor services to attract people to attend:

Bill1: "But eh, em, there's a meeting I came to and it was advertising and they had a leaflet which I thought was atrocious, and this is a leaflet that was put in doctors surgeries and the layout on the front cover was dismal, you opened it up, it was the story of a man and his wife who'd been diagnosed cancer and what he'd done. And then it finished there was no 'come along and have a chat' [...] I said that this leaflet is soul destroying. If I saw it on the rack I'd just pass it by and the actual content, I don't want to know what happened to Joe Smith, just don't. I tried to find out about the lad in [name of city] and I'm going back Phhh 15, 20 years, he was diagnosed with cancer and he's still going strong. I'd like to know what his story was."

As a result, men may not always be encouraged to attend services if advertising material that services use is not positive enough.

Timing, along with symptoms and side effects can also influence appraisal and coping. Although the initial uncertainty for Ian2 (70 or above, skin cancer) was difficult, he showed a sense of acceptance from the point of diagnosis:



Ian2: "When I was first diagnosed, well your mind just sort of goes, 'Boom! Boom! Boom!' Because I came in just before Christmas, there was quite a spell of time before I got the results of the operation [...] I didn't dwell on it, let's put it that way, about the outcome, I've got this 'c'est la vie', if it's going to be it's going to be' and that's it."

Later Ian2 found that his manageable symptoms, along with his secondary appraisal of seeing his cancer as controllable due to regular check-ups all contributed to him feeling like his cancer was manageable. Some support from his ex-wife also assisted, as did his reflection on his personality as being more introverted and the use of coping through a distracting, relaxing activity (fishing):

Ian2: "I didn't really feel unwell, I didn't need support. My wife, or my, though we're separated and we've been separated for a long time, she gave me a fair bit of support and she was there for me. But apart from that, and of course coming to the [name of specialist centre] every three months or so, they've been good, but I've just never ever felt unwell [...] maybe if I hadn't got involved in these trials [involving regular check-ups], I might be more inclined to come to someplace like the Maggie Centre I don't know [...] I'm quite a, what would you say, self-sufficient sort of person and quite used to being in my own company, but had I felt ill or something along with it, I might've been looking for a bit more support, but I've never really felt ill [...] Em, well you tend to deal with sort of things that bother you when you go fishing and you sit down on the bank out there in the wide open spaces and the trees and the birds and everything and thinking stop being stupid and get on with it. So it's a good distraction and a way of relaxing and you know relax your mind and relax your body too and concentrate on catching these fish."

Ian2 continued further to suggest that nothing would attract him to engage with services:

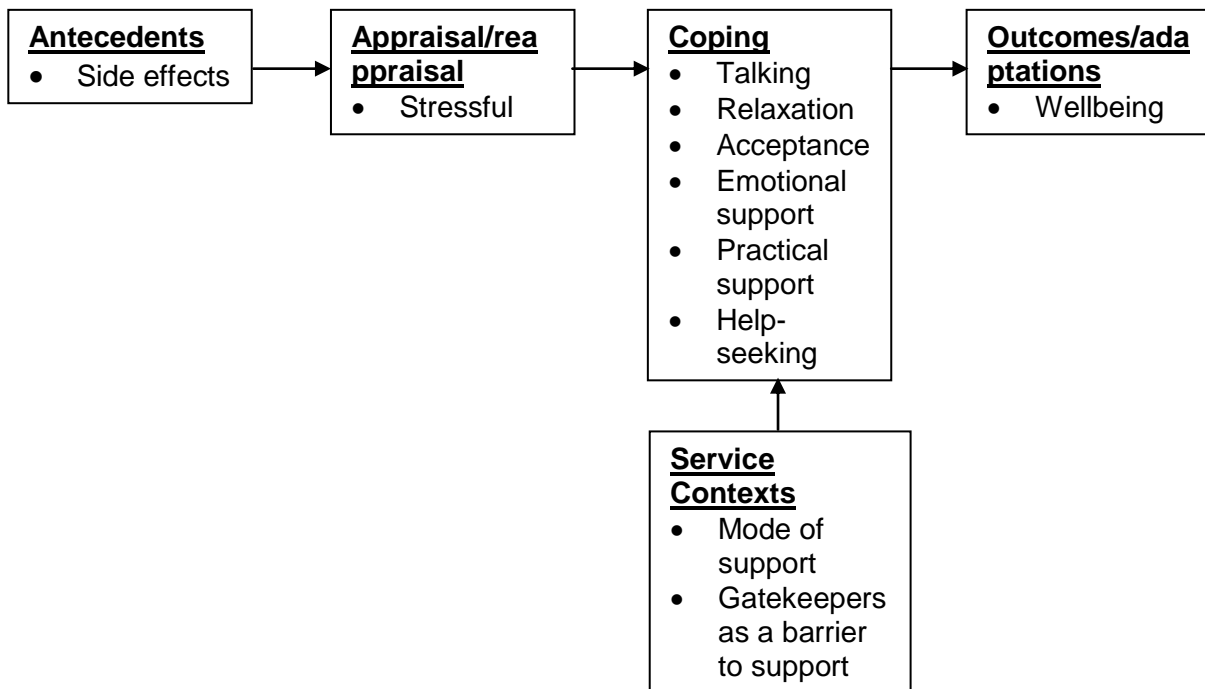
Interviewer: "The last thing I just want to ask you about is some services try to attract men in by maybe having something above a room in a pub or they've had this men shed idea where you have this shed and you do woodwork and other stuff with your hands. What do you think of that?"

Ian2: "What about making it a more social place? Em I don't think, that wouldn't sort of make it any different for me I don't think, I don't know when I was last in a pub to be honest. No, I don't think that would make any odds to me, it wouldn't make it more attractive to go to."

Consequently, for some people like Ian2, a combination of having mild symptoms and side effects (antecedents), meant that he appraised things as manageable. Some use of social support from his (separated) wife enabling him to talk when he needed, and engagement in fishing (utilising emotion- and problem-focused coping), meant that he adapted to cancer and did not feel the need for further support. Therefore, the story relayed by Ian2, somewhat contradicted part of the modified model, since service contexts did not have an influence on whether or not he accessed services. In fact, Ian2 felt that no matter now a service was set up or advertised, he would not be persuaded to utilise the support offered. This demonstrates that the modified model is not reflected in the data from every man with cancer, however collectively it may represent experiences of this population well.

Harry (70 and above, male genital organ cancer), found the side effects of his cancer initially stressful. He attributed his later acceptance down to the Maggie's Centres. In addition, the particular type of stressor - cancer - may have legitimised help-seeking, since he acknowledged this was stressful. As

such, the context of stress may affect what coping methods are seen as acceptable to use, and which are indeed utilised:



Interviewer: "So when you were first diagnosed did you feel that you needed more support from anywhere?"

Harry: "Well I, I felt that they should have gave me mare information about it ye know. I mean they telt me about this the brace ken that didnae put me up nor doon. But this doon there [his penis] did, I must admit I was, oh I could have murdered somebody you know cos, I've nothing doon there I says in fact I says when I go for a pee I says there's sometimes I cannae hud [find] it, you know there's nothing there ye ken it [...] I have been upset but eh, na it's as I say I've accepted ma lot sort of thing you know and I'm living."

Interviewer: “Yeah, so what’s happened to make you accept that?”

Harry: “Well, it was Maggie’s [cancer caring centre] actually you know I went to tae [to] Maggie’s and eh you were made welcome, complete stranger walked in [...]”

Gatekeepers can play a big role whether or not people access support services. No one had mentioned the available support from the Maggie’s Centres to Harry, therefore, there were missed opportunities for him to access support at an earlier date. He eventually accessed the service due to the encouragement and practical support from his daughter. The mode and content of support, being welcoming, relaxed and informal, coming from a voluntary sector service, facilitated talking and relaxation. This narrative again demonstrates how the contextual factors of services are an important addition to the modified transactional model of stress and coping. Harry’s narrative, therefore represents the modified model well, since elements from all key aspects of the whole model were apparent. He benefitted from the support through gaining an acceptance of treatment side effects, bringing a better sense of wellbeing, and being able to talk both about cancer and other things but could have benefitted more at an earlier time.

Interviewer: “Do you think you would have benefitted from going to Maggie’s at an earlier stage?”

Harry: "Aye I would have. Definitely, if eh, I mean naebody ever says to me 'Maggie's, you can go to Maggie's' and eh fur anything you know, not a not a dickey bird you know [...] my daughter took me, that was, I wouldnae have went myself I don't think [...] you're talking about what 5 years an a bit before we found Maggie's you know. But oh it's been a godsend to me and I mean [name of wife] and I goes that Wednesday night you know, it's only once a month ken. You could talk, it doesn't matter you can talk about anything ye like it doesn't need to be about prostrate cancer ye ken, you can talk about things that's going through the day or through the week you know [...]"

Interviewer: "And is that something that you've found elsewhere or not?"

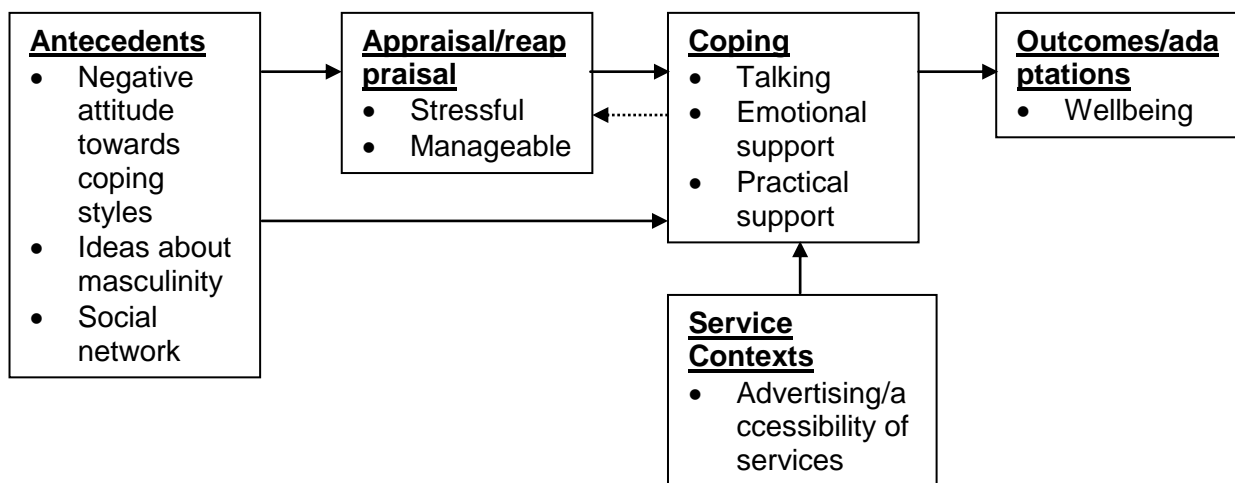
Harry: "Nut, no no just Maggie's."

Interviewer: "Yeah, what do you think it is about Maggie's that gives it that particular feel?"

Harry: "I don't know it, it's the people. I mean [name of worker] and [name of worker] eh whenever you go in if they're not engaged with somebody they sit and blether to you, you know, they get a cup of coffee for you if you want a cup of coffee and they'll sit and blether to you [...] I'd no inhibitions or anything you know, normally before this carry on I'd never have dreamt tae talking to a

stranger the way I've been talking to you about doon here, no way you know but, I don't know Maggie's just makes you alright, you know?"

Similar to other men with cancer, Robert (under 70, male genital organ cancer) discusses how talking comes more easily to women and society helps make it acceptable for them. This viewpoint is reinforced for Robert since he has women within his circle of friends, family and professionals (social network) who are all very supportive and easier to talk to than men. The perception that men talk less, means he is unlikely to share things with men around him, and feels that he would be happy to discuss any issues if the barrier to talking did not exist for other men:



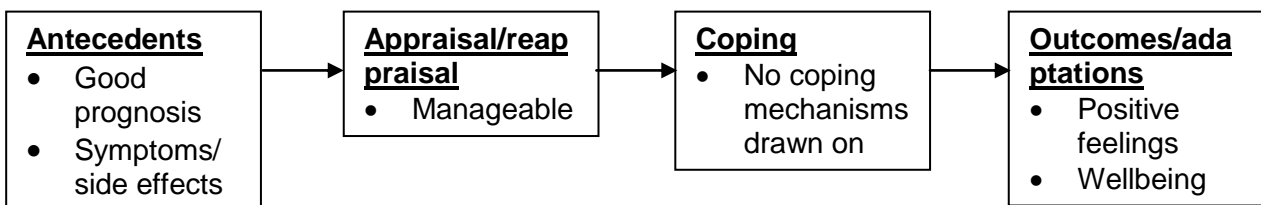
Robert: " [...] I'm drawn to females em, I have neighbours around about here but they're mostly men eh cos it's all single folks houses but the person I've got that offered to help me and do my cooking and my cleaning and change my bed is woman a, a, again. So I, I, would say that ever, everybody that have supported me have been females so then that has been a great help. I've not bounced off

men where it's harder to do because they're too manly to listen they, they they're oh get a grip of yourself they would say you know [...] it's not that I've got the barrier its them that's got the barrier."

When he was asked about accessing support, his preconceptions about what that would entail influenced his reluctance to access certain supports:

Robert: "I think it would be dep, depressing listening to everybody's sad stories [at a support group] and it's not that it wouldnae be helpful I would just feel stressed out with it all everybody handles it differently. Who I've all got between who have helped like you being here the, the nurses from the health centre the cancer nurse em, the social work and the finance side of the Macmillan Trust that is like being as much support that I could hope for so I don't think I'm being selfish."

For some, the way they appraised and coped with their cancer meant that no additional support was required, as seen in this exchange with Chris (under 70, skin cancer):



Interviewer: "Can you describe why you felt you didn't have the need for that [support from organisations]".

Chris: "Em, because mentally and physically I haven't felt different from before diagnosis so my life hasn't changed, for me it hasn't changed, apart from the physical you know, having the operation done, but apart from that I'm as, well I feel as fine as I did beforehand. I've got a wee bit more weight, but that's not a bad thing I don't think, so [trails off] [...]."

Interviewer: "And you mentioned obviously having a wife. Do you feel that that's helped in terms of you not needing support from other places or do you just feel that you haven't needed support full stop?"

Chris: "I don't know, em. No it's not the fact of having a wife that I haven't needed support, I just, [sighs]. I wouldn't like to, I didn't feel a need to go for support because my circumstances, circumstances haven't changed you know. I didn't feel any worse or you know and it didn't affect me mentally so I thought, well, there's a lot, I think there's a lot more people off in a far worse situation than me that will need the care or support that the Maggie Centre can provide, but I just don't feel. I'm still working full time, I'm still doing the things that I did beforehand."

Interviewer: "So not much has changed."

Chris: "It's not, it hasn't, things haven't changed for me so I don't think there was a need to go and ask for that extra support when, it doesn't, you know, it doesn't play on my mind at all so. Why, why go and ask for something. Well, it's taking up other people's time when there's really no need, in my opinion, I don't feel there is."

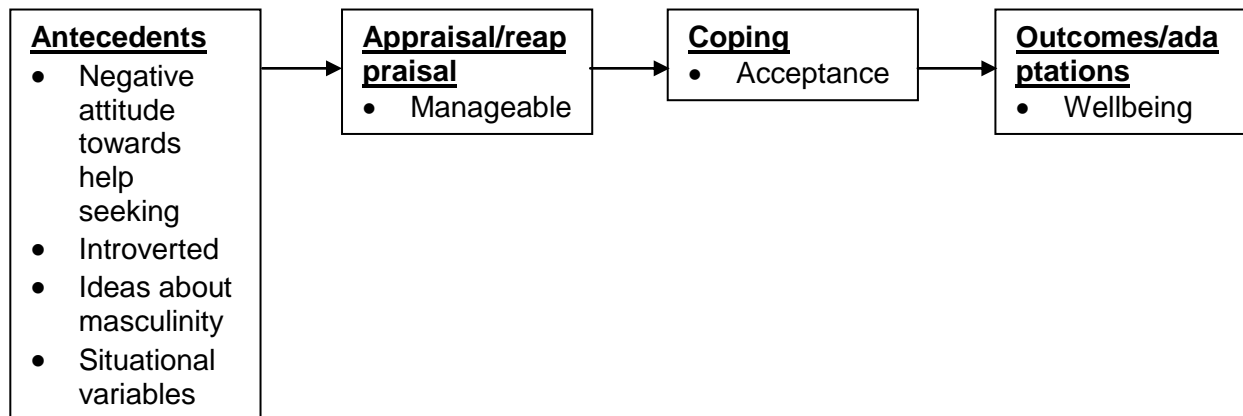
Interviewer: "Do you feel there's any circumstances that you might end up, that would make you want to access support?"

Chris: "Yeah, but I think that's, that would surely be a follow on from further check-ups. If things had changed and my condition had changed and I came back or whatever and the prognosis was you know different or worse or whatever then I suppose then if it affects me in a different way then I would probably have to look at, if I think I need it, then yeah, but I think that's something only time can tell really. I think possibly the answer would be yes, there might be a time that I might need to go, but we're gonna have to wait and see."

This exchange suggests that Chris' primary appraisal was that his cancer was manageable in the context of the diagnosis not being life-threatening, leading him to feel that there was no need to adapt the way he was coping or access services. He felt that he would consider accessing services if things changed for him, however, there was no current need. As a result, although much of the data gathered from Chris' interview aligns with the modified

transactional model of stress and coping, the fact that he did not feel the need to utilise coping mechanisms, means that not all components of the model need to be applied. Similar to Ian2, this reflects the individual nature of men with cancer and that although a model may represent men on the whole, individual narratives will differ.

Perceptions of the role of masculinity in help-seeking are evident in a range of quotes discussed earlier. There was a strong sense in the narrative from John (under 70, male genital organ cancer) that being a man influences how difficult it is to draw on coping strategies. This includes the use of talking and help seeking by using available services services, which may then contribute to fewer men accessing support services. John discussed his dispositional style as introverted and he linked this to being male, or the fact that being male contributed further to making it difficult to talk. However, this was within an important context of him being busy and not having the time to access support. He also feels that he does not need help, though this may have been influenced by his reference to feeling 'like a fraud sometimes'. These factors are not captured by the transactional model of stress and coping but may relate to common and historical ideas that cancer is always a very serious condition. Therefore, although the modified transactional model of stress and coping predominantly captures all data within men's narratives, there are a few factors that are not included. This factor did not seem to align with any part of the modified model, and was not expressed by a any other participants. It was, consequently, not added to the modified model.



John: "I was probably, oh god how would you describe, say that there was, intro, introverted, not an outgoing person [...] I'm not the kind of person to go and tap somebody on the shoulder and say 'look I've got a woe I need to talk to you' [...] So, in some respects I've probably kept myself busy and kept you know not really needing any support plus I have friends you know and family. It's not really, I've not reached the stage of sort of really climbing the walls and you now help help help. [...] I don't have much time to (laughs) to do anything [...] You feel a fraud sometimes [...] I think, I think ladies are, do like to be bit more sociable for some, for things shall we say if you want to call it sociable [...] But there again as I said ladies still always tend to go, like to congregate, you know more that the men possibly, I don't know if that's what you it call a macho image that men have, I'm fine. I don't need any help, maybe some do maybe some don't [...] I think they possibly might find it more difficult to persuade a man to go to use the services. If he hasn't, if he's never been already and maybe time has gone on a bit you know it depends what their problems are I don't know I think you might find a man probably kind of reluctant to go and use the services unless it's really in the, in the initial st, stages or whatever the case may be."

7.7 The Role of Cancer, Appraisal and Coping in Affecting Health

Behaviour

Although some men discussed in the quotes above how they had coped with, and adapted to, cancer through engagement with activities, including sport and exercise, many did not draw on changing health behaviours as part of their coping or adaptation to cancer. Others, in fact, engaged in unhealthy behaviours to help them cope, for example, by turning to alcohol or cigarettes, preventing the adoption of healthier behaviours. This is important since it represents how a cancer diagnosis does not result in lifestyle change for everyone:

Robert: "But it's been a wee bit of a co, comfort having a fag. You know it's eh it relieves boredom as such and I know if you've never smoked you would never miss it because you've never had it to miss."

Rom: "Well I don't say, put it this way, I'll put it badly anyway, but it will probably come about on a day when you might be feeling a bit sorry for yourself you know 'why the hell should I have it and everybody else is (laughs) hasn't got it', I think, but um I think there could be a reflection there, but, and it's a big but, that what I'm saying applies to everybody who's got some kind of disease which isn't cancer which is getting them down and they take to the bottle and it's so easy to do that [...] Ah, the attraction is easy for somebody to pour something into a glass and um it's rather nice and if they hadn't got cancer they would tell

themselves don't be stupid and you don't have to do this and you shouldn't do it. If you've got cancer it's um the hell with it.

For others, although they were aware that lifestyle changes may be of benefit, the systems or people attempting to help them change, did not succeed:

Drew: "I must admit in spite of all the leaflets about diet and the rest of it the cancers I have never changed my eating habits one little bit because I just felt well if I get a problem I'll get it if I don't well I'll be okay. And, and that's just it so why should I change?"

Gary: "Dr [name of doctor] will say to me have you stopped smoking and he goes 'tch' but that's really – they dinnae gie you lectures. It's the same with Dr [name of another doctor] he says 'are you still smoking?' and I says 'yeah' and he says 'Christ!'"

As such, for Drew, the leaflets he has seen about diet and cancer have not helped him to want to change. Similarly, for Gary, although there is potentially a way for health professionals to support lifestyle change, the approach that some doctors take around lifestyle is not always conducive to supporting men to appraise that they can change their behaviours.

For Ian1, efforts by his wife to help him improve his diet were ignored:

Interviewer: "Yeah, yeah so I know I mentioned kind of lifestyle things you feel there's a lot of barriers around engaging men in lifestyle issues as well?"

Ian1: "Yeah because we don't like to be told what to do you know and you but I joke with my wife about that you know [...] we're terribly bad for that. Em, our wives tell us not to eat something specific then we'll go out just [eat it] [...] men don't like to be preached at that's the word when it comes to lifestyle because obviously we know better."

Dissonance was also a strong factor, both in terms of men's perceptions of what lifestyle factors had contributed to their cancer, and around their engagement in some health behaviours. At the same time, Gary shows an element of insight into his dissonance:

Gary: "I havenae stopped smoking which I should have. I've cut down. But you'll think I'm daft, but I've got this wee thing here, I used to take Sweetex instead of sugar, I took it for three or four years and I remember hearing that there was a thing about it could cause cancer so I got that stuck in my head that that's what caused it, it's no the fags so that's probably me just saying, trying to blame something else, it's no the alcohol or the cigarettes it's that bloody Sweetex you know so that's how I think, but I dinnae feel that I need any help or advice on diet or that, I probably wouldnae do anything with it, so [...] I think anybody with any sense would've stopped smoking, but like I say I'm telling myself it's no

that, it's no the cigarettes, it's the [trails off] [...] I would love to know what they would say if I didnae smoke or drink, what caused it. Just out of interest. I think it's too easy to just say it's the fags, but who knows, that's just my opinion. I may be wrong!"

Some men were very much focused on the healthy behaviours they were engaging in and ignored their engagement in unhealthier lifestyle behaviours (dissonance):

Interviewer: "And I know we talked mainly about support services that offer mainly practical or emotional support, what do you think about services that might help people be a bit healthier in terms of smoking, diet, exercise, alcohol?"

David: "Eh well, I don't smoke (laughs). Anyway, sorry where were we?"

Interviewer: "I was just saying about services that might help you improve your health like smoking, diet, exercise, alcohol."

David: "Eh, I don't know I've never, well I don't smoke, I drink, but I don't drink to excess."

Therefore, David does not consider exercise and diet in his discussion of lifestyle, despite it being prompted. Bill's reaction is very similar:

Interviewer: "And in addition to those, there's sometimes services available to help people in view of their health like around stopping smoking, reducing alcohol intake, healthy eating and exercise, how would you feel about going to one of those services if someone suggested it?"

Bill2: "No, I don't drink and I don't smoke so, (laughs), no I don't drink and I don't smoke. Aye, that's about everything I think."

As a result, there remain huge challenges in supporting cancer patients to both use health behaviours as a means of coping, and supporting them to change their lifestyle to support their wider wellbeing and potentially to help manage their symptoms and/or improve medical outcomes for some cancers.

