# What are the long-term psychological needs of men with prostate cancer?

Jennifer Louise Kirby

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The candidate confirms that the work submitted is her own and that appropriate credit has been given where reference has been made to the work of others.

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## Abstract

**Background:** Prostate cancer is the most common cancer affecting UK men. Prostate cancer survivors may experience functional and psychological effects of the disease and its treatment for many years, which can significantly impact upon their quality of life (QoL). The National Cancer Research Institute (NCRI) has highlighted the importance of understanding the short and long-term psychological impacts of cancer and its treatment. Research has explored depression, anxiety, suicidality, illness representations, body image and masculinity in prostate cancer survivors. However, there is currently a lack of research relating to strategies for improving and supporting their long-term psychological wellbeing, and factors associated with variation in this. Understanding factors which contribute to the long-term psychological wellbeing of people with prostate cancer could aid the development and efficacy of person-centred interventions, improving outcomes of survivorship and QoL. This study aims to describe the long-term psychological needs, and explore the relationship between these and QoL, in people with prostate cancer.

**Method:** A cross-sectional online survey design was used to conduct this observational, exploratory study. Participants were recruited through contacting third sector cancer charities and organisations and via online platforms. Data from 156 prostate cancer survivors were analysed. Participants provided demographic information, and then a set of validated questionnaires were used to gather information related to psychological needs (QoL, depression, anxiety, illness representation, body image, masculinity, and masculine self-esteem).

**Results:** The median global QoL score for the participant group was 75 (interquartile range *(IQR)* = 58.33-83.33). For analysis, the QoL variable was transformed into two categories: low-moderate QoL, containing 58 (37.18%) participants, and high QoL, containing 98 (62.82%) participants. The median QoL score for the low-moderate QoL group was 50 (*IQR* = 41.67-66.67) compared with 83.33 (*IQR* = 75-91.67) in the high QoL group. Fully adjusted logistic regression models indicated three significant independent factors associated with poorer QoL. These were higher levels of depression (*odds ratio (OR)* 1.62, *confidence intervals (CI)* 1.14-2.31, $p = 0.007$), lower perceptions of personal control (*OR* 0.82, *CI* 0.68-0.99, $p = 0.04$) and prominence and importance of strength/fitness as a component of masculinity (*OR* 0.27, *CI* 0.08-0.89, $p = 0.03$).

**Discussion:** This study found that, consistent with previous research, as a group prostate cancer survivors report good group median QoL and psychological wellbeing. Depression and anxiety scores for the overall group were comparable to that of the general population. However, this study explored factors which may be associated with poorer QoL in this group. Higher levels of depression, lower perceptions of personal control, and prominence and importance of strength and fitness (as a component of masculinity) were found to be significant independent factors associated with lower QoL in this population. The findings of this study contribute to existing

research on the psychological needs of people with prostate cancer. It is hoped it will inform future research and clinical practice, which could explore how these findings could be integrated into assessments and interventions for prostate cancer survivors.

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# List of Abbreviations

| Abbreviation | Meaning |
|---|---|
| ADT | Androgen deprivation therapy |
| BIS | Body image scale |
| CBT | Cognitive behavioural therapy |
| CI | Confidence intervals |
| CSM | Common-sense model |
| EORTC QLQ-C30-V3 | European Organization for Research and Treatment of Cancer quality of life questionnaire for cancer patients – version 3 |
| GAD-7 | Generalised anxiety disorder scale 7-items |
| HRQoL | Health-related quality of life |
| IPQ-R | Illness perceptions questionnaire - revised |
| IQR | Interquartile range |
| M | Mean |
| MCD-I | Masculinity in chronic disease inventory |
| Mdn | Median |
| MSE | Masculine self-esteem scale |
| NCRI | National Cancer Research Institute |
| OR | Odds ratio |
| PHQ-8 | Patient health questionnaire 8-items |
| PCA | Principal components analysis |
| PSA | Prostate-specific antigen |
| QoL | Quality of life |
| SD | Standard deviation |
| SoMREC | School of Medicine Research Ethics Committee |

# Chapter 1: Introduction

This chapter begins by presenting the results of a scoping literature review. This literature review first discusses cancer, and then specifically prostate cancer, epidemiology. Next, it introduces the Common-Sense Model (CSM) of self-regulation, which can provide a framework for understanding coping, illness outcomes and adjustment to cancer survivorship. The literature review then highlights the functional and psychological difficulties experienced by prostate cancer survivors, including: anxiety, depression and suicidality; quality of life (QoL); body image problems; and the impact of prostate cancer and its treatments on masculinity and masculine self-esteem. Next, it will consider the impact of social support on prostate cancer survivors, before reviewing the effectiveness of psychosocial interventions for this group. Finally, this chapter will discuss the rationale for the current study, and present the research aims and questions.

Relevant research was identified through conducting a search of the University of Leeds online library and various databases: PubMed, PsychNet, and PsychInfo, in July 2020, August 2020, January 2021, February 2021, and April 2022. A thorough list of search terms was used, which included: prostate cancer (and cancer, chronic illness, and survivorship); illness perceptions (and CSM, illness representations, self-regulation model, illness cognitions, and illness beliefs); and psychological wellbeing (and QoL, coping, psychological needs, mental health, mood, depression, anxiety, suicide, distress, body image, identity, masculinity, and masculine self-esteem). Appropriate articles were reviewed and included in the literature review.

Understanding the psychological impact of prostate cancer and supporting psychological wellbeing is a current priority for prostate cancer survivorship research (National Cancer Research Institute [NCRI], 2020). Previous literature has explored QoL, anxiety, depression, illness representations, body image and masculinity in people with prostate cancer. Although research on the prevalence of these phenomena has been conducted, there is less research on how these factors impact upon the long-term wellbeing of prostate cancer survivors, and factors associated with variation in this. Understanding factors which contribute to the long-term psychological wellbeing of people with prostate cancer could aid the development and effectiveness of appropriate, person-centred interventions, improving outcomes of survivorship and QoL.

## 1.1 Cancer epidemiology

Cancer occurs when abnormal cells divide uncontrollably and spread to other parts of the body (National Cancer Institute, 2021). Worldwide, in 2018 there were approximately 17 million new cases of cancer diagnosed, with 9.6 million deaths resulting from cancer in the same year (Cancer research UK, 2022d). In the United Kingdom (UK), approximately 375,000 new cases of cancer are diagnosed each year, with mortality rates reaching over 166,000 annually (Cancer Research UK, 2022a). According to Cancer Research UK (2022a), the most common cancers in the UK (2016-2018) are breast, prostate, lung, and bowel, which account for 53% of all new UK cases. Over the last 40 years, UK cancer survival rates have doubled, with approximately 50% of those diagnosed (2010-2011) now surviving for 10 years or more (Cancer Research UK, 2022a).

## 1.2 What is prostate cancer?

The prostate is a walnut sized gland, which sits beneath the bladder surrounding the urethra (Prostate Cancer UK, 2019a). It is present in those assigned male at birth (including cis men, trans women and non-binary people originally assigned male at birth), and some intersex people (Prostate Cancer UK, 2019a). The prostate has two lobes and an outer layer called the capsule (Macmillan Cancer Support, 2020a). It helps create semen and grows as men age (Prostate Cancer UK, 2019a). The prostate is controlled by testosterone (the male sex hormone) and produces the prostate-specific antigen (PSA) protein, which can be measured and used to diagnose prostate issues (Macmillan Cancer Support, 2020a).

Prostate cancer occurs when cells in the prostate grow uncontrollably (Prostate Cancer UK, 2019a). It can be contained within the prostate (localised or early prostate cancer), spread through the capsule surrounding the prostate into surrounding tissue and organs (locally advanced prostate cancer), or spread outside of the prostate (advanced or metastatic prostate cancer) to other body parts (Macmillan Cancer Support, 2020b).

The most recent data from Cancer Research UK highlights prostate cancer as the most common cancer affecting UK men, with 52,254 new cases diagnosed each year in the UK (Cancer Research UK, 2022c). Prostate cancer typically impacts men over 50, with risk increasing with age; though it is possible to develop prostate cancer younger than this (Prostate Cancer UK, 2019b). The most common age range for being diagnosed with prostate cancer is 65 to 69 (Prostate Cancer UK, 2019b). Alongside age, family history of prostate cancer and Black ethnicity are main risk factors for prostate cancer diagnosis (Orchid, 2019; Prostate Cancer UK, 2019b). Black African / Black Caribbean men are at double the risk of getting prostate cancer than men from other ethnicities (Orchid, 2019), with 1 in 4 black men getting prostate cancer in their lifetime (Prostate Cancer UK, 2019b). The reasons for this are not yet well understood, and research to understand this is growing. Whilst prostate cancer accounts for 27% of new cancer diagnoses and is the second biggest cause of cancer death in UK men, an estimated 78% survive after diagnosis for ten years or more (Cancer Research UK, 2022c). It is increasingly recognised that survivorship does not necessarily mean living well, and there has been an important shift in focus to thinking about how to support people after prostate cancer diagnosis (Brunckhorst et al., 2021).

Treatments for prostate cancer include active surveillance, surgery, radiotherapy and hormone therapy (Macmillan Cancer Support, 2020c; Wilt et al., 2008). Active surveillance involves regular PSA screening, MRI scans, and occasionally biopsies to signal progression of prostate cancer as early as possible (National Health Service, 2021). It aims to avoid unnecessary treatments, which carry significant side effects, whilst identifying changes in the prostate which indicate need for further treatment decisions (National Health Service, 2021). Surgery involves removal of the prostate (radical prostatectomy), and is most often used to treat prostate cancer which has not spread beyond the prostate (Macmillan Cancer Support, 2020c; National Health Service, 2021). Radiation therapy (including Brachytherapy) involves use of high energy X-rays to damage cancer cells (Macmillan Cancer Support, 2020c). It is often used to treat prostate cancer which has not spread far beyond the prostate, and is conducted in short sessions, 5 days a week, for 4-8 weeks (National Health Service, 2021). Due to the risk of cancer reoccurring, men often continue to engage in active surveillance post-surgery or radiation therapy (National Health Service, 2021). Hormone therapy, such as androgen deprivation therapy (ADT), involves taking medication, having an implant or receiving injections to suppress testosterone production (Macmillan Cancer Support, 2020c). Alone, it is not a cure for prostate cancer, but can slow the progression of advanced disease, by blocking the effects of testosterone and controlling the growth of cells in the prostate (National Health Service, 2021). It can be used independently or in conjunction with other treatments, on an intermittent or continuous basis, and for a limited or indefinite amount of time (Macmillan Cancer Support, 2020c). Many men may continue to have hormone therapy for the rest of their lives.

As survival times are increasing, prostate cancer is often considered a chronic illness (Watts et al., 2014), and men may experience the functional and psychological effects of prostate cancer and its treatment for many years. This can have a significant negative impact on their QoL and those that care for them (Lehto et al., 2017). This has called for a shift away from focusing on mortality rates, to considering how to treat people with prostate cancer with individual long-term consequences of the disease (Fervaha et al., 2019; Otto et al., 2022; Watts et al., 2014). Prostate cancer survivorship refers to those living with and beyond cancer, capturing the long-term consequences of the disease and its treatment (Davies & Batehup, 2011). It starts from initial diagnosis and lasts until end of life (Shapiro, 2018). However, research on prostate cancer survivorship is lacking, with most studies investigating functional QoL only (Fervaha et al., 2019; Harrop et al., 2011).

## 1.3 Leventhal's Common-Sense Model of self-regulation

Individual adjustment to prostate cancer survivorship may be influenced by perceptions of the illness, its treatment, and its impact, rather than the physical elements of disease alone (Traeger et al., 2009). The CSM of self-regulation suggests that an individual's illness perceptions (i.e. their thoughts, ideas and beliefs about the illness), alongside their emotional responses towards the disease and its treatments, influence how cancer survivors adapt to the disease, the coping strategies they select and illness outcomes (Ashley et al., 2015; Cook et al., 2015; Leventhal et al., 1980). According to the CSM, when facing illness people form cognitive representations or beliefs about the disease, and have emotional experiences or representations which affect their functional and psychological outcomes through impacting on coping (Ashley et al., 2015; Dempster et al., 2015). Hopman and Rijken (2015) suggest these illness perceptions relate to:

- identity (labels and symptoms)
- duration
- cause
- perceived consequences
- coherence (understanding)
- perceptions of control over the illness (by the self or the treatment)
- emotional representations (e.g., experiences of symptoms of anxiety or depression).

Illness perceptions can influence emotional and behavioural responses to illness diagnosis and treatment (Traeger et al., 2009).

Illness representations have been associated with poorer psychological wellbeing in a range of health conditions, accounting for 25-30% of the wellbeing variance in a recent meta-analysis (Dempster et al., 2015). This association was mediated by use of avoidant or emotion-focused coping strategies, which are designed to control intense and perceptually threatening emotions around the illness (Guan et al., 2020). Though associations between illness perceptions and outcomes vary across samples, commonly, perceptions of lower control (by both the self and treatment), negative consequences of the disease, and negative emotional representations around the illness are related to poorer outcomes (Ashley et al., 2015). This suggests that illness perceptions play a significant role in illness outcomes and may be an appropriate target for intervention in order to improve outcomes and wellbeing (Ashley et al., 2015).

Illness representations have been associated with coping and illness outcomes specifically in people with cancer (Richardson et al., 2017), although research is scarce, inconsistent, and largely cross-sectional, meaning causality cannot be inferred (Hopman & Rijken, 2015). Hopman and Rijken (2015) demonstrated the association between illness perceptions and selection of coping strategies. They found that people with cancer generally perceived their illness to be chronic (despite many participants being diagnosed over five years prior), and perceived lower levels of personal control and higher levels of treatment control. Ashley et al. (2015) explored the impact of illness perceptions in people with breast, colorectal and prostate cancer 6 months post-diagnosis, and the impact of this on health-related quality of life (HRQoL) at 15 months post-diagnosis. They found that cognitive and emotional illness perceptions were an independent predictor of HRQoL in this sample.

A meta-analysis and systematic review by Richardson et al. (2017) found that, in mixed cancer samples, perceptions of control were associated with adaptive coping styles (problem solving and cognitive reappraisal), whereas emotional representations were associated with unhelpful emotion-focused coping styles (avoidance and denial). The authors also found that illness perceptions were associated with anxiety (lower perceptions of personal and treatment control, greater emotional representations, and negative consequence perceptions); depression (lower perceptions of personal and treatment control, greater emotional representations, negative consequence perceptions, and perceptions of chronicity); psychological distress (greater emotional representations, negative consequence perceptions, perceptions of chronicity, and higher levels of illness identity or perceived symptoms); and poorer QoL (higher levels of illness identity, perceptions of the prostate cancer as being cyclical, negative consequence perceptions, greater emotional representations, and lower perceptions of personal and treatment control).

Research exploring illness perceptions in prostate cancer is in its infancy (Otto et al., 2022). However, one longitudinal study of 183 men found that perceived consequences of the disease was related to increased anxiety, both at base line and over time, and reliance on both emotion and problem-focused coping (Otto et al., 2022). Traeger et al. (2009) conducted a cross-sectional survey of 214 men who had completed treatment for early-stage prostate cancer less than 18 months prior. They found although emotional wellbeing was not significantly different to that of a nationally representative sample of adult males, in prostate cancer survivors, emotional wellbeing was associated with greater perceptions of treatment control, greater illness coherence, less perceived negative consequences and less beliefs about personality or behaviour related causes of prostate cancer. Personal control was not associated with emotional wellbeing (Traeger et al., 2009). These results persisted after adjusting for demographic and clinical factors. Furthermore, increased life stress mediated the relationship between consequence perceptions and poor emotional wellbeing (Traeger et al., 2009). However, due to the nature of the design, causality cannot be inferred. These findings suggest that perceived consequences of prostate cancer, in combination with life stressors may predict meaningful differences in emotional wellbeing. Although generally prostate cancer survivors may recover to experience comparative QoL to the general population, it is important to understand the individual factors which may contribute to variance in emotional wellbeing in this group.

This literature highlights the need to consider the perceived experiences of prostate cancer survivors, in order to understand and support greater wellbeing. Prostate cancer survivors endure numerous physical and psychological side effects, which may influence illness perceptions, and in turn their wellbeing. These side effects will be outlined in the following sections.

## 1.4 Functional difficulties

The prevalence of functional side effects from prostate cancer treatments is well documented (Stein et al., 2008; Wallis et al., 2018). Prostate cancer and its treatments can result in significant functional consequences, which prostate cancer survivors may experience for many years (Watts et al., 2014). Lehto et al. (2017) conducted a nationwide survey of 1239 men with prostate cancer, to investigate the negative functional effects of prostate cancer treatments. They found that functional difficulties were common and enduring, with 33-48% reporting at least one symptom up to five years post-treatment. Symptoms were found to be highly bothersome, and sometimes started as a late effect following radiotherapy (Lehto et al., 2017). These functional effects included: sexual difficulties, such as erectile problems and loss of libido; urinary difficulties, such as incontinence and irritation or obstruction; and bowel problems, such as incontinence, pain, and bloody stools (Lehto et al., 2017; Watson et al., 2015). Surgery has been associated with more negative effects and a significantly higher percentage of men report dissatisfaction with surgery compared with alternative treatments (Donovan et al., 2016; Lehto et al., 2017). Lehto et al. (2017) found that 45-70% of men reported urinary leakage (dependent on treatment type) and of these 74-80% were bothered by it. Notably, 7-10% reported this as a “major bother”; though older age decreased perceived bother. Lehto et al. (2017) suggest that urinary problems are better tolerated by older men. Approximately 50% of men who received radiotherapy and 15% who received brachytherapy suffered from bowel problems (Lehto et al., 2017). These were considered bothersome by 90% of those reporting them, and the duration of the difficulties was related to how bothersome they were. Hormone therapy was specifically associated with hot flushes (73%), sore breast-tissue (52%) mood disruption (46%) and swollen feet (Lehto et al., 2017).

All active (non-monitoring) treatments were associated with sexual difficulties, with 81-93% reporting an impact on their sex life (Lehto et al., 2017). Lehto et al. (2017) found that whilst 62-82% of respondents reported an active sex life with their partner prior to prostate cancer treatment, this significantly decreased following all treatments. In their study, 70-92% of men reported sexual difficulties (impotence, loss of libido). Specifically, 22-57% reported erectile problems (particularly after surgery). Only 4-10% reported loss of sexual desire alone (Lehto et al., 2017). 18-25% of participants reported both erectile problems and loss of desire following surgery or radiotherapy, which rose to 45% following hormone therapy (Lehto et al., 2017). Additionally, participants reported their sex life to have ended in 38%, 30%, 20% and 58% of participants who had surgery, external radiation, brachytherapy, and hormone therapy respectively (Lehto et al., 2017). Lehto et al. (2017) suggest that across treatments the combination of having erectile problems and loss of libido resulted in the most harmful impact. Erectile difficulties alone had a weaker association. Furthermore, having a pre-treatment sex life predicted a stronger impact on sex life post-treatment (Lehto et al., 2017). This effect was less when there was post-treatment sex life and when the man was older. Lehto et al. (2017) suggest that the stronger impact on sex life following surgery was likely due to these men being younger, more likely to have a pre-treatment sex life and the presence of erectile difficulty without loss of desire, which was associated with perceived "bother" (Lehto et al., 2017). These findings suggest that the change in functioning from pre-post treatment is highly impactful, and this impact may change based on age and pre-treatment experience. For example, the negative impact may be most relevant in relation to younger men who experienced a more active sex life pre-treatment. The functional difficulties (particularly urinary) associated with prostate cancer treatment, and how bothersome these were perceived to be, was associated with poorer satisfaction and psychological wellbeing (Lehto et al., 2017). However, it is noteworthy that, due to the cross-sectional nature of the design, causality cannot be inferred.

In another survey, over one third (36.5%) of men diagnosed with prostate cancer reported a "moderate/big" problem with ongoing sexual difficulties (Watson et al., 2015). Other common function difficulties experienced by men with prostate cancer as a "moderate/big" problem included: urinary problems (15.2%), bowel problems (5.1%), fatigue (20%), weight gain (13%), hot flushes (19.1%) and breast-tissue tenderness (2.8%) up to two years post-diagnosis (Watson et al., 2015). Greater symptom burden (and perception of how bothersome the symptoms are) and being younger have been associated with poorer psychological wellbeing, reduced treatment satisfaction, lower self-efficacy, and more perceived unmet needs (Lehto et al., 2017; Watson et al., 2015; Wilding et al., 2019).

In one study of 1643 UK men, urinary incontinence and erectile problems were found to be more persistent in men who received surgery, at both 6 months and 6-year follow-up, than those who received radiotherapy with neoadjuvant ADT (Donovan et al., 2016) (Table 1).

Table 1. *Percentages of men using absorbent pads for urinary incontinence and reporting* erections *firm enough for intercourse, by treatment type (Donovan et al., 2016).*

| Treatment Type | *Use of absorbent pads (%)* | | | *Erections firm enough for intercourse (%)* | | |
|---|---|---|---|---|---|---|
| | Baseline | 6 months | 6 years | Baseline | 6 months | 6 years |
| Surgery | 1 | 46 | 17 | 67 | 12 | 17 |
| Radiotherapy with ADT | 1 | 5 | 4 | 67 | 22 | 27 |
| Active monitoring | 1 | 4 | 8 | 67 | 52 | 30 |

Radiotherapy has been associated with urinary leakage, urinary irritation, and bowel problems (Donovan et al., 2016; Lehto et al., 2017). However, Donovan et al. (2016) found more improvement in these symptoms over time than in other treatment groups. These findings have been supported by systematic reviews investigating the impact of primary treatments for localised prostate cancer (Lardas et al., 2017; Whiting et al., 2016). ADT is related to mood disturbances, tenderness of the breast-tissue, changes in cognitive functioning (Lehto et al., 2017), fatigue, pain / discomfort, difficulty with usual activities, mobility issues, and to a lesser degree urinary or bowel problems (Wilding et al., 2019). Wilding et al. (2019) found that cancer-related symptoms were reported by a greater percentage of men who were treated with ADT, compared with those who were not.

The findings outlined in this section suggest that the impact of functional difficulties may be fluid, and change based on other factors such as age and both pre- and post-treatment experiences of the individual. The severity of symptoms experienced by men with prostate cancer may contribute to poorer psychological wellbeing by affecting how the illness is perceived by the individual, in relation to identity, illness duration and consequences, and perceptions of control.

## 1.5 Psychological difficulties

The prevalence of functional side effects from prostate cancer treatments is well documented (Stein et al., 2008; Wallis et al., 2018) and a whole research area in its own right. However, the interaction between these difficulties (as documented in section 1.4) and the psychological wellbeing of prostate cancer survivors is less explored and is now receiving increased attention (Brunckhorst et al., 2021). Watson et al. (2015) found that men with prostate cancer report lower satisfaction for psychosocial follow-up care (*median (Mdn)* = 4, *interquartile range (IQR)* = 3-5) than physical follow-up care (*Mdn* = 5, *IQR* = 4-5). Furthermore 17% and

10.2% of men with prostate cancer report moderate-to-severe anxiety and depression respectively (Watson et al., 2015). Considering this, the importance of psychological assessment at various stages of diagnosis and treatment has been recognised, though support is often reactive to expression of emotional distress at present (Cook et al., 2015).

The NCRI has identified understanding the short-term and long-term psychological impacts of cancer and its treatment, and how to support psychological wellbeing, as one of the top ten research priorities for those living with and beyond cancer (NCRI, 2020). However, there is a lack of research related to strategies for improving the long-term psychosocial consequences of prostate cancer survivorship (Maggi et al., 2019; Weber & Sherwill-Navarro, 2005), and the efficacy of current psychological interventions is limited (Cook et al., 2015). Furthermore, a refined understanding of what contributes to men's experiences of psychological distress is lacking, which could inform appropriate, person-centred supportive interventions (Matheson et al., 2020). Therefore, this project will focus on the psychological needs of men with prostate cancer and factors associated with this.

Research on the psychological wellbeing of men with prostate cancer reports varying outcomes. Cross-sectional research of men who had completed treatment for early-stage prostate cancer less than 18 months prior found that QoL was not significantly different to that of a nationally representative sample of adult males; though statistical significance was not reported (Traeger et al., 2009). Case-control research suggests that longer-term prostate cancer survivors (>5 years post-diagnosis) have poorer mental health than comparable men in the general population ($p < 0.001$), particularly in association with higher physical symptom burden (van Stam et al., 2017). The impact of prostate cancer and its treatments on the HRQoL of prostate cancer survivors is well described; however, broader research on the long-term consequences of prostate cancer survivorship is lacking (Chambers et al., 2017). This includes research on global QoL, subgroups which may be vulnerable to poorer wellbeing and the psychological wellbeing of prostate cancer survivors (Chambers et al., 2017).

Vulnerability factors associated with poorer psychological wellbeing include: being widowed; having completed fewer years of formal education, general health, and sexual satisfaction; and having higher pain and urinary difficulties (van Stam et al., 2017). Furthermore, younger age has been associated with increased psychological problems (Lehto et al., 2017). In men treated with ADT, alongside cancer-related symptoms, further factors related to poorer psychological wellbeing have been identified as unemployment, being younger, being separated / divorced, comorbidity of other long-term conditions and previous support for mental health difficulties (Wilding et al., 2019). Furthermore, clinically significant fatigue has been related to severe psychological distress and poor wellbeing (Wilding et al., 2019). However, these findings should be interpreted with caution, due to the cross-sectional nature of the research, meaning that temporal and causal inferences cannot be made.

### 1.5.1 Anxiety, depression, and suicidality

Depression and anxiety are prevalent mental health difficulties experienced by people with cancer, which are often overlooked and can impact upon treatment adherence and outcomes (Brunckhorst et al., 2021; Maggi et al., 2019; Watts et al., 2014). In prostate cancer, they can be caused by the psychosocial impact of being diagnosed, as well as the hormonal, physical and psychological effects of the disease and its treatments (Brunckhorst et al., 2021). Brunckhorst et al. (2021) note that prevalence estimates for anxiety, depression and suicidality in prostate cancer vary, and lately there has been an increase in research in this area. In a recent systematic review and meta-analysis of observational studies Brunckhorst et al. (2021) found that prevalence of clinical diagnoses of depression in men with prostate cancer (5.81%), was comparable to estimates for the global population (4.4%) and men aged 55-74 specifically (5.5%). Prevalence of clinical depression was noted to be higher (8.2%) in another recent survey of 2445 prostate cancer survivors (Fervaha et al., 2021). Brunckhorst et al. (2021) found there was also a high prevalence of both significant depression and anxiety symptoms (17.07% and 16.86% respectively). Furthermore, 9.85% had experienced recent suicidality, compared with 2% in the general population, with suicide mortality rates also being comparatively higher (Brunckhorst et al., 2021).

Similarly, Watts et al. (2014) conducted a systematic review and meta-analysis of 4494 patients with prostate cancer, finding that prevalence of anxiety (15.9-27.4%) and depression (14.7-18.4%) symptoms in this group is higher compared with men over 65 in the general population (6% and 9% respectively, statistical significance not reported). Watts et al. (2014) found that anxiety and depression are particularly prevalent in patients who have been diagnosed but not yet undergone treatment (27.4% and 17.27% respectively) and those who have completed treatment (18.49% and 18.44% respectively), compared with those who are receiving treatment (15.90% and 14.70% respectively).

Sharp et al. (2016) conducted a survey of 3348 men with prostate cancer finding that urinary difficulties, ADT-related symptoms, fatigue, and financial difficulties were associated with significantly increased risk of depression (17%), anxiety (16%) and distress (11%). Furthermore, bowel difficulties were associated with significantly increased risk of anxiety and distress, insomnia was associated with significantly increased risk of depression and distress, and dyspnoea was associated with significantly increased risk of anxiety (Sharp et al., 2016). Sharp et al. (2016) suggested that although there were large individual differences, greater cancer-related symptom burden was associated with poorer psychological wellbeing. They also speculate that loss of masculinity in those who received ADT treatment, and social withdrawal caused by urinary difficulties may explain their findings. However, although Sharp et al. (2016) chose to analyse symptoms as predictors of psychological wellbeing, the cross-sectional design means that causality was not established.

Research suggests that factors which may make men with prostate cancer vulnerable to developing depression include: advanced stage of disease, greater symptom burden, being at the top or bottom of the group age range, poor coping, poor social support, being unmarried, lower income, and having a history of mental health difficulties (Esser et al., 2020; Fervaha et al., 2021; Fervaha et al., 2019; Luckenbaugh et al., 2022). A longitudinal study of 1064 men diagnosed with prostate cancer assessed over a 6-year period, found that poorer long-term psychological wellbeing was associated with being younger, having a lower income, having health comorbidities, and receiving active (non-monitoring) treatments (Chambers et al., 2017).

Furthermore, a recent systematic review and meta-analysis found that men who have received ADT have 41% greater incidence of depression, compared with those not exposed to ADT; though causality was not established (Nead et al., 2017). Other studies have found no significant association between treatment type (surgery, radiotherapy, or active surveillance) and depression in men with localised prostate cancer (Luckenbaugh et al., 2022) .

A recent, large, retrospective cohort study explored long-term depression and mortality in 40,412 veterans diagnosed with prostate cancer (Parikh et al., 2021). The authors found that African American veterans were more likely than White veterans to be diagnosed with depression. They were also less likely to be prescribed antidepressants and more at risk of mortality associated with depression than White veterans (Parikh et al., 2021). The authors suggest this may reflect other social factors which impact on the health of African Americans. Such factors may include lack of access to transport and food security, lower education and socioeconomic status, experiences of racism and differences in interactions with health systems (Parikh et al., 2021).

In recent years prostate cancer-related anxiety (including prostate cancer anxiety, fear of recurrence and PSA anxiety) has been recognised as a unique circumstantial experience of many prostate cancer survivors, with the first two domains particularly impacting upon HRQoL (Erim et al., 2020). Erim et al. (2020) analysed secondary cross-sectional data of 1016 prostate cancer survivors, finding that prostate cancer-related anxiety was further associated with depression and productivity loss. Although causality cannot be inferred, these findings have implications for regular screening for prostate cancer-related anxiety and depression in this group.

A recent longitudinal study exploring illness representations, coping and anxiety in men with localised prostate cancer found that, irrespective of treatment type, men reported increased anxiety levels (sub-clinical) immediately after diagnosis, which significantly declined after 6 months (Otto et al., 2022). Furthermore 10% of men reported clinical levels of anxiety. Otto et al. (2022) also found that perceived increase in negative consequences was associated with increased anxiety and reliance on both emotion and problem-focused coping. The authors suggest that whilst anxiety levels may be lower in men with prostate cancer than for other cancer groups, potentially due to the potential for optimistic prognosis, masculinity concepts may impact upon emotional expression in this group. Therefore, they argue that even comparatively lower anxiety levels demand attention.