7.8 Brief Discussion

The data presented here first show the key themes that emerged, then go on to discuss these in relation to a modified version of the transactional model of stress and coping. This model assists in explaining men's appraisal of and coping with cancer, and contributes to our understanding of the factors that affect coping and help-seeking in this group. Lazarus and Folkman (1984) acknowledge that the key factors in the model do not always act in a linear relationship. However, the authors of the original model did not represent it diagrammatically. The modified version for men with cancer includes that factors in the model are not unidirectional but loop back. This is explicitly

represented diagrammatically, and is a key facet of the model, rather than an additional discussion point as it seems to have been for Lazarus and Folkman (1984). For example, just as appraisal affects coping, coping can affect re-appraisal. On the whole, the modified transactional model of stress and coping represents the men's narratives well. However, there are times when their narratives contradicted, or at least did not have all components of this modified model. For example, where the utilisation of new coping strategies is not needed, where contextual factors of services do not influence men's help seeking, and when occasional additional factors (such as feeling like a fraud) are expressed by individuals. This has been acknowledged in the discussion, however it is recognised that individual narratives will vary in how much they reflect the model.

The findings around the role of masculinity were interesting. Some men suggested that masculinity was a huge barrier to seeking support, yet they accessed services themselves. This suggests that the perception of the strength of masculinity as a barrier is greater than how it acts as a barrier in day-to-day life for these men with cancer. Thus, ideas about masculinity – common stereotypes – can act as a barrier to engaging in some helpful coping strategies, yet, not to the extent that many people assume. Nevertheless, this remains a barrier for some and challenging or breaking down the cultural stereotypes around masculinity may further assist more men to access services. The broad ideas about masculinity are discussed in the context of cancer. It might be that within this context, the disease may act to legitimise the challenges people face with illnesses and therefore, seeking help and talking

about cancer may be more acceptable. Indeed, the traditional ideas about 'persuasive women' may also help legitimise help seeking for men. Consequently, the masculine ideals become less strong in shaping behaviour. Engagement in activities not traditionally associated with masculinity, that is, talking, crying, accessing services, was also re-framed as a masculine thing to do. Legitimisation of help-seeking through a re-framing of masculinity has been previously found in the area of testicular cancer self-help groups (Seymore-Smith, 2010). Men are having to re-negotiate what is acceptable for them to do and justify their actions based on ideas about masculinity, and expectations of cancer patients.

Ideas about age and generation were also influential. This sometimes assisted older men to cope with cancer, since they did not have dependent children and they felt that they had lived their lives. For younger patients, their cancer was sometimes more difficult to deal with. This was coupled with the fact that some services were primarily attended by older men, who they felt they could not engage well with. This has implications for the way that services are set up. It also highlights, as in the quantitative study, that younger men may be more vulnerable. The role that services play in supporting men to access them is important. This is particularly around accurate and comprehensive advertising, and making these services acceptable to men. In order to attract men, services may need to help dispel any myths or preconceptions about that type of service, along with offering a range of options for support to suit different preferences. Generally, there appeared to be a preference for more informal services, such as the Maggie's centres.

Health behaviours were discussed somewhat less than psychosocial issues or outcomes. When they were discussed, there was often dissonance that contributed to people engaging in unhealthy behaviours, with a minority engaging in healthier behaviours such as exercise.

This modified model, therefore incorporates explicitly the influential factor of masculinity, along with contextual factors around services, which clearly influenced help seeking and health service utilisation. Further, the model builds our understanding of the clear feedback within the model, for example of coping to re-appraisal. The model helps build our understanding of the complex biopsychosocial factors influencing utilisation of coping strategies and services in men with cancer, and gives insight into what may be supportive of better biopsychosocial outcomes for this group. This brief discussion will be further expanded upon in Chapter 8, and built on in the recommendations (Chapter 9).

8. The Relationships between Psychosocial Issues, Health Behaviours, Appraisal, Coping, and Help Seeking

This discussion brings together the research presented in previous Chapters. In particular, the discussion draws on the cross-sectional questionnaire study exploring psychosocial issues, health behaviours and desire for help seeking and, the semi-structured interview study investigating barriers and facilitators to support seeking in men with cancer, along with the broader influence of appraisal of, and subsequent coping with, cancer. It also draws on findings from the systematic review of psychosocial and behaviour change interventions for men with cancer, an update to this review and the wider literature, which reflect a partially changing landscape of relevant research from thesis commencement. Here, the findings will be discussed in relation to the research questions detailed in Chapter 3. Chapter 9 will then discuss how the findings relate to recommendations for research and practice.

8.1 Which Demographic and Disease Factors, including Marital/Relationship Status, Affect Psychosocial Issues and Health Behaviours in Men with Cancer?

Previous research has demonstrated the vulnerability of those without a partner (e.g., Kanski et al., 2006; Wilson & Oswald 2005). This study suggests that in terms of social support and depression, men who are divorced and separated fare the worst and show clinically significant levels of depression compared to men of other marital status. Previous research suggests that one

reason why those who are not married suffer worse outcomes is a lack of social support (Lewis et al., 2006; Shor et al., 2012; Wyke & Ford, 1993). The questionnaire study also found a relationship between low levels of social support and depression. Therefore, being divorced or separated may contribute to depression through lower levels of social support.

The results confirmed previous findings that younger cancer patients may experience greater anxiety and distress with a small clinical significant difference compared to older patients (Linden et al., 2012; Macefield et al., 2009; Step et al., 2013). Results also showed that younger men were more likely to be smokers. Some research has previously found that younger cancer patients may be more likely to engage in poor health behaviours (Eakin et al., 2007; Hawkins et al., 2010; Humpel et al., 2007; Satia et al., 2004). This finding was only replicated here for smoking. In addition, whilst national smoking rates have not specifically been reported previously for men with cancer, in the general population, prevalence of smoking has been shown to decline worldwide in the over 65s, and in Europe (including the UK) in the over 45s (Palipudi et al., 2012; Zatoński, et al., 2012). Accordingly, this finding is not surprising and confirms that population trends are consistent for men with cancer.

Living in an area of high deprivation was a further key factor to indicate poor psychological health, specifically higher risk of depression and anxiety (the clinical significance being stronger around anxiety), and lower levels of exercise. Living in an area of higher deprivation has previously been associated with engagement in less physical activity in the general population

(Mackenbach, 2006; Michie et al., 2008). Depression and physical activity are factors that are often linked in the general population, though it is difficult to determine the direction of the relationship (Harris et al., 2006; Scully et al., 1998). Deprivation may, thus, contribute to both psychological issues and difficulties in the uptake of exercise and exacerbate a possible cyclical pattern. Interventions to improve mood may be required for some cancer patients prior to lifestyle interventions or conversely lifestyle interventions may also assist in improving mood. This may include brief behavioural activation interventions (Hopko et al., 2009) integrated into the start of a lifestyle intervention if targeting people with low mood.

Also of interest are the demographic and disease variables that failed to have any association with psychosocial and health behaviour factors. There were no relationships between rurality or number of cancer diagnoses with any variable. Previously, rurality has only been linked to mortality not psychosocial issues or unhealthy lifestyles (Campbell et al., 2000; Sabesan & Piliouras 2009); therefore, this result is perhaps unsurprising. Multiple cancer diagnoses have been linked to poorer psychological health, but this was not replicated in the current study (Burriss & Andrykowski 2011). Consequently, these factors may not significantly impact psychosocial health and health behaviours over and above other key vulnerabilities.

Age and deprivation were the only demographic factors to be significantly associated with a lifestyle factor; smoking and exercise, respectively. The low number of demographic factors linked to lifestyle suggests that there may not be clear indicators of vulnerability in men with cancer that may highlight those

who may benefit from lifestyle interventions. As such, it may be important to develop ways of screening all men with cancer for health behaviours and offering interventions to those not meeting government or professionally-derived guidelines.

Data from the questionnaire study which aimed to answer research question 1 suggest that being divorced or separated, of younger age, or living in an area of higher deprivation may make men more vulnerable to psychosocial issues and engagement with unhealthy behaviours. All these factors showed a either a small clinical significant difference (where there is at least a 10% difference between groups), or a larger clinical significance (where the two groups will fall into different categories on scales). This means that to the clinician working in practice, it is likely that for all of these factors of vulnerability discussed, there would be a noticeable difference between patients falling into different categories (on average). Knowledge of the demographic factors contributing to a person's vulnerability may provide a useful tool in addition to screening and clinical interview to assist with early identification and provision of support for psychosocial problems and behaviour change.

8.2 What is the Relationship among Psychological Issues, Social Factors, Health Behaviours and Desire for more Help in Men with Cancer?

Some important demographic factors explored in the questionnaire study were identified as contributing to poorer psychological health, as discussed above. Lack of social support, however, was a consistent indicator in these relationships, being associated with worse psychological health and greater

levels of smoking. Lack of social support has been linked to poorer psychological health in the general and cancer populations (de Leeuw et al., 2000; Linden and Vodermaier, 2012; Mehnert et al., 2009). Therefore, it may be that this factor prevails as having a strong link with psychological variables over and above demographic variables. Given that men tend to seek support less than women (White & Banks, 2004), this may indicate a need for services to identify men with psychological difficulties and intervene to help them to seek support that suits their needs.

Social support was also associated with smoking, which has been discussed previously contributing to poorer health behaviours (Piwoński *et al.*, 2012; Wyke & Ford, 1992). Having social support has certainly been shown to increase a smoker's chance of quitting in the general population (Mermelstein, 1986; Murray et al., 1995). In prostate cancer patients, Kassianos and colleagues (2015) found that men need support from their partners in order to make dietary changes, further indicating links between support and lifestyle change.

In addition to the analyses discussed above, structured equation modelling aimed to provide further insight into the relationships among social support, distress, health behaviours, and desire for help. These results highlight the complexities among these relationships. The modelling analysis revealed that, social support affects distress, as previously found (Karnell et al., 2007; Scroevers, et al., 2003; Walker et al., 2006) which in turn affects desire for help (Steginga et al., 2008). As such, distress is the mediator between social support and desire for help. Therefore, only if men with cancer are experiencing anxiety,

depression, or distress coupled with lower levels of social support will they typically desire additional help. In other words, low levels of social support alone are not enough to lead men with cancer want more support. Previous research has shown that men's help seeking for mental health problems is independent to the severity of distress, and that both men and women may cite a perception that their difficulties are not severe enough to warrant help seeking, or that they would rather manage it themselves (Clover et al., 2014; Leydon et al., 2000; Nekolaichuk et al., 2011; Oliver et al., 2005).

The modelling data support and build on this by suggesting that it is a combination of low social support and distress that triggers seeking help in men with cancer. Accordingly, social support may have an influence on men's desire for more help around psychosocial issues and health behaviours, but only if that person has emotional difficulties at the time. Yet, men may experience distress in ways that are different to women, and this could lead to a lack of acknowledgement, or recognition by others, that they are distressed, given that women's ideas about distress dominate western culture (Kilmartin, 2005; Ridge et al., 2011). Therefore, health professionals working in oncology may need to be aware of this and ensure that men's psychological needs are assessed and addressed. It may also be possible to coach patients to self-assess their own emotional state at the appropriate stage in their cancer journey, which could be key to enabling them to get more support.

Distress plays a key role in men's awareness of the need for help, as well as actual need. Men with cancer may desire more help for a range of issues (including lifestyle change) because of experiencing psychological

distress. It may also mean that having psychological distress is a key factor in legitimising help seeking. The acceptability of seeking help for health-related issues can be linked to family values, community capacity, more general cultural norms, the need to conceal vulnerabilities, the need to legitimise any help seeking, and specific social norms (Kilmartin, 2005; Robertson, 2007; Seymour-Smith, 2010; Sloan et al., 2010). Robertson (2007) contends that men alone can change their behaviours should they wish to do so. Consequently, wanting help for these issues may challenge their own ideas about their masculinity and expectations of themselves or others about what they should be able to achieve on their own. Research exploring the ideas about masculinities produced in Men's Health magazine in the UK suggests that messages may reinforce the role that men can play in managing their health, yet, this may counter help-seeking efforts (Crawshaw, 2007). Therefore, men's ideas about masculinity may play a role in their help seeking efforts (or lack of), yet, psychological difficulties may support them seeking help through legitimisation.

Men's difficulties in attending support services may be further compounded by the multitude of campaigns and charities for women's health issues, raising the profile of cancer in women to the potential detriment of men's health (O'Brien & White, 2003). This is coupled with a historical lack of advocacy for men's health issues (Scott et al., 2010). Together, these factors may have resulted in fewer targeted interventions for men, impacting men's experience of cancer, their ability to accept their own need for additional support and, therefore, their expressed desire for more help for psychosocial issues and health behaviours. For example, there may be particular difficulties for men with

prostate cancer who are undergoing androgen deprivation therapy. This can cause a loss of function of sexual organs, which can be problematic due to men's ideas about what it means to be a man (Aucoin & Wassersug, 2006). Re-negotiation of meanings around masculinity or a re-affirming that they are masculine in other ways may be particularly required for this group (Coles, 2009; de Visser & McDonnell, 2013).

These findings help clarify some key areas for intervention with men with cancer. A crucial issue is that the desire for the provision of greater levels of support is dependent on the distress experienced by the patient. Accordingly, screening for distress alongside enquiring about desired support may assist in enabling men to access any needed services (Waller et al., 2013). Distress, rather than lifestyle behaviour, also predicted respondents' wanting help to improve diet and exercise as seen in the modelling analyses. Accordingly, where a person presents with both emotional difficulties and health compromising behaviours, distress and emotional adjustment may need to be targeted first prior to tackling goals related to lifestyle change. In summary, psychosocial issues dominated rather than the patient's lifestyle behaviour in influencing whether or not someone desired more help to change health behaviours. This may in part be due to a lack of awareness or focus of lifestyle on one's health, compared to the more direct negative effects people face from emotional difficulties, which may legitimise their desire for more help. Further implications for how services could respond to this are detailed in Chapter 9.

8.3 What, if any, Additional Support do Men with Cancer Desire for Improving Psychosocial Issues and Health Behaviours?

This research question was answered by the findings from both studies (questionnaire and interviews). The quantitative research gave an indication of the percentage of participants desiring more support, and gave insight into the type of support desired. For example, roughly 12-14% of people desired more support to help them feel less distressed, have less anxiety and depression, and to overall feel more supported. In general, men seek help less than women and unmet need exists among men for a range of issues (All Party Parliamentary Group on Cancer, 2009; National Cancer Intelligence Network, 2009; Puts et al., 2012; Smith et al., 2013; White & Banks, 2004). However, less is known about men's desire for more support and indeed whether this is related to help seeking. Desire for help may not directly translate to a need for help either. Nevertheless, it acts as an indication of perceived unmet need. For example, there may be people who need help but do not desire it and vice versa. This is perhaps reflected by only around half of those who fell in the range of distress desiring more help, in line with previous research looking at those who access help (Waller et al., 2013). However, there was a significant relationship between poorer scores on all psychosocial issues and wanting more support for that issue, indicating at least some overlap between psychosocial difficulties and desire for help.

These findings may collectively indicate that some men feel they have the support around them to cope with emotional difficulties, have the strength themselves to cope or they may feel unable to access support services and

therefore do not desire help. While others who are in need do require and desire more support. Interestingly, of the men who were interviewed, most did not express a great need or desire for more psychosocial health. Many men were already accessing services, while others had developed ways of coping. Yet, men did recognise that there were times when they did want or need more help prior to getting it. Men also reflected that they would have benefitted from accessing help sooner. Work to help reduce barriers to seeking help may be needed and will be discussed further in section 8.4.

When detailing the type of support men would like around psychosocial issues, much of this centred around problem- and emotion-focused supportive strategies. Desired practical help identified in the questionnaire study included domestic and gardening assistance, respite care, and more company. It also included a desire for support around specific areas, such as exercise and nutrition, sexual or urination problems, help for concentration and restlessness, as well as being able to talk to people and have more time and space for themselves. Only a few people commented that they would like more meaning-focused support, which was focused on spirituality. In addition, there was a fairly even mix of participants desiring support to come from friends and family versus professionals. This indicates that there may sometimes be a need for greater access to services by professionals, and other times, men may need to be better supported to utilise or ask for support from friends and family.

Where support was desired from professionals, men wished this to come from their GP, a support group, a counsellor or sometimes anyone who could help and/or home visits. This suggests that the professional providing the help

did not matter to men with cancer, as long as they were able to meet their needs. Some men in the interview study also revealed specific services that they would find beneficial such as, a life coach or a buddy and services that you could just drop into as and when they needed a bit of extra support. Previous research has suggested that men with prostate cancer mostly desire support to be individualised, to come from their partner or one-to-one peer support (King et al., 2015; Shapiro et al., 2004). The questionnaire and interview studies suggest that men with any cancer may desire a broad range of support and indicates the need for tailoring of support to individuals.

There was a preference by some men for support to come from female staff members and volunteers. Yet, others felt that more male staff and volunteers may help more men to attend services. This indicates that individual preference is important in relation in some contextual service-related factors. Many of the suggestions men made for the types of additional support that may be of help are already available to cancer patients (e.g., drop-in services for support, nutrition classes, medical and psychosexual help for sexual problems). Men, though, were not always accessing these services. Therefore, there may be a need for services to undertake better advertising and promotion, in ways that help men to want to attend. Staff who are in regular contact with patients may need to encourage use of these services.

When examining the support men may want around improving their health behaviours, a more mixed picture emerged. Desire for more help assessed in the questionnaire study was high for smoking (60%). This may be influenced by smokers reporting that they felt unconfident to stop smoking,

therefore, being more motivated to seek support. Smokers, however, were not specific in what help they would want, other than mentioning medication. In addition to confidence affecting desire for more help, increased media attention on smoking cessation programmes and the wide availability of a range of methods and services to help people quit smoking may legitimise seeking help. Indeed, some evidence shows a correlation between mass media campaigns and uptake to NHS stop smoking services in the UK (All Party Parliamentary Group on Smoking and Health, 2010). Conversely, the desire for more support to reduce alcohol consumption was very low, which could have been influenced by most drinkers feeling confident that they could reduce their drinking if they wanted to. This is also perhaps due to the stigma that is often associated with seeking support to reduce alcohol intake (Keyes et al., 2010; cf. Schmidt et al., 2007). There may also be a lack of recognition that alcohol consumption is relevant to health status, other than the better known effect upon liver problems.

For diet and exercise, desired support by the sample of men with cancer was 36-43%, perhaps suggesting that support, in the right context and mode may be desired and accessed by some men with cancer. Typically, interest in interventions to improve diet and exercise has been lower in men than in women (Adams et al., 2015). The results found here give promise that it may be possible to harvest men's interest in interventions to improve their diet and activity levels. In the open answer questions, there was a very wide range of support desired for exercise and diet, within the problem- and emotion-focused support categories. Men desired support in finding the right diet, nutrition and recipes, along with cooking classes, practical support in coaching them in doing

exercise, and working out an exercise regime. One person suggested that changes to the environment may be supportive of their lifestyle change around more pre-prepared healthy choices in shops. Others suggested that they needed more support, encouragement and motivation; thus, services utilising behaviour change techniques may be of benefit to these patients. It was noteworthy that in the interview study, men did not reveal wanting support for exercise or diet. Dissonance may have played a part in men feeling that their lifestyles were good and therefore, would not need or desire help for these issues.

Overall, results from both studies suggest that there are various contexts, such as service-specific factors and cultural factors that affect whether or not men desire additional support. Men sometimes have to accept their own desire for more support through legitimising their physical or mental health severity. Desired support centred on emotion- and problem-focused coping strategies. Some men, however, do not desire any additional support and appear to cope well with a cancer diagnosis, without needing to utilise additional coping strategies. The next section will discuss further the factors that influence whether or not men seek help for the issues they face, focussing on the barriers and facilitators that men may have in accessing support.

8.4 What are the Barriers and Facilitators to Men with Cancer Seeking Support, including the Influence of Masculinity?

Findings relating to this question are evident throughout the qualitative analysis and touched on in the questionnaire study. Some men discussed that

there was no need for support or that there were no barriers. Others discussed that things were getting in the way of them accessing support, or that factors has previously acted as barriers. The relating of the findings to the transactional model of stress and coping bring a depth and breadth of understanding to this issue. The strongest factors acting as barriers and facilitators will be discussed below, before a discussion of the whole model and how it can help us understand barriers and facilitators to men's service access.

8.4.1 The role of masculinity in help seeking

The qualitative data reveal the added complexities of cultural factors, particularly the role that masculinity plays. For example, some men felt that masculinity is a barrier to admitting they may be struggling, to talking with others and to help-seeking. This is in line with previous literature suggesting that seeking help can be perceived as a threat to masculinity, and that men with cancer may want to preserve a masculine image when ill to avoid appearing vulnerable (Courtenay, 2000; Handberg et al., 2014; Wenger, 2013). Others expressed that showing emotions can be a masculine activity, and engagement with support can be a way of taking control as a legitimate way of improving their wellbeing. Psychosocial difficulties may help to legitimise help seeking, despite the perceived pressures of masculinity.

A diagnosis of cancer itself may too legitimise help seeking, due to the perceived severity of cancer in society. Men, therefore, negotiated their own coping strategies as being acceptable and 'right' for them, though these stories differed immensely in how masculinity was framed and how it influenced their individual perceptions and choices. Legitimation of help-seeking through men

becoming accepting of their self-help group participation has been previously documented (Seymore-Smith, 2010). Re-framing behaviours not traditionally associated with masculinity (e.g., talking, crying, help-seeking), as being part of their own masculinity, or aligning with other traditionally masculine constructs including taking action and responsibility, has been discussed previously (Emslie et al., 2006; Farrimond, 2012; Johnson et al., 2012; O'Brien et al., 2005).

Masculinity also appeared to influence the types of coping strategies that some men were willing to utilise. For men who shunned the idea of more support, they typically engaged in problem-focused strategies (for example, engagement with enjoyable activities). This type of coping appeared to be more acceptable to these men and was perceived as more helpful to them than emotion-focused strategies would have been.

For most participants, once their ideas about masculinity had been re-negotiated, it was not a significant barrier to accessing support. Some men were very aware of how traditional ideas about masculinity can influence pressures that men face, and their behaviours (Wenger, 2013). This may have helped them to accept a different narrative around masculinity and therefore seek help. Ideas about masculinity never, though, seemed to be framed as a facilitator. It was more the way it was used or reframed that may have supported men to access services.

There were also different opinions by study participants around whether men and women are different in their approach to coping with stressors and seeking help. Some men felt that there was no difference between men and

women's ability to access support services; they felt it was more down to individual factors. Many of the men who suggested that ideas about masculinity were a barrier to men's help seeking had in fact sought help themselves. It may be that perceptions of masculinity as a barrier is stronger than masculinity as a concrete entity. However, this may mean that common ideas about masculinity are reinforced for some men, and those who cannot legitimise their help seeking in some way may struggle to seek help. Many men, therefore, recognised masculine pressures, yet also saw the strength of individual factors in help seeking. One man also discussed how he would be happy to discuss his difficulties with men but that he perceived that other men did not want to do so; therefore, he only discussed these things with women. Accordingly, some men with cancer may avoid seeking help from male friends who could be reluctant to support them, since their male friends remained to be influenced strongly by ideas about masculinity, or there was a perception that this was the case.

Men may especially perceive threats to their masculinity if they have prostate cancer, since these perceptions have been shown to shape emotional coping and functioning (Hoyt et al., 2013). Testicular cancer can also be seen as particularly threatening to masculinity for men, yet, men also reconstruct their own ideas about masculinity (Gurevich et al., 2004). Therefore, interpretations of potential threat based on cultural ideas of what it means to be a man is significant in shaping men's reactions to cancer, and help seeking behaviour. Given that men have been found to re-frame their ideas about masculinity, it is possible that being confronted with a large perceived threat to masculinity (e.g., testicular or prostate cancer) may act as a catalyst for such re-framing. Some

research suggests that masculinity can be capitalised on in a positive way to promote help seeking and engagement in healthy masculine behaviours, particularly through accruing 'masculine capital' through the engagement of traditionally masculine behaviours (de Visser & McDonnell, 2013; Gough, 2013). For example, if men engage in traditionally masculine behaviours, they may feel that they have accrued 'masculine capital' (though engagement in 'masculine' activities) so are more able to engage in activities that do not align with their ideas about masculinity (Gough, 2013).