Donovan et al. (as cited in Otto et al., 2022) reported results from an RCT with 1500 participants, finding that 15.2% of men report anxiety levels above the clinical cut off score on the Hospital Anxiety and Depression Scale, up to 6 years after diagnosis. Similar results were found by Venderbos et al. (2017), though the authors note that long-term anxiety levels were not significantly different for those under active surveillance, compared with those who had received active (non-monitoring) treatments (Otto et al., 2022). However, other studies suggest that curative treatments such as surgery and radiotherapy are associated with poorer long-term psychological wellbeing (Chambers et al., 2017). Wade et al. (2020) explored the experiences of those undergoing active surveillance and strategies they employ to deal with the uncertainty of having a prostate cancer diagnosis without concurrent active treatment. They found that men who were able to successfully seek clarification (e.g. around processes for triggering more invasive treatment) and reassurance from medical professionals, gain control where they could (e.g. around disclosing the diagnosis and lifestyle changes) and be considered within the context of their individual experiences and responses (e.g. caring responsibilities, friend and family experiences) were more comfortable with continuing active surveillance and having active treatment when medically indicated.

Research also suggests that men with prostate cancer have a higher risk of suicide compared to the general population (Klaassen et al., 2018). One study found that 14.4% of their sample of men with prostate cancer scored in the range for clinically significant risk of suicide (Tripp et al., 2020); though it was not reported whether this was significantly different to the general population of men the same age. Tripp et al. (2020) suggested that poorer prostate cancer QoL may relate to increased depression, and subsequently increased psychological pain, perception of being a burden and feeling socially isolated, resulting in higher suicide risk. They argue that this highlights the importance of considering psychological distress and perceptions of how the person fits into their social world, in managing prostate cancer. Klaassen et al. (2018) suggest that vulnerability factors for increased risk of suicide include White ethnicity, being unmarried, older age, advanced disease, and being >15 years post-diagnosis. However, it is worth noting that the use of data from participants >15 years post-diagnosis makes associative inferences between prostate cancer and current mental health problematic, due to the opportunity for long-term confounding variables.

Illness perception research in people with cancer has found that emotional representation perceptions (emotional responses to illness) are associated with maladaptive coping such as avoidance and denial, which could relate to poorer emotional wellbeing (Richardson et al., 2017). The findings outlined in this section highlight varied estimates for the prevalence of depression and anxiety in prostate cancer survivors (Brunckhorst et al., 2021; Traeger et al., 2009; Watts et al., 2014). However, particularly as subscription to masculine ideals may impact upon emotional expression in this group, assessment and exploration of these psychological needs and factors associated with variation in these is still warranted (Matheson et al., 2020; Sharp et al., 2016). This could help to identify vulnerable groups and inform person-centred interventions, for those struggling with the long-term impacts of prostate cancer and its treatments.

### 1.5.2 Quality of life

QoL is subjective and can be impacted upon by numerous factors, including a person's mental state, personality, and values (Dąbrowska-Bender et al., 2015). Dąbrowska-Bender et al. (2015) highlight that in those with cancer, diagnosis in itself can impact upon QoL by increasing anxiety and uncertainty for the future. Assessing QoL in people with cancer can inform treatment decisions, highlight the impact of the cancer and its treatments, and provide valuable insight into patients' emotional and social functioning (Dąbrowska-Bender et al., 2015).

QoL in prostate cancer has been well researched, particularly in relation to functional or HRQoL (Baker et al., 2016; Lardas et al., 2017; Whiting et al., 2016). Although cancer survivors largely report similar HRQoL to the general population, a significant proportion report ongoing functional and psychological difficulties (Ashley et al., 2015). There is less research in relation to factors which contribute to variation in this. A systematic review of the research suggests that HRQoL in people with prostate cancer is generally poor (Odeo & Degu, 2020). A 6-year longitudinal study of men with prostate cancer found that poorer physical QoL was associated with being older, having lower levels of education and being treated with ADT (Chambers et al., 2017). Men had poorer life satisfaction if they were younger and single, and poorer QoL if they were younger and had received either surgery or radiotherapy (Chambers et al., 2017). Furthermore, Chambers et al. (2017) found that lower income, presence of comorbidities and poorer urinary, bowel and sexual functioning predicted poorer QoL, satisfaction with life and psychological wellbeing. These results highlight an important role for socioeconomic disadvantage in reduced coping and the long-term negative effects of symptom burden, which, in line with illness perceptions theory, may increase cancer distress over time (Chambers et al., 2017). Chambers et al. (2017) suggest that symptom burden, uncertainty, and the psychological demands of living with cancer may have a greater impact on younger men and their life goals, explaining the association with reduced life satisfaction and psychological wellbeing. Poorer physical QoL in older men may reflect natural increases in comorbidity and physical decline due to aging (Chambers et al., 2017). Finally, these results highlight the importance of social support in promoting life satisfaction in this group.

One study which explored global QoL in men with prostate cancer found that 10.84% of participants perceived a significant deterioration in their health due to their prostate cancer (Dąbrowska-Bender et al., 2015). Additionally prostate cancer and its treatment significantly impacted upon all domains of QoL, particularly in relation to physical functioning and experiences of fatigue. However, contrary to other similar research, the authors found no significant differences in QoL based on age group, whether cancer treatment was completed or not, or type of treatment.

Hinz et al. (2017) explored global, functional and symptom related QoL in people with cancer, compared with the general population. They found that overall, the global QoL score (Mean (*M)* = 69.3, standard deviation (*SD)* = 20.7) of people with cancer was similar to that of the general population (*M* = 73.1, *SD* = 20.7). Functioning and symptom scale scores indicated significantly worse QoL in people with cancer than in the general population (Hinz et al., 2017). For prostate cancer specifically, participants generally reported good global QoL (*M* = 73.0, *SD* = 19.2). Their symptom scale score was not significantly different to those in the general population, though they showed slightly poorer functioning (Hinz et al., 2017). It is noteworthy that participants were those 6 months post discharge from rehabilitation clinics, and therefore results may not be generalisable to those at different points in their cancer journey.

Guan et al. (2020) conducted a cross-sectional study of 263 people with prostate cancer, to explore how illness uncertainty impacts upon QoL in this group. Illness uncertainty relates to difficulty with meaning making in relation to illness, and is constructed from the person's perceptions of the ambiguity surrounding their illness experiences, the complexity of the illness and communication about it, and illness unpredictability in relation to functioning, potential recurrence and survivorship (Guan et al., 2020). The authors found that illness uncertainty was negatively associated with both physical and psychological QoL, and positively associated with adoption of avoidant coping strategies. Furthermore, use of these avoidant coping strategies was associated with poorer psychological QoL, and this mediated the impact of illness uncertainty on psychological QoL. Guan et al. (2020) suggest these findings may be explained by Mishel's "uncertainty in illness" theory (Mishel, 1988). This theory states that how an individual evaluates their illness influences their coping, either maintaining or relieving illness uncertainty. This in turn impacts upon illness outcomes, including stress and QoL (Mishel, 1988). These findings provide a rationale for supporting prostate cancer survivors with managing illness uncertainty and illness perceptions, and developing more active, problem-focused coping strategies, designed to alleviate this uncertainty (Guan et al., 2020).

It is noteworthy that research shows men monitored by active surveillance report good QoL, and experience little anxiety and depression, though long-term studies are needed to confirm the longevity of this (Bellardita et al., 2015).

In summary, prostate cancer and its treatments have been found to impact upon QoL (Chambers et al., 2017; Dąbrowska-Bender et al., 2015). Global QoL may be comparable to that of the general population in people with prostate cancer 6 months post rehabilitation (Hinz et al., 2017). However, there has been little research exploring factors which contribute to poorer QoL, or variation in this, in this group. Such factors may include the individual's illness perceptions and perceptions of uncertainty around the prostate cancer (Guan et al., 2020).

### 1.5.3 Body image

Research suggests that symptoms of prostate cancer and its treatment may negatively impact on body image, which relates to an individual's evaluation of their body's functioning and appearance (Gentili et al., 2019). Body image dissatisfaction in men with prostate cancer may contribute to negative illness perceptions, specifically those related to identity, consequences and control, which have been associated with psychological distress (Richardson et al., 2017). In mixed cancer samples, body image dissatisfaction is negatively associated with both general and cancer-specific QoL (Chow et al., 2019). In breast cancer survivorship research, body image difficulties have been related to physical and psychological distress as well as problems with sex and intimacy (Paterson et al., 2016). One study on people with gynaecological cancer found that poorer body image was associated with poorer emotional wellbeing (Teo et al., 2018). However, body image research in prostate cancer is still in its infancy. It has largely been conducted qualitatively and focused on men treated with ADT. Additionally, the majority of treatment interventions have not yet been investigated in terms of the possible impact on body image.

A recent qualitative meta-synthesis reviewed the literature on body image in prostate cancer (Bowie et al., 2022). The authors found that body image was negatively affected by the reduced functioning and capability of the body, which many viewed as consequently 'deficient' and shameful. The authors propose that this impacted on their self-esteem, perceptions of being 'lesser men', and tendency to withdraw from normal life (Bowie et al., 2022). Bowie et al. (2022) also found that body image in people with prostate cancer was negatively affected by their perceptions of how others viewed and treated their body. This was particularly around experiencing a loss of ownership of their body (through prolonged medical treatment), and physical signs of illness such as premature aging, scarring, and catheter use, which resulted in loss of confidence and shame.

One qualitative study found that men treated with ADT were particularly distressed by feminisation of the body and sexual difficulties, and perceived their body to be significantly different to pre-cancer (Gentili et al., 2019). The authors suggest this may have threatened their masculinity. Harrington et al. (2009) found that men treated with ADT had significantly higher body image concerns, compared with men with prostate cancer that had a different treatment, and that this may operate through negative changes in sexuality and masculinity. However, body image dissatisfaction and negative changes in masculinity in men with prostate cancer may extend beyond those treated with ADT (Langelier et al., 2018). Therefore, further investigation into body image dissatisfaction across the treatment groups may be warranted.

Horschke et al. (2020) conducted a cross-sectional study investigating factors associated with body image in men with prostate cancer and their partners, from the perspective of self-acceptance (the individual's satisfaction and acceptance of their body) and partner-acceptance (the individual's perception of their partner's evaluation of their body). They found that men with prostate cancer assumed lower partner-acceptance than that actually reported by their partners. Horschke et al. (2020) also found that higher cancer-related distress, and lower relationship satisfaction and partner-acceptance, were related to poorer self-acceptance. Furthermore, self-acceptance was positively associated partner-acceptance.

Body image dissatisfaction in men with prostate cancer may also mediate other psychological difficulties. One longitudinal study found that baseline body image scores, as well as changes in body image over time, significantly predicted changes in QoL (Taylor-Ford et al., 2013). Furthermore, in a mixed cancer sample body image mediated the impact of stigmatisation on depression (Esser et al., 2018). In prostate cancer specifically, Esser et al. (2018) found that the mediating effect of body image was greater in relation to negative thoughts and feelings towards the body than in relation to perceptions of strength and vitality.

This research highlights a role for negative body image in the poorer psychological wellbeing of people with prostate cancer. Although more rigorous research is needed in order to fully understand the relationship between body image and QoL, body image dissatisfaction may be associated with changes in perception of masculinity in this group (Harrington et al., 2009; Langelier et al., 2018).

### 1.5.4 Masculinity

Langelier et al. (2019) suggest that loss of or change in perceptions of masculinity can be a significantly debilitating side effect of prostate cancer and its treatments, increasing psychological distress. Langelier et al. (2019) suggest that changes in perceived masculinity can be a product of sexual difficulties, feminisation of the body and emotional or behavioural changes (such as feeling out of control, needing to seek help and emotional transparency). McAteer and Gillanders (2019) found that poor masculine self-esteem was significantly associated with increased distress and poorer QoL in men with prostate cancer. Furthermore, masculine self-esteem moderated the association between cancer-related symptoms and psychological distress, though this was buffered by higher psychological flexibility.

A qualitative study investigated experiences of psychological distress in a subsample of prostate cancer survivors (Matheson et al., 2020). Matheson et al. (2020) found that men who adhered to masculine ideals had a stronger sense of loss around:

- the self (in relation to identity, sexuality, masculinity, and confidence),
- physical functioning,
- interpersonal connection,
- sense of control (in relation to their future and emotional experiences).

Prostate cancer survivors also exhibited coping strategies such as avoidance, concealment and social isolation which could be associated with poorer psychological wellbeing (Matheson et al., 2020). The sense of loss experienced by these men may contribute to negative illness perceptions, specifically those related to identity, consequences and control, which have been associated with psychological distress (Richardson et al., 2017).

Burns and Mahalik (2008) conducted a cross-sectional study of post-treatment prostate cancer survivors, exploring the impact of treatment type and the masculine norm of emotional control (restriction of emotions) on physical wellbeing. They found that emotional control was associated with poorer wellbeing. Furthermore, men who were emotionally controlled and selected treatments other than brachytherapy (with more side effects) had poorer wellbeing scores (Burns & Mahalik, 2008). The authors suggest that men who adopt emotional control are less open to describing their vulnerability, which results in greater risk of poor adjustment due to reduced support, particularly when engaging in treatment with more significant side effects. Although this was not found in relation to some hormone therapies which have significant side effects (Burns & Mahalik, 2008).

A recent qualitative meta-synthesis reviewed the literature on masculinity in prostate cancer (Bowie et al., 2022). The authors found that masculinity was negatively impacted and threatened by reduced sexual functioning, which they suggest relates to preconceived masculine ideals around men’s typical sexual functioning. Men reported shame around erectile dysfunction and incontinence, perceiving themselves as ‘useless for sex’ and unworthy of or unable to be a man. They were concerned by both loss of functioning and libido (Bowie et al., 2022). Furthermore, some reported that concerns around preserving sexual function had impacted on their selection of treatment, even if the selected treatment was suggested to reduce survival. Participants additionally reported difficulty discussing sexual dysfunction with medical professionals, due to it not being bought up as a topic by doctors, and their own unwillingness to disclose their perceived loss of masculinity (Bowie et al., 2022). Bowie et al. (2022) also found that for men with prostate cancer masculinity was threatened by perceptions of losing part of their manhood (e.g., after surgery), and feminisation of the body and becoming more emotional (e.g., after ADT). The authors report that many men described invalidation of their masculine ideals, which induced a sense of loss, and perceived inadequate provision of information regarding the side effects of treatments prior to their selection.

Although in the meta-synthesis by Bowie et al. (2022) men who were inflexible with their perceptions of masculine ideals reported threats to their masculinity, some men described the process of being able reaffirm their masculinity, and partners were crucial in providing emotional support. According to Bowie et al. (2022), this process included:

- accepting that physical, sexual, and psychological changes did not diminish their identity as a man, and were necessary in order to preserve health
- redefining sex as acts which did not involve an erection
- regaining control over their life and illness trajectory e.g., through information gathering, engaging with PSA testing, endeavouring to protect their loved ones from the impact of the illness, and looking after physical health
- accounting for changes in their masculinity as natural consequences of aging
- minimising the impact of prostate cancer on their life and masculinity
- trying to think young' and more positively in order to combat the illness and its effects, which allowed them to align with masculine ideals centred around strength and ability to fight the disease.

The outlined research highlights that loss of masculinity may have a crucial impact on QoL, and therefore, providing support around this should be a key focus for interventions supporting prostate cancer survivors. In particular, support around changes in sexual and bodily functioning should be considered, including encouraging flexibility around masculine ideals. Furthermore, the finding that men may select less effective prostate cancer treatment in order to preserve sexual functioning has important implications for clinicians, who should provide clear information regarding the side effects of treatments and opportunities to discuss experiences which may threaten masculinity and impact upon QoL (Bowie et al., 2022).

## 1.6 Social impact

Alongside physical and psychological side effects, prostate cancer and its treatment may also have a negative social impact. The definition of cancer survivorship extends to include the support network of the patient, including family members, friends and caregivers, recognising that the impact of cancer does not stop with the individual (Shapiro, 2018). Cliff and Macdonagh

(2000) found that cancer distress was present in both people with prostate cancer and their partners (47% and 76% respectively). Furthermore, this was described as severe in 11% of people with prostate cancer and 30% of partners. Partners were more concerned than people with prostate cancer about treatments, pain and physical difficulties; people with prostate cancer were more concerned about sexual difficulties than partners; and both experienced concerns related to urinary difficulties (Cliff & Macdonagh, 2000).

In a study of 35,823 men with prostate cancer, whilst most men were socially resilient, 10% were found to be socially distressed (Wright et al., 2019). This distress was strongly associated with unemployment, comorbidity and to a lesser extent previous mental health difficulty, being diagnosed with stage 4 cancer, body mass index >30, being treated systemically or with ADT, low socioeconomic status, being separated, Non-White ethnicity and being a carer. Notably, the youngest and oldest age groups were the most socially distressed (Wright et al., 2019).

Perceived and received social support, as well as satisfaction with this, has been associated with improved QoL in prostate cancer survivors and other long-term conditions (Paterson et al., 2013). Therefore, understanding elements of social support that are helpful for prostate cancer survivors may be important when designing interventions to address social distress.

## 1.7 Effectiveness of psychosocial interventions

Prostate cancer survivors report a range of unmet needs (McIntosh et al., 2019; Paterson et al., 2015), including in relation to intimacy (64.7%), physical problems (47.1%), information needs (76.5%), and psychological and emotional needs (52.9%). Paterson et al. (2015) found that increased psychological need was related to uncertainty about remission, sexual difficulties, and insufficient access to information about the long-term effects of treatment. Furthermore, many men report mild (43.3%) or severe (20%) treatment regret, particularly if they felt a lack of involvement with this, had lower HRQoL, and had significant difficulties with urinary, bowel or sexual functioning (Wilding et al., 2020). It is important to develop effective psychosocial interventions, in order to address these unmet needs.

Psychosocial interventions for men with prostate cancer may involve support for coping with sexual problems, psychoeducation, cognitive behavioural therapy (CBT), relaxation strategies, counselling and peer support interventions (Crawford-Williams et al., 2018). Crawford-Williams et al. (2018) conducted a systematic review of the evidence for interventions and found that psychosocial interventions may improve fatigue (psychoeducation, CBT) and coping with sexual problems (psychoeducation, CBT, peer support). However, there is mixed support for the benefit of psychosocial interventions for improving QoL, anxiety and depression (Crawford-Williams et al., 2018). A recent systematic review and meta-synthesis found some evidence for the efficacy of mindfulness based interventions in improving psychological outcomes and QoL in men with prostate cancer, with a small-moderate effect (Crawford-Williams et al., 2018). However, the authors noted that the lack of research and poor methodological rigour of included studies obscured solid conclusions.

Research investigating depression and anxiety suggests that improvement can be seen from peer support and psychotherapy interventions; however, this is not maintained long-term (Crawford-Williams et al., 2018). Combinations of CBT, communication from health professionals, psychoeducation and peer support were found to be most used and effective in reducing decision-related distress, and improving mental health and QoL outcomes (Crawford-Williams et al., 2018). The authors suggest that the variation in effectiveness of psychosocial interventions demonstrated across systematic reviews calls for the need for interventions to be person-centred and individualised. Therefore, in order to design appropriate interventions, it is important to improve understanding of factors which contribute to the long-term poorer psychological wellbeing of men with prostate cancer.

## 1.8 Summary and rationale for the current study

As highlighted within this literature review, prostate cancer is the most common cancer affecting UK men (Cancer Research UK, 2022c). However, survival times are increasing and prostate cancer is commonly considered a chronic illness (Watts et al., 2014). Prostate cancer survivors may experience functional and psychological effects of the disease and its treatment for many years, which can significantly impact upon their QoL (Lehto et al., 2017). This has called for a shift in focus towards considering how to treat people with prostate cancer with individual long-term consequences of the disease (Fervaha et al., 2019; Watts et al., 2014).

The CSM model of self-regulation has been used as a framework for understanding coping, illness outcomes and adjustment in numerous health conditions, including cancer survivorship (Dempster et al., 2015). In mixed cancer samples, illness perceptions have been associated with coping style selection, anxiety, depression, psychological distress and poorer QoL (Richardson et al., 2017). Research exploring illness perceptions in prostate cancer is in its infancy (Otto et al., 2022). However, illness perceptions have been found to be associated with poorer emotional wellbeing (Traeger et al., 2009), anxiety, and coping style selection in this group (Otto et al., 2022). This literature highlights the role of perceived experiences in supporting wellbeing in prostate cancer survivors.

The prevalence of functional side effects from prostate cancer treatments is well described (Stein et al., 2008; Wallis et al., 2018). However, the interaction between these difficulties and the psychological wellbeing of prostate cancer survivors is less explored (Brunckhorst et al., 2021). The NCRI has highlighted the importance of understanding the short and long-term psychological impacts of cancer and its treatment (NCRI, 2020). However, there is a lack of research relating to strategies for improving and supporting the long-term psychosocial wellbeing of prostate cancer survivors (Maggi et al., 2019; Weber & Sherwill-Navarro, 2005), and understanding factors which contribute to this (Matheson et al., 2020).

This literature review has highlighted research on the prevalence and experiences of depression, anxiety, suicidality, illness representations, body image and masculinity (including masculine self-esteem), in people with prostate cancer. However, there is a paucity of research relating to how these factors impact upon the long-term wellbeing of prostate cancer survivors, including QoL, and factors associated with variation in this. Understanding factors which contribute to the long-term psychological wellbeing of people with prostate cancer could aid the development and efficacy of person-centred interventions, improving outcomes of survivorship and QoL. Currently, there is mixed support for the benefit of psychosocial interventions for improving QoL, anxiety and depression (Crawford-Williams et al., 2018). Crawford-Williams et al. (2018) suggest that variation in their effectiveness demonstrates the need for individualised interventions, and therefore highlight the importance of improved understanding around factors which contribute to the long-term poorer psychological wellbeing of people with prostate cancer. Based on the literature review, for the purpose of this thesis psychological needs are defined as the long-term impact of prostate cancer on depression, anxiety, illness representations, body image, masculinity (and masculine self-esteem), and QoL.

## 1.9 Research aims and questions

This project focuses on exploring the long-term psychological needs of men with prostate cancer. The aim is to:

1. Describe the long-term psychological needs of men with prostate cancer.
2. Explore the relationship between long-term psychological needs and QoL in men with prostate cancer.

Understanding the psychological impact of prostate cancer and supporting psychological wellbeing is a current priority for prostate cancer survivorship research (NCRI, 2020). However, research in this area is in its infancy. The presented literature highlights that QoL may be associated with the psychological wellbeing of people with prostate cancer. Therefore, this project will consider QoL, anxiety, depression, illness representations, body image and masculinity (including masculine self-esteem). Although research on the prevalence of these phenomena has been conducted, there is less research on how these factors impact upon the long-term wellbeing of prostate cancer survivors, and factors associated with variation in this. Therefore, this project will also consider demographic information, time since diagnosis and treatment received.

Understanding factors which contribute to the long-term psychological wellbeing of people with prostate cancer could aid the development and effectiveness of appropriate, person-centred interventions, improving outcomes of survivorship and QoL.

### 1.9.1 Research questions

**Primary research question:**

- What are the long-term psychological needs of men with prostate cancer?

**Secondary research questions:**

- What is the relationship between psychological needs (e.g., depression, anxiety, body image, masculinity, masculine self-esteem, illness representation) and QoL in men with prostate cancer?
- What is the relationship between demographic and clinical factors (e.g., age, ethnicity, time since diagnosis, treatment received) and QoL in men with prostate cancer?

# Chapter 2: Methodology

This chapter first discusses the research design for the study and highlights the ethical clearance granted. The participant selection and recruitment are then outlined, as well as the procedure and measures used. Finally, the data available, and the process of data cleaning, management and analysis is described.

## 2.1 Design

The study used a cross-sectional design to investigate the long-term psychological needs of people with prostate cancer via an online survey, hosted by the 'Online Surveys' platform. The survey captured data related to demographic information, time since diagnosis, treatment received, cancer stage and information related to psychological needs. As it was hoped that insight would be gained into what the long-term psychological needs of people with prostate cancer are and the impact of these, this study called for population-based research. This type of research lends itself to being answered by a quantitative survey and conducting this online allowed opportunity for a national sample, covering a range of age groups. Furthermore, an online survey was a low cost method for achieving a larger sample size. Given the impact of coronavirus restrictions, it was also appropriate to deliver the survey via a methodology that did not require face to face contact. The limitations of this design are also acknowledged. The online, voluntary nature of the survey may have invited response bias, such as those already seeking support from cancer charities and organisations. Additionally, the cross-sectional nature of the design means that causality cannot be inferred.

## 2.2 Ethical clearance

This study was approved by the School of Medicine Research Ethics Committee (SoMREC) in May 2021 (MREC 20-046) (Appendix A).

## 2.3 Participants

### 2.3.1 Sample

This was an observational, exploratory study. However, a previous survey (identified in section 1.5.4 of the literature review) modelled a similar patient participant group (McAteer & Gillanders, 2019) and estimated the variance around QoL, which was used to calculate sample size. Based on a 95% level of confidence and margin of error of 3, the suggested minimum sample size was 132.

### 2.3.2 Recruitment

For recruitment of participants, several third sector cancer charities and organisations were contacted, including: Prostate Cancer UK; Prostate Cancer Research Centre Movember; Cancer Research UK; Maggie's Centres; and Tenovus Cancer Care. Movember were unable to support with recruitment, however the other organisations were able to support recruitment. Additionally, the Centre for Ethnic Health Research Centre, regional cancer charities and online prostate cancer support groups were also contacted and were able to support in the following ways:

1. Email – Maggie’s Centres (a charity which gives free cancer support and information across the UK) were able to send an email invitation to the Centre Heads of Maggie’s Centres which met the study criteria. Additionally, several prostate cancer support groups were able to forward the email invitation to their members and mailing lists. The email included a summary of the research for participants and the link to access the survey.

2. Online platforms – The majority of charities and organisations were able to support recruitment by advertising on various online platforms, including their website, online forums, blog, newsletter, and social media pages (e.g., Twitter and Facebook). A poster was provided to support this, which included a summary of the research for participants and the link to access the survey.

To further support recruitment, the poster and link to the survey were also posted directly onto Twitter periodically throughout the recruitment period. Where possible and appropriate, this recruitment strategy was used to link in with notable dates and groups, such as Movember and men’s health week.

### 2.3.3. Inclusion and exclusion criteria

The following inclusion and exclusion criteria were agreed for participation in the study:

- **Inclusion criteria**: In order to participate in the survey participants were required to: be aged 18 or above; have had a diagnosis of prostate cancer; be 12 months or more post-diagnosis; be able to understand the content of the questionnaires unaided / independently.

- **Exclusion criteria**: Participants were unable to participate in the survey if they: have not had a diagnosis of prostate cancer; were aged 17 or below; were less than 12 months post-diagnosis; were unable to understand the content of the questionnaires unaided / independently.

As the study was investigating the long-term psychological needs, the decision was made to survey people who are more than 12 months post-diagnosis. People who are less than 12 months post-diagnosis tend to have a larger amount of 1:1 support, and therefore their psychological needs are relatively better defined. This population excludes those who are experiencing the acute psychological impact of a new diagnosis and treatment, whilst including those who have experience of the long-term effects. The decision to exclude those under the age of 18 was made as the psychological needs of those under 18 are likely to be different from those of adults. Whilst the importance of making reasonable adjustments to support inclusivity is acknowledged, the online nature of the survey (meaning no direct contact with participants) and lack of resources meant it was difficult to make adjustments for those who were unable to understand the content of the questionnaires independently. Furthermore, the questionnaires used in the survey have been validated in English, and therefore translating them into other languages would result in both copyright and psychometric problems. For these reasons, participants were required to understand English sufficiently enough to answer the questionnaires.

## 2.4 Procedure

The study was hosted using the ‘Online Surveys’ platform. Participants first viewed an information sheet and gave their informed consent by clicking to continue on to the survey. Participants were then provided with supplementary information which acknowledged the sensitive nature of the survey area, and a screening page to ensure they were eligible to participate. The survey first collected demographic information (age, gender identity, ethnicity, relationship status, employment status, education status), and clinical information (time since diagnosis and treatment received both previously and currently (e.g., surgery, radiotherapy, hormone therapy or active monitoring), and cancer stage at time of diagnosis). It then used a set of validated questionnaires, to gather information related to psychological needs and wellbeing as identified by the literature (QoL, depression, anxiety, illness representation, body image, masculinity, and masculine self-esteem).

Prior to the survey going live, feedback was sought from ‘experts by experience’ (people diagnosed with prostate cancer) to determine whether it was understandable and acceptable for this particular group. To do this, Yorkshire Cancer Community were contacted via email, with the request to share the survey with members of their Patient and Public Involvement group. The email contained information about the research and a link to view the survey, along with a feedback form (Appendix B). Yorkshire Cancer Community agreed to forward the email to three individuals who run prostate cancer support groups in Yorkshire. This resulted in three individuals completing the pilot survey, two of whom provided feedback. The feedback provided suggested that there were no concerns raised about the time taken to complete the survey or about the questions being distressing. Additional feedback indicated that one individual found the survey ‘interesting’ and ‘a step in the right direction’. Consideration was given to whether to pursue further avenues for feedback at this stage, however as no concerns were raised over the length or nature of the questions, it was decided not to expose the survey to other support groups, as this was a recruitment strategy for the study.

Once the survey was live, it remained open for 6 months, during which time a sufficient number of participants were recruited as per sample size calculations.

## 2.5 Measures

### 2.5.1 Demographic and clinical information

Table 2 highlights the demographic and prostate cancer related information that participants were asked to report.

Table 2. *Demographic and clinical information collected.*

| **Variable** | **Response format** |
|---|---|
| **Demographic** | |
| Age | Years |
| Sex | Male / female / other |
| Ethnicity | White / White mixed / Black or Black British / Asian or Asian British / Other ethnic group |
| Relationship status | Married / single / widowed / divorced / civil partnership / in a relationship / other) |
| Employment status | Employed (full-time) / employed (part-time) / unemployed / self-employed / retired / disabled, not able to work / other |
| Education level | GCSE’s or equivalent / A-level’s or equivalent / university undergraduate degree or higher |
| **Clinical** | |
| Time since diagnosis | Years |
| Type of treatment (currently and previously) | Active surveillance / surgery / radiotherapy / hormone therapy / other |
| Cancer stage at diagnosis | Stage 1 / stage 2 / stage 3 / stage 4 / unsure |

### 2.5.2 Standardised self-report outcome measures

Table 3 outlines the standardised and validated questionnaires used to gather information related to psychological needs and wellbeing in the study.