However, interventions may need caution when utilising 'masculine capital' since programmes aimed at drawing on masculine ideals to attract men to change their behaviours, in this case weight management, have been shown to enhance men's perceived masculinity (Hunt et al., 2013). There are also men's 'manuals' (that are reminiscent of car manuals) that exist aiming to help enable men to be healthier (Gough, 2009). However, Gough suggests that some health promotion approaches may reinforce some of the factors that act as barriers and consequently, may be counter-productive. These health promotion approaches that capitalise on and preserve masculinity may support men into such programs, but may not help change men's attitudes towards help seeking more broadly, and barriers to help seeking in other contexts may remain.

Links have also been found between men's ideas about masculinity and engagement in risky health behaviours (such as alcohol use and driving without a seatbelt; Mahalik et al., 2007). If men perceive their risk behaviour to be 'compatible' with their masculinity, this may too influence their desire to change,

as well as their desire to seek help to change. Conversely, engaging in healthy behaviours, such as exercise, healthy eating and reducing smoking, can be seen as 'physically strengthening' and therefore adopted by men with cancer (Wenger & Oliffe, 2013). Interventions may need to strike a careful balance between utilising traditional masculine ideas in ways that do not result in unintended consequences (such as enhancing barriers to men accessing other services) and advertising services so that men are inclined to attend.

What appears to be evident from the data is that it is (men's differing) ideas about masculinity rather than masculinity *per se* that is influential in their appraisals of cancer and their utilisation of different coping efforts. Utilising talking and engaging with supportive service are particularly influenced by ideas about masculinity. These culturally-embedded ideas, however, can be challenged since they may not accurately describe the embodiment of masculinity by the majority of men and/or men are able to re-negotiate their relationship with the concept of masculinity and find ways of legitimising help seeking.

8.4.2 The role of other antecedents

Although masculinity appeared to be the strongest antecedent within the transactional model of stress and coping that related to service access, there were other antecedents of note. A second cultural factor of importance was ideas about age and generation. Several men who saw themselves as older, had lived full lives, and/or had grown-up children felt that they were able to cope with the threat of cancer better than younger patients may be able to. For some, this was a key factor in them coping with cancer and having no need to seek

help. This also sometimes tied into meaning-based coping, whereby men would develop an acceptance of their cancer and/or frame their lives as having had purpose and meaning, and therefore, there was a greater acceptance of the death. For younger men, cancer and the threat of death was more problematic. In addition, the dominance of cancer support services by older men could be off-putting for younger men. As a result, services may need to consider ways to engage young men with cancer in acceptable ways.

Sometimes, the difficulties experienced by men with cancer were relating to other situational factors (environmental antecedent), for example bereavement, and not the cancer. This suggests that difficulties for some men who have cancer are unrelated to the cancer and therefore, any support desired may be more in relation to other issues. This is important to note, since health professionals may have a role in helping support the wider factors that are influencing coping in men with cancer.

Disease (biological antecedent) factors were also prominent. Several men discussed how their cancer was not very severe and/or that their prognosis was very good. Hence, their appraisal was that it was manageable and either they did not feel that they needed to develop ways of coping, or that they easily put in place some coping mechanisms that enabled them to adapt easily to having cancer. These men did not generally access any support services, nor did they feel the need to. For others, the disease was more severe and/or terminal. This led to a more challenging appraisal and at times men were not able to cope well with having cancer. For these people, additional support was almost always needed, which often helped. Similar findings have been reported

previously, whereby those feeling that the cancer was treatable coped better, and perceived severity of cancer had a stronger effect on emotional difficulties than other variables such as coping effort (Hopman & Rijken, 2015).

Interestingly, the disease status was sometimes used to legitimise help seeking. In other words, having a narrative of a severe disease meant that accessing help was acceptable and almost expected. Conversely, disease status could act as a barrier for some people who perceived their cancer as not severe who may have benefitted from more support. Cancer patients often meet other patients who may have worse disease status or prognosis. For men whose disease status is better than others, this can act to reduce the legitimacy of them needing help and therefore they are less likely to seek help. One participant in the questionnaire study felt that a barrier to them accessing support was that they felt that other people more in need should be prioritised, which reinforces this point. If there is no legitimisation through disease status, these men may need more support to access further services where needs do exist.

Several individual (individual/psychological antecedent) factors influenced the types of coping and help seeking utilised. Quite simply, a positive attitude towards some coping methods and/or help seeking facilitated men to access support services, or utilise emotion-focused coping strategies. This was sometimes influenced by extraversion. This personality trait may mean that some men are more outgoing and comfortable talking to others, and thereby influencing the attitude to engage with certain services (Von Dras & Siegler, 1997).

Individual awareness of the link between lifestyle and cancer seems to be influential in whether or not men show adaptations to their lifestyle. The questionnaire study showed that other than for alcohol, there was no relationship between being engaged in unhealthy behaviours and desire for more help for that issue. It may be that there is a lack of awareness of the link between lifestyle and cancer, except for smoking where the effects upon lung cancer risk are well known (Ferrucci et al., 2011; Sanderson et al., 2009). This was evident in the interviews where men showed dissonance around the potential causes of their cancer, sometimes dismissing the role of lifestyle. An ambivalence around the acceptance of the role of lifestyle in cancer has previously been found (Bell, 2010).

Men's own dissonance may be coupled with little discussion by cancer medical teams that exercise, diet and weight may have contributed to their cancer. Linked to that, there may also have been a lack of discussion around the role that lifestyle may have in affecting their current cancer prognosis, recurrence or other cancers (Miles et al., 2010). Naturally, this may have some positive effects for patients' psychological health through helping them distance themselves from the fact that lifestyle may have contributed to their cancer and consequently minimising any guilt. However, given the links between healthy lifestyle behaviours and mental wellbeing (Dale et al., 2014), along with potential positive effects of lifestyle change on cancer recurrence and/or outcome, there may also be missed opportunities for lifestyle change both through information available to the public, and from discussion from health professionals (Daley et al., 2008; Keogh et al., 2013; Williams et al., 2015). This

is further supported by the quantitative data which showed that 10-19% of people had not thought about changing their health behaviours.

As such, there appears to be further opportunities for health professionals to promote the benefits of living a healthy lifestyle. This is pertinent given that there are mixed research findings around whether a cancer diagnosis results in lifestyle change. Other than for smoking, where cessation is easily measured, self-report of change appears to be higher than more objective measures. Therefore, people's perception of change may be greater than actual change (Bluethmann et al., 2015; Broderik et al., 2014; Hackshaw-McGeagh et al., 2015; Hawkins et al., 2010; Karlsen et al., 2012; Low et al., 2014; Parsons et al., 2010; Stevinson et al., 2013; Thorsen et al., 2008; Westmaas et al., 2015; Williams et al., 2013).

Psychosocial health also influenced desire for help for lifestyle issues. As discussed above, the modelling data suggest that lack of social support coupled with experiencing mental health problems can lead to people wanting to seek support. The mediation analyses showed that distress also affected desire for more help for improving lifestyle factors, whereas the addition of health behaviours to the model did not significantly alter the model. Poor psychological health in individuals may motivate a desire for help in many aspects of men's lives. Further, poor psychological health may have a greater influence on desire for more help to improve lifestyle issues than lifestyle status in men. Therefore, the factors influencing whether or not men want more support for lifestyle issues are highly complex.

It appears that social support, psychological health and wider social factors, including stigma and societal narratives around the causes of cancer, may influence help-seeking. There is little doubt then that challenges remain around motivating men to improve many lifestyle behaviours that may ultimately improve their long-term health following a cancer diagnosis (Demark-Wahnefried et al., 2007). Accordingly, a whole range of individual factors may affect psychosocial and lifestyle adaptations in men with cancer.

Consequently, a range of antecedents appear to influence appraisal and coping with cancer and the adaptations or outcomes. As discussed, ideas about masculinity appear to be the strongest, but individual, environmental and biological factors also have an effect and are well captured by the transactional model of stress and coping.

8.4.3 The effect of service-specific contextual factors

Although not part of the original transactional model of stress and coping discussed by Lazarus and Folkman (1984), service-specific contextual factors had a clear influence on help-seeking behaviour.

Practical factors affected service access. This tended to revolve around the ability to travel to access services. It is not surprising that practicalities affected utilisation of support, and services may need to consider this in models of delivery. Similarly, time got in the way of men going to support services. For both of these barriers, however, the men referring to practicalities and time as barriers to help-seeking, they discussed how they did not feel a great need for more support. Therefore, for most men with cancer, perhaps where support needs are greatest, time and practicalities can be overcome to enable access.

Gatekeepers, such as nurses and social care professionals, were highly influential in men's utilisation of services to help them cope with cancer. Interview data showed that gatekeepers let men with cancer know about support services, which often led to them accessing such support quickly. Gatekeepers perhaps played different roles. The first was information provision about services that men may have not known about or that they did not know they could access, due to misconceptions. Secondly, gatekeepers legitimised men with cancer to access services through the suggestion that a man may benefit from accessing services. Conversely, gatekeepers made decisions about whom to inform about services based on their own perceptions of who would be interested and likely to attend.

There were times when men with cancer discovered a service years after first being diagnosed. Often they had no recollection of ever being told about such services, and indeed felt that they would have benefitted from accessing the service(s) sooner (e.g., as soon as they were diagnosed). Of course, it could be that services had been discussed with these men by health professionals, but, if this is done at the time of diagnosis, men may not take on board this information due to the emotions that can emerge at the time of diagnosis (Mills & Sullivan, 1999).

There is potentially a role for services to provide written information or to inform men of available services at several time points to help encourage men to access them should they wish or need to. Similarly, men may have heard of services and there could be missed opportunities for gatekeepers to encourage access. By not doing so, there is no legitimising of help-seeking for men with

cancer and more unmet need may arise. There is a dearth of literature around the role of gatekeepers in supporting patients to access services. Where this does exist, it suggests that gatekeepers can play a key role in helping people with suicidal ideation to access help and support (Hom et al., 2015). The findings discussed here support this and go further to suggest that gatekeepers have a role in legitimising help-seeking. Naturally, any encouragement from professionals for men to access services would have to be done in a sensitive and appropriate way, given the low confidence and/or general reluctance to accept support that some men with cancer experience. Health professionals working in the field of cancer may benefit from further training in men's health issues, to help them to better tailor support to them (McCaughan & McKenna, 2007).

Accessibility and advertising of services were also significant barriers or facilitators to men accessing support. There were times where desired services were not available, or where it was problematic for men to access them because they had cancer. For example, accessing fitness centres can be difficult due to concerns by centre managers about the health risks for cancer patients. NHS services may not always be available at the time of need, for example physiotherapy for rehabilitation. Advertising of services was influential both in informing people about a service that they may not have known of but also in helping people have accurate views of services, since the interviews suggested that men's ideas about services were not always accurate. One man discussed the off-putting advertising of a service, which talked about a cancer patient. Others had clear misconceptions about services, which did not make

them want to utilise them. Services have potential to support more men to access them through better advertising, as well as improved accessibility.

The mode of support (i.e. how it was delivered) was important to many participants. There was significant discussion about how informality was key in providing support. An informal service delivery was one of the reasons that many men benefitted from the services offered by the Maggie's Centres in the voluntary sector. Further, in the questionnaire study, it was found that of support services accessed, Maggie's cancer caring centres were by far the service accessed by the majority of respondents. The informality of Maggie's Centres is particularly apparent when compared to traditional NHS support services since it offers drop-ins at any time, informal chats, as well as a variety of groups that can be attended when desired. Cancer support groups were the next highest accessed service which were often run jointly by the NHS and Maggie's centres. Other health professionals, including psychologists were only accessed by five out of 127 participants in the questionnaire study. The interview study supported the idea that the informal nature of Maggie's Centres, along with the range of services offered is attractive to many men. Men specifically discussed being put off by services that they would have to commit to regularly attending. Some men who did not wish to utilise services were willing accept informal support from people they know and indeed informal support from professionals when it was not labelled as 'support'.

People's confidence to access services also impacted on service access, as evident from the questionnaire study and from the interviews. Many men commented how they would not have accessed support services had it not

been for the influential females in their lives (wives, sisters, or friends) that supported, encouraged, or persuaded them to access support services. Indeed, these women may be supporting the legitimisation of men accessing support services (Seymore-Smith et al., 2002). Research has shown that women who attend prostate cancer support groups with men, typically take on the role of 'social facilitator' (Bottorff et al., 2008). Women may, therefore, help facilitate social connectedness within support settings, in addition to assisting men to attend support.

Lastly, again in relation to seeking help, sex of the support provider was important to men, although they differed in their preferences for this. This demonstrates the diversity of the needs of the sample and men more broadly, and highlights the challenges that services have in engaging men with cancer. There was a quandary between feeling that men may rather speak to other men, especially around sexual issues, yet, that this may bring challenges, since men would not want to seem vulnerable in front of other men. It is clear from the data discussed above that services can, do and should have a key role to play in helping men to access them and feel that they can access them.

8.4.4 Bringing together the transactional model of stress and coping

Some key barriers and facilitators to men accessing further support have been discussed above in relation to antecedents and service-related contextual factors. These are all part of a wider picture of how the appraisal of, and coping with, cancer can act as barriers and facilitators to help seeking. It is clear that the rich dataset from the interviews presents a complex picture of coping with

cancer, acceptance and receiving of support, and gives insight into the coping strategies men utilise. Although the original aims of the study were to explore support use and its barriers and facilitators, wider factors have emerged that are evidently influential, which has led to the framing of results within an expanded version of the transactional model of stress and coping for men with cancer. This model, along with service-related contextual factors comprehensively represents the data. The transactional model of stress and coping is a useful way of conceptualising the journey of men with cancer from diagnosis to adaptive changes. As noted in Chapter 7, there are negative cases where individual's narratives deviate from the model slightly. Since these represent minor points that were coded for single individuals, these were not integrated into analyses, as were not representative of multiple individuals.

In exploring the data in relation to the transactional model of stress and coping, the primary appraisal responses varied. Most appraised a cancer diagnosis as stressful and inducing fear, fatalism, and/or denial. Some, however, found it manageable either from the start or once an initial period of shock and fear had passed. Secondary appraisal reflected that most people perceived the cancer to be uncontrollable. Nevertheless, sometimes men felt that with cancer treatments and their existing coping strategies, it was more in their control. Past coping behaviours affected people's perceived ability to engage in helpful methods of coping. Self-efficacy had an influence here too, which has previously been reported (James et al., 2006). This suggests that interventions to increase self-efficacy to engage in methods of coping for men with cancer may be helpful.

A wide range of coping methods were utilised in response to a cancer diagnosis. Men's emotional coping strategies and their perceived usefulness varied. For example, some approaches, such as distraction, talking, and relaxation were seen as helpful to some people. Anger was the primary coping response that was perceived as unhelpful by men. It is possible, then, that men may be more amenable to seek and accept help to address anger if they perceive it to be unhelpful. Attitude towards engaging in some coping strategies was particularly influential around help seeking and talking, which likely is influenced by men's own ideas about masculinity and/or how much they subscribe to common discourses of masculinity.

Many men, however, did engage in relaxation and talking, which helped to improve their psychosocial health. These activities (relaxation and talking) are not generally considered 'masculine' in the UK. Yet, many sought to legitimise this through the fact that they had been diagnosed with cancer, the severity of their cancer, or that a 'persuasive' woman (e.g. a wife) had supported them to engage in activities. Therefore, a physical diagnosis and support from others can legitimise psychological difficulties and help seeking for this. The use of humour to cope with the challenges of cancer was a common thread, which is a strategy that has previously been related to reduced stress in cancer patients (Christie & Moore, 2005).

As discussed earlier, dissonance about men's own health behaviours appeared to support avoidance of engagement with some health behaviours that could have been helpful in coping with cancer. This was especially evident around exercise and diet, whereby those who did not smoke or drink to excess

seized on their non-smoking and drinking status to re-frame themselves as 'healthy' people. Therefore, they perceived that they could not make changes to improve their health. Being accepting of health promotion messages for men has been discussed as admitting weakness (Doyal, 2001). Consequently, dissonance may assist men in avoiding feelings of weakness. Dissonance served a second purpose in enabling some men to distance themselves from their own behaviours that could have contributed to cancer. For example, some men drew on discredited risk factors such as sweeteners and waxing as having influenced their cancer onset, rather than the more established risk factors of smoking and sun exposure. It is known that people commonly exaggerate or underplay their risk of cancer, which can be related to lifestyle behaviours (Peters et al., 2006).

Some research suggests that the vast majority of patients with cancer feel that advice on lifestyle would be beneficial and that they feel it is the doctor's duty to discuss this and most suggested that it would not be intrusive or suggest blame (Williams et al., 2013). Recent research also suggests that there may be link between cancer patients recalling having received lifestyle advice and engagement in healthier behaviours (Fisher et al., 2015). Staff are not always sure as to the best time to discuss lifestyle and they have a tendency to have such conversations with patients that they perceive as more motivated (Coa et al., 2014). Training needs for cancer professionals around discussing weight management have been highlighted, therefore, health professionals may need to be supported to feel more confident to discuss sensitive issues around lifestyle change (Anderson et al., 2013).

The media's role in reporting risk factors for cancer may contribute to people's ideas about cancer risk and 'assist' them to re-frame some of their behaviours that are strong risk factors for cancer as less important in contributing to their disease status (Clarke, 2004). There is increasing awareness in the UK that lifestyle contributes towards cancer (World Cancer Research Fund, 2015). However, only half of Britons believe that being inactive is a contributing factor to cancer (World Cancer Research Fund, 2015). Therefore, people may not always be aware of the links between lifestyle and cancer. Furthermore, there are critiques of the war on cancer because of seeing cancer as an 'enemy' that is hard to fight (Hauser & Schwarz, 2015). It is, thus, feasible that the focus on a 'war on cancer' may distance people from their own roles in the prevention of cancer and the adoption of healthy lifestyles once diagnosed with cancer.

When exploring problem-focused coping efforts, these were all considered to be helpful strategies by men. Participants found practical ways to cope with cancer through information and help seeking, problem solving and engaging with activities that they found enjoyable. Similar to problem-focused coping, all meaning-based coping strategies were also perceived by men as helpful. These were: acceptance, a factor frequently associated with coping with a condition and psychosocial adjustment in women with cancer (Stanton et al., 2000); spiritual or religious coping; and finding purpose or meaning, which again have previously been shown to be helpful to psychosocial wellbeing (Yanez et al., 2009).

Social support in its various guises - emotional, practical, and informational - was received by all participants, with emotion-focused coping the most prominent. Support generally helped men's adjustment to, and coping with, cancer, which is consistent with the well accepted stress-buffering hypothesis (which proposes that support can help buffer the effects of stressful events; Cobb, 1976; Cohen & Wills, 1985). This included social support from others to engage in coping strategies that were helpful, where very often it was a female partner, relative or friend that 'pushed' or supported men to access support services. Seymore-Smith and colleagues (2002) argue that men's framing of being pushed by someone else to access support helps men negotiate acceptance of the help they need. This appeared to be evident here and may be helpful for some men to feel that seeking help is an acceptable coping strategy. Being pushed by someone else to seek help may also feel acceptable to men, given that a traditional discourse among men can include the 'nagging wife' (Weiner & Boss, 1985; p18) where women can persuade them into things. This may be particularly useful in men who endorse gender role stereotypes and their own gender identity (de Visser & McDonnell, 2013). Traditional ideas about masculinity again show relevance; this time in a way that may be supportive of men seeking help.

Men's health scholars increasingly discuss how men's behaviours relating to health is very much shaped by context (Calasanti et al., 2013; Gough, 2006). In this thesis, cancer is the common context and may itself legitimise help seeking. Further contexts of experiencing distress and/or a 'nagging' wife or female in their lives can further legitimise help seeking.

Therefore, having cancer may support men to seek help, and additional contexts may shape this further. This influential factor may have implications for single men should they have few people around them to support such activities, and could potentially lead to further vulnerabilities in an already vulnerable group. Indeed, single men with cancer have been found to have difficulties in receiving the type and level of support that they desire from friends and neighbours around them (Benoot et al., 2015).

In addition to social support, the individual/psychological antecedents such as introversion/extraversion and optimism appeared to influence coping. Introversion often led to less engagement in support services and talking to others, which has been documented previously (Von Dras & Siegler, 1997). There was no direct suggestion from the participants who identified themselves as introverted that non-engagement with support services had any negative effect on their psychosocial health. However, some of these men discussed struggles with depression or worries for which some services could have supported them with. The qualitative study showed that the need for additional support is very much influenced by appraisal of cancer, utilisation of existing coping strategies, and the wider individual, social, environmental, and biological antecedents. The transactional model of stress and coping helps represent the qualitative data that emerged from the interviews conducted with men with cancer.

The transactional model of stress and coping in the field of cancer has been seldom utilised. The model was recently used by a research team through qualitative methods to explore and explain support needs in head and neck

cancer patients (Pateman et al., 2015; Moore et al., 2014). They found that the original model (Lazarus and Folkman, 1984) stood true; however, it was represented a little differently diagrammatically since they explicitly showed a cyclical model. The model has also been used more broadly to help explain the reactions, coping, and implications for required support in a critical care population (Byers et al., 1997). The research presented here, perhaps shows the relevance of this model to a larger and broader cancer population than has previously been studied. Compared to previous use of the model in cancer patients (Pateman et al., 2015; Moore et al., 2014), here, the strong influence of masculinity is evident, as are the contextual factors of services. Therefore, the model emerging from this research differs somewhat to that previously found and highlights additional important factors.

It is also important to note that the data revealed that not everyone has a hugely difficult reaction to cancer. A minority of men adjust to a diagnosis quickly and cope well even at the primary appraisal stage. Not everyone will need to seek further help or develop particular ways of adapting to cancer. This is further supported from the questionnaire study since a large number of participants responding to the question about barriers to accessing support services stated that there was no need to access support. Yet, others find it incredibly difficult to cope with a diagnosis of cancer and need to both develop their own coping strategies and access further support to help them cope. For some men with cancer who were interviewed, it was months or years before they accessed the services that eventually helped them. Men often needed a suggestion or 'push' from someone to help support them to utilise services,

demonstrating the role of gatekeepers and wider social support in helping men access support services

8.5 What are the Implications of Findings for the Development of Interventions within Health Services (e.g., the NHS), Including how Services can Reduce any Barriers of Access for Men with Cancer?

The implications of the findings for applied practice are drawn from the systematic review and both research studies. However, given the length of time since the systematic review was undertaken, it was felt that an updated review would be required to ensure that the most up-to-date studies are considered in this discussion. Further, the wider literature on interventions in cancer patients is also consulted. The recommendations leading from the implications of the findings will be explored in greater depth in Chapter 9.

8.5.1 Updated review

As discussed in Appendix 1 (for methods, results and table of characteristics of included studies), a rapid update review of psychosocial and behaviour change interventions for men with cancer was undertaken. This was to systematically explore the literature that has emerged since the previous review (Chapter 2), which was undertaken in 2008. The updated review showed that nine further papers targeting men with cancer were published between 2008 and March 2015. These were more multinational than earlier papers, with studies undertaken in Australia and Malaysia as well as North America and Europe. Studies also and sometimes targeted lifestyle and psychosocial issues

together (Ames et al., 2011; Carmody et al., 2012) and there was a greater range of intervention types used, including those using more than one approach. This is compared to the original review, where studies predominantly utilised a single intervention method (e.g., CBT). In the previous review, all studies including samples of 100% men targeted prostate cancer. The updated review contains one paper that includes both colorectal and prostate cancer patients. This suggests that further intervention research is still required, aiming for samples with 100% men with a range of cancer diagnoses, to ensure that results of intervention trials are not just, or predominantly, relevant to men with prostate cancer.

All interventions showed some positive results, however, these varied and sometimes just one measure at one time point was found to be statistically significant. Interestingly, all interventions with a lifestyle component showed strong positive results that were maintained to a degree at follow-up (Ames et al., 2011; Bourke et al., 2014; Bourke et al., 2011; Carmody et al., 2012; Culos-Reed et al., 2010). These interventions used a range of behaviour change techniques, including goal setting, problem solving, demonstration of activity (e.g., through physical activity sessions), exploration of barriers, and discussion of social support.