Table 3. *Standardised questionnaires used in the survey.*

| Measure | Construct | Reference |
|---|---|---|
| European Organization for Research and Treatment of Cancer Quality of Life Questionnaire for Cancer Patients – Version 3 (EORTC QLQ-C30-V3) | Quality of life | Aaronson et al. (1993) |
| Patient Health Questionnaire (PHQ-8) | Depression | Kroenke et al. (2008) |
| Generalised Anxiety Disorder Scale (GAD-7) | Anxiety | Spitzer et al. (2006) |
| Revised Illness Perceptions Questionnaire (IPQ-R) | Illness representations | Moss-Morris et al. (2002) |
| Body Image Scale (BIS) | Body image | Hopwood et al. (2001) |
| Masculinity in Chronic Disease Inventory (MCD-I) | Masculinity | Chambers et al. (2016) |
| Masculine Self-esteem Scale (MSE) | Masculine self-esteem | Clark et al. (2003) |

#### EORTC QLQ-C30-V3 (Aaronson et al., 1993)

The EORTC QLQ-C30-V3 was used to assess QoL. It is a 30-item self-report questionnaire which includes five functional scales (physical, role, cognitive, emotional and social), three symptom scales (fatigue, pain and nausea / vomiting), single item scales (financial difficulties, dyspnoea, appetite loss, sleep disturbance, constipation, and diarrhoea), and a global health and QoL scale (Aaronson et al., 1993). For the functional, symptom and single item scales, participants are required to indicate their response on a 4-point scale (not at all, a little, quite a bit, very much), considering how much the statement applies to them. For the global health and QoL scales, participants are required to indicate their response on a 7-point Likert scale, ranging from 1 (very poor) to 7 (excellent). Scores for each subscale range from 0-100, with higher scores on the functional, symptom, and global health and QoL subscales indicating healthier level of functioning, higher levels of symptomatology / problems, and better QoL respectively. The EORTC QLQ-C30 has been validated, and is found to be acceptable, valid and reliable in people with cancer (Aaronson et al., 1993), and specifically in people with prostate cancer (Arraras Urdaniz et al., 2008). Aaronson et al. (1993) reported Cronbach's alpha for the subscales as ranging from 0.52-0.89. Although Cronbach's alpha for the 'role' subscale was reported to be 0.52, the remaining 8 scales were all reported to be >0.7. The EORTC QLQ-C30 is thought to be the "gold standard" in assessing QoL in people with cancer (Mickeviciene et al., 2013).

### PHQ-8 (Kroenke et al., 2008)

The PHQ-8 was adapted from the PHQ-9 (Kroenke & Spitzer, 2002) and was used to assess depression. It is an 8-item self-report questionnaire which asks participants to indicate how bothered they have been by depression symptoms in the last two weeks, on a 4-point scale (0 - not at all, 1 - several days, 2 - more than half the days, 3 - nearly every day). Total scores range from 0 to 24, with scores of 5-9 indicating mild depression, 10-14 indicating moderate depression, 15-19 indicating moderately severe depression and 20-24 indicating severe depression. The PHQ-8 has frequently been used to measure depression in illness groups, and has been found to be reliable (Cronbach's alpha 0.82) and valid (Pressler et al., 2011). There is less risk of producing inflated scores, due to less focus on questions which features of illness can cause, than on other questionnaires.

### GAD-7 (Spitzer et al., 2006)

The GAD-7 was used to assess anxiety. It is a 7-item self-report questionnaire which asks participants to indicate how bothered they have been by anxiety symptoms in the last two weeks, on a 4-point scale (0 - not at all sure, 1 - several days, 2 - over half the days, 3 - nearly every day). Total scores range from 0 to 21, with scores of 5-9 indicating mild anxiety, 10-14 indicating moderate anxiety, 15-21 indicating severe anxiety. The GAD-7 has frequently been used to measure anxiety in illness groups and has been found to be reliable (Cronbach's alpha 0.89) and valid (Bernd et al., 2008). There is less risk of producing inflated scores, due to less focus on questions which features of illness can cause, than on other questionnaires.

### IPQ-R (Moss-Morris et al., 2002)

The IPQ-R was used to assess illness representations. It is an 84-item self-report questionnaire, which has been widely used and adapted to assess illness representation in different cancer groups, including those with prostate cancer (Mickeviciene et al., 2013). The IPQ-R assesses components of illness representation (identity, consequences, timeline acute/chronic, timeline cyclical, personal control, treatment control, illness coherence, emotional representations). Initially, 14 symptoms of illness are presented, and participants are required to indicate (yes/no) whether firstly they have experienced the symptom since their diagnosis, and secondly whether they believe the symptom to be related to the diagnosis. This contributes to an identity representation score. Next a number of illness representation statements are presented (related to the components above), and participants are required to indicate their response on a 5-point Likert scale (ranging from strongly disagree to strongly agree). The final section of the IPQ-R assesses how participants attribute causes of their illness. This includes psychological attributions, risk factors, immunity and accident or chance. Higher scores on the first 4 components (as listed above) indicate strong beliefs about the number of symptoms attributed to the illness, negative consequences, and the chronic, recurrent nature of the illness (Hill, 2010). High scores on the control and coherence subscales indicate positive control beliefs and understanding of the illness (Hill, 2010). The IPQ-R has been used with numerous illness groups and found to be reliable (Cronbach’s alpha 0.79-0.89) and valid (Moss-Morris et al., 2002).

### BIS (Hopwood et al., 2001)

The BIS was used to assess body image. It is a 10-item self-report measure which asks participants to indicate the degree to which each statement describes them on a 4-point scale (0 – not at all, 1 – a little, 2 – quite a bit, 3 – very much). Total scores range from 0 to 30, with higher scores indicating poorer body image. The BIS has been used in previous literature to assess body image issues in people with cancer, showing high reliability (Cronbach’s alpha 0.93) and good validity (Hopwood et al., 2001). Although the BIS originally includes 10-items, in previous research it has been adapted for prostate cancer groups by removing an item which was felt to be less relevant for this patient group (van den Driessche et al., 2016). In line with this, the item ‘‘Have you been dissatisfied with the appearance of your scar?’’ was also removed in this study.

### MCD-I (Chambers et al., 2016)

The MCD-I was used to assess masculinity and was specifically developed for use with prostate cancer (Bowie et al., 2020). It is a 22-item self-report measure which asks participants to indicate the degree to which each statement describes them, on a 5-point scale (ranging from 1 – not true at all to 5 – very true). It measures five subscales of masculinity: strength/fitness, sexual priority/importance, family responsibilities, emotional self-reliance, and optimistic action. Higher scores indicate higher prominence and importance of these masculine attributes. The MCD-I has demonstrated reliability (Cronbach’s alpha 0.69-0.92) and validity (Chambers et al., 2016).

### MSE (Clark et al., 2003)

The MSE was used to assess masculine self-esteem. It is an 8-item-self report subscale which forms part of the Prostate Cancer-Related QoL Scales (Clark et al., 2003). It asks participants to indicate the degree to which each statement describes them, on a 5-point scale (ranging from 1 – not at all to 5 – very much). Total scores range from 0 to 40 (standardised scores range from 0-100), with higher scores indicating poorer masculine self-esteem. The MSE has demonstrated reliability (Cronbach's alpha 0.91) (Clark et al., 2003).

## 2.6 Data collected

Completed survey responses were stored securely on the 'Online Surveys' platform. Table 4 summarises the available data following participants' completion of the questionnaires detailed in section 2.5. QoL was the primary outcome of interest. The relationship between depression, anxiety, illness representations, body image, masculinity on QoL was explored through logistic regression modelling. Demographic and clinical data were used as confounders.

Table 4. *Summary of data collected.*

| **Concept** | **Measure** | **Data type** | **Outcome** | **Predictor** | **Confounder** |
|---|---|---|---|---|---|
| Demographic | Age | Continuous | | | X |
| | Sex | Categorical | | | X |
| | Ethnicity | Categorical | | | X |
| | Relationship status | Categorical | | | X |
| | Employment status | Categorical | | | X |
| | Education status | Categorical | | | X |
| Clinical | Years since diagnosis | Continuous | | | X |
| | Cancer stage at diagnosis | Categorical | | | X |
| | Current treatment | Categorical | | | X |
| | Previous treatment | Categorical | | | X |
| | Number of treatments | Categorical | | | X |
| | Treatment – Active Surveillance exposure | Dichotomous | | | X |
| | Treatment - Active Surveillance only | Dichotomous | | | X |
| | Treatment - Radiotherapy exposure | Dichotomous | | | X |
| | Treatment - Radiotherapy only | Dichotomous | | | X |
| | Treatment - Hormone therapy exposure | Dichotomous | | | X |
| | Treatment - Hormone therapy only | Dichotomous | | | X |
| | Treatment - Surgery exposure | Dichotomous | | | X |
| | Treatment - Surgery only | Dichotomous | | | X |

| Concept | Measure | Data type | Outcome | Predictor | Confounder |
|---|---|---|---|---|---|
| | Treatment - Chemotherapy exposure | Dichotomous | | | X |
| | Treatment - Chemotherapy only | Dichotomous | | | X |
| | Treatment - Other treatment exposure | Dichotomous | | | X |
| | Treatment - Other treatment only | Dichotomous | | | X |
| | Treatment - No treatment | Dichotomous | | | X |
| Quality of Life | Global health status / QoL score | Continuous/categorical | X | | |
| | Functional subscale | Continuous | | X | |
| | Symptom subscale | Continuous | | X | |
| Depression | Overall score | Continuous | | X | |
| Anxiety | Overall score | Continuous | | X | |
| Illness perception | Identity subscale | Continuous | | X | |
| | Consequences subscale | Continuous | | X | |
| | Timeline acute/chronic subscale | Continuous | | X | |
| | Timeline cyclical subscale | Continuous | | X | |
| | Personal control subscale | Continuous | | X | |
| | Treatment control subscale | Continuous | | X | |
| | Illness coherence subscale | Continuous | | X | |
| | Emotional representations subscale | Continuous | | X | |
| | Causes – personal factors subscale | Continuous | | X | |
| | Causes – external factors subscale | Continuous | | X | |
| | Causes – health factors subscale | Continuous | | X | |

| Concept | Measure | Data type | Outcome | Predictor | Confounder |
|---|---|---|---|---|---|
| Body image | Overall score | Continuous | | X | |
| Masculinity | Overall score | Continuous | | X | |
| | Strength/fitness subscale | Continuous | | X | |
| | Sexual priority/importance subscale | Continuous | | X | |
| | Family Responsibilities subscale | Continuous | | X | |
| | Emotional self-reliance subscale | Continuous | | X | |
| | Optimistic action subscale | Continuous | | X | |
| Masculine self-esteem | Overall score | Continuous | | X | |

*Note:* Colours have been used as a visual aid.

## 2.7 Data extraction

Once the recruitment phase of the study was complete, the anonymised quantitative data were extracted from the 'Online Surveys' platform into a password protected Excel spreadsheet, stored securely on University of Leeds servers. Following data cleaning (detailed below), the data were then imported into IBM SPSS Statistics (Version 26) for processing and analysis.

## 2.8 Data cleaning

Once the data had been extracted from the 'Online Surveys' platform, they were first subjected to a data cleaning process. The data cleaning process involves checking the data for errors, and erasing, correcting or editing these in order to prepare for data analysis (Pallant, 2020). Such errors may include incorrect data, missing data or data which are not in the required format. A complete summary of the data cleaning process is provided in Appendix C. The following section highlights the data that were modified prior to analysis.

### 2.8.1 Demographic factors

#### Age

One participant reported their age to be 23. As prostate cancer mainly affects those over the age of 50 (Prostate Cancer UK, 2019a), and this individual had attributed the cause of prostate cancer to aging in a subsequent questionnaire (IPQ-R), this was assumed to be an error. Therefore, this participant was assigned an age of 70, which was the average age of the sample.

#### Relationship status

For the relationship status question, one participant responded 'other'. However, using their qualitative response (living together with a long-term partner), this was recoded to 'in a relationship'. For this variable, the categories were collapsed to create new, larger variables, in order to reflect whether the participant was in a relationship (indicating a level of support), or not in a relationship. The categories married, in a relationship, and civil partnership were recoded as 'in a relationship' and the categories single, divorced, and widowed were recoded as 'not in a relationship.'

#### Employment status

For employment status, two participants responded 'other'. However, using their qualitative responses, these were recoded into categories which already existed (see Appendix C for further details). For this variable, the categories employed (full-time), self-employed and employed (part-time) were recoded as 'employed'.

### 2.8.2 Clinical factors

#### Years since diagnosis

For the years since diagnosis question, 34 responses required modification due to not being presented in the required format, as this question was set up on the survey as a free-text box. For consistency, the decision was made to report the years since diagnosis as a numerical value only. Therefore, responses were modified into this format. Some examples include: the response '2 years' being changed to 2; the response '18 months' being changed to 1.5; and the response '2017' being changed to 4.

#### Treatment

Due to the complexity of the treatment data, reflecting the individual experiences of the participants, it was not possible to use the data in their original form to model the complexities of the treatment combinations in further statistical analysis. Therefore, the current and previous treatment data were combined to reflect the participants' exposure to treatments during the course of their prostate cancer. See Appendix D for a full breakdown of the treatment category frequencies. The data were also transformed to reflect the number of treatments the participant had, whether the participant had been exposed to a particular treatment at any time, and whether they had had the experience of only receiving a single treatment. For example, the 'hormone therapy exposure' variable was created to reflect whether a participant had been exposed to hormone therapy at any time during their prostate cancer journey. The 'hormone therapy only' variable reflected whether hormone therapy was the single course of treatment that the participant had received throughout their prostate cancer. Due to low numbers in the 0 and 5 treatment count categories (*n* = 1) these were subsumed into a '0-1' treatments category and '4-5' treatments category respectively.

Initially, for the questions relating to previous or current treatment, 44 participants selected 'other' for either question. Using qualitative responses two new treatment categories of 'chemotherapy' and 'None' were created. Subsequently, using qualitative responses, the majority of 'other' responses were recoded into existing categories. Some examples include: the response 'treatment other - PSA annual after surgery' being changed to active surveillance; the response 'treatment other brachytherapy' being changed to radiotherapy; and the response 'treatment other – Zoladex' being changed to hormone therapy.

### 2.8.3 Standardised self-report outcome measures

#### EORTC QLQ-C30-V3

For analysis, the QoL score was transformed into categories based on the scale, creating three QoL groups. As possible scores range from 0-100, with higher scores reflecting better QoL, scores ranging from 0-33.33 were categorised as ‘low QoL’, scores ranging from 33.34-66.67 were categorised as ‘moderate QoL’ and scores ranging from ‘66.68-100’ were categorised as high QoL. The decision to create the three groups based on the scale, rather than create equal sized categories based on the number of participants, was made as it was felt that it was more clinically meaningful and would better reflect the experience of the participants. It was felt that it was important to define the size of the group by their experience, which is what is being measured, rather than by the size of the group. For the low QoL group $n = 10$ (6.4%), for the moderate QoL group $n = 48$ (30.8%), and for the high QoL group $n = 98$ (62.8%). As only 10 participants were found to have low QoL, they were subsumed into a broader category containing participants with low and moderate QoL ($n = 58$, 37.18%).

#### IPQ-R

For the question ‘this symptom is related to my prostate cancer’ on the IPQ-R, ten participants responded ‘yes’ for some symptoms despite reporting that they were not actually experiencing the symptom. Therefore, for these participants the response to ‘this symptom is related to my prostate cancer’ was recoded to ‘no’. Additionally, six participants reported incongruent responses on the ‘timeline acute/chronic’ subscale of the IPQ-R. For example, one participant reported that they agree their prostate cancer will last a short time, but also agree that it would be permanent, that it will last a long time, and that they will have it for the rest of their life. The decision was made to recode the incongruent responses for these participants, by taking the first response as correct and recoding the contradictory responses to the opposite coding (strongly agree to strongly disagree, agree to disagree, disagree to agree, and strongly disagree to strongly agree).