Studies targeting psychosocial issues alone were somewhat less successful in improving anxiety, depression, stress, distress and wellbeing, since improvements were not seen across all measures and were often not maintained in the long-term (Isa et al., 2013a; Isa et al., 2013b; Livingston et al., 2010; Osei et al., 2013). These studies aimed to provide psychological and/or

social support to patients through progressive muscular relaxation (Isa et al., 2013a; Isa et al., 2013b), offering calls from nurses staffing a cancer helpline (Livingston et al., 2010), and an online support group (Osei et al., 2013). These are arguably low-level interventions, which may account for their lack of long-term effects across all measures, particularly when compared to the strong findings of the CBT interventions detailed in the original review. The studies by Isa and colleagues (2013a; 2013b) suggest that the progressive muscular relaxation may have benefits for stress, anxiety and quality of life, but may not be effective in improving depressive symptoms.

Implications for future interventions based on both reviews are that interventions to improve psychosocial issues for many cancer patients may need to be high-intensity to see substantive, sustained changes, such as those using Cognitive Behavioural Stress Management, or other CBT- or coping-based interventions. Lower-intensity interventions may be effective for some symptoms of stress or anxiety. Therefore, matching the intervention to need in cancer patients may be an important principle to follow. Interventions targeting health behaviours appear to have more robust reporting in the updated review compared to the original review, since specific behaviour change techniques were introduced. This reflects a more general evolution around the way behaviour change interventions are specified (Bourke et al., 2014; Michie et al., 2013). The updated review indicates that classes with demonstrations (for physical activity or diet) and a combination of goal setting, problem solving and integration of social support may enable lifestyle change in a range of settings. The updated review helps to further inform the potential content of effective

interventions for men with cancer, builds on the previous review and contributes to the wider evidence discussed here.

8.5.2 Wider intervention literature

In addition to the original and updated review and literature discussed in Chapter 3, a range of insights from the recent broader cancer intervention literature is relevant in informing future services for men with cancer. Naturally, given the lack of interventions solely on men with cancer, insights discussed here are from studies targeting both men and women. Important factors around the mode of delivery, as well as the content of interventions, may be key to developing acceptable and effective interventions for men with cancer. For example, personally tailored interventions may be effective in recruiting men (as well as women) and result in lifestyle change (Anderson et al., 2010). Some research suggests that group- and home-based interventions both have high rates of participation (van der Bij et al., 2002). Others suggest that no single format will suit all, and therefore, how the intervention is delivered needs to be flexible (Fawzy, 1999). There can be a preference for one-to-one, rather than group –based formats for interventions (Jones & Demark-Wahnefried, 2006), which was also found in the questionnaire study.

The systems of care can impact on outcomes. Integrated care which sees multiple professionals co-located and sharing care has had staggering results in primary care in the USA (Gottlieb et al., 2008; Graves, 2013) and may have relevance to the oncology field. Integrated care for depression and/or anxiety can significantly improve outcomes for patients with cancer, including those who are palliative (Ouwens et al., 2009; Sharpe et al., 2014; Walker et al.,

2014). However, Ouwens and colleagues (2009) note that definitions of integrated care differ. Recently, in the US, clear definitions of integrated behavioural health care have been developed from levels 1-6 (SAMHSA-HRSA, 2013). The literature discussed here falls short of the highest level (6) of integration. Integrated behavioural care, which has increasingly been implemented since the commencement of this thesis, shows promise for improving psychosocial outcomes. However, is yet to be trialled fully in the field of cancer and yet to be tested in the UK in any setting.

When exploring effective interventions to improve psychosocial outcomes in oncology on mixed-sex populations, there is a strong evidence base, which largely existed prior to thesis commencement, but has developed further in some areas. Reviews show positive psychosocial effects for interventions utilising: mindfulness (Shennan et al., 2010); mindfulness-based stress reduction (Smith et al., 2005); structured group or individual support (Clark et al., 2003); CBT (Newell et al., 2002; Osborn et al., 2006; Rehse & Pukrop, 2003); group therapy (Newell et al., 2002); counselling (Newell et al., 2002; Trijsburg et al., 1992); psychotherapeutic approaches (Rehse & Pukrop, 2003); one-to-one peer support (Meyer et al., 2015); and social support (Rehse & Pukrop, 2003). Other reviews are more questioning of effects, for example, for psychosocial interventions for head and neck cancer patients (Semple et al., 2013). Given that these are on a mixed-sex population, there needs to be caution when drawing conclusions for men with cancer specifically, especially given the usual dominance of women in clinical trials.

Interventions exploring the effectiveness of interventions with cancer patients on improving lifestyle have focused on the area of physical activity. A range of review papers exist showing improvements in exercise through: behaviourally-based interventions (van der Bij et al., 2002); aerobic or mixed-activity exercise (Speck et al., 2010); exercise prescription (Schmitz et al., 2005); exercise classes (Beaton et al., 2009); and cardiovascular training (Galvão & Newton, 2005).

In the area of smoking, behavioural and psychological interventions on individual and group levels were effective in supporting smokers to quit, but, self-help materials were less effective (Lancaster et al., 2000). Interventions to reduce alcohol intake and improve diet have been studied less so have not warranted reviews as in the areas of smoking and exercise. Single studies have shown some positive effects on alcohol intake (Duffy et al., 2006) and diet (Hébert et al., 2012; Li et al., 2008; Parsons et al., 2008). Interestingly, some lifestyle interventions had positive psychosocial effects too (Courneya & Friedenreich, 1999; Granger et al., 2011; Knobf & Dorward, 2007; Oldervoll et al., 2004), which had been found previously in the general (non-cancer-specific) literature (Dale et al., 2014). Exercise can also have a positive effect on cancer-related fatigue (Cramp & Byron-Daniel, 2012; Larkin et al., 2014; Paramanandam & Dunn, 2015; Speck et al., 2010)

8.5.3 What is unique about men with cancer?

A legitimate question to be asked is how men differ from women in terms of help seeking for support services in cancer. Given this study only focused on

men with cancer, the wider literature exploring both men and women with cancer needs to be drawn on to assist in answering this question.

A common narrative in health care is that men seek help less than women for physical symptoms, psychosocial issues, and health behaviours (Nekolaichuk et al., 2011; White and Banks, 2004; Wilkins et al., 2008). Yet, increasingly gender-comparison studies are being undertaken that suggest that the effect of sex upon help seeking is less than previously thought. Therefore, whilst men may be less likely to seek help for physical symptoms, the magnitude of this difference compared to women is relatively small (Lyratzopoulos et al., 2012; Macleod et al., 2009; Smith et al., 2005; Wang et al., 2013). Research also shows that the information that men and women with cancer seek is the same and focused on site-specific information, emotional support, publications and specific therapies (Boudioni et al., 2001). Therefore, although men may seek help less, the difference between men and women is not as great as people's perceptions.

There is a theme in the interview data of many men having to legitimise seeking help. This may be one area where ideas about masculinity have an impact on men in particular. Legitimation of help-seeking has not been discussed in relation to women's health. This might be because it has not been studied rather than it not existing. Indeed, whilst the role of gender may not play a strong role in women's help seeking, there may be other barriers that women face where acknowledging the challenges they face could be useful in moving them towards seeking help. However, legitimisation is a factor that has been discussed in relation to men's help-seeking. This may mean that when

compared to women, men typically have a delay in seeking help, while they re-negotiate their perceptions so that they feel it is acceptable to seek help; legitimisation can act as a catalyst to this. It may also mean that men are less likely than women to access help, if they are not able to re-negotiate their relationship with seeking help. Based on research studying both men and women, including gender-comparison studies, it is not clear that men stand out as hugely different to women (Lyratzopoulos et al, 2012; Macleod et al., 2009; Smith et al., 2005; Wang et al., 2013). Clearly, further research is needed to explore these factors further in both men and women.

8.5.4 Implications for Policy

The results discussed above have a range of implications for policy, particularly policies around cancer survivorship. In Scotland, and the UK more widely, in the last 8-10 years, cancer policies have shifted to recognise that cancer can be a long-term condition for some people (Department of Health, 2011; MacMillan Cancer Support, 2009; NHS Scotland, 2013; The Scottish Government, 2008b). This is sometimes discussed as cancer survivorship and the findings in this thesis tie into this policy agenda, given the focus on post-treatment interventions.

Findings around what interventions are effective for psychosocial issues and health behaviours have implications for policy recommendations relating to the survivorship agenda. These are particularly around the content of interventions that are effective for improving psychosocial health (e.g., high intensity CBT) and health behaviours (e.g., the behaviour change techniques of goal setting and demonstration of behaviour). The findings reported here may,

therefore, potentially influence future policy recommendations around the content of interventions for men with cancer.

Similarly, the key findings around engaging men with cancer in services have key policy implications. The thesis findings support the need that some men have in being supported into services to improve their psychosocial health and health behaviours. If this were to be recognised in policy to a greater extent, it may support services to invest in exploring the best ways to engage men with cancer.

Cancer policy may too discuss the role of health professionals in supporting patients with cancer. To support the survivorship agenda, health professionals have a key role in helping legitimise men's service access to support their better psychosocial health and health behaviours, which may contribute to a lower risk of cancer recurrence or further diagnoses. This research suggests that policy could potentially give this area greater recognition and incorporate such findings into recommendations for practice. Similarly, given there are groups of men who are more at risk of poorer psychosocial health and health behaviours, policy may need to highlight the need for health professionals to be aware of more vulnerable groups (whatever the characteristics of vulnerability may be), and play a greater role in case managing these patients. There is also a need to screen patients for psychosocial issues and health behaviours. This does feature already in some applications of policies (NHS Scotland, 2013), however could be more widely recognised, which is supported by this research.

8.5.5 Implications for intervention services

This thesis first set out to identify what makes an effective intervention for men with cancer to improve psychosocial issues and health behaviours.

Drawing on the original and updated review, along with the wider literature, there are insights for the content of interventions. In addition, by undertaking the two studies in this thesis, it has brought a breadth and depth to understanding not only the content of interventions, but also what sub-groups of men with cancer may need more support and help to access services, along with how services can better attract men with cancer. The findings presented here add to our understanding, and help guide future research and practice. The implications for interventions in practice can broadly be categorised into three parts:

1. How services can identify vulnerable groups of men with cancer to help reduce the psychosocial burden of cancer and improve health behaviours;
2. What content of interventions are likely to best improve psychosocial issues and health behaviours in men with cancer;
3. How services can best attract men with cancer to access support services when needed and reduce barriers to make service access acceptable to them.

These are systematically discussed as below:

8.5.3.1 Identifying vulnerable groups of men with cancer

The links found between demographic factors and poorer psychosocial issues and health behaviours seem to support some of the research discussed in the introduction. Implications for interventions are focused here on the identification of more vulnerable groups.

Men who are separated and divorced, rather than those who are single, appear to be more vulnerable to psychosocial problems. Similarly, those living in areas of higher deprivation and those who are younger also appear more at risk of psychosocial issues or engagement in unhealthy lifestyles. In order to help support men with these characteristics, services could do two things. Firstly, they could target psychosocial or health behaviour change interventions toward these vulnerable groups. The interview data suggest that some younger men with cancer may welcome more support for those of a similar age group. Yet, targeting interventions specifically at men from areas of higher deprivation or those who are separated or divorced may be stigmatising, so may not be effective or advisable. The second change that services could make, which may be more appropriate, is have a greater awareness of the demographic characteristics that may make men more likely to have difficulties, and use this as an adjunct to screening and clinical interview. This may help ensure that these men are supported as best as possible into any relevant interventions. Training may be needed to enable staff (for example oncology nurses and doctors) to be aware of the demographic factors that make some sub-groups of men more vulnerable.

In addition to identifying the characteristics that may make men more vulnerable, services should ensure they screen men at regular intervals for psychosocial issues and health behaviours. This would need to be with well-validated screening methods to avoid known problems of screening tools through over-or under-detection of problems (Mitchell et al., 2011). This is important given that more and more people are surviving cancer for longer, problems could linger if they are not screened for and appropriate onward referral or signposting made. From the questionnaire study, it is clear that there is a link between those who are experiencing psychosocial difficulties and desire for more help. As a result, these individuals may be more motivated to access services and their difficulties may help legitimise help-seeking. For exercise and diet, however, there was no significant relationship between those not meeting government guidelines and those wanting to improve their health. This suggests that more work to help motivate men to improve their lifestyles around these issues may be needed.

8.5.3.2 Content of interventions

As well as identifying men for interventions to improve psychosocial issues and health behaviours, the content of interventions is crucial for effectiveness. Understanding what assists interventions to be effective ties into the survivorship agenda and the need to develop interventions for cancer patients post-treatment. Interventions to improve psychological health may benefit from drawing on cognitive and behavioural techniques and therapies, based on both reviews and the wider literature, which shows strong effects for CBT but lesser effects for lower-intensity interventions (for example relaxation

or online support groups). The wider literature (not specifically on men with cancer) suggests that mindfulness-based interventions, counselling in most forms, psychotherapy, peer support, and social support may be effecting in improving psychosocial outcomes in cancer patients. These may have relevance to men, although they require further testing before they can be fully endorsed.

The interviews showed that a broad range of coping strategies was useful for men in coping with the psychological difficulties of a cancer diagnosis. This included the use of relaxation, talking to others, both informally and through formal support services, finding purpose and meaning, engagement with enjoyable activities, distraction, and the use of humour. These coping mechanisms may not always be required to be facilitated through face-to-face interventions, and indeed may not always be as effective if they are done in that way, given how many men engaged in such coping informally. Services may need to play a role in supporting men to identify their own helpful coping mechanisms and supporting them to be able to utilise them, whether it be informally, or through formalised support. This may serve to help men re-appraise their cancer as manageable.

When exploring interventions to improve lifestyle, the area of exercise has the strongest evidence-base. This suggests that a range of intervention types are effective from exercise classes to multi-component interventions utilising a range of behaviour change techniques. Similarly, the update review in particular showed that drawing on behaviour change techniques (as opposed to psycho-education) may be effective in supporting men with cancer to improve

their health behaviours, more broadly, which may result in reduced risk of recurrence for some cancers, and further disease for others.

8.5.3.3 Enabling men to access services

Supporting men to access services is needed since, although there are some men who will access services with little problem, there are others for whom barriers get in the way. Despite the broad type of factors that can influence men's service access, tangible things that services can do to support men are likely to be on the individual and organisational levels.

On an individual level, there are men who may be more vulnerable since they do not accept support, they avoid help-seeking, or simply showing a hesitance in accessing services. These may be due to psychological factors, such as introversion, the cultural factor of masculinity, or biological factors, for example, having a cancer prognosis that is curable. Gatekeepers (as previously mentioned) can play a role in helping legitimise help-seeking in men with cancer. There may also be a need for clinicians to deliver evidence-based approaches to help men become more motivated to change their behaviours and seek help.

Some research suggests that medical staff should be better trained to use communication styles such as motivational interviewing with patients. However, this comes with challenges, since there can be resistance from some medical staff in adopting new styles of engagement (Söderlund et al., 2008; The Health Foundation, 2011). Evidence also suggests that the typically brief training programmes that are used are not always enough to result in patient change (Butler et al., 2013). Therefore, there may need to be a balance

between up-skilling existing staff and providing a more multidisciplinary approach in health care teams. This may include staff with psychological/behaviour change expertise who may not only work with patients, but may also work to support the wider team to adopt consistent screening and have a greater awareness of psychosocial and health behaviour issues.

Integrated behavioural health care may be part of the solution, which has been found to improve psychosocial outcomes in patients in other areas (Gottlieb et al., 2008; Graves et al., 2013; London et al., 2013). This situates behavioural health experts within medical teams to work with patients around psychosocial issues and health behaviours and supports the staff to work in ways that are more collaborative and holistic with patients (Graves et al., 2013). Therefore, by offering behavioural expertise to patients, and enabling the whole team to work in ways that better support change for patients, change can be effected (SAMHSA-HRSA, 2013).

There may be broader structural factors that can be implemented to support men to access services. This may include better advertising so that any misconceptions about services that could act as barriers are corrected. Indeed, previous research has shown that lack of awareness of services is a key barrier to accessing them (Steginga et al., 2008). Services that are more informal and include the ability to 'drop-in' may be more attractive to many men with cancer. This was true for the Maggie's Centres, which are known for their relaxed atmosphere and welcoming ethos. NHS services may be able to support men into such services. NHS services may also be able to learn from the voluntary sector, such as the Maggie's Centres, by bringing a greater sense of informality,

yet, maintaining professionalism. This could help men feel more able to access mainstream services, which could sometimes offer interventions that are not available in the voluntary sector.

There was a clear role of masculinity in influencing service access. Staff may be able to help legitimise men to access services, and services may be able to carefully tailor interventions to be more acceptable to men.

Nevertheless, there needs to be a balance between services attracting men through drawing on traditional masculine discourses, and those that legitimise help seeking in other ways. Studies that aim to, and succeed in, enabling men to enhance their masculinity through accessing them, such as lifestyle programmes delivered through prominent football clubs (Gray et al., 2013; Hunt et al., 2013; Zwolinsky et al., 2013), enables some men who otherwise would not access services, to access support.

Yet, the 'promotion' of masculinity to improve health has been cautioned (de Visser & McDonnell, 2013; Gough, 2009) since it can reinforce traditional masculine values and make men more reluctant to access other services. So, although such services may be effective in enabling men to access them for that specific issue, men may not change their broader ideas about seeking help for other issues. Therefore, for some men, services that capitalise on traditional ideas about masculinity may reinforce their own masculine ideas, and make it even harder for men to access other future services. There may be a need for services to investigate other ways to appeal to men that do not rely solely on ideas about masculinity. Some other factors appeared to legitimise help seeking, for example gatekeepers, supporting men to re-frame their ideas about

masculinity and validating that men may need to access support. Interventions that utilise these methods may not only help support men into existing interventions but also make them more likely to seek help in the future. They also more broadly avoid reinforcing traditional societal ideas about masculinity. Accordingly, on an individual and organisation level, there are ways to better support men to access services, however interventions to improve access to services by men are little recognised in current practice and policy.

8.6 Thesis Strengths and Limitations

There are strengths and limitations of the thesis relating to the philosophical and overall theoretical approach taken. The overarching ontological and epistemological positions were grounded in critical realism. As with all philosophical approaches, critical realism has received critique. This is particularly in its ability to acknowledge and accept a more fluid reality, acknowledging that there can be both objectivity and subjectivity, which to some is not possible to reconcile (Cruickshank, 2004; Steele, 2005).

In addition, the particular approach within mixed methods of utilising an explanatory sequential design influenced the study design, and therefore results. Since the qualitative research questions were informed by a preliminary analysis of the quantitative study, this brought a strength, since key questions that were not able to be answered by the quantitative study were addressed in the qualitative research. These may have not otherwise have been specifically addressed. It is, though, recognised that using a different approach to the qualitative research may have meant that the results differed in emphasis or

focus. For example, a concurrent triangulation mixed methods approach would have developed and undertaken both pieces of research at the same time (Creswell, 2003). The emergent results would have been interpreted together and the ability to achieve triangulation assumed (which was not within this thesis as discussed in Chapter 6).

The sample recruited in both studies has some limitations. Recruiting a broad range of cancer patients at one point in time may limit the ability to detect any differences relating to a specific cancer type, such as lung or prostate cancer. Nevertheless, given research on men with cancer as a whole is scarce, this study adds to our understanding of the complex relationships among psychosocial factors, lifestyle and help seeking issues in men with cancer. Although the studies were not wholly focused on participants post-major treatment, efforts were made to recruit participants at this point in their cancer journey, particularly for the questionnaire study. The mean time since diagnosis for the questionnaire study was 5 years, suggesting that most participants would be post-major treatment. However, since this was not part of the inclusion criteria (for reasons detailed in Chapter 4), the exact treatment status of participants for either study cannot be determined and influences the results in terms of the inferences made for specific in-treatment or out-of-treatment groups. It is possible, however, that a greater need around psychosocial issues would be identified in a population that was solely in treatment (Ciaramella and Poli, 2001; Dunn et al., 2013). Further, given that cancer is diverse and affects roughly one-third of the population, there may be questions about how specific these findings are to men with cancer, compared to men with illness on the

whole. Since cancer has a range of connotations, particularly around the assumed severity and historical stigma, I would argue that at least some of the findings are specific to men who have cancer, rather than men more generally. This is especially so around the challenges of treatment, and side effects, along with the using of cancer and/or severity as sometimes legitimising the use of certain coping styles of help-seeking.

Further limitations lie in the fact that only men were included in the research. It is, therefore, difficult to draw out which findings are specific to men. Interviewing both men and women may have better established whether factors that appeared to be related to masculinity were unique to men, or whether the same factors may have been related to something different in female participants. However a discussion of the wider literature, including gender-comparative studies, and with discussion of perceptions of masculinity as important rather than masculinity *per se* have helped compensate for this. Further research would benefit from exploring similar issues in larger and mixed-sex samples.

Both samples were recruited opportunistically, through the NHS and relevant cancer charities, whereby staff in these organisations were asked to inform adult men with cancer of the research. This can enable a larger number of participants to be recruited. However, it can often result in a sample that is not representative of the wider population, which is a significant limitation. For the qualitative study, however, there was an element of purposive sampling, which is discussed later. For the quantitative study (also discussed later), the sample was representative by demographic but not disease characteristics.

There are also specific limitations and strengths of each study. One key limitation of the quantitative study is the relatively small sample size. This meant that the study was underpowered in places and limited the analytical approaches, both in terms of undertaking parametric tests, and statistical tests on sub-samples. This was particularly apparent when exploring the effect of cancer type on psychosocial issues, since post-hoc tests did not detect significant results. Therefore, important differences among different cancer sites may not have been identified. Although the sample size was compensated for through bootstrapping in the multiple regression and modelling analyses, it prevented the addition of demographic and disease factors from being tested in the model.

In addition, since the analysis of data from the questionnaire study was exploratory, this meant that multiple analyses were undertaken, first individually, then in multiple regression analyses. The primary limitation of multiple testing is that it increases the chance of a type 1 error (where a false positive result is found, since the chance of a significant result increased as the number of tests do (Benjamin and Hocherg, 1995). Multiple testing undertaken in this thesis was balanced by the small sample size, which means there is less chance of a type 1 error. Because of this, it was decided that methods of correcting for multiple testing (e.g. the Bonferroni correction, where the alpha level is reduced according to the number of tests), was not necessary given the limitations of correcting for multiple testing, and that there is no agreed method of addressing multiple testing (Asendorpf et al., 2012; Nakagawa, 2004; Perneger, 1998).

Further, the advantages of employing path analysis to fit a mediational model were regarded sufficient to outweigh the threats of making a false interpretation. Yet, the risks of applying such models to cross-sectional data are acknowledged, including the possibility of reverse causality in the model (Cole and Maxwell 2003). However, previous research detailed earlier confirms the directionality within the proposed model. Replications with longitudinal datasets specified with variable intervals between assessments are strongly recommended, which would allow for confirmatory analyses and strengthen the model's validity. More broadly, the cross-sectional study design limitation means that causal inferences in particular are problematic to make. Where causality is discussed, it is done very much in line with the literature, which supports the direction of causation, and should be interpreted with caution.

There may be limitations in some of the scales used in the quantitative research. There are recent critiques of the use of the HADS, particularly around the two-factor structure (Cosco et al., 2012; Coyne & van Sonderen, 2012). Nevertheless, the modelling analysis focuses on distress as a latent variable made up of the HADS anxiety and depression scores and the DT which may in fact bring a strength to the model in assessing emotional distress. In addition, a pragmatic decision was made to undertake individual analyses using anxiety and depression as measured by the HADS as separate (but related) constructs, given the levels of anxiety and depression indicated by the HADS were different (20% for depression and 29% for anxiety and there was only some overlap of cases). The findings suggested different demographic variables were associated with greater depression and anxiety, perhaps revealing that the

constructs may be worthy of separate analysis. The complex interactions between these factors and the small sample size make interpretation difficult. Thus, larger scale, including longitudinal, studies are recommended. This would allow for confirmatory analyses, may strengthen the robustness of the current findings, and develop more complex modelling.

When examining the quantitative study sample compared to the Scottish Longitudinal Study sample from the same area, the study sample appears, reassuringly, to be largely representative. Key areas of difference were the number of people with multiple diagnoses, time since diagnosis, and primary cancer diagnosis. Primary cancer diagnosis may not be wholly reflective of the prevalence of cancers in Scotland, as this is most likely due to variability in recruitment rates across areas geographical areas.

Demographically, the sample is representative yet by specific disease variables, it was not wholly representative. This perhaps presents fewer issues given that disease factors were either not significant or could not be explored further (in the case of cancer type), due to the small sample size and lack of significant post hoc tests. The findings of scores on measures of psychological issues and health behaviours show that the majority of these results are comparable with that observed previously in the literature, with the exception of smoking and alcohol, which appeared lower in our sample (Bellizzi et al., 2005; Demark-Wahnefried et al., 2004; Massie, 2004). This further supports that this sample may be representative more broadly of men with cancer in the UK and possibly in other higher-income countries.

The qualitative study had limitations in that it makes inferences based on a sample of 20 participants. Whilst this is not uncommon for qualitative research, the applicability of the findings to all men with cancer may be questioned. However, it is noted that saturation was reached prior to the 20th interview and most findings discussed are common across several participants. This suggests that there is an element of generalisability in the qualitative research.

As discussed earlier, the sampling for the qualitative research was opportunistic, since participants were recruited through all relevant NHS oncology staff and those from the voluntary sector services. An element of purposive sampling was introduced after seven participants had been recruited. This was since all seven participants had accessed the Maggie's centres. The research aimed to explore the barriers and facilitators to accessing support services, therefore, it was considered important at this point to ensure that not all participants had accessed support services. Consequently, recruitment from the Maggie's centres was no longer actively pursued after the seventh participant had been recruited. This could be considered a strength, since the decision was in response to the characteristics of participants who had been recruited and helped ensure a sample that better reflected the general population (i.e., one that did not only include those who had accessed support services. Had the need for purposive sampling been considered to be important prior to commencement of recruitment, a stratified purposeful sampling method would likely have been chosen (Palinkas et al., 2015). This would have purposefully selected participants who had accessed support services, and

those who had not, in order to capture major variation across this key factor of interest (Palinkas et al., 2015).

Naturally, there is subjectivity in qualitative research. This is acknowledged and ways to help reduce this bias included the involvement of supervisors at several stages of analysis. Further, reflexivity in the interview and analytic process is discussed in Chapter 6 as influencing the conduction and analysis of interviews.

A range of factors have likely influenced the findings presented. These may be seen as a strength, since certain factors helped enable a depth of information to be gleaned in the interviews, and my Health psychology background has influenced the interpretation of the qualitative data. This could also be seen as a weakness, since researchers with different training would no doubt make different conclusions and there could be a strength in a multi-disciplinary team of researchers analysing qualitative data. Qualitative research, however, does not and cannot aim to be wholly objective.

Nevertheless, both studies contribute to a limited literature on men with cancer and begin to shed light on the vulnerabilities of men with cancer. The studies collectively also identify that the psychosocial and lifestyle needs of men with cancer is vital. The factors that affect support seeking and have drawn insights beyond the original research questions.

8.7 Summary

This Chapter aimed to systematically answer each research question. It has highlighted vulnerable groups of men with cancer; demonstrated linkages

between psychosocial issues, health behaviours and desire for more help; elucidated desired support by men with cancer; explored the barriers and facilitators to support within an expanded transactional model of stress and coping; and presented implications for the development of interventions. This leads onto recommendations for further research and current practice in Chapter 9.

9. Legitimising Help Seeking, Better Advertising, Identifying Needs of Men with Cancer, and Larger Studies: Recommendations for Future Research and Current Practice

Chapter 8 brought together the research studies and wider literature in answering the research questions. Here, the implications of findings for the development of interventions are built on by discussing the recommendations for future research and current practice.

9.1 Recommendations for Current Practice

A range of recommendations for current practice are detailed here. Recommendations are aimed at the UK model of the NHS. Some of these recommendations apply particularly for cancer patients following any major treatment (for example, the recommendations around lifestyle change). However, other recommendations are applicable to cancer patients at all points in the treatment journey (such as the need to screen patients for psychosocial issues, and for cancer teams to embed behavioural care). Table 30 summarises the key factors that services should consider, in order to ensure they are addressing the psychosocial and health behaviour needs of men with cancer; therefore, providing a quick guide that services may access and utilise.

The first recommendation is that NHS services need to embed routine screening for psychological and social issues (where they do not already do this). This should not just be at a single time point, given that men with cancer have difficulties at different times in their cancer journey, reflected in reports

from cancer patients in the questionnaire and interview studies showing that difficulties can arise at any point.

Table 30. Key factors for services to consider to address the psychosocial and health behaviour needs of men with cancer

Assessing need	NHS service set up and delivery	Promoting legitimisation
Screening for: <ul style="list-style-type: none"> • Psychological difficulties • Social support • Health Behaviours 	Utilising CBT and behaviour change techniques in psychosocial and health behaviour interventions respectively	Gatekeepers promoting the use of support services (including voluntary sector services) by men
Training for staff (e.g. oncology doctors and nurses) in screening for psychosocial issues and health behaviours	Utilising the teachable moment within interventions for lifestyle change, including training for staff to utilise this.	Staff providing feedback on results of screening tests for psychological difficulties since distress can legitimise help seeking
Being aware of demographic factors that may make men more vulnerable to psychosocial issues and poor health behaviours	Embedding psychological/behavioural support within medical services	Staff emphasising the role that significant females could play in supporting men to access services
	Signposting to voluntary sector services and learning from services that are highly utilised in how they operate and deliver services.	Services advertising themselves well to help dispel any myths and enable men to feel that service access is acceptable
		Services legitimising help seeking through being gender sensitive and tailoring to men, yet not over-focusing on traditional ideas about masculinity

Services may benefit from being aware of characteristics of men with cancer that make them more vulnerable to psychosocial issues as an adjunct to screening and clinical interview. Health professionals have a key role in supporting patients in coping with illnesses as has previously been discussed (Lang et al., 2013), and this includes supporting men to know about, accurately perceive and feel able to access other support services.

Given that situational variables and wider social and environmental factors impacted on men's appraisal of, and coping with, cancer, health professionals (e.g. cancer nurses and doctors) may need to be aware of the wider factors affecting men and that this may have implications for them needing more support at any point in the cancer journey.

Since few demographic factors appear to be related to health behaviours, screening of all men with cancer for lifestyle behaviours may be beneficial. There could be a particular focus on targeting behaviour change services towards men who are not meeting the evidence-based government guidelines for lifestyle behaviours, given the link between lifestyle and development/recurrence of cancer. Since there are missed opportunities for enabling health behaviour change, teachable moment interventions may have promise and may help support individuals to feel motivated to improve their lifestyle behaviours (Ozakinci et al., 2010). These may need to be flexible in their approach, since a teachable moment may not happen at one specific time point for all patients (Dale et al., 2010). There may be a role to support men to make some changes during major treatment, since lifestyle change can be supportive of a better treatment experience (e.g. stopping smoking and being of

a healthy weight for operations, and exercise to cope with chemotherapy; Mustian et al., 2007; Nickelsen et al., 2005). However, for others, supporting men with cancer to make changes following major treatment may be more realistic, given the side effects of, and limitations associated with some treatments.

Training for health professionals in using screening methods for psychosocial issues and health behaviours, along with motivational approaches to help support the use of the teachable moment, may help encourage improvements in these areas. This may need to focus on training oncology staff who are heavily involved in patient care, such as cancer nurse specialists and doctors in appropriately using screening methods. There may also be a benefit to utilise staff with psychological expertise. Staff with psychological expertise could potentially support doctors and nurses to utilise a biopsychosocial approach, including the use of screening and/or could lead on the development and implementation of screening and interventions for psychosocial issues and health behaviours. There are, however, challenges in supporting staff to develop new methods of care. For example, holistic needs assessment helps ensure that psychosocial and spiritual needs in cancer patients are assessed. This is promoted in the UK (MacMillan Cancer Support, 2014), nevertheless, research suggests a reluctance among health professionals to adopt this into routine practice (Wells et al., 2015b).

Given that there are challenges in training and supporting staff to develop new practice, making teams more multidisciplinary may be one way to engender change. Embedding psychosocial/behavioural expertise into a multi-

disciplinary team may not only provide immediate support to patients where needed but also support the wider team to change the way they work (Graves, 2013; SAMHSA-HRSA, 2013). This may be more effective than providing training courses to medical professionals and policy change. Integrating psychosocial and behavioural services into medical services, both in primary care and the acute sector, may also help legitimise men's use of such services throughout and after treatment. Approaches such as integrated behavioural care may be successful in enabling acceptable and easy access to such services in primary care and have relevance to the acute sector (Bakerly et al., 2009).

The content of interventions specifically targeting men with cancer requires more investigation. However, based on the research on post-treatment interventions to date, services may benefit from utilising CBT-based approaches to improve psychosocial issues. Interventions aiming to improve health behaviours may be most effective when they are utilising evidence-based behaviour change techniques.

In supporting men to access services, there is a key role of legitimisation. Five factors that can be utilised to help legitimise men to access support are:

1. Gatekeepers: They can play a large role in informing men of services and suggesting men may benefit from attending. Further, by gatekeepers (for example, health and social care professionals) not informing men of services, this may contribute to men feeling like it is not legitimate for them to access services. Work with health professionals may also be required to

enable them to normalise help seeking for men regardless of their perceptions of acceptability.

2. Men experiencing distress: Distress in men with cancer may help men legitimise help-seeking themselves. Services may also play a role feeding back screening scores to help validate men's help seeking. Services to support men to utilise emotion-focused coping strategies, may especially benefit from efforts to legitimise their utilisation by men.
3. Influence of female figures: Given that there was a clear role for wives or other female figures to help support men to access support, services may have a role in encouraging any females who attend appointments with men, to support them to seek further help. However, this must be done in ways that are sensitive to the emotional burdens already borne by women who are providing support to men with cancer (as well as potentially other older or younger significant others, such as children). There may be a useful role for interventions that help enable significant others for men with cancer to help men to utilise supports that are available.
4. Advertising: It appeared that advertising of services, for example, for smoking cessation, may help legitimise men's utilisation of them. Better advertising of other services that men with cancer can access may further support this for other areas, for example the Maggie's centre, for which there were frequent misconceptions cited.
5. Re-framing masculinity: Lastly, re-framing meanings of masculinity when advertising services may help legitimise men's access of services. As previously stated (Doyal, 2001), health promotion policies need to be

gender-sensitive in order for messages to be recognised and for these to result in behaviour change. Further, there needs to be a careful balance between tailoring services to men and not over-emphasising traditional roles and understandings of masculinity (Gleb et al., 2011). Whilst a men's health approach of capitalising on masculine roles may bring immediate success in attracting men to services, they may not support men to more broadly seek, or continue to obtain support. Therefore, for long-term gains in reducing men's health inequities, legitimising men to access services through means other than solely using masculinity may be more successful. Wider efforts to challenge cultural stereotypes around men and masculinity may be important. This is particularly key since the *perception* of masculinity as a barrier by men was generally greater than the strength of masculinity in preventing men access services. This sometimes impacted on men avoiding speaking to other men about their problems since there was a perception that they would not be interested because they were men.

If these ways of helping men to legitimise their help seeking were utilised by services and staff, it may enable more men to access services. There also appears to be a key role for the voluntary sector in providing services that are arguably more welcoming than NHS services. NHS services could do more to promote men accessing these services, given the role of gatekeepers in supporting men into services. NHS services may, too, learn from the successes of voluntary sector organisations. For example, NHS support services, including psychology, may need to find ways of attracting men, perhaps through embedding themselves into cancer services within systems of integrated care.

This may help men to see such services as more welcoming. A drop-in service for psychology in the NHS may help in achieving this. However, there is a broader service delivery that exists within the Maggie's centres (for example the informal set up of space allowing a sharing of stories between patients) that would be more difficult to capture.

There was more legitimisation of utilising emotion-focused coping styles needed by men prior to using such styles, which is consistent with research suggesting that women use emotion-focused coping styles more than men (Tamres et al., 2002). It may be that action-oriented interventions (which take a problem solving/practical approach) may be more attractive to men with cancer. These may be a 'way-in' to utilising strategies that are emotion-focused as a 'by-product' of other activities (Galdas et al., 2005; Galdas et al., 2015). The way such services are advertised is important and may need to clearly articulate the purpose of the service, and place an emphasis on tangible results (Galdas et al., 2005; Galdas et al., 2015). The word 'support' in particular may be off-putting for men, therefore, the tailoring of services for men, may include framing the support in ways that appear more acceptable to them. Services and interventions would benefit from drawing on research that considers the role of masculinity, such as being aware of the use of words and framing of interventions that may challenge men's masculinity. Yet, services should avoid solely using traditional ideas about masculinity to tailor services. In addition, it may also help to involve men in shaping the design of services and how they are advertised.

9.2 Recommendations for Future Research

There are five main foci for future research based on the work presented here. These are:

1. Given the relatively small sample size in the quantitative study, undertaking a similar study with a larger sample of men with cancer may be beneficial, in order to test the replicability in a larger group. This could particularly explore the potential role of cancer type in influencing psychosocial factors. It would also mean that the modelling analysis would be better powered and could include more variables to explore other mediators and assess the completeness of the model. These may include the role of demographic factors, and factors from the transactional model of stress and coping, such as appraisal and coping.
2. There is also an argument to undertake both quantitative and qualitative studies exploring similar factors with mixed-sex samples in order to draw more firm conclusions about what is specific to men and what may be common in all cancer patients. Some research on women suggests some female-specific factors (for example bra discomfort; Gho et al., 2010) as well as non-sex specific factors (such as self-efficacy; Rogers et al., 2006) may be barriers to exercise. However, less is known about the sex differences that may apply to other areas explored in this study, particularly the role of legitimisation.
3. Longitudinal studies would better draw out causality in the factors assessed in the quantitative study, especially around the modelling analysis. Whilst

longitudinal studies would not be a conclusive test of causality, it would be a stronger suggestion of causal direction.

4. More generally, exploratory and intervention studies on cancer patients may benefit from breaking down their results by demographic factors, including sex and marital status. This may help further elucidate any differences by demographics.
5. More research is required exploring whether the content and mode of interventions that have been found to be effective on mixed-sex samples are also effective for men specifically. Since there is poor reporting in trials, there is a need for intervention studies to report in detail what behaviour change techniques they have used. There is also a need to accurately report the wider context, given that this can affect the findings (Wells et al., 2012).

Although larger samples and longitudinal research are recommended for future research based on the quantitative study, the recommendations for current practice are unlikely to significantly change. This is because most interventions or services would not focus solely on vulnerable groups. Rather they would use known vulnerabilities to help ensure that men fitting these characteristics are screened and offered services (as should be the case for all men). Further research would, though, enable a greater understanding of the psychosocial issues and health behaviours in men with cancer, the inter-linkages between factors and what may make men more vulnerable.

9.3 Conclusions

This mixed-methods study, along with wider literature, has revealed answers to the research questions posed. As a group, men with cancer face multiple morbidities and interventions to improve morbidity typically have less of an evidence base than that for women with cancer. The study reveals some sub-categories of men with cancer that are more vulnerable to psychosocial and lifestyle issues, particularly those who are separated/divorced, younger patients, and those living in an area of deprivation. It may be useful for health professionals to use these highlighted demographic factors as an indicator, in addition to screening, to assist in early identification and intervention for those with poorer psychological health and health behaviours. Interestingly, social support was consistently associated with all psychological variables; therefore, identification of support in men with cancer is also important. Low levels of social support were linked to desire for more help, though this was mediated through psychological distress. Accordingly, for some men, there may need to be a combination of low perceived social support and psychological issues before they desire more support.

There was not, though, a huge amount of additional support desired by men with cancer. Where additional services were desired, men had a preference for more informal support. Desired support also focused on emotion- and problem-focused coping. Very often such services were already available, therefore, barriers to men accessing these were apparent. In the interview study, many men discussed that there were no barriers to them accessing support. Upon further discussion, it became apparent that often barriers had

existed and they had overcome them. Barriers intersected biopsychosocial antecedents, appraisal of and coping with cancer. As such, the modified transactional model of stress and coping acts as a useful framework for the discussion of results. The important addition of contextual factors around services acknowledges the wider influence of services on whether or not men choose to utilise them as part of their coping with cancer. Within the social antecedents, there was a clear role of ideas about masculinity. Men often navigated this, sometimes with the help of others, which helped them to legitimise engagement with certain coping strategies, including help seeking.

Legitimisation of support seeking also came through disease – so having cancer, which is generally seen as very serious, can itself enable men to feel that seeking help is acceptable. Having psychological difficulties can also mean that seeking help feels acceptable to men with cancer. Traditional roles of men and women can counteract the role of masculinity through significant females supporting their access and be used as an excuse for men to access help. For some men, just one of these factors may legitimise their complaints sufficiently to result in help seeking. For others, it may be a combination of factors, for example, both having cancer and psychological difficulties, that legitimises help seeking.

Services too may be able to help support men better to access support for psychosocial and health behaviour issues through legitimisation of seeking help. This is through gatekeepers and advertising in particular. The content of services or interventions is crucial if these services are going to be effective in supporting men's health. There is some evidence to indicate that CBT and

behaviour change techniques may make effective interventions, yet, further research on interventions men with cancer as a group is needed.

Finally, recommendations for future practice are very much linked to the implications of findings. These include: the screening of patients to identify intervention need throughout the cancer journey, which may require training for staff, including in utilising the teachable moment; the use of CBT and behaviour change techniques within interventions; and, the legitimisation of men's help seeking, especially through the use of gatekeepers, female figures, advertising and re-framing masculinity. Recommendations for future research include larger confirmatory studies and mixed-sex studies to further our understanding of these issues.

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Appendix 1. Methodology and Results for the Rapid Update Review

Update Review Aims

Given the systematic review was undertaken at the start of the thesis, and men's health research in cancer has developed further over recent years, an update review was undertaken in March 2015. This is with the aim of ensuring an inclusion of up-to-date literature around psychosocial and behaviour change interventions for men with cancer within the discussion and recommendations. The update review assists in ensuring coverage of papers and objectivity. However, given that systematic reviews can be flawed both in terms of search criteria not capturing papers, and through the inclusion criteria limiting papers, the broader literature will also be considered when discussing the current literature around interventions for men with cancer. Therefore, a combination of papers drawn from the original review, this rapid update review, and the broader literature will contribute to arguments made in the discussion. This will, therefore, add to the findings from the quantitative and qualitative studies undertaken to provide a further insight into how interventions may be able to support psychosocial issues and health behaviours in men with cancer. A rapid review was undertaken due to the constraints of time, along with the knowledge that the broad search criteria and comprehensive searches undertaken as part of the systematic review captured a high proportion of duplicates and irrelevant articles. Learning from the search criteria and processes used in the original review helped inform the current rapid review. Undertaking a review with fewer databases searched, and a narrower search

criteria enabled the identification of key texts for inclusion in a shorter amount of time (Khangura et al., 2012).

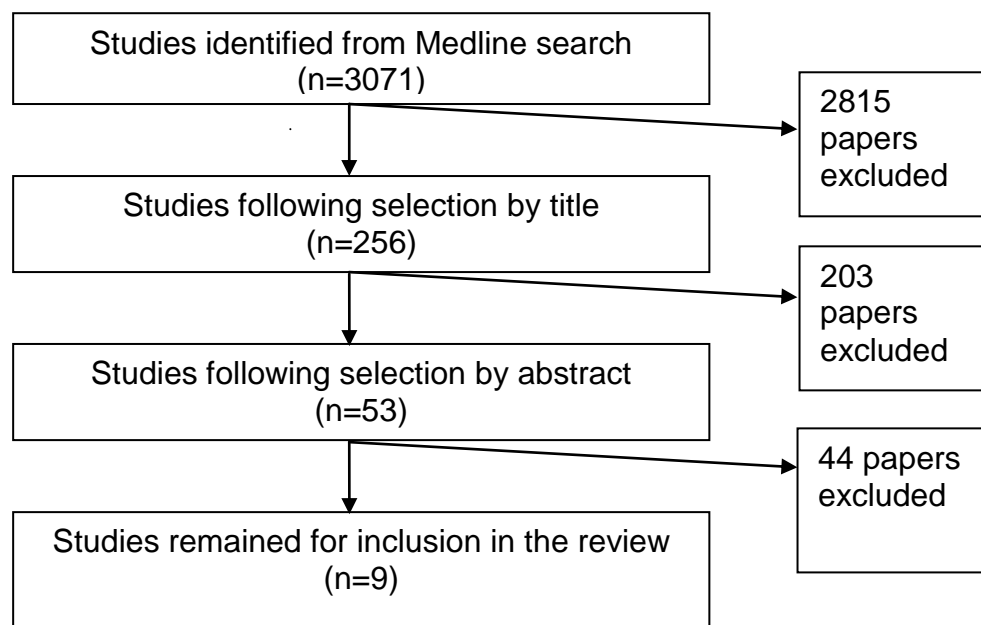
Methods

The original search identified 9937 studies that did not meet the inclusion criteria, and only 11 that did. It was decided that the term 'men' or 'male' would be added into the search and the inclusion criteria changed to include only studies with 100% men. Therefore, the search terms were: (cancer* malignan* tumor*) AND intervention AND (Behavio* psycholog* engage* social support) AND (male men). The decision to restrict papers to 100% men was also made since when inclusion criterion for studies of at least 50% men was utilised in the earlier review, only four studies were included that had samples of 50-99% men. Three of these (Allison et al., 2004b; Gielissen et al., 2006; Vilela et al., 2006) added little to the findings that would shape differently the recommendations made in Chapter 9. Whilst it could be argued that the inclusion of the study by Lioffi and White (2001) introduced a new potential intervention (hypnosis), given that the wider evidence base for hypnosis is weak (e.g. Coelho et al., 2007), it is unlikely to be a recommended intervention in the NHS in the UK. Further this study and the study by Gielissen and colleagues (2006) had samples of 54% and 52% men respectively and did not present results by sex. Therefore conclusions for populations of men with cancer are perhaps limited. It was, therefore, decided that it was reasonable in the context of a rapid review, to restrict the previous inclusion criteria to 100% men. In addition, papers would not be co-screened by a supervisor. Therefore all

inclusion criteria remained the same except now only studies with 100% men would be included.

Just one database was searched, given that almost half of papers in the original search were omitted simply because they were duplicated. Medline was chosen given it is the largest database previously used and helps ensure good coverage (January 2008-5th March 2015).

Figure I. Flow of papers through the systematic selection procedure



Results

Following screening by title, abstract and full papers, 9 papers remained that met the inclusion criteria (see Figure I for flow of papers through the systematic review procedure), two of which reported different outcome measures from the same sample (Isa et al., 2013a and 2013b). Table I, below, shows the characteristics of studies included. These are further discussed within the Chapter 8.