For the ‘consequences’ subscale of the IPQ-R, the responses of nine participants appeared to be incongruent as they endorsed either ‘strongly agree’ or ‘agree’ on *both* the ‘my prostate cancer has major consequences on my life’ and the ‘my prostate cancer does not have much effect on my life’ items. As this was a substantial number of participants, a sensitivity analysis was conducted in order to understand the impact of the incongruent responses on the overall subscale score (see Appendix E.1). In order to do this, the original (unchanged) subscale scores were compared to a recoded (changed) subscale score. To obtain the changed subscale score, the incongruent responses were recoded by taking the first response as correct and re-coding the contradictory response to the opposite coding (strongly agree to strongly disagree, agree to disagree, disagree to agree, strongly disagree to strongly agree). From observation, the summary scores for the unchanged and changed consequence subscale looked very similar. The median and IQR was 18 (15-20) and 18 (15.25-21) respectively. However, a Wilcoxon Signed Rank Test revealed this change was statistically significant, $z = 2.81$, $n = 156$, $p < 0.05$, with a small effect size *(r* = 0.16). As the study has a large sample, it is likely that small changes are creating mathematical significance; however, this may not be clinically meaningful. Therefore, it was decided that the next step should be to explore how the unchanged / changed consequence subscale scores impact on the primary outcome variable (QoL). The median and IQR scores were extremely similar for the unchanged / changed consequence subscales, across the three QoL categories. Therefore, as the impact of changing the consequence subscale score on the outcome variable was so small and unlikely to be clinically meaningful, and it is best practice to do as little modifying of the data as possible, it was decided to leave the incongruent responses for this subscale unchanged.

### Factor analysis

Factor analysis is recommended for scoring the causes section of the IPQ-R. Factor analysis is appropriate to generate subscales when the sample size is greater than 85 (Moss-Morris et al., 2002). Factor analysis is a data reduction technique, and is an umbrella term for several related techniques including principal components analysis (PCA) and factor analysis (Moss-Morris et al., 2002). Although both techniques similarly aim to collapse original variables in a way that accounts for most of the variation and often produce similar results, Stevens (1996) notes that PCA is psychometrically sound, and avoids potential difficulties with ‘factor indeterminacy’, and Tabachnick and Fidell (2013) suggest PCA when an empirical summary of the data is required (Pallant, 2020). Therefore, PCA was performed on the 18 items on the causal section of the IPQ-R using IBM SPSS Statistics (Version 26). See Appendix E.2 for full details.

Prior to doing PCA, the suitability of the data was evaluated. The correlation matrix showed the presence of several coefficients of 0.3 and above. The Kaiser-Meyer-Olkin value was 0.88, exceeding the recommended value of 0.6, and Bartlett's Test of Sphericity was statistically significant ($p<0.05$), supporting the factorability of the correlation matrix (Pallant, 2020).

PCA revealed five components with eigenvalues greater than 1, explaining 39.31%, 11.24%, 8.68%, 6.29% and 5.74% of the variance respectively. However, the scree plot showed a clear break after the third component. Therefore, it was decided to keep three components for further investigation. The three-component solution explained a total of 59.23% of the variance, with Component 1 contributing 39.31%, Component 2 contributing 11.24% and Component 3 contributing 8.68%. To support the interpretation of these components, oblimin rotation was conducted. The rotated solution revealed that the three components showed multiple strong loadings, with variables loading considerably on one component.

Based on the PCA analysis, three components were identified which included the following:

- Personal factors (included 7 variables) – stress or worry, my mental attitude, my emotional state, my personality, overwork, family problems or worries, and my own behaviour.
- External factors (included 4 variables) – a germ or virus, altered immunity, pollution, and accident or injury.
- Health factors (included 6 variables) – aging, alcohol, smoking, poor medical care, diet, and hereditary causes.

These three causal factors were subsequently used as subscales during further analysis.

### 2.8.4 Missing or incomplete data

No missing or incomplete data were identified during data cleaning. All participants provided a complete data set.

## 2.9 Analysis

The data were analysed using IBM SPSS Statistics (Version 26). Descriptive statistics were used to explore all variables and were calculated both for the overall sample and stratified by the two QoL categories (low-moderate QoL and high QoL).

Continues variables were: age, years diagnosed, QoL (including subscales), depression, anxiety, illness representations subscales, body image, masculinity (including subscales) and masculine self-esteem. The distributions of the continuous variables were explored using estimates of skewness and kurtosis and histograms with a normal distribution curve (Appendix E.3). Age was found to be normally distributed, whilst all other continuous variables were not normally distributed. Therefore, the mean and SD were calculated for the age variable, and the median and interquartile range (IQR) were calculated for the remaining (not normally distributed) continuous variables.

Categorical variables were: sex (male/female), ethnicity (White/Non-White), relationship status (in a relationship/not in a relationship), employment status (retired/employed/disabled or unable to work), education level (university degree/A-level's/GCSE's), cancer stage (unsure/stage 1/stage 2/stage 3/stage 4), number of treatments (0-1/2/3/4-5), treatment exposure (yes/no response to the following categories: active surveillance, radiotherapy, hormone therapy, surgery, chemotherapy and other), and single treatment exposure (yes/no response to the following categories: active surveillance, radiotherapy, hormone therapy, surgery, chemotherapy, other and no treatment). Frequency count and proportions were calculated for categorical variables.

Differences in descriptive statistic between the two QoL categories (low-moderate QoL and high QoL) were explored using Pearson's Chi$^2$ tests for categorical variables, Mann-Whitney U tests for not normally distributed continuous variables, and independent samples t-tests for normally distributed continuous variables. The intention here was to further describe the sample of survey respondents by identifying any statically significant differences in demographic, clinical and psychological variables between the two QoL categories. P-values of $\leq 0.05$ were considered to be statistically significant.

Inferential statistics in the form of logistic regression models were used to quantify the relationship between the two QoL categories (outcome) and psychological needs (depression, anxiety, illness representations, body image, masculinity, and masculine self-esteem), as well as demographic and clinical (confounder) variables. Preliminary checks suggested that there was no multicollinearity. Additionally, the omnibus tests of model coefficients goodness of fit test returned a statistically significant Chi$^2$ statistic ($p < 0.001$), indicating that the model performed significantly better than the baseline intercept-only model (Pallant, 2020). The Hosmer-Lemeshow goodness of fit test also returned a non-significant Chi$^2$ statistic ($p > 0.05$), further supporting the model fit.

Two logistic regression models quantified the relationship between demographic, clinical and psychological variables, and QoL category. The first models were univariate, main effect models used to quantify the unadjusted relationship between each psychological variable (independent) and QoL (outcome). The second model was a fully adjusted model, where each independent and cofounder variable were entered into the model to quantify the adjusted relationship between QoL (outcome), and each psychological variable (independent) and demographic and clinical variables (cofounders). The output for each model is presented in the form of odds ratios (OR) and 95% confidence intervals (CI). P-values of $\leq 0.05$ were considered to be statistically significant. ORs of greater than one indicate a positive relationship and ORs between zero and one indicate a negative relationship.

# Chapter 3: Results

This chapter outlines the findings of the study. Descriptive statistics were first used to describe the demographic and clinical characteristics (section 3.1) and psychological variables (section 3.2) of the overall sample. Secondly, descriptive statistics were used to explore differences in the demographic and clinical characteristics and psychological variables stratified by the two QoL categories. Finally, this chapter reports the results of two logistic regression models used to further explore the relationship between demographic, clinical and psychological variables, and QoL.

## 3.1 Demographic and clinical characteristics of the sample

Between May 2021 and November 2021, a total of 156 people who had been diagnosed with prostate cancer for longer than a year participated in the online survey. Participants were aged between 48-90 (*M* = 70.12, *SD* = 7.52, Table 5), predominantly identified as male (99.4%) and were primarily White (97.4%). As there was little variation in the ethnicity reported by participants, ethnicity categories were collapsed to 'White' and 'Non-White' for any further analysis. In terms of relationship status, 72.4% were married, 16% widowed, 10.3% in a relationship, 6.4% single, 5.1% divorced, and 1.3% in a civil partnership. Based on the category collapsing described in section 2.8, the proportion of people in a relationship was 84% and the proportion of people not in a relationship was 16% (Table 5). Across all survey participants, 76.9% were retired, 10.3% employed full-time, 7.1% self-employed, 3.2% employed part-time, and 2.6% disabled or unable to work. Based on the category collapsing described in section 2.8, the proportion of people who were retired was 76.9%, the proportion of people who were employed was 20.5% and the proportion of people who were disabled or unable to work was 2.6% (Table 5). Education status varied across participants: 46.2% had a university degree or higher, 25% had A-levels or equivalent, and 28.8% had GCSE's or equivalent (Table 5).

All participants had been diagnosed with prostate cancer at least one year previously. The years since diagnosis ranged from 1-23 (*Mdn* = 5 (*IQR* = 3-10), Table 5). There was variation in the stage at which participants were diagnosed with prostate cancer: 13.5% diagnosed at stage 1, 25.6% at stage 2, 25% at stage 3, 13.5% at stage 4, 22.4% were unsure of their cancer stage at diagnosis (Table 5).

There was considerable variation in type of anti-cancer treatment or combinations of treatments that participants had received (Appendix D). The most common treatment combinations were active surveillance, radiotherapy, and hormone therapy (n = 25, 16%), followed by active surveillance and surgery (n = 20, 12.8%). Radiotherapy and hormone therapy, surgery alone, active surveillance alone, and surgery, radiotherapy and hormone therapy represented *n* = 13 (8.3%), *n* = 13 (8.3%), *n* = 11 (7.1%) and *n* = 11 (7.1%) respectively.

In terms of number of different anti-cancer treatments participants had received: most participants reported having had two treatments (34.6%) or three treatments (31.4%). In terms of which treatments they had received: the majority had had radiotherapy (56.4%), active surveillance (55.1%), hormone therapy (55.1%) and surgery (43.6%). One participant (0.6%) reported that they had not received any treatments. These data are summarised in Table 5. In terms of exposure to only one type of treatment, 7.1% were exposed to active surveillance alone, 1.9% to radiotherapy alone, 5.8% to hormone therapy alone, 8.3 % to surgery alone, and 0.6% to 'other treatments' alone.

## 3.2 Psychological needs of the sample

A key aim of this study was to describe the psychological needs of men with prostate cancer. This section describes participants responses to psychological questionnaires on depression, anxiety, illness representations and masculinity. These data are summarised in Table 5.

For depression, the median score for the overall sample was 3 (*IQR* = 1-7). As scores range from 0-24 and the cut score for mild depression is 5 or more for this measure, these findings indicate that overall levels of depression are minimal in this group.

For anxiety, the median score for the overall sample was 3 (*IQR* = 0-7). As scores range from 0-21 and the cut score for mild anxiety is 5 or more for this measure, indicating that overall levels of anxiety are minimal in this sample.

For illness representations, the descriptive summary data in Table 5 show a wide variation in IPQ subscale scores. As higher scores on the subscales represent more strongly held beliefs, these findings suggest that overall, the sample hold strong beliefs about their prostate cancer being chronic, having negative consequences, being controllable (both personally and slightly less so by their treatment), and having an emotional impact on them. The results suggest that they hold slightly weaker beliefs that they have a good understanding about their prostate cancer, and about their prostate cancer being cyclical in nature. The findings also suggest that they hold comparatively weaker beliefs about the symptoms they are experiencing being attributed to the prostate cancer, and the prostate cancer being caused by personal, external or health factors.

For body image, the median score for the overall sample was 9 (*IQR* = 3-14). As scores range from 0-27, with higher scores reflecting poorer body image, these results suggest that participants in this sample report moderately low levels of body image dissatisfaction.

In terms of masculinity, the median masculinity score was 52 (*IQR* = 35.25-70). As scores range from 0-110, with higher scores reflecting higher prominence and importance of these masculine attributes, these results suggest that participants in this sample report moderate levels of masculinity. Masculinity subscale scores range from 0-5, and higher scores indicate higher prominence and importance of these masculine attributes. The masculinity subscale scores (Table 5) suggest that overall, the sample view all components (strength/fitness, sexual priority / importance, family responsibilities emotional self-reliance and optimistic action) as reasonably prominent and important concepts of their masculinity.

In terms of masculine self-esteem, the median standardised score for the overall sample was 40.63 (*IQR* = 18.75-56.25). As scores range from 0-100, with higher scores indicating poorer masculine self-esteem, these results suggest that participants in this sample report moderate levels of difficulty with masculine self-esteem.

## 3.3 Quality of life of the sample

The global QoL score ranged from 0 (poor) to 100 (excellent). Participants in this survey reported a median global QoL score of 75 (*IQR* = 58.33-83.33), indicating overall good QoL. For the functional and symptom subscales, the median scores were 82.22 (*IQR* = 66.67-93.33) and 12.82 (*IQR* = 5.13-25.64) respectively. As scores for each subscale range from 0-100, with higher scores on the functional, and symptom subscales indicating healthier level of functioning and higher levels of symptomatology / problems respectively, these scores suggest that the sample experience healthy levels of functioning and low levels of symptomology overall.

As described in section 2.8.3, for analysis, the QoL variable was transformed into categories based on the EORTC QLQ-C30-V3. Scores ranging from 0-66.67 were categorised as ‘low-moderate QoL’ and scores ranging from 66.68-100 were categorised as high QoL. The low-moderate QoL category contained 58 (37.18%) participants, and the high QoL category contained 98 (62.82%) participants. As shown in Table 5, the median QoL score for the low-moderate QoL group was 50 (*IQR* = 41.67-66.67) compared with 83.33 (*IQR* = 75-91.67) in the high QoL group.

### 3.3.1 Variation in outcomes across the two QoL categories.

Pearson’s Chi$^2$ tests, Mann-Whitney U tests, and independent samples t-tests were used to explore the difference in demographic, clinical and psychological variables between the two QoL categories (Table 5). No significant differences in age, ethnicity, relationship status, employment status, years since diagnosis, cancer stage, number of treatments, or exposure to treatments (except for hormone therapy and surgery) were found between the two QoL categories.

Pearson’s Chi$^2$ test was not conducted for sex, due to the low variance in responses. Similarly, although Chi$^2$ tests were conducted for the exposure to single treatment variables (including none), due to low numbers across the QoL categories these variables violated the Chi$^2$ assumptions regarding meeting the minimum expected cell frequency. Therefore, this was not pursued, and these variables were not taken forward into further analysis. See Appendix F for further detail on how these variables were broken down across the QoL categories.

There were significant differences in education status found across the QoL categories, $X^2$ (2, $n$ = 156) = 10.90, $p$ = 0.00, *Cramer's V* = 0.26, with a small-medium effect size. For participants whose highest education level was GCSE, 60% had high QoL. For participants whose highest education level was A-level, 43.59% had high QoL. For participants whose highest education level was a university degree or higher, 75% had high QoL.

Significant differences were also found for both hormone therapy and surgery across the QoL categories for. For hormone therapy, $X^2$ (1, $n$ = 156) = 4.03, $p$ = 0.05, *phi* = -0.16, with a small effect size. For participants who had been exposed to hormone therapy, 55.81% had high QoL, compared with 71.43% of those who had not been exposed to hormone therapy. For surgery exposure, $X^2$ (1, $n$ = 156) = 4.41, $p$ = 0.04, *phi* = 0.17, with a small effect size. For participants who had been exposed to surgery, 72.06% had high QoL, compared with 55.68% of those who had not been exposed to surgery. However, it is recommended that when using a 2x2 table, the Yates' Correction for Continuity test statistic is used rather than Chi$^2$, as this compensates for the overestimation of the Chi$^2$ test in this design (Pallant, 2020). For both hormone therapy and surgery exposure, the Yates' Correction for Continuity test returned a non-significant result ($p >$ 0.05). Considering this, and that when running multiple comparisons 1 in 20 will be significant by chance, this result should be interpreted with appropriate caution.

Significant differences were found across the QoL categories for the EORTC QLQ-C30-V3 subscales. Significantly higher functional subscale scores were found in the high QoL group (88.89 (82.22-95.56)) than the low-moderate QoL group (62.22 (51.11-71.67)), $U$ = 5219.5, $z$ = 8.74, $p$ = 0.00, $r$ = 0.70, with a large effect size. For the symptom subscale, the high QoL group recorded a significantly lower median score (7.69 (2.56-15.38)) than the low-moderate QoL group (28.21 (17.95-38.46)), $U$ = 737, $z$ = -7.74, $p$ = 0.00, $r$ = 0.62, with a large effect size. These findings suggest that participants with better QoL experience fewer symptoms and healthier levels of functioning.

For depression, there were significant differences found across the QoL categories, $U$ = 700, $z$ = -7.91, $p$ = 0.00, $r$ = 0.63, with a large effect size. Participants in the high QoL group recorded a significantly lower depression score compared with the low-moderate QoL group (8 (4-12), 2, (0-3) respectively). These findings suggest that participants with better QoL experience lower levels of depression.

For anxiety, there were significant differences found across the QoL categories, $U$ = 894.5, $z$ = -7.24, $p$ = 0.00, $r$ = 0.58, with a large effect size. The high QoL group recorded a significantly lower median score (1 (0-3)) than the low-moderate QoL group (7 (4-11.75)). These findings suggest that participants with better QoL experience lower levels of anxiety.

For illness representations, there were no significant differences found across the QoL categories for the following subscales: timeline (acute/chronic), illness coherence and the external and health causal subscales. Significant differences were found for the remaining subscales:

- For the identity subscale, the high QoL group recorded a significantly lower median score (1 (0-4)) than the low-moderate QoL group (5 (2-6)), $U = 1466$, $z = -5.13$, $p = 0.00$, $r = 0.41$, with a medium effect size.
- For the consequence subscale, the high QoL group recorded a significantly lower median score (17 (14-20)) than the low-moderate QoL group (19.5 (16-21)), $U = 1858$, $z = -3.63$, $p = 0.00$, $r = 0.29$, with a small-medium effect size.
- For the personal control subscale, the high QoL group recorded a significantly higher median score (17 (15-19)) than the low-moderate QoL group (15.5 (12-18)), $U = 3551$, $z = 2.61$, $p = 0.01$, $r = 0.21$, with a small effect size.
- For the treatment control subscale, the high QoL group recorded a significantly higher median score (14 (12.75-16)) than the low-moderate QoL group (13 (12-15)), $U = 3388.5$, $z = 2.02$, $p = 0.04$, $r = 0.16$, with a small effect size.
- For the timeline (cyclical) subscale, the high QoL group recorded a significantly lower median score (8 (4-11)) than the low-moderate QoL group (10.5 (8-12)), $U = 1839$, $z = -3.74$, $p = 0.00$, $r = 0.30$, with a medium effect size.
- For the emotional representations subscale, the high QoL group recorded a significantly lower median score (15.5 (12-19)) than the low-moderate QoL group (19.5 (14-22)), $U = 1715.5$, $z = -4.14$, $p = 0.00$, $r = 0.33$, with a medium effect size.
- For the personal factors causes subscale, the high QoL group recorded a significantly lower median score (2 (1.25-2.46)) than the low-moderate QoL group (2.43 (1.68-3)), $U = 2283$, $z = -2.06$, $p = 0.04$, $r = 0.16$, with a small effect size.

These findings suggest that participants with better QoL had: lower scores for having a strong illness identity (attributing symptoms to be a consequence of their prostate cancer); lower scores for viewing prostate cancer as having a great effect on themselves and their family; lower scores for perceiving the condition as cyclical; lower scores for being greatly emotionally impacted by the prostate cancer; lower scores for attributing the cause of the prostate cancer to personal factors; higher scores for perceiving they have a high level of control over their prostate cancer; and higher scores for believing that prostate cancer treatments have been effective.

Mann-Whitney U tests revealed that for body image, there were significant differences found across the QoL categories, $U = 1503$, $z = -4.92$, $p = 0.00$, $r = 0.39$, with a medium effect size. The high QoL group recorded a significantly lower median score (6 (2.75-11)) than the low-moderate QoL group (13 (7-19)). These findings suggest that participants with better QoL experience better body image.

For masculinity, there were no significant differences found for the overall masculinity score, or for the sexual priority/importance, family responsibilities and emotional self-reliance subscales, across the QoL categories. Significant differences were found across the QoL categories for the remaining subscales. For the strength/fitness subscale, the high QoL group recorded a significantly higher median score (4.33 (3.33-4.67)) than the low-moderate QoL group (3.67 (3.25-4.09)), $U = 3485$, $z = 2.38$, $p = 0.02$, $r = 0.19$, with a small effect size. For the optimistic action subscale, the high QoL group recorded a significantly higher median score (3.83 (3.33-4.33)) than the low-moderate QoL group (3.56 (2.97-4)), $U = 3470$, $z = 2.31$, $p = 0.02$, $r = 0.18$, with a small effect size. These findings suggest that overall participants' masculinity does not significantly vary regardless of their QoL. However, participants with better QoL had higher scores for physical strength, fitness, and competitiveness, indicating this was an important part of their self-concept. These participants also had higher scores for holding a positive mind set and preferring an action-focused approach to difficulties.

For masculine self-esteem, there were significant differences found across the QoL categories, $U = 1301.5$, $z = -5.66$, $p = 0.00$, $r = 0.45$, with a medium-large effect size. The high QoL group recorded a significantly lower median score (29.69 (8.59-46.88)) than the low-moderate QoL group (56.25 (40.63-68.75)). These findings suggest that participants with better QoL had lower scores for experiencing problems with masculine self-esteem.

Table 5. *Participant characteristics and psychological needs, overall and across QoL categories.*

| | | | **Quality of Life Categories** | | |
|---|---|---|---|---|---|
| | | | **Low-moderate QoL** | **High QoL** | |
| **Variable** | **Level** | **All (n=156)** | **N=58 (37.18)** | **N=98 (62.82)** | **P value** |
| **Demographic variables** | | | | | |
| Age | Mean (SD) | 70.12 (7.52) | 70.03 (7.05) | 70.17 (7.82) | 0.91$^{c}$ |
| Sex | Male | 155 (99.4) | 58 (37.42) | 97 (62.58) | - |
| | Female | 1 (0.6) | 0 (0) | 1 (100) | |
| Ethnicity | White | 152 (97.4) | 57 (37.5) | 95 (62.5) | 1.00$^{a}$ |
| | Non-White* | 4 (2.6) | 1 (25) | 3 (75) | |
| Relationship status | In a relationship | 131 (84) | 49 (37.4) | 82 (62.6) | 0.89$^{a}$ |
| | Not in a relationship | 25 (16) | 9 (36) | 16 (64) | |
| Employment status | Retired | 120 (76.9) | 43 (35.83) | 77 (64.17) | 0.76$^{a}$ |
| | Employed | 32 (20.5) | 13 (40.63) | 19 (59.38) | |
| | Disabled / unable to work | 4 (2.6) | 2 (50) | 2 (50) | |
| Education status | University degree | 72 (46.2) | 18 (25) | 54 (75) | 0.00$^{a}$ |
| | A-level's | 39 (25) | 22 (56.41) | 17 (43.59) | |
| | GCSE's | 45 (28.8) | 18 (40) | 27 (60) | |
| **Clinical variables** | | | | | |

| | | | | | |
|---|---|---|---|---|---|
| Years Diagnosed | Median (IQR) | 5 (3-10) | 5 (2.88-9.25) | 5 (3-11) | 0.34[b] |
| Cancer stage | Unsure | 35 (22.4) | 16 (45.71) | 19 (54.29) | 0.66[a] |
| | Stage 1 | 21 (13.5) | 7 (33.33) | 14 (66.67) | |
| | Stage 2 | 40 (25.6) | 12 (30) | 28 (70) | |
| | Stage 3 | 39 (25) | 14 (35.9) | 25 (64.1) | |
| | Stage 4 | 21 (13.5) | 9 (42.86) | 12 (57.14) | |
| **Treatment factors** | | | | | |
| Number of treatments | 0-1 | 38 (24.4) | 13 (34.21) | 25 (65.79) | 0.17[a] |
| | 2 | 54 (34.6) | 16 (29.63) | 38 (70.37) | |
| | 3 | 49 (31.4) | 20 (40.82) | 29 (59.18) | |
| | 4-5 | 15 (9.6) | 9 (60) | 6 (40) | |
| AS[†] exposure | No | 70 (44.9) | 23 (32.86) | 47 (67.14) | 0.40[a] |
| | Yes | 86 (55.1) | 35 (40.7) | 51 (59.3) | |
| Radiotherapy exposure | No | 68 (43.6) | 23 (33.82) | 45 (66.18) | 0.55[a] |
| | Yes | 88 (56.4) | 35 (39.77) | 53 (60.23) | |
| Hormone therapy exposure | No | 70 (44.9%) | 20 (28.57) | 50 (71.43) | 0.05[a] |
| | Yes | 86 (55.1%) | 38 (44.19) | 48 (55.81) | |
| Surgery exposure | No | 88 (56.4) | 39 (44.32) | 49 (55.68) | 0.04[a] |
| | Yes | 68 (43.6) | 19 (27.94) | 49 (72.06) | |
| Chemotherapy exposure | No | 144 (92.3%) | 51 (35.42) | 93 (64.58) | 0.13[a] |
| | Yes | 12 (7.7) | 7 (58.33) | 5 (41.67) | |
| Other treatment exposure | No | 143 (91.7%) | 51 (35.66) | 92 (64.34) | 0.24[a] |

| | | | | | |
|---|---|---|---|---|---|
| | Yes | 13 (8.3) | 7 (53.85) | 6 (46.15) | |
| **Psychological variables** | | | | | |
| **EORTC QLQ-C30 – V3** | | | | | |
| QoL continuous | Median (IQR) | 75 (58.33-83.33) | 50 (41.67-66.67) | 83.33 (75-91.67) | - |
| Functional subscale | Median (IQR) | 82.22 (66.67-93.33) | 62.22 (51.11-71.67) | 88.89 (82.22-95.56) | 0.00[b] |
| Symptom subscale | Median (IQR) | 12.82 (5.13-25.64) | 28.21 (17.95-38.46) | 7.69 (2.56-15.38) | 0.00[b] |
| **PHQ-8** | | | | | |
| Depression (continuous) | Median (IQR) | 3 (1-7) | 8 (4-12) | 2 (0-3) | 0.00[b] |
| **GAD-7** | | | | | |
| Anxiety (continuous) | Median (IQR) | 3 (0-7) | 7 (4-11.75) | 1 (0-3) | 0.00[b] |
| **IPQ-R** | | | | | |
| Identity | Median (IQR) | 2 (0-5) | 5 (2-6) | 1 (0-4) | 0.00[b] |
| Timeline (acute/chronic) | Median (IQR) | 18 (15-18) | 18 (16-18) | 17.5 (14-18) | 0.38[b] |
| Consequence | Median (IQR) | 18 (15-20) | 19.5 (16-21) | 17 (14-20) | 0.00[b] |
| Personal control | Median (IQR) | 17 (13-18) | 15.5 (12-18) | 17 (15-19) | 0.01[b] |
| Treatment control | Median (IQR) | 14 (12-15) | 13 (12-15) | 14 (12.75-16) | 0.04[b] |
| Illness coherence | Median (IQR) | 12 (9-13) | 12 (9.75-13) | 12 (9-13) | 0.93[b] |
| Timeline (cyclical) | Median (IQR) | 8 (4-12) | 10.5 (8-12) | 8 (4-11) | 0.00[b] |
| Emotional representation | Median (IQR) | 17 (13-20) | 19.5 (14-22) | 15.5 (12-19) | 0.00[b] |
| Causes: personal | Median (IQR) | 2 (1.29-2.86) | 2.43 (1.68-3) | 2 (1.25-2.46) | 0.04[b] |
| Causes: external | Median (IQR) | 2 (1.5-2.75) | 2.25 (1.94-2.75) | 2 (1.19-2.75) | 0.11[b] |

| | | | | | |
|---|---|---|---|---|---|
| Causes: health | Median (IQR) | 2.58 (2.17-3) | 2.67 (2.33-2.88) | 2.5 (2-3) | 0.28[b] |
| **BIS** | | | | | |
| Body image | Median (IQR) | 9 (3-14) | 13 (7-19) | 6 (2.75-11) | 0.00[b] |
| **MCD-I** | | | | | |
| Masculinity (overall) | Median (IQR) | 52 (35.25-70) | 48.5 (34.25-66.5) | 56.5 (35.75-73) | 0.41[b] |
| Strength/fitness | Median (IQR) | 4 (3.33-4.33) | 3.67 (3.25-4.09) | 4.33 (3.33-4.67) | 0.02[b] |
| Sexual priority/importance | Median (IQR) | 4 (3-4.75) | 4 (3-4.75) | 4 (2.75-4.75) | 0.37[b] |
| Family Responsibilities | Median (IQR) | 4.25 (3.75-4.75) | 4.25 (3.75-5) | 4.25 (3.5-4.75) | 0.50[b] |
| Emotional self-reliance | Median (IQR) | 3 (2.5-4) | 3 (2.5-4) | 3 (2-4) | 0.38[b] |
| Optimistic action | Median (IQR) | 3.67 (3.25-4.22) | 3.56 (2.97-4) | 3.83 (3.33-4.33) | 0.02[b] |
| **MSE** | | | | | |
| Masculine Self-esteem | Median (IQR) | 40.63 (18.75-56.25) | 56.25 (40.63-68.75) | 29.69 (8.59-46.88) | 0.00[b] |

[a] *p* values derived from Pearson's Chi$^2$ tests.

[b] *p* values derived from Mann-Whitney U tests.

[c] *p* values derived from independent samples t-tests.

* Includes: White mixed (n=1), Black or Black British (n=2), Turkish Cypriot (n=1).

† Active surveillance

## 3.4 Quantifying the relationship between QoL and the psychological needs of people with prostate cancer

Logistic regression models were used to explore the relationship between demographic, clinical and psychological variables, and the two QoL categories. Specifically, these models were used to assess the impact of independent and confounder variables on the odds that participants would be in the low-moderate QoL category.

Some variables were not carried forward into the regression model. Gender was excluded due to the low variation in responses, and there being 0 participants in one of the categories. Similarly, ethnicity had to be excluded due to the low variation in responses. Having categorical predictors with a small number of cases in a category can impact on the regression analysis e.g., by causing the problem of the solution failing to converge. An attempt was made to run the logistic regression with ethnicity included, however this resulted in the model not running properly (Appendix E.4). The EORTC QLQ-C30 – V3 functional and symptom subscales were also excluded from the analysis. These variables have a clear relationship with the outcome and are priming people to report the outcome. This is supported by preliminary checks assessing for multicollinearity, which showed that although the subscales were not beyond commonly used the cut off scores (Pallant, 2020) for multicollinearity (tolerance < 0.10 and VIF >10), they were approaching these (particularly the functional subscale tolerance = 0.11, VIF = 9.12) and were also highly correlated with the QoL outcome variable. The inclusion of these subscales could have resulted in an over adjustment of the main effect, due to the high association, meaning that the relationships between other variables and the QoL outcome may be obscured.

Two ordinal logistic regression models explored the extent to which demographic, clinical and psychological variables, were associated with QoL category:

Model 1 – univariate (unadjusted) main effects model (Figure 1)

Model 2 – multivariate model, all factors included, a fully adjusted model (Figure 2)

These models are referred to as model 1 and model 2 respectively in the text, and are reported in Table 6. Theoretical models of association, tested using the logistic regression modelling, are depicted in Figures 1 and 2.