Table I. Study characteristics

Author & location	Participant demographics	Intervention length, content & groups	Measures & follow-up	Reported results	Author's conclusions
Ames et al., 2011 USA	N = 57 Median age = 76 Prostate cancer Attrition = 0%	Eight weeks 1. Weekly 1 hour group sessions including relaxation, mood management, nutrition, goal setting, problem solving, physical activity and conditioning 2. Wait list control	FACT-P (Functional Assessment of Cancer Therapy-Prostate) SF-36 (Medical Outcomes Study 36-item short form survey) MAX-PC (Memorial Anxiety Scale for Prostate Cancer PSS (Perceived Stress Scale-10) POMS-B (Profile of Mood States Brief) Measured at baseline, 9 weeks and 6 months	Intervention had a positive effect on quality of life (FACT-P) and anxiety (MAX-PC) at 9 weeks (end of treatment) and 6 months, with effect sizes decreasing by 6 months. There was also an improvement in scores on the mental health composite scale of the SF-36 at 9 weeks but not 6 months. There was no effect on POMS-B scores	"Results suggest that the QOL intervention may reduce prostate cancer specific anxiety and enhance disease-specific QOL and mental health aspects of general, non-disease specific, QOL." (p438)
Bourke et al., 2014 UK	N = 100 Mean age = 71 Prostate cancer Sedentary men Attrition = 15% at 12 weeks and 32% at 6 months	12 weeks 1. Tapered behaviour change support, exercise and dietary advice, guided aerobic and resistance exercise, self-directed exercise, goal setting, exploring of barriers, discussion of social support, and small group healthy eating seminars every 2 weeks. 2. Usual care	FACT-P FACT-F (Functional Assessment of Cancer Therapy-Fatigue) Godin Leisure Score Index (measuring total exercise) Symptom-limited graded exercise text (measuring aerobic exercise tolerance) Blood pressure (BP) Body Mass Index (BMI) 3-d diet diaries Measured at baseline,	Significant improvements in exercise behaviour in intervention group compared to controls at 12 weeks and 6 months but to a lesser extent Significant improvements in fatigue and aerobic exercise tolerance at 12 weeks and 6 months. Significant improvements in disease-specific quality	"Beneficial effects on disease-specific QoL, exercise behaviour, aerobic exercise tolerance, fatigue, and dietary fat content are apparent with a supervised tapered intervention up to 12 weeks. However, at 6 months in the absence of support, improvements in QoL diminish." (p870)

			12 weeks and 6 months	of life at 12 weeks only. Dietary improvements seen. No significant changes in BMI or BP	
Bourke et al., 2011 UK	N = 50 Mean age = 72 Prostate cancer Attrition = 4%	12 weeks 1. Lifestyle intervention combines supervised and self-directed exercise with dietary advice, behavioural component exploring incorporation of exercise in daily lives, social support, identification of goals, and small group healthy eating seminars every 2 weeks 2. Usual care	FACT-P FACT-F FACT-G (Functional Assessment of Cancer Therapy-General) Godin Leisure Score Index (measuring total exercise) Symptom-limited graded BMI (Body Mass Index) 3-d diet diaries Measured at baseline, 12 weeks and 6 months	Significant improvements in exercise behaviour in intervention group compared to controls at 12 weeks and 6 months Significant reductions in energy intake Fatigue improved significantly at 12 weeks and 6 months. FACT-P FACT-F and BMI scores showed no difference between groups	“This preliminary evidence suggests that pragmatic lifestyle interventions have potential to evoke improvements in exercise and dietary behavior, in addition to other important health outcomes in men with advanced prostate cancer receiving AST [Androgen Suppression Therapy].” (p647)
Carmody et al., 2012 USA	N = 36 Mean age = 69 Prostate cancer Attrition = 6%	11 weeks 1. Weekly 2.5 hour classes with didactic and experiential dietary change components, including learning to shop and cook meals, along with 15 minutes mindfulness training of sitting meditation and mindful body-stretching. 2. Usual care	24-hour dietary recall of the Nutrition Data System for Research (measuring dietary intake) Minutes of out-of-class formal mindfulness practice during 6 month study measurement period Measured at baseline, 3 months and 6 months	Significant shift from consuming animal protein to vegetable protein in intervention but not control group, and significant reductions in saturated fat At 6 months, 65% of intervention group reported regular out-of-class mindfulness practice	“These pilot results provide encouraging evidence for the feasibility of a dietary program that includes mindfulness training in supporting dietary change for men with recurrent prostate cancer...” (p1822)
Culos-Reed et	N = 100 Mean age = 68	16 weeks 1. Individualised home-	EORTC QLQ C30 (European	Significant increase (71%) increase in	“As predicted, the intervention was

<p>al., 2010 Canada</p>	<p>Prostate cancer Attrition = 34%</p>	<p>based exercise program developed by a fitness instructor. Weekly group booster sessions with 1 hour of exercise in a fitness centre and half hour physical activity education/ discussion 2. Wait list control</p>	<p>Organisation for the Research and Treatment of Cancer, Quality of Life Study Group measuring quality of life) FSS (Fatigue Severity Scale) CES-D (Centre for Epidemiological Studies Depression Scale) Blood pressure and other physiological measures Measured at baseline, and post-intervention (16 weeks)</p>	<p>physical activity in intervention group and decrease in controls Blood pressure significantly improved in the intervention group. No change in quality of life, fatigue or physiological measures</p>	<p>successful in significantly increasing PA behavior, which was further supported by concomitant changes in various fitness and body composition measures.” (p596)</p>
<p>Isa et al., 2013a and 2013b Malaysia (same sample; each paper reports different outcome measures)</p>	<p>N = 155 Mean age = 72 Prostate cancer Attrition = 11%</p>	<p>6 weeks 1. Applied Progressive Muscle Relaxation Training (APMRT) 3 2-hour sessions with principal investigator focussing on abdominal breathing to enhance relaxation. Encouraged to practice on their own daily 2. Given information about anxiety, depression and stress and minimal health education on how to improve these</p>	<p>DASS-21 (Depression Anxiety Stress Scale with sub-scales measuring depression, anxiety and stress separately) SF-36 Measured at baseline, 4 months and 6 months</p>	<p>Significant improvement in anxiety stress and quality of life, but not depression, in intervention group, maintained at 6 months In the comparison group there were significant improvements in stress between baseline and follow up</p>	<p>“The improvement in MCS and overall QOL showed the potential of APMRT in the management of prostate cancer patients. Future studies should be carried out over a longer duration to provide stronger evidence for the introduction of relaxation therapy among prostate cancer patients as a coping strategy to improve their QOL.” (p2241)</p>

<p>Livingston et al., 2010 Australia</p>	<p>N = 571 Mean age = 64 Prostate (N=389) and colorectal (N=182) cancers Attrition = 11%</p>	<p>6 months 1. Active referral-4: received 4 calls from an existing cancer helpline at 1 and 6 weeks, 3 and 6 months 2. Active referral-1: received 1 call from an existing cancer helpline at 1 week 3. Passive referral: no calls received but referred to cancer helpline (to resemble usual care) All participants given toll-free number for contacting the helpline at any point</p>	<p>Adapted measure of cancer-specific distress asking about worry about 6 different aspects of the cancer experience HADS (Hospital Anxiety and Depression Scale) Measured at baseline, 4 months, 7 months and 12 months</p>	<p>Most scores non-significant and did not differ significantly between the two active referral arms Single significant result showed greater improvement in depression scores between 4 and 7 months in active referral-4 compared with passive referral.</p>	<p>“In conclusion, further research is required to determine the best approach for providing information and supportive care for men newly diagnosed with prostate cancer or CRC. It is conceivable that a program that includes referral and telephone follow-up by cancer nurses may be of greater benefit and more effective if directed to men who do not have psychosocial support or have unmet information needs.” (p624)</p>
<p>Osei et al., 2013 USA</p>	<p>N = 40 Mean age = 67 Prostate cancer Attrition = not given</p>	<p>6 weeks 1. Online support group offered providing education and a supportive network around prostate cancer; advised to access it at least 3 times per week 2. Control group</p>	<p>SF-12 (Short-Form Health Survey 12-item short form survey) EPIC-16 (Extended Prostate Cancer Index Composite, measuring quality of life) Satisfaction with Life Scale Relationship satisfaction questionnaire as part of MIDUS (Midlife in the United States)</p>	<p>Significant improvement in the intervention group around urinary irritation and obstruction health, sexual health and hormonal health; this improvement was not maintained at week 8.</p>	<p>“Providing support using online methods is effective; the length of time this intervention should be provided to patients will require further research” (p123)</p>

			National Longitudinal Study of Health and Well-Being) Measured at baseline, 6 weeks and 8 weeks		
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Appendix 2. Prisma Checklist for the Reporting of the Systematic Review

Table II. Prisma (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) checklist for the reporting of systematic review

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	31
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	N/A
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	31-32
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	33
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	N/A
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	34-35
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	37
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	354
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	37-38
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	38
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	N/A

Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	38
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	N/A
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	N/A
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	N/A
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	N/A
Results			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	38-39
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	41-47
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	N/A
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	N/A
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	N/A
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	N/A
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	N/A
Discussion			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	52-62
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	60
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	52-62

FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	N/A

Appendix 3. Systematic Review Search Terms

The following list represents the search strategy for all databases in OVID:

Term (T) 1 cancer*

T 2 malignan*

T 3 tumor*

T 4 (T1 OR T2 OR T3)

T 5 Intervention

T 6 Behavio*

T 7 psycholog*

T 8 engage*

T 9 social support

T 10 (T6 OR T7 OR T8 OR T9)

T 11 (T4 AND T5 AND T10; therefore representing the search used to identify papers to be screened as part of the review)

Appendix 4. Patient Questionnaire

An examination of the psychological and social factors, including marital status, that affect social support and lifestyle behaviours in men with cancer

Thank you for your help with this research. Please answer all questions as honestly and as fully as possible. By completing and returning the questionnaire you are consenting for the information you give to be used in this research. If you have any questions or want help completing the questionnaire, please contact Hannah Dale on:

01334 696336, 07766 998863 or hannahdale@nhs.net

Section A. asks a bit about yourself, your cancer diagnosis, where you live, and support services accessed

1. What is your relationship status? (please tick one box only)

Single Married Civil partnership Separated
Partnered/In a relationship Divorced Widowed

2. What are your living arrangements? (please tick one box only)

Live alone Live with partner or spouse Live with parents or relatives
Live with friends **Live with children** Other please state _____

3. What is your age? _____ (in years)

4. What cancer(s) have you been diagnosed with? (please include sites of the cancer(s))

5. When were you diagnosed? (please state approximate month and year)

6. Were you told about the stage of disease or prognosis? If yes, what were you told? (e.g. 0-4 stage and/or treatable/non-treatable) _____



7. Have you received any treatment(s) for your cancer? (please detail e.g. surgery, radiotherapy) _____

8. What is your postcode? (I will not be able to identify your house from this information)

9. Are you aware of any support that is available to you? (this may be within the NHS or from voluntary organisations such as Maggie's, MacMillan or Cancer Network Fife).



Yes No

10. Have you accessed any cancer support services?

Yes <input type="checkbox"/> (please answer question 11) 	No <input type="checkbox"/> (please answer question 12) 
11. Please give details of any services accessed and if you feel they have helped you. _____ _____ _____	12. If there is anything stopping you from accessing these services please give details. _____ _____ _____

Section B. asks about your relationship with other people and the support you receive



Please read each question and place a tick in the box that comes most closely to describing your situation. E.g. if you feel a statement is very true you tick 'strongly agree'.

Social Provisions Questionnaire	Strongly disagree	Disagree	Agree	Strongly agree
1. There are people I know will help me if I really need it				
2. I do not have close relationships with other people				
3. There is no-one I can turn to in times of stress				
4. There are people who call on me to help them				
5. There are people who like the same social activities as I do				
6. Other people do not think I am good at what I do				
7. I feel burdened because I take care of someone else				
8. I am with a group of people who think the same way I do about things				
9. I do not think that other people respect what I do				
10. If something went wrong, no one would help me				
11. I have close relationships that make me feel good				
12. I have someone to talk to about decisions in my life				
13. There are people who value my skills and abilities				
14. There is no one who has the same interests and concerns as me				
15. There is no one who needs me to take care of them				
16. I have a trustworthy person to turn to if I have problems				
17. I feel a strong emotional tie with at least one other person				
18. There is no one I can count on for help if I really need it				
19. There is no one I feel comfortable talking about problems with				
20. There are people who admire my talents and abilities				
21. I do not have a feeling of closeness with anyone				
22. There is no one who likes to do the things I do				
23. There are people I can count on in an emergency				
24. No one needs me to take care of them				
25. Do you feel you would like to receive help so you feel more supported?				
Yes <input type="checkbox"/> (Please answer question 26 below)  No <input type="checkbox"/> (please go to next page) 				
26. Please give details of the types of support you feel would help. _____				

Section C. asks about how you have been feeling in the past week

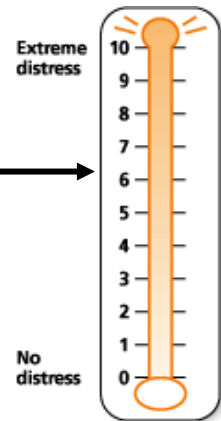
Hospital Anxiety and Depression Scale

Please read each item and circle the box that comes most closely to how you have been feeling in the past week. Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought out response.

	Answer Choices			
1. I feel tense or 'wound up'	Most of the time	A lot of the time	Time to time, occasionally	Not at all
2. I still enjoy the things I used to enjoy	Definitely as much	Not quite as much	Only a little	Hardly at all
3. I get a sort of frightened feeling as if something awful is about to happen	Very definitely and quite badly	Yes, but not too badly	A little, but it doesn't worry me	Not at all
4. I can still laugh and see the funny side of things	As much as I always could	Not quite so much now	Definitely not so much now	Not at all
5. Worrying thoughts go through my mind	A great deal of the time	A lot of the time	Not too often	Very little
6. I feel cheerful	Never	Not often	Sometimes	Most of the time
7. I can sit at ease and feel relaxed	Definitely	Usually	Not often	Not at all
8. I feel as if I am slowed down	Nearly all the time	Very often	Sometimes	Not at all
9. I get a sort of frightened feeling like 'butterflies' in the stomach	Not at all	Occasionally	Quite often	Very often
10. I have lost interest in my appearance	Definitely	I don't take as much care as I should	I may not take quite as much care	I take just as much care as ever
11. I feel restless as if I have to be on the move	Very much indeed	Quite a lot	Not very much	Not at all
12. I look forward with enjoyment to things	As much as I ever did	Rather less than I used to	Definitely less than I used to	Hardly at all
13. I get sudden feelings of panic	Very often indeed	Quite often	Not very often	Not at all
14. I can enjoy a good book or radio or television programme	Often	Sometimes	Not often	Very seldom
15. Do you feel you would like to receive support to help improve how you are feeling? Yes <input type="checkbox"/> (Please answer question 16 below)  No <input type="checkbox"/> (please go to the next page) 				
16 Please give details of the types of support you feel would help. _____ _____ _____				

Distress Thermometer

Instructions: Please circle or mark the number (0-10) that best describes how much distress you have been experiencing in the past week, including today.



Please indicate **below** if any of the following has been a cause of distress in the past week, including today.

Be sure to check **YES** or **NO** for each.

Practical Problems	YES	NO	Physical Problems	YES	NO
Housing	<input type="checkbox"/>	<input type="checkbox"/>	Pain	<input type="checkbox"/>	<input type="checkbox"/>
Insurance	<input type="checkbox"/>	<input type="checkbox"/>	Nausea	<input type="checkbox"/>	<input type="checkbox"/>
Work/school	<input type="checkbox"/>	<input type="checkbox"/>	Fatigue	<input type="checkbox"/>	<input type="checkbox"/>
Transportation	<input type="checkbox"/>	<input type="checkbox"/>	Sleep	<input type="checkbox"/>	<input type="checkbox"/>
Child care	<input type="checkbox"/>	<input type="checkbox"/>	Getting around	<input type="checkbox"/>	<input type="checkbox"/>
			Bathing/dressing	<input type="checkbox"/>	<input type="checkbox"/>
Family Problems			Breathing	<input type="checkbox"/>	<input type="checkbox"/>
Dealing with partner	<input type="checkbox"/>	<input type="checkbox"/>	Mouth sores	<input type="checkbox"/>	<input type="checkbox"/>
Dealing with children	<input type="checkbox"/>	<input type="checkbox"/>	Eating	<input type="checkbox"/>	<input type="checkbox"/>
			Indigestion	<input type="checkbox"/>	<input type="checkbox"/>
Emotional Problems			Constipation	<input type="checkbox"/>	<input type="checkbox"/>
Worry	<input type="checkbox"/>	<input type="checkbox"/>	Diarrhea	<input type="checkbox"/>	<input type="checkbox"/>
Fears	<input type="checkbox"/>	<input type="checkbox"/>	Changes in urination	<input type="checkbox"/>	<input type="checkbox"/>
Sadness	<input type="checkbox"/>	<input type="checkbox"/>	Fevers	<input type="checkbox"/>	<input type="checkbox"/>
Depression	<input type="checkbox"/>	<input type="checkbox"/>	Skin dry/itchy	<input type="checkbox"/>	<input type="checkbox"/>
Nervousness	<input type="checkbox"/>	<input type="checkbox"/>	Nose dry/congested	<input type="checkbox"/>	<input type="checkbox"/>
Loss of interest in usual activities	<input type="checkbox"/>	<input type="checkbox"/>	Tingling in hands/feet	<input type="checkbox"/>	<input type="checkbox"/>
			Feeling swollen	<input type="checkbox"/>	<input type="checkbox"/>
Spiritual/Religious Concerns	<input type="checkbox"/>	<input type="checkbox"/>	Sexual	<input type="checkbox"/>	<input type="checkbox"/>
			Appearance	<input type="checkbox"/>	<input type="checkbox"/>
			Memory/Concentration	<input type="checkbox"/>	<input type="checkbox"/>

Please detail any other concerns not listed above. _____

1. Do you feel you need any support to help reduce anything that causes you distress?

Yes (please answer question 2 below) **No** (please go to the next page) →

2. Please give details of the types of support you feel would help. _____



14. How many portions of fruit and vegetables do you eat per DAY?

One portion is approximately a handful, e.g. 1 apple, a handful of grapes, 2 plums, 3 tablespoons of peas.

15. Do you want to improve your diet, for example increasing your fruit and vegetable intake? (please tick one only)

Yes

No

Haven't thought about it

16. How confident are you that you could improve your diet if you wanted to? (please tick the statement that best describes how confident you feel)

Very
confident

A little
confident

Neither
confident or
unconfident

A little
unconfident

Very
unconfident

17. Do you feel you need any support to help you improve your diet?

Yes (please answer question 18 below)

No (please go to question 19)

18. Please give details of the types of support you feel would help. _____



19. How many hours of moderate or higher-intensity exercise do you do per WEEK? _____

Moderate exercise is any activity that causes a slight increase in your heart rate, breathing and temperature. This may include walking.

20. Do you want to increase the amount of exercise you do? (please tick one only)

Yes

No

Haven't thought about it

21. How confident are you that you could increase the amount of exercise you do if you wanted to? (please tick the statement that best describes how confident you feel)

Very
confident

A little
confident

Neither
confident or
unconfident

A little
unconfident

Very
unconfident

22. Do you feel you need any support to help increase the amount of exercise you do?

Yes (please answer question 23 below)

No (please go to question 24)

23. Please give details of the types of support you feel would help. _____

24. Please write below if there are any other lifestyle issues you feel you need help with and the types of support you feel would help _____

Section E. asks about any additional support you feel you may need

1. Please tick any of the following options that you feel may encourage you to access support services. (please tick all that apply)

One-to-one <input type="checkbox"/> appointments	Same-sex <input type="checkbox"/> groups	Mixed-sex <input type="checkbox"/> groups	Evening <input type="checkbox"/> appointments
Weekend <input type="checkbox"/> appointments	Drop-in service <input type="checkbox"/> (so you don't need an appointment)	Referral to service <input type="checkbox"/> from staff members (e.g. oncology team)	Being able to <input type="checkbox"/> self-refer to service
A service in a <input type="checkbox"/> community venue (e.g. library)	A service available <input type="checkbox"/> at hospital	A service available <input type="checkbox"/> in your local health centre or GP surgery	A service that will <input type="checkbox"/> come to your home

Other(s) (please detail) _____

2. If you feel there are any barriers to you accessing support services please give details:

3. How confident are you in accessing support services? (please tick the statement that best describes how confident you feel)

Very <input type="checkbox"/> confident	A little <input type="checkbox"/> confident	Neither <input type="checkbox"/> confident or unconfident	A little <input type="checkbox"/> unconfident	Very <input type="checkbox"/> unconfident
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4. Do you have a particular belief/life philosophy that you feel helps you deal with cancer?
No Yes Please give details: _____

5. Do you feel there is anything in particular about your situation that makes it difficult for you to live with cancer? Please give details. _____

6. If you feel that the help you require has changed since diagnosis, please give details.

7. Do you feel there are, or have been, any particular points in your illness that you would have benefited from additional support services? Please give details. _____

8. Do you feel you would like help to access additional services?
Yes (please answer question 9 below) No (please go to the next page)

9. Please give details of the types of support you feel would help. _____

Appendix 5. Interview Schedule; Topic Guide

An examination of the psychological and social factors, including marital status, that affect social support and lifestyle behaviours in men with cancer

- How did you find out about the study?
- What made you want to take part?

To examine current and historical access to cancer support services

I'm interested in support and before we start, I wanted to tell you what I mean by support when I ask about it in questions. I'm generally using a very broad definition, so this may be going to a specific service to receive support, feeling supported by friends or family or receiving support during contact with a medical professional or in another setting. So really anything that helps you feel supported.

- Can you start by telling me about any support you've received since being diagnosed with cancer?
 - How regular was the support
 - Can you tell me more about it?
- Have you sought out any kind of support from more formal services?
 - Who or what service was it?
 - Have you been there often?
 - How many times have you attended?
 - Are there any other services you've been to?
- Are you aware of other services that are available to you?
 - Prompt other services that are available to them to explore if they have heard of them e.g. Maggie's, MacMillan benefits advisors, Circle of comfort.
- Are there places that you've received informal support, such as just chatting with other patients during treatment, work colleagues or other people?
 - How often did you receive that sort of support
- Is there any support that you've received that you haven't wanted or that you've felt was unhelpful?

To explore reasons for and for not accessing services

- Why do you access services in general?
- Why do you go there [name of specific service/organisation] for support?
 - Was there anyone in particular who encouraged you to go or helped you to get there?
 - Was there anything that triggered you wanting to go there?
 - Has your experience of that service influenced you accessing other services? In what way?
- Do you know if other people have had similar experiences when going to the service/services?
- Is there any particular reason why you don't access support services?
 - Are there particular things that get in the way of you accessing more support?
 - Do you feel you could gain anything from going to support services
- Do you feel there is anything particular about your circumstances that has affected you attending/not attending support services?
- Do you feel there are any particular things that get in the way of other people accessing services?

To explore perceived gender differences

- In your experience, do you think men access support to the same extent that women do?
 - Why do you think that is?
- Do you feel this is any different for cancer support services than other general health services?
- Do you feel that being male has an influence on you accessing services?
 - Do you think that being male has an affect on your willingness to go?
 - We know from services that some men are reluctant to go; why do you think that is?
 - Why do you think other men may be more/less willing to go to services for support?
 - There are groups in some areas for men with cancer; have you been to any of these groups?
 - Would anything make you want to go?
 - What were your reasons for going?

To look at what could be done to improve access to services

- How satisfied do you feel with the services overall that are available to you?
 - Ask about a specific service they have accessed
- Do you feel there are particular types of support you would have benefited from?
 - Is this at a particular time point since being diagnosed?
- Are there things that could be done to help you access services more?
 - Are there particular practical things that could be done to help you access services more?
 - How would you like to find out about support services?
 - When would you like to be informed about support services?
 - What would have helped you access support?
- Are there things that you feel could be done to help others access services more?
 - Thinking back to your problems that other people may face, do you have any thoughts about how to overcome them?
- What could be done about the way services are advertised or promoted to male cancer patients to encourage you/others to attend?
- If a charity had funds to develop services to better support men with cancer, what would you do with the funding?
 - Services or suggestions in other areas include: room above a pub, in Australia there are sheds where men hang out and do woodwork and other crafts and through that get support, walking groups.

Appendix 6. Consent Form

An examination of the psychological and social factors, including marital status, that affect social support and lifestyle behaviours in men with cancer

Please tick the box if you agree with the statement (leave blank if you disagree):

- I have read (or had read to me) about this project and I understand what this project is about
- I have had an opportunity to ask any questions
- I understand it's OK to stop taking part at any time
- I understand that the interview will be recorded, and kept for 6-12 months on a secured NHS computer before being destroyed
- I understand that the recording and any quotes made in reports will be made anonymous (will not include my name or any details that could identify me)
- I am happy to take part

If you do want to take part, you can write your name below:

Your name _____

Date _____

Signature _____

The researcher who explained this project to you needs to sign too:

Print Name _____

Date _____

Sign _____

Thank you for your help.

Appendix 7. Coding Framework for Qualitative Analysis

Table III. Coding framework for qualitative analysis

Note shading to indicate level of code: Highest level code (theme), next level code (sub-code), lowest level code (further sub-code)

Code Name	Description	Detail of how to know when the theme occurs (i.e. how to “flag” the theme)	Examples from the data to help eliminate possible confusion when coding data
Antecedent: individual/psychological	Describes something relating to that individual or psychological factors that is impacting on appraisal/coping	See sub-codes	See sub-codes
Value-commitments	Demonstrating the importance of values or commitments and how this links to appraisal or coping	This could be around any value, such as valuing freedom, honesty, committing to things	<ul style="list-style-type: none"> • "I as I say I think if you give people leaflets then they can make up their own mind which leaflets they're going to read and which ones they're going to pay attention to and that's it." Drew • "...know what's important and what's not and it's not things or possessions its people and relationships." Ian1
Beliefs-assumptions	Participant implicitly or explicitly discuss beliefs or assumptions about something in relation to cancer or use of coping styles/support	This may be in relation to their diagnosis/prognosis, help seeking, services or something else	<ul style="list-style-type: none"> • Interviewer: "So what do you think it would be like say if you went along to the Maggie Centre?" Gary: "I really don't know, you can only imagine there's people sitting around saying oh "I've got cancer", "so have I", but I don't know, I would have to say I don't know." • Interviewer: "So can I ask what you think they might involve, that sort of the stop smoking services, what's your idea..." Chris: "Em, what these counselling, the sessions" Interviewer: "Yeah the stop smoking sessions yeah."