Figure 1. *Theoretical model of association for model 1 - simple univariate model*

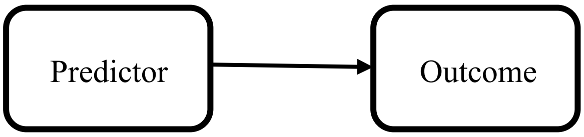
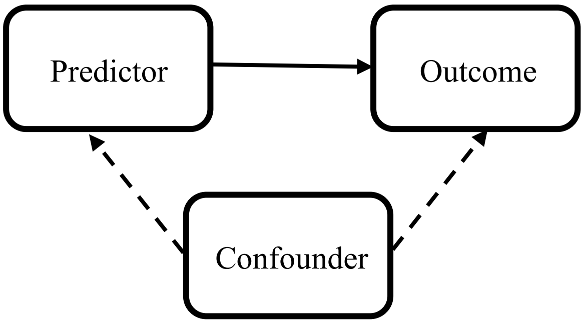


Figure 2. *Theoretical model of association for model 2 - simple univariate model with confounders*



The results of both the main effects and fully adjusted regression models are next explored in more detail.

Model 1 indicated that compared to participants who were educated to university degree level or higher, for people who had achieved up to an A-level the odds of being in the low-moderate QoL category were 3.88 times greater (*OR* 3.88, *CI* 1.70-8.88, *p* = 0.001). Table 5 shows that 22 (56.41%) participants with A-levels were in the low-moderate QoL group compared to 17 (43.59%) in the high QoL group. Comparatively, 18 (25%) participants with a university degree or higher were in the low-moderate QoL group compared to 54 (75%) in the high QoL group. For those who had achieved GCSEs compared to a university degree the odds of being in the low-moderate QoL category were 2 times greater, however this difference was not statistically significant to the odds for those in the university degree category (*OR* 2.00, *CI* 0.90-4.45, *p* = 0.09). The relationship for A-levels slightly attenuated and became non-significant in model 2 (*OR* 3.63, *CI* 0.79-16.65, *p* = 0.10)

Model 1 showed that for a unit increase in depression score, the odds of being in the low-moderate QoL category increased by 59% (*OR* 1.59, *CI* 1.37-1.84, *p*<0.001). Model 1 also indicated that for a unit increase in anxiety score, the odds of being in the low-moderate QoL category increased by 43% (*OR* 1.43, *CI* 1.27-1.61, *p*<0.001). However, for anxiety this relationship attenuated and become non-significant in model 2 (*OR* 1.18, *CI* 0.92-1.51, *p* = 0.20).

Model 1 indicated that for each additional symptom participants identified in association with their prostate cancer on the IPQ-R identity subscale, the odds of being in the low-moderate QoL category increased by 36% (*OR* 1.36, *CI* 1.19-1.55, *p*<0.001). Table 5 shows that the median IPQ-R identity subscale score in the low-moderate QoL category was 5 (*IQR* 2-6) compared with 1 (*IQR* 0-4) in the high QoL category. However, this relationship attenuated and become non-significant in model 2 (*OR* 1.11, *CI* 0.83-1.49, *p* = 0.49).

Model 1 also showed that for each unit increase in score on the IPQ-R consequences subscale, the odds of being in the low-moderate QoL category increased by 22% (*OR* 1.22 *CI* 1.09-1.35, $p<0.001$). Table 5 shows that the median IPQ-R consequence subscale score in the low-moderate QoL category was 19.5 (*IQR* 16-21) compared with 17 (*IQR* 14-20) in the high QoL category. However, this relationship slightly attenuated and become non-significant in model 2 (*OR* 1.13, *CI* 0.89-1.44, $p = 0.30$).

Model 1 indicated that for each unit increase in score on the IPQ-R personal control subscale, the odds of being in the low-moderate QoL category decreased by 12% (*OR* 0.88 *CI* 0.80-0.96, $p = 0.003$). Table 5 shows that the median IPQ-R personal control subscale score in the low-moderate QoL category was 15.5 (*IQR* 12-18) compared with 17 (*IQR* 15-19) in the high QoL category.

Model 1 also showed that for each unit increase in score on the IPQ-R timeline (cyclical) subscale, the odds of being in the low-moderate QoL category increased by 20% (*OR* 1.20 *CI* 1.09-1.33, $p<0.001$). Table 5 shows that the median IPQ-R timeline (cyclical) subscale score in the low-moderate QoL category was 10.5 (*IQR* 8-12) compared with 8 (*IQR* 4-11) in the high QoL category. However, this relationship attenuated and become non-significant in model 2 (*OR* 1.07, *CI* 0.87-1.31, $p = 0.52$).

Model 1 indicated that for each unit increase in score on the IPQ-R emotional representations subscale, the odds of being in the low-moderate QoL category increased by 17% (*OR* 1.17 *CI* 1.08-1.26, $p<0.001$). Table 5 shows that the median IPQ-R emotional representations subscale score in the low-moderate QoL category was 19.5 (*IQR* 14-22) compared with 15.5 (*IQR* 12-19) in the high QoL category. However, this relationship attenuated and become non-significant in model 2 (*OR* 0.91, *CI* 0.74-1.12, $p = 0.39$).

Model 1 also showed that for each unit increase in score on the IPQ-R personal causes subscale, the odds of being in the low-moderate QoL category increased by 47% (*OR* 1.47 *CI* 1.01-2.13, $p<0.05$). Table 5 shows that the median IPQ-R personal causes subscale score in the low-moderate QoL category was 2.43 (*IQR* 1.68-3) compared with 2 (*IQR* 1.25-2.46) in the high QoL category. However, this relationship slightly attenuated and become non-significant in model 2 (*OR* 1.43, *CI* 0.51-2.31, $p = 0.50$).

Model 1 indicated that for each unit increase in score on the BIS, the odds of being in the low-moderate QoL category increased by 14% (*OR* 1.14 *CI* 1.08-1.20, $p<0.001$). Table 5 shows that the median score on the BIS in the low-moderate QoL category was 13 (*IQR* 7-19) compared with 6 (*IQR* 2.75-11) in the high QoL category. However, this relationship attenuated and become non-significant in model 2 (*OR* 0.91, *CI* 0.77-1.09, $p = 0.31$).

Model 1 also showed that for each unit increase in score on the MCD-I strength/fitness subscale, the odds of being in the low-moderate QoL category decreased by 35% (*OR* 0.65 *CI* 0.43-0.99, $p = 0.04$). Table 5 shows that the median MCD-I strength/fitness subscale score in the low-moderate QoL category was 3.67 (*IQR* 3.25-4.09) compared with 4.33 (*IQR* 3.33-4.67) in the high QoL category.

Model 1 indicated that for each unit increase in score on the MCD-I optimistic action subscale, the odds of being in the low-moderate QoL category decreased by 44% (*OR* 0.56 *CI* 0.35-0.92, $p = 0.02$). Table 5 shows that the median MCD-I optimistic action subscale score in the low-moderate QoL category was 3.56 (*IQR* 72.97-4) compared with 3.83 (*IQR* 3.33-4.33) in the high QoL category. However, this relationship attenuated and become non-significant in model 2 (*OR* 1.21, *CI* 0.40-1.06, $p = 0.73$).

Model 1 also showed that for each unit increase in masculine self-esteem score, the odds of being in the low-moderate QoL category increased by 4% (*OR* 1.04 *CI* 1.03-1.06, $p<0.001$). Table 5 shows that the median masculine self-esteem score in the low-moderate QoL category was 56.25 (*IQR* 40.63-68.75) compared with 29.69 (*IQR* 8.59-46.88) in the high QoL category. However, this relationship slightly attenuated and become non-significant in model 2 (*OR* 1.02, *CI* 0.97-1.06, $p = 0.49$).

Model 2 was statistically significant $X^2$ (35, $n$ = 156) = 108.12, $p < 0.001$, suggesting that the model was able to distinguish between participants in the low-moderate and high QoL categories. Overall, the model explained 68.2% of the variance in QoL. Table 6 shows that only three of the independent variables made a unique statistically significant contribution to the model, when controlling for all other variables. These will be discussed next.

Model 2 showed that depression score remained a significant independent factor associated with being in the low-moderate QoL group compared to the high QoL group, with the relationship becoming slightly stronger, in model 2 (*OR* 1.62, *CI* 1.14-2.31, $p = 0.007$). This suggests that higher depression score was significantly and independently associated with lower QoL.

Model 2 also showed that IPQ-R personal control subscale score remained a significant independent factor associated with being in the low-moderate QoL group compared to the high QoL group, with the relationship becoming slightly stronger, in model 2 (*OR* 0.82, *CI* 0.68-0.99, $p = 0.04$). This suggests that lower personal control subscale score was significantly and independently associated with lower QoL.

Finally, model 2 showed that MCD-I strength/fitness subscale score remained a significant independent factor associated with being in the low-moderate QoL group compared to the high QoL group, with the relationship becoming significantly stronger, in model 2 (*OR* 0.27, *CI* 0.08-

0.89, $p = 0.03$). This suggests that lower strength/fitness subscale score was significantly and independently associated with lower QoL.

There were no significant relationships found between the following variables and the QoL categories, in either model 1 or model 2: age, relationship status, employment status, years diagnosed, cancer stage, number of treatments, IPQ-R timeline (acute/chronic) subscale, IPQ-R treatment control subscale, IPQ-R illness coherence subscale, IPQ-R external causes subscale, IPQ-R health causes subscale, masculinity overall score, masculinity sexual priority/importance subscale, masculinity family responsibilities subscale, and masculinity emotional self-reliance subscale.

Table 6. *Logistic regression models to predict QoL (high QoL (referent): n=98; low-moderate QoL: n=58).*

| **Variable** | **Level** | **Model 1**<br>OR (95% CI) | **Model 2***<br>OR (95% CI) |
|---|---|---|---|
| **Demographic variables** | | | |
| Age (continuous) | Participant age | 1.00 (0.96-1.04) | 1.10 (0.98-1.24) |
| Relationship status | In a relationship (referent) | - | - |
| | Not in a relationship | 0.94 (0.39-2.29) | 1.18 (0.19-7.15) |
| Employment status | Retired (referent) | - | - |
| | Employed | 1.23 (0.55-2.72) | 0.62 (0.09-4.21) |
| | Disabled / unable to work | 1.79 (0.24-13.17) | 1.31 (0.03-50.77) |
| Education status | University degree (referent) | - | - |
| | A-level’s | 3.88 (1.70-8.88)* | 3.63 (0.79-16.65) |
| | GCSE’s | 2.00 (0.90-4.45) | 1.48 (0.30-7.40) |
| **Clinical variables** | | | |
| Years Diagnosed | Years since diagnosis | 0.97 (0.91-1.03) | 0.97 (0.85-1.10) |
| Cancer stage | Unsure (referent) | - | - |
| | Stage 1 | 0.59 (0.19-1.83) | 1.00 (0.12-8.11) |
| | Stage 2 | 0.51 (0.20-1.31) | 1.09 (0.18-6.54) |
| | Stage 3 | 0.67 (0.26-1.69) | 0.11 (0.01-1.05) |
| | Stage 4 | 0.89 (0.30-2.65) | 0.94 (0.11-8.48) |

| | | | |
|---|---|---|---|
| Number of treatments | 0-1 (referent) | - | - |
| | 2 | 0.81 (0.33-1.97) | 1.59 (0.27-9.30) |
| | 3 | 1.33 (0.55-3.20) | 1.21 (0.22-6.77) |
| | 4-5 | 2.89 (0.84-9.88) | 19.55 (0.90-424.20) |
| **Psychological variables** | | | |
| **EORTC QLQ-C30 – V3** | | | |
| **PHQ-8** | | | |
| Depression (continuous) | Depression score | 1.59 (1.37-1.84)* | 1.62 (1.14-2.31)† |
| **GAD-7** | | | |
| Anxiety (continuous) | Anxiety score | 1.43 (1.27-1.61)* | 1.18 (0.92-1.51) |
| **IPQ-R** | | | |
| Identity | Identity score | 1.36 (1.19-1.55)* | 1.11 (0.83-1.49) |
| Timeline (acute/chronic) | Timeline acute/chronic score | 1.05 (0.96-1.15) | 0.97 (0.80-1.18) |
| Consequence | Consequence score | 1.22 (1.09-1.35)* | 1.13 (0.89-1.44) |
| Personal control | Personal control score | 0.88 (0.80-0.96)† | 0.82 (0.68-0.99)† |
| Treatment control | Treatment control score | 0.88 (0.77-1.01) | 1.28 (0.94-1.74) |
| Illness coherence | Illness coherence score | 0.95 (0.82-1.10) | 0.79 (0.56-1.10) |
| Timeline (cyclical) | Timeline cyclical score | 1.20 (1.09-1.33)* | 1.07 (0.87-1.31) |
| Emotional representation | Emotional representation score | 1.17 (1.08-1.26)* | 0.91 (0.74-1.12) |
| Causes: personal | Personal causes score | 1.47 (1.01-2.13)† | 1.43 (0.51-3.99) |
| Causes: external | External causes score | 1.46 (0.96-2.21) | 1.08 (0.42-2.77) |

| | | | |
|---|---|---|---|
| Causes: health | Health causes score | 1.37 (0.82-2.27) | 0.74 (0.24-2.31) |
| **BIS** | | | |
| Body image | Body image score | 1.14 (1.08-1.20)* | 0.91 (0.77-1.09) |
| **MCD-I** | | | |
| Masculinity (overall) | Overall masculinity score | 1.00 (0.98-1.01) | 1.01 (0.98-1.05) |
| Strength/fitness | Strength/fitness score | 0.65 (0.43-0.99)† | 0.27 (0.08-0.89)† |
| Sexual priority/importance | Sexual priority/importance score | 1.14 (0.86-1.49) | 1.46 (0.69-3.08) |
| Family Responsibilities | Family responsibilities score | 1.15 (0.81-1.65) | 1.26 (0.50-3.20) |
| Emotional self-reliance | Emotional self-reliance score | 1.15 (0.87-1.52) | 1.20 (0.66-2.20) |
| Optimistic action | Optimistic action score | 0.56 (0.35-0.92)† | 1.21 (0.40-3.70) |
| **MSE** | | | |
| Masculine Self-esteem | Masculine self-esteem score | 1.04 (1.03-1.06)* | 1.02 (0.97-1.06) |

*p<0.001, †p<0.05

## 3.5 Summary of key significant and interesting findings

The key significant and interesting findings of the analysis are presented in Table 7.

Table 7. *Key findings from the analysis.*

| **Variable** | **Relationship with poorer QoL** |
|---|---|
| Higher depression<br>Lower perceptions of personal control<br>Lower prominence and importance of strength and fitness | Significant and independent association |
| Education status<br>Higher anxiety<br>Higher body image dissatisfaction<br>Lower masculine self-esteem | Univariate significant association only |
| Age | No significant association |

# Chapter 4: Discussion

This chapter will first give an overview of the main findings of the study, as outlined in the results chapter. It will then discuss these findings in relation to relevant literature and the original aims of the study. This chapter will next highlight some study strengths and limitations, and discuss implications for clinical practice and potential future research. Finally, the overall conclusions will be presented.

## 4.1 Summary of the main findings

This study aimed to describe the long-term psychological needs of men with prostate cancer, and explore the relationship between these needs and QoL in this group. In this study, long-term was defined as over a year post-diagnosis, and psychological needs were defined as depression, anxiety, illness representations, body image, masculinity (and masculine self-esteem), and QoL. The findings suggest that increasing levels of depression were significantly and independently associated with poorer QoL in this sample. Additionally, the results suggest that perceptions of lower personal control over prostate cancer, as well as lower prominence and importance of strength and fitness (as a component of masculinity) were significantly and independently associated with poorer QoL. Interestingly, age was not associated with QoL in this sample of people with prostate cancer. Though in univariate modelling education level, anxiety, body image and masculine self-esteem were significantly related to QoL category (Table 6, model 1), these significant relationships did not persist in the fully adjusted model (Table 6, model 2), indicating that they were not independently associated with QoL in this sample. These findings will be considered within the context of existing literature discussed in Chapter 1.

### 4.1.1 Quality of life

This study found that the median QoL in this group was 75 (*IQR* 58.33-83.33). Participants