Code Name	Description	Detail of how to know when the theme occurs (i.e. how to “flag” the theme)	Examples from the data to help eliminate possible confusion when coding data
			<p>Chris: “I really, I wouldn’t like to think, I would hate to think it’s everybody sat round and telling about their experiences and how many they smoke a day and that sort of goes back to Alcoholics Anonymous and stand up and I am.... And I smoke forty a day...Probably it’s been imposed on to my mind without having any read knowledge or anything like that about it so probably misguided in that aspect I suppose.”</p> <ul style="list-style-type: none"> • “You could probably make people more aware of what actually happens at the group meetings and like who goes because how a lot of people are like if you see like films, if there’s a support group on a film or something on TV they’re always.... Hmmmm, so I think people have got that in their mind...like they’re a bunch o’ saddos or something which obviously they’re no, but ken what I mean, but that’s no the reason I dinnae go, I just dinnae go.” Gary • Interviewer: “So it’s [Maggie’s Centre] just open during the day and it’s for anyone to drop in and have a cup of tea and have a chat either about cancer or about anything else you would like to chat about and they also do various groups such as tai chi and creative writing and nutrition and men’s groups and women’s groups and other things, so it’s aimed at cancer patients, but it’s, they’re always designed by fairly famous architects so they always have really interesting designs so it’s really just open during the day during the week for people to drop in if they want to.” <p>Rom: “Oh that’s, yes it’s.... but that sounds, that sounds very much as if it’s directed at</p>

Code Name	Description	Detail of how to know when the theme occurs (i.e. how to “flag” the theme)	Examples from the data to help eliminate possible confusion when coding data
Attitude towards coping styles	Attitude towards coping styles or other positive change (e.g. health behaviour) influences behaviour	Implicit or explicit reference to attitude affecting desire to engage in certain coping styles – likely specific to a particular type of coping	<p>loners shall we say.”</p> <ul style="list-style-type: none"> • “Aha, em, well for the likes of, well exercise or that there’s the new campus that has a swimming pool and gym, it has all the recreational stuff there for, you know if you wanted to use it, which I don’t (laughs).” David • “Yeah because we don’t like to be told what to do you know and you but I joke with my wife about that you know but it is the, we’re terribly bad for that. Em, our wives tell us not to eat something specific then we’ll go out just... the, the message is valid and it’s very good but they’ll just close off because you’re telling me what I can and can’t do. So yeah no I’ll just close off.” Ian1 • “I wouldnae want people asking me. My pal, aye he’s asked me a few times how are you, how’s your, I cannae mind what he called it, it wasnae bladder, how are you doon below or something like that and I said fine and that was it, fine and when he’s asked again a few weeks later and I said fine and that was that so he’s never asked again.” Gary
Attitude towards help seeking	Attitude around accessing support influences desire to access it	Their attitude is influencing them accessing support	<ul style="list-style-type: none"> • “Well I, at first I thought oh well am I going to gain anything by going...I thought oh well I might go along in February and just see what it’s like so I went along in February just to see what it was like. And I as I say I found it a help to talk to people that have the same eh type of cancer as you have.” Leonard • “The only person that had mentioned it was [name of nurse specialist]... Anyway this sort of switched on a wee light bulb in my head and I thought here this sounds the sort of thing that I might enjoy, because I like interacting with

Code Name	Description	Detail of how to know when the theme occurs (i.e. how to “flag” the theme)	Examples from the data to help eliminate possible confusion when coding data
			<p>people...” Jim</p> <ul style="list-style-type: none"> • “They’re not like me I’ll try anything once; sometimes I’m pleasantly surprised as I was here.” Bill1 • “And places that you could go to, na I I’m not really interested in that no. Em who I have coming in eh in on the health side is I’m quite happy with I I’m I wouldnae want to venture out to seek more than what, what I’ve, I’ve got.” Robert
Cognitive coping styles	Discussion of pre-existing cognitive factors that are impacting on appraisal/coping	See sub-codes	<ul style="list-style-type: none"> • See sub-codes
Optimism	Discussion of being optimistic, positive attitude or similar word in supporting coping	More discussed implicitly or explicitly as a trait coping style (always coped in that way)	<ul style="list-style-type: none"> • “We’ve a had similar attitude, to get on with life, make the best of it and that’s what we did ... I would say I’ve always been that way...” Mike • “No I just kept a positive attitude which is what I’ve got... Just my own self and thinking positive and eh not necessarily being frightened of something like that.” Robert • “I don’t know whether it’s age-wise I mean I was in the RAF five and a half years, I was only flying for the last two and a half but yeah, one expected to end up in a ditch, if you were lucky so that translated to now (laughs), it would be wrong to say this is nothing, it’s very important, but one and one includes myself, takes I suppose a more relaxed view of it.” Rom
Introversion/extraversion	Speaks of being introverted or extraverted (or similar words relating to personality e.g. not sociable, not in their	May be framed as a negative or positive thing	<ul style="list-style-type: none"> • “I’ve never been inhibited but then again it goes back again to the jobs I’ve had, so I’ve always been fairly outgoing and I take people as I see them.” Mike • “With feeling that that’s a, adequate and I’m

Code Name	Description	Detail of how to know when the theme occurs (i.e. how to “flag” the theme)	Examples from the data to help eliminate possible confusion when coding data
	nature, outgoing etc) and that contributes to whether or not they access support		<p>not the type to venture out to meetings and things with loads of people that have got psychiatric problems or cancer problems or what whatever, I’m just content with what I’ve had... I think it, it, it would be em out with my comfort zone you understand that?” Robert</p> <ul style="list-style-type: none"> • “Not really no. I’m quite a, what would you say...Self-sufficient sort of person and quite used to being in my own company...I’m just not really a very social person to be honest. I just tend to keep myself to myself. I mean I’ve been asked to come here a couple of times by eh, you know the Macmillan nurse, to attend things, but I’ve never done it you know.” Ian2 • “Pff, that’s a, I don’t honesty think so but probably if I was probably, oh god how would you describe, say that there was, intro, introverted, not an outgoing person.” John
Antecedent: social	Describes something relating to social factors that is impacting on appraisal/coping	See sub-codes	See sub-codes
Socio-economic status	Discusses something relating to socio-economic status that makes the situation difficult		<ul style="list-style-type: none"> • “I was homeless for a short time I was then declared bankrupt and I then had cancer all within a 6 month period.” Ian1
Cultural templates	Participant discusses something cultural that is impacting on their interpretation of cancer, or willingness to use certain coping strategies	Any type of wider cultural factor impacting on appraisal of, or coping with cancer	<ul style="list-style-type: none"> • See sub-codes
Ideas about masculinity	Participant discusses that something about being	Male, macho, masculinity or other	<ul style="list-style-type: none"> • “I would think [men] probably less so than women would [access services], em, women

Code Name	Description	Detail of how to know when the theme occurs (i.e. how to “flag” the theme)	Examples from the data to help eliminate possible confusion when coding data
	male or masculinity affects their appraisal or coping style	similar word. May also be implicit using different words	<p>tend to be a more social animal than us men you know.” Ian2</p> <ul style="list-style-type: none"> • “I think, em on my side, obviously my side I haven’t needed it but I think men tend to hide things a, a lot more that women eh, ladies are always together, ladies like to have a chit chat over coffee whatever you know even with problems, you know. It’s sort of I don’t know if it’s a ladies social thing, whatever problems you’ve got with kids, husbands, whatever the case may be I think they all seem to want to be together. Men, ‘how are you doing today Jim?’ ‘Fine’, okay then. You know that’s it ...you know more that the men possibly, I don’t know if that’s what you it call a macho image that men have, I’m fine. I don’t need any help, maybe some do maybe some don’t.” John • Interviewer: “I was just wondering in your experience do you think men need support as much as women?” Ian1: “Oh yeah we’re all emotional retards, we are it’s men are the worst because there’s this macho perception of and I sure suffer from it periodically where you know.” • “A lot of men as well ken the culture, you dinnae speak about your problems, you dinnae dae this, that’s wi a lot of men. I mean I was, I was a bit like, ken I’m a man’s man type thing ken, never show emotion and stuff like that ken, but I tell people I ken a guy, I use to go to school wi him and he’s no well and I says look you dinnae have to go doon there and burst into tears, there’s nothing to stop you from speaking to them. I says if you burst into tears they’re no going to think anything less of you

Code Name	Description	Detail of how to know when the theme occurs (i.e. how to “flag” the theme)	Examples from the data to help eliminate possible confusion when coding data
			<p>because he sits there day after day and he’s gave up and I’m like dinnae gie up. I think a lot of men are scared of showing their emotions, that’s what it is.” Fred</p> <ul style="list-style-type: none"> “It’s getting over that barrier of masculinity the, the I’m, I’m, a man and you know I shouldn’t be worrying about things like that. Men don’t get that sort of thing real men real men smoke Marlboro and ride horses across the prairie. (laughs) But em, you know real men do get cancer and lots of them lots and lots and lots of them.” Clark
Ideas about age/ generation	Discusses age or generation as affecting appraisal or coping style	Age of someone or generational issues likely to be explicitly stated	<ul style="list-style-type: none"> “I imagine that some people may um, I mean cancer has a very bad name obviously and think they ought to keep it to themselves and probably not even tell their friends about it and eh take a very, I hate to use the phrase, but old fashioned view about it.” Rom “I mean years ago the Big C you never spoke about the Big C you ken it was kept under the carpet sort of thing you know but no noo it’s, folks open and talking about it you know.” Harry “No, no not at all no. I’m quite, em as far as I’m concerned and I think probably it’s an age thing, if I were thirty-two or forty-two instead of ninety-two I would probably approach it differently, but as far as I’m concerned I think I’m jolly lucky to have got to where I have got age-wise and so you know pinprick things which I might latch on to.” Rom “Maybe they’ve said to themselves oh he’s 74, 75 years old, he won’t be doing very much.” Bill1
Social network	Discusses something	This may be about	<ul style="list-style-type: none"> Interviewer: “And being a man yourself have

Code Name	Description	Detail of how to know when the theme occurs (i.e. how to “flag” the theme)	Examples from the data to help eliminate possible confusion when coding data
	about their existing social network that has affected their appraisal/coping with cancer	individuals or groups that form part of their social network	<p>you got any ideas as to how what can help men overcome that?”</p> <p>David: “Not really no! Em...a good wife to push you (laughs)”</p> <ul style="list-style-type: none"> • “I mean let’s face it half the men that come to Maggie’s their wives are pushing, pushing, pushing, they don’t come of their own free will.” Bill1 • “I was just travelling every day which kind of took it out of you, but luckily friends and neighbours they took a turn in taking us down so it saved [name of wife] she only had to do it twice a week, maybe sometimes three times a week.” David
Antecedent: environmental	Describes something relating to the environment that is impacting on appraisal/coping	See sub-codes	<ul style="list-style-type: none"> • See sub-codes
Situational variables	Any non-cancer events that are adding to or alleviating difficulties or affecting their appraisal/coping	This may be bereavement, other people’s illnesses, moving house or other life event adding to the pressure of having cancer	<ul style="list-style-type: none"> • “I’m still here but since my wife died I’ve become even more complacent. I used to think that life was everything and I don’t think life is everything, I think that marriage is everything. And since my wife died I’ve sort of gone down.” Bill1 • “All in all I’ve coped with it better than I thought I would and the em the doctor praised me and was proud of me for the way I handle things. Not the sort of “oh no I’ve got cancer I’ve got cancer” I was quite cool when I was told I’ve got cancer eh cos I’ve had a pretty hard life I would say I’ve had loads of ups and downs so nothing is a surprise as such... I just kept a positive attitude which is what I’ve got now after being diagnosed with it.” Robert

Code Name	Description	Detail of how to know when the theme occurs (i.e. how to “flag” the theme)	Examples from the data to help eliminate possible confusion when coding data
Timing	Discussion of something around the timing of cancer or other things contributing to a difficult situation	Something about the timing of cancer diagnosis or treatment contributing to difficulties	<ul style="list-style-type: none"> “I had a whole load of things going on in my life at the time em, that all sort of, I’d separated from my wife em, I was homeless for a short time I was then declared bankrupt and I then had cancer all within a 6 month period.” Ian1
Ambiguity	Ambiguity relating to the situation or specifically the cancer diagnosis	This could be a discussion of finding the ambiguity difficult or coping ok with it.	<ul style="list-style-type: none"> “As I was told, the, eh, what the future is full of ifs and buts, and I could understand that, nobody can, nobody has an x-ray vision not could they predict the future so until they’d carried out the tests that they had in the programme, they couldn’t give me an answer so it was pointless me asking the question before there was a need to.” Mike “I don’t know whether I’ve got 6 months or 5 years or 10 years and it could be any of them... I don’t like the uncertainty of it em.” Clark
Social and material resources	Discussion of having or a lack of social or material resource	This is most likely in relation to then appraising and coping with cancer	<ul style="list-style-type: none"> “So my brother was supportive that way in that he brought my wife down one night and his wife drove his car home and he took my car home, and it’s amazing that in the depths of this physical unwellness it was good to know that my car had been taken home, so I think that these wee practical things can be very helpful as well...” Jim
Antecedent: biological	Describes something relating to biological factors that are impacting on appraisal/coping	See sub-codes	<ul style="list-style-type: none"> See sub-codes
Diagnosis/ prognosis/ treatment	Discusses how the particular diagnosis, prognosis and/or treatment are affecting appraisal/coping	May be implicit or explicit	<ul style="list-style-type: none"> “Not really no, I’m quite a, what would you say, self-sufficient sort of person and quite used to being in my own company, but, had I felt ill or something along with it, I might’ve been looking for a bit more support, but I’ve never really felt ill.” Ian2 “Ah well it would only appeal to me I think if

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			<p>circumstances altered so much I though, I might think well I wonder how so and so or this person or that person gets along with it and they might be able to tell me how they get round it, but at the moment I’m not being (hopefully) big headed, but I’m quite content in either getting on with it shall we say in my own time and I don’t, I don’t need any kind of help in that way and again I mean it’s getting to be quite a litany, only at this moment.” Rom</p> <ul style="list-style-type: none"> • “Yeah, yeah, eh, but I mean I’ve never needed anything...You know as I say, everything everything’s been tickety boo you know...” Drew
Symptoms/side effects	Discusses how symptoms and/or side effects are affecting appraisal/coping	May be implicit or explicit	<ul style="list-style-type: none"> • “No, I find it very hard to accept like, people’s perception of cancer I think 99% of people just think well that’s it then ken, you get a tumour and well that’s it...I do self-catheterisation for my bowel and my bladder and that takes a long time to get my head round then ken...” Fred • “Yeah, aye cos I read, I’m going through books like nothing on earth. I just read quite a lot now, just to pass the time cos it does get a bit frustrating at times, not being able to do things cos I do some things...”David
Appraisal: primary appraisal	Discussion of appraisal of cancer diagnosis	See sub-codes	<ul style="list-style-type: none"> • See sub-codes
Stressful	Appraising cancer as stressful	Discussion that they are finding cancer stressful. May include more subtle references to stress and may not include the word ‘stress’.	<ul style="list-style-type: none"> • “I got diagnosed on the Friday, operated on the Monday and my life had totally changed. It was upside down it wasnae, I didnae even have a clue I had cancer.” Fred • “When I was first diagnosed, well your mind just sort of goes, boom! Boom! Boom!” Ian2 • “You know I mean I think ,well after the

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			initial shock eh and then when I was going about in a daze for a wee while wondering how long I was going to have to live you know.” Leonard
Manageable	Appraising stress associated with cancer as manageable	May discuss cancer as stressful, however that they feel that it was manageable	<ul style="list-style-type: none"> • “Again, I didn’t, em I’m trying to think back. It didn’t really strike me as being all shock and awe, it was just sort of well this is what it was, it was a, a mole there that had to be removed and then tested, it came back positive.” • “I’ve sort of dealt with cancer in the family before, my mother and father they both died of cancer so, it wasnae a word that frightened me really” Ian2
Fearful	Appraised the cancer diagnosis as causing fear	Discussion of cancer as causing them to be scared or fearful or a word with a similar meaning	<ul style="list-style-type: none"> • “I was, I used to be frightened of it at first but not now.” Jimmy • “...then em took me in and told me and they actually showed me the scan and that really knocked me for six then they started going on about they’d have to go in the side and take a biopsy. Then they started going on about what would maybe happen to me and I thought oh jeezy peeps...just knowing that tch, I could have died. [gets teary]. Phew, excuse me [teary].” David • “Some of it was a wee bit frightening but eh I was just concentrating on the treatment that I was getting so that seems to be alright and I think it’s quite eh.” Leonard
Denial	Was not able to fully accept the diagnosis of cancer that has been given	Includes direct or indirect reference to denial about cancer	<ul style="list-style-type: none"> • “It’s just like a just like your big toe it’s there...But that didnae dae anything fur ma cancer. Cos I dae think I’ve got cancer ye ken...I think they’re just winding me up.” Jimmy • “Even now I still think oh they’ve got it wrong. I still wake up every morning and think oh they’re gonna phone us and say they’ve got

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			it wrong, ken what I mean. No, I find it very hard to accept like.” Fred
Fatalistic	Appraisal of cancer including beliefs or assumptions that it will be fatal	Discussion of their cancer diagnosis as fatalistic	<ul style="list-style-type: none"> • “Well the first day I was diagnosed that was in the morning eh, in the afternoon I went up and got the price of cremation you know I was that, the way my brain was going round and then within a week or so I made a will ...You know you see people maybe diagnosed with cancer that and within about a year or sometimes within a few months eh they’ve died.” Leonard • “Yeah I to start with em no not very easily em I went through that whole panicking that people go through of Hell I’ve got cancer I’m going to die.” Clark
Appraisal: secondary appraisal	Discussion of appraisal of their ability to cope with the challenges of their diagnosis of cancer	See sub-codes	<ul style="list-style-type: none"> • See sub-codes
Controllability of cancer	Discussion of appraising the controllability of cancer	This may be reference to cancer as controllable or uncontrollable directly or indirectly	<ul style="list-style-type: none"> • “I’m quite a black and white person and I em operate better in knowing the facts the uncertainty of is it a month is it 5 years is it 10 years doesn’t sit well with me.” Clark • “I think if someone’s been in charge of their life for so many years and something happens, traumatic happens they’re floundering and they’re in a zone that they can’t deal with and they’re frightened.” Mike • “I mean whatever the PSA reading is or if they think it’s getting worse the consultant sees it and then decides because I got a letter once when the PSA was going up eh to take another tablet...so I got that and then the PSA came down a bit. But it’s rising just a wee bit now but I go again next week for another injection so

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			everything’s more or less under control you know.” Leonard
Self-efficacy	Discussion of self-efficacy in doing things to cope with cancer	May discuss confidence or ability to do something in relation to coping with cancer	<ul style="list-style-type: none"> “Aye, I took up gliding when I was 60, flying an aircraft without an engine and I was pushing and pulling gliders across the airfield and what not, and to have a sort of, an iron curtain put down, “Oh ye won’t be able to do this, you won’t be able to do that, you won’t be able to do the next thing” It’s like a, a youngster applying for a job these days, the answer was no, no, no. And yet I felt within myself yes I can [do more activity on the ward].” Bill1
Past coping behaviour	Discussion of using similar coping strategies in the past for other stressors	Previous use of similar strategies helps enable them to use them now in coping with cancer	<ul style="list-style-type: none"> “I really needed somebody to talk to. And that was the start of it.... but I’ve done this kind of thing before, I went to counselling for a while there for about six months or so and that helped, just to get talking about it and trying to come to terms with it.” Kyle “I don’t like sitting in the house, as I say used to go out and walk even when it was raining you know just to get out and git a bit of fresh air...And that’s how, oh I’ve got to get out for a bit of fresh air I mean I just go out for 20 minutes or so it, if it’s cold like that I feel better if I do go out but I usually try to get out at, well during the summer I’m out in the garden tidying up and eh but during the winter I usually like to get out if it’s reasonable at least an hour, sometimes a wee bit more.” Leonard “If I get too out of breath doing normal things that I never have been in the past or the weight has increased dramatically then I’ll go back out and start walking and running and things like that.” Chris
Coping: emotion-	Discusses something that	This may be something	<ul style="list-style-type: none"> See sub-codes

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focused coping	would be considered emotion-focused coping	involving talking, avoidance or other emotional way of dealing with something, or anything in sub-codes	
Distraction	Discusses the use of distraction as a coping mechanism	Discusses the deliberate or accidental use of distraction as a way of coping	<ul style="list-style-type: none"> • “Yeah, aye cos I read, I’m going through books like nothing on earth. I just read quite a lot now, just to pass the time.” David • “Yes, I go there on the Wednesday and Thursday for the Tai Chi, there’s nothing else better to do sort of thing, so I , I find that if I keep myself occupied you know it’s not so bad you’re not sitting in the house sort of thinking about it.” Leonard • “Kept myself busy and kept you know not really needing any support.” John • “Maggie’s Centre is great for support and for trying to keep you busy, trying to keep your mind active ken. Just, and they’re good I ken I can go in there any day... somewhere like the Maggie Centre is a good place to go and forget about it.” Fred
Anger	Discusses anger as a way of coping with cancer.	Deliberate or non-deliberate use of anger. May include a sense of unfairness.	<ul style="list-style-type: none"> • “I get angry, a bit hurt wi it like, but I dinnae dwell on it like, eah cos I never, I never knew things like that existed ken cos my thing as well I says look I train, I eat properly I dinnae drink, I dinnae smoke, I’ve never touched drugs I’ve never touched steroids, why me?” Fred • “cos it does get a bit frustrating at times, not being able to do things cos I do some things then I start getting tired then I start shaking and things like that so it kind of, make you, grrr, I’m no saying angry, just kind of aggravated.” David • “I was very, very angry, really angry and I’m no different to a lot of other people I’ve spoken

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			<p>to that have been very angry, but then you have this thing of why me and all this and it’s quite normal you know.” Kyle</p> <ul style="list-style-type: none"> • “But there are time that it just it feels like I’m not in control I’m completely gone I’m, I’m and then I somehow come out of it and I’m like, God! Shouting and screaming and swearing like a complete arse hole...” Clark
Relaxation	Something that helped relax and calm the mind	May include meditation, reiki, other relaxation etc	<ul style="list-style-type: none"> • “There was, if I felt down which I did on a number of occasions I would excuse myself, go upstairs and I was very fortunate I would apply self-hypnosis, for about 30 years I studies martial arts and stuff and it gave me that insight. I can calm myself down...” Mike • “Like I say they’re good for that and the Maggie Centre are good for, what I liked about it, it was a good place to go and relax in their room up the stair you could just sit up there, it was good for that.” Fred • “Em, well you tend to deal with sort of things that bother you when you go fishing and you sit down on the bank out there in the wide open spaces and the trees and the birds and everything... a way of relaxing and you know relax your mind and relax your body too and concentrate on catching these fish. I would recommend fishing to anybody that’s bothered by.” Ian2 • “Well I, I feel eh, I suppose you could say I feel a bit calmer to a certain extent after doing it [Tai Chi]...” Leonard • “Dru yoga is all to do with, you mainly use your core muscles and it’s all about strengthening the muscles in your body every, nearly every part of it... I find it very relaxing.”

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Talking	Discusses talking as a way of coping	This may explicitly talking to cope or implicitly that talking, moaning, off-loading etc has helped them.	<p>Kyle</p> <ul style="list-style-type: none"> “I think I’ve come to terms with that now and that’s been a really big change by talking about it and some of the questions that the counsellors asked me and got me talking about things so that’s, I think that’s been a big step forward coming to terms with that.” Kyle “...its almost like having a virtual friend, you don’t meet the person face to face but you text, you talk about the weather, we talk about the fact that we’re going to decorate the bedroom or this happened and that happened, but it can also be serious stuff as well, in a few weeks time I will get a card through to say “your next CT scan is due” and the lead up to that I will share my feeling with these other 2 people on quite an intensive level and they will try and reassure me as much as possible and immediately after I have been to my hospital appointment they will be in touch to ask “ how did you get on?” Now that I think is very supportive, very supportive eh...” Jim “Well the, actually the prostate support group actually meets there eh once a month and eh I go there and I find it helps you now you’re talking to men there that are in the same positions, some are worse than you and some aren’t so bad.” Leonard “Oh one of, my ulterior motives in coming here is to get someone to talk to, it doesn’t matter about what.” Bill1
Turning to alcohol or cigarettes	Discusses use of alcohol or cigarettes as a way of coping	Use of alcohol or cigarettes to cope. Likely a direct reference	<ul style="list-style-type: none"> “But if you’ve got cancer there is just the thought oh well you know I’ll take a chance. Maybe there’s something there, I just don’t it’s, I think terribly easy to uh, not only have a

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			<p>drink with cancer, but also to seek solace in having a drink with cancer (laughs), it’s only an excuse...” Rom</p> <ul style="list-style-type: none"> • “But it’s been a wee bit of a co comfort having a fag. You know it’s eh it relieves boredom as such and I know if you’ve never smoked you would never miss it because you’ve never had it to miss.” Robert
Humour	Discusses the use of humour as a coping mechanism	May be a direct reference to the use of humour or keeping laughing about things, or may be more implicit use of humour in the language	<ul style="list-style-type: none"> • “My family and friends, they would have to deal with the, my loss you know it would have been a big loss but (laughs).” Mike • “That’s right yeah, but at least a lot of guys they would talk about it and we would all have a laugh about it you know there was a lot of jokes made about it which was good because that reduces it down to good normal conversation and that’s good because then people are more aware of it whereas it’s not a mystique or something that’s away up there somewhere.” Kyle • “There’s still a lot of concerns and issues, there’s lot of family stuff and but there’s also a lot of laughter and a lot of just, just chatting away you know, just being here, you can be as serious as you want to be but equally you can still have a laugh you know sort of light hearted conversation.” Jim • “I’ve been told I can either wear a pouch for the rest of my life or die so I thought Bugger it I’ll wear a pouch and that’s it and my sons they say do you think about it if you wanted when you were emptying it you could put water in it mix it all up put it in bottles instead of baby bio. You’d have baby (inaudible) sell it in the shops (laughs). Fertilizer. (laughs).” Drew

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Dissonance	Avoidance of acknowledging that lifestyle may have contributed towards cancer through discussion of other reasons – dissonance. Or may be avoidance of acknowledgement that changing their lifestyle may help avoid further cancers - dissonance	Likely to be implicit in the data, rather than a direct reference to it	<ul style="list-style-type: none"> • “Just probably the same, I dinnae feel, I havenae stopped smoking which I should have, I’ve cut down. But you’ll think I’m daft, but I’ve got this wee thing here, I used to take Sweetex instead of sugar, I took it for three or four years and I remember hearing that there was a thing about it could cause cancer so I got that stuck in my head that that’s what caused it, it’s no the fags so that’s probably me just saying, trying to blame something else, it’s no the alcohol or the cigarettes it’s that bloody Sweetex you know so that’s how I think, but I dinnae feel that I need any help or advice on diet or that, I probably wouldnae do anything with it, so... Another part of the reason I don’t stop smoking is I’m scared that I’ll put on loads of weight so...Just out of interest, I think it’s too easy to just say it’s the fags, but who knows, that’s just my opinion, I may be wrong!” Gary • “I’ve never been a sunbather but hopefully it’ll not stir up. They don’t know what caused that particular mole to. Maybe, something, I meant to ask him once as a bet I was in company and they were going on, women were going on about having their legs waxed and they said you kiffs wouldn’t do it and I said oh that’d be no bother at all so I actually let them wax my legs and whether, I think I read in one of the pamphlets, the Macmillan pamphlet that that could you know getting the hair ripped out your legs, it could activate a mole.” Ian2 • Interviewer: “I was just saying about services that might help you improve your health like smoking, diet, exercise, alcohol” David: “Eh, I don’t know I’ve never, well I don’t

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			<p>smoke, I drink, but I don't drink to excess.”</p> <ul style="list-style-type: none"> • “Another part of the reason I don't stop smoking is I'm scared that I'll put on loads of weight so... if somebody said you cannae hae another drink as long as you live that probably wouldn't bother me, although I do enjoy it. Same with eating, if somebody says you cannae ever eat chocolate and cakes again that would be fine. Smoking is different.” Gary • “Yeah well, I stopped once and I put on two and a half stone in weight and I couldn't do my job because I was, not physically but mentally I wasn't right to do my work with that so I started back smoking again and it all fell off and that was twenty years ago so there's no way that I'm going back to that.” Bruce
Coping: problem-focused coping	Discusses something that would be considered problem-focused coping	See sub-codes	<ul style="list-style-type: none"> • See sub-codes
Enjoyable activities	Discusses enjoyable activities as helping them cope	Enjoyable activities could be spending time with people, hobbies or activities	<ul style="list-style-type: none"> • “I'm getting invited to parties and things you know eh, I play the gui, the gui, the guitar and that so there's a party coming up with a friend of mine eh whose step-daughter is having a birthday party and there's a live band that they're hiring the whole pub for them so they want me to come to that, so that's all a boost for you to think positive eh...” Robert • “Oh aye, it's my life (laughs), if I'm not fishing I'm collecting stuff to do my fishing or whatever.” Ian2 • “No I like, I play the accordion, I've got a key accordion and I sit through there in the bedroom and play it at night you know, maybe once a week, sometimes twice a week you know I go through for about half an hour and sit

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Problem solving	Discussed any type of coping that is tied into solving problems	This may be a named as solving problems or it may be alluded to.	<p>and play that and that keeps me happy.” Bill2</p> <ul style="list-style-type: none"> • “Now in my profession again I was, when I look upon job I had, I used what was sequential organisation, stick it into the box, deal with the box, don’t move to the next one until you’ve completed that... Everything was combated with medication as long as I stuck to the medication and the order of the sequence, I had it fixed in my mind, right that’s day 1, that’s day 2, that’s 3, that’s day 4, only another couple of days to go and I got it down to 5 days.” Mike • “It was just like following a process and I’ve been used to that all my life. So they says right it’s positive and we’ll have to remove it, right okay and through the dyes and nuclear stuff they done it had traced so that they went for the lymph nodes and so.” Chris
Information seeking	Discusses finding out information or educating self assisting in coping	Information in relation to reactions to or coping with cancer	<ul style="list-style-type: none"> • “I got some information from the specialist nurse and some information from Maggie’s and eh that helped...Well I think mainly, going to the group and talking to people that had had the experience of cancer and reading more information on it and as I said eh realising that it wasn’t as dangerous as some of the other cancers, you know once I sort of calmed down a bit and after a few months I didn’t feel any worse.” Leonard • “But while I thought that I wasn’t prepared to read the bad things but you do read things that does stick in your mind and if you get the leaflets, more books, leaflets then you could look at them and you could make up your mind whether [opens leaflet] oh it says if you’ve got a stoma don’t eat orange pips, oh I’ll remember that.” Drew

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Coping: meaning-focused coping	Discusses something that would be considered emotion-focused coping	See	<ul style="list-style-type: none"> See sub-codes
Spiritual/religious	Coping through religion/spirituality	May be linked to a specific religion or may not be	<ul style="list-style-type: none"> Mike: “I have a very strong faith, there is a superior being looking after us on this earth and I’ve had that faith for many, many years.” Interviewer: “And what difference do you think that’s made to you?” Mike: “A whole massive difference, I know that there’s, I can, there’s many things going in, in the world that are much worse than the trauma that I experienced.” “It’s the only thing that has kept me, it, I always say when I’m speaking to our own staff it is by the grace of God I stand here before you today em, and it’s the only thing and I unashamedly say it was my crutch, God was my, God got me here it wasn’t anything else.” Ian1 “I’m not religious and I just feel you know if it’s your time to go it’s your time to go and there’s nothing much you can do about it” Ian2 “I don’t tend to worry as much about things, I’m a comme-ci, comme-ca. If it happens it happens and if it doesn’t it doesn’t. Thank God for small mercies I’m still here but since my wife died I’ve become even more complacent.” Bill1
Acceptance	Discusses difficulties with accepting and understanding/dealing with own illness as a reason not to attend a support service	Acceptance problems relating to support service access May include denial	<ul style="list-style-type: none"> “As I was told, the, eh, what the future is full of ifs and buts, and I could understand that, nobody can, nobody has an x-ray vision not could they predict the future so until they’d carried out the tests that they had in the programme, they couldn’t give me an answer so it was pointless me asking the question before there was a need to. And that’s how I

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			<p>went through it.” Mike</p> <ul style="list-style-type: none"> • “So that kinda impacted on me but after that I just accepted the fact that well, that’s it.” David • “Aye well I mean you’ve got a soreness, you’ve got a disease, you’ve got something there’s no point worrying about it I cannae do anything about it.” Jimmy • “And this thing this cancer that I have it doesn’t really upset me any. I can’t say I like it, whatever happens is inevitable, what will happen and I’m not unduly worried about what’s going to happen.” Bruce
Finding purpose/meaning	Looking for or finding purpose or meaning in life	In relation to cancer or generally, including finding meaning through offering support or advice to others	<ul style="list-style-type: none"> • “Em so it’s better I think for all that I do what I want to do which is just take my time, I can still do some things I can do voluntary work and things like that em and still have a purpose in life... I might go back to university next year not for a not for any learning to do with the job just for learning to do with something that I want to do”. Clark • “I used to go along to men’s groups and speak about it particularly testicular examination” Ian1
Support: emotional support	People describing emotional support that they’ve received	Usually oriented around feelings and feeling better due to support	<ul style="list-style-type: none"> • “I’ve two particular women friends that I’ve known a long, long time and I’ve really opened up to them and talked to them and they’re good and they listen and they understand and you know it’s just the way they are, the way it is so it’s nice having people like that, it really is and they understand.” Kyle • “I think that’s wonderful because everybody that’s there has had ca, well most people that’s there [Maggie’s centre] have had cancer. And because everybody’s had it nobody minds talking about it and it disnae bother me but I

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			<p>can see where it is a great help to a lot of people and that.” Drew</p> <ul style="list-style-type: none"> • “Eh and [name of worker] comes in when I phone him... He just sits and talks to you... after we had this oper this blether in the hospital I don’t know I just felt uplifted kind of thing just I felt a lot, lot better.” Jimmy • “The professional support was excellent it was ach, the, the Macmillan nurse and Backup were fantastic and the telephone helpline I could phone any time day or night I could as I did cr, cry down the phone and they were just excellent, I, really they were fantastic.” Ian1
Support: practical support	Something practical that was supportive to the patient	This may be an offer of help, something that kept them busy or anything else practical that helped the patient from services or friends/family	<ul style="list-style-type: none"> • “I was just travelling every day which kind of took it out of you, but luckily friends and neighbours they took a turn in taking us down so it saved [name of wife] she only had to do it twice a week, maybe sometimes three times a week” David • “Em then if I did have any problems well I had their phone numbers, I could phone up and they arranged whether to see Dr [name of doctor] or whether it was worthwhile seeing her or just changing my medication or something like that.” David • “I took a friend up so I let my friend ask all the questions so it was easier for him to absorb what the cancer nurse was saying because I sometimes get mixed up maybe picking things up the, the wrong way so of course my friend keeps me right for what he heard from the cancer nurse and that.” Robert • “The the woman that does my cleaning and that, I’m getting my vegetables every day beautifully cooked food, she’s a basic ordinary

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			rough and tough type of fe female oh aye she is but she’s got a heart of gold once you get to know her and she’s making sure I’m getting fed well and I’m happy with that.” Robert
Support: informational support	Discusses getting information in the context of this being supportive	May be information from medical staff, charities, support group or others	<ul style="list-style-type: none"> • “I got a lot of, see Macmillan Welfare they’re great for money advice and for welfare advice and filling in forms and stuff...” Fred • “Eh, I went to eh a nutrition course; I went to that about eh food and that was quite interesting.” Leonard
Support: help-seeking	Specifically discusses activity that seeks out help	This may be from friends, family, professionals or others	<ul style="list-style-type: none"> • “But she’s very good and a couple of times I rang her [Clinical Nurse Specialist] and I was in tears and she was great and this is before I even went into hospital you know.” Kyle • “Because, eh, the stoma was eh, when you wiped it there was blood and so I phoned up about that and I was told, that’s okay, you know that happens occasionally and that was it and that’s the only problem I’ve ever had I think.” Drew • “Well, it was Maggie’s actually you know I went to tae Maggie’s and eh you were made welcome, complete stranger walked in, I walked in one day before I actually went into the meeting and I was up that way, I cannae mind where I had been, oh I’d been at the doctors for my prescription and that and I sat at the top o the path and I says to hell wi it I’m goin along tae Maggie’s and I went in...” Harry • “I did go to the Maggie Centre and I’m thinking of going back again because they’ve got like a Writer’s Club on a Friday and one of the people one of the volunteers in the Palliative Care Unit she does the Reiki stuff and that for you ken. She was sitting speaking today

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			and she said you should write all that down, I was just laughing like and I said yeah I’ll maybe do that so I’m thinking of going back to the Maggie Centre.” Fred
Outcome: positive or negative feelings	Discusses outcomes of appraisal/coping in relation to positive or negative feelings	Implicit or explicit	<ul style="list-style-type: none"> • “I went down quite a bit but then eventually I did go there [Maggie’s] and I’ve been going there for a few months now and that has made such a difference to my life. The support and the kindness and the laughs you know. I went to counselling for a while there for about six months or so and that helped, just to get talking about it and trying to come to terms with it...” Kyle • “But oh it’s been a godsend to me and I mean [name of wife] and I goes that Wednesday night you know...” Harry
Outcome: health/illness (including health behaviours)	Discusses outcomes of appraisal/coping in relation to health/illness, including health behaviour	Implicit or explicit	<ul style="list-style-type: none"> • “Having the diagnosis has made me cut down [on cigarettes].” Gary • “I was trying to exercise to keep myself as fit as I could...” Clark
Outcome: wellbeing	Discusses outcomes of appraisal/coping in relation to wellbeing	Implicit or explicit	<ul style="list-style-type: none"> • “I’d never have dreamt tae talking to a stranger the way I’ve been talking to you aboot doon here, no way you know but, I don’t know Maggie’s just makes you alright, you know?” Harry • “Maggie’s simply provides a spirit of wellbeing, I mean it’s not as if the can operate and take out a tumour or whatever and there’s a lot of men think this is eh what should be done, Maggie’s is not a surgery...I mean I turned up at 10 o’clock this morning, worked my way through traffic when it was light, first thing. I got up to make myself a mug of coffee, you just, I’m home!” Bill1

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Outcome: social functioning	Discusses outcomes of appraisal/coping in relation to social functioning	Implicit or explicit	<ul style="list-style-type: none"> “I was approached by one of the MacMillan nurses, 'look [name of surgeon] has been talking about forming a support group.' I thought it was great because you meet people like yourself and eh others within the departments who'll come along and who can fire the questions...” Mike
Contextual factor: practicalities	Something practical affects whether or not they can access support	This may be something like ability to travel to get support, tiredness, symptoms etc.	<ul style="list-style-type: none"> “I think probably if it had been closer at hand I might've used it, but it's just that it's so far away you know, it's an hour and a quarter or an hour and a half depending on the times and you know– I believe it could have been.... I probably would've used it if it had been closer to hand, but em.” David “I suppose it would be handier if it was nearer my home, or in the Medical Centre at [name of area] something like that, but em even if it was just round the corner from me the chances of me going would probably be quite slim.” Ian2 “If I was impaired in any way that I couldn't drive then that would restrict me to go to any of the help and that unless I got a service to help me to go to the services because all my family is down in England.” Bruce
Contextual factor: time	Discusses their available time as influencing coping strategies used	Likely explicit discussion of this	<ul style="list-style-type: none"> “Being honest I actually haven't really gone for any support em, I, I've found my life has, I've been busy enough during my life as it is...So, in some respects I've probably kept myself busy and kept you know not really needing any support.” John “Yes, I go there on the Wednesday and Thursday for the Tai Chi, there's nothing else better to do sort of thing, so I, I find that if I keep myself occupied you know it's not so bad you're

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			not sitting in the house sort of thinking about it.” Leonard
Contextual factor: advertising/accessibility of services	Discusses something that may mean a service is more acceptable or that advertising is important. The ability to access a service may also be important	Either implicitly or explicitly	<ul style="list-style-type: none"> • “Aye, so I went to my doc and I said ‘if they won’t let me in the gym, if they won’t let me in the pool, there’s nothing there’s no arrangements made for people who have had the operation to get them back their life really’ I said ‘ I am stagnating’... And eh that’s when I started thinking about stamina and things like that, but I’m disappointed that convalescing at the [name of hospital], there was no, no physiotherapy, whatsoever.” Bill1 • “I don’t I don’t think, I don’t know but eh aye as I say I possibly people that have, it’s impressions, what people’s impressions are, now just Maggie’s in [name of town], an awful lot of people mistake Maggie’s for the hospice and things like that and I suppose if that’s the case people have an idea in their head that eh Maggie’s is for women and they won’t go and think it’s for people that’s dying and they won’t go, you know eh, I suppose it’s what people think of things you know but that’s it.” Drew • “But eh, em, there’s a meeting I came to and it was advertising and they had a leaflet which I thought was atrocious, and this is a leaflet that was put in doctors surgeries and the layout on the front cover was dismal, you opened it up, it was the story of a man and his wife who’d been diagnosed cancer and what he’d done. And then it finished there was no “come along and have a chat...aye and eh I said that this leaflet is soul destroying.” Bill1
Contextual factor: content of support	Discussion that the content of support has an	Could be discussion of anything related to the	<ul style="list-style-type: none"> • “I did go to the Maggie Centre and I’m thinking of going back again because they’ve

Code Name	Description	Detail of how to know when the theme occurs (i.e. how to “flag” the theme)	Examples from the data to help eliminate possible confusion when coding data
	influence	content that influences access e.g. having a service that aligns with interests may assist access,	<p>got like a Writer’s Club on a Friday and one of the people one of the volunteers in the Palliative Care Unit she does the Reiki stuff and that for you ken.” Fred</p> <ul style="list-style-type: none"> • “I’m sure everybody’s got their, their idea of what would be, or what they would need to prompt them, but it would be different for everybody. Like some guys might go and play a round of golf and like that, but I don’t know, but you would have to have, you’d have to have one in the pub, one in the welding shop, one in the garage, one in the golf course you know, it’s just too much you know!” Gary • “I mean when you look at things like the local projects like bums off seats where local people are encouraged to join sort of rambling groups etc. So I think that something that’s a wee bit more active because I think that we’ve all got sort of different attitudes, different skills and different likes you know. I know a lot of people who come here who only come if there’s a formal event on or a formal group. You know they’re not interested in coming for a cup of coffee and a chat, they’ve got to come for a reason so maybe that’s what we’re talking about here that if there was a specific purpose something that really appealed to me I would go but not just the generic, you know, just having a wee blether.” Jim
Contextual factor: mode of support	How a service is structured or facilitated (mode) may affect attendance	May be a stepped service, an organised service or someone facilitating improvements relating to cancer	<ul style="list-style-type: none"> • “When I get so far down I, I phone him and I I’ll see if I could come in you know ‘I’ll hae to see my diary’ but he comes in and sees me you know ... but that’s the only thing I’ve had support in any kind way shape or form about cancer.” Robert

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			<ul style="list-style-type: none"> • “Yeah it’s like you’re not forced, every Wednesday at ten o’clock you’ve got to go somewhere whereas this you could, right enough I suppose there’s some places you’d have to be kinda... but as long as you didn’t have to go every week, you know, just pop along when you needed it sort of thing then you weren’t put up or down whether you went... a couple of times I made arrangements to see a, to go to a clinic just because I wasn’t em, just you know...cos they were quite good at drawing it out of you (laughs), em, but no as I say apart from that I just worked away. David • “Well the group doesn’t meet in July and August because of the holidays and things like that so I started going there. It’s nice easy slow eh, exercise... I went to eh a nutrition course; I went to that about eh food and that was quite interesting.” Leonard • “I’d registered to go to Maggie’s and it made the point that all you need to do is just drop in, I didn’t believe that I thought well how do you just drop into place like that? ...I said ‘I’m really phoning to find out about what’s this concept of drop in, do you just, well drop in?’ ‘Of course there’s always somebody here, anytime at all you know during opening hours just drop in eh somebody will, will meet you and hopefully you’ll eh, eh you know just sort of come into the fold and sit and have a coffee or something.’ Totally non threatening you don’t need appointments etc.” Jim
Contextual factor: gatekeepers to support	Discussion of a gatekeeper in relation to accessing services	This may be someone finding out about support, gaining access	<ul style="list-style-type: none"> • “She said eh, have you ever thought to go to Macmillan’s, eh no Macmillan’s, Maggie’s, I says No, she says well if ye like I’ll go wi ye,

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		<p>or not gaining access due to someone else (a gatekeeper)</p>	<p>you an um on Wednesday night. I says fine so took us up and I met eh the woman that runs it, I canny mind her name... when my daughter took me, that was, I wouldnae have went myself I don't think.” Harry</p> <ul style="list-style-type: none"> • “Em I don't think enough's told or if it is the first couple of chats about whether you've got cancer is not the right place to tell people about that because you you're in such a state em that maybe you go away with goody bag maybe you get a goody bag or something but (laughs) but em...So that so a list of things you can do or are entitled to or here's a list of things that you may not know and you maybe don't want to talk to anybody about it or you maybe just want to read about it discreetly do what you want to do. Em I think would be good as well because em people don't remember things em accessing them I didn't have a problem I don't think in accessing any services but then I've been I guess quite proactive myself em and that's been because I haven't had anybody else.” Clark • Interviewer: “And have you been told about any other support services that you could access if you wanted to?” Leonard: Eh, no but I've never asked and I'm no interested so...” • “After that I phoned [name of worker] and said 'I've been to Maggie's and it was great' and [name of worker] said to me 'Jim of all my patients you're the one person I knew would gain a lot from it' she said 'a lot of people, it's not for them' she says 'bit I was sure that em with your nature and your approach to these

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			<p>things that you would enjoy it” Jim</p> <ul style="list-style-type: none"> • Interviewer: “How did you find out about the Maggie Centre initially?” Fred: “That was the hospital staff.” • “Aye I would have. Definitely, if eh , I mean naebody ever says to me Maggie’s you can go to Maggie’s and eh fur anything you know, not a not a dickey bird you know... but eh no I never heard of anybody mentioning it till my daughter mentioned it you know.” Harry
Contextual factor: sex of professionals delivering support	Discusses the sex of people offering support or target of support as affecting whether or not they’d likely attend	This may be in terms of volunteers or paid members of staff or the target of support	<ul style="list-style-type: none"> • “Especially if it is something like just a testicular because then you then they have all sorts of questions as I did about sex and all the rest of it and that it’s difficult for men to ask a stranger especially a woman so yeah I think that’s a big barrier.” Ian1 • “The one thing I did think about the Maggie Centre, it is a great place right and they have got groups for men, but 85-90% of it is for women so you’re kind of like oh, well you can only do this one because. Same wi [palliative care unit] it was only a Friday the men went, the rest of the week it was for women ...Dinnae get us wrong the nurses and a’ that up there, they’re great ken they really do. And the volunteers ken the women that go in there they’re baking all day and ken they really are nice like ken...I think if there was, I think if there was mair [more] male volunteers it might help...” Fred • “Oh it is, very noticeable. Well I go to these relaxation things, I’m the only man there because the rest is six or seven women and even the support group most, ninety-nine percent. You go to yoga, I’m the one man. It’s

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			<p>like that in lots of places.” Kyle</p> <ul style="list-style-type: none"> • Interviewer: “Em, do you think there’s any reasons why men might be less willing to go along [to the Maggie’s Centre] than women?” Drew: “(laughs) Maybe it’s the name. Maybe if it was Jimmy’s Centre they would go (laughs).” • “So I, I would say that ever everybody that have supported me have been females so then that has been a great help I’ve not bounced off men where it’s harder to do because they’re too manly to listen they, they they’re oh get a grip of yourself they would say you know... You don’t feel you’ve got to have a barrier up with females eh.” Robert

Appendix 8. Example of a Memo used in Qualitative Analysis

Memo 07-10-13

- Persuasion from others legitimised help seeking.
- Interview 13 was adamant he didn't want any support even for lifestyles but then when I asked about a stop smoking service which would help him stop without gaining weight he said he was interested. Something about dissonance. Also, around perceptions of a service – advertising. To help enable people to access support, perhaps people need things to be sold in such a tailored way to them. Or maybe by talking about it, it meant that it became more acceptable?
- There's some stuff coming out about life events e.g. interview 5 discussing death of his wife and his son having operations. Not sure where to code these – come back to at a later date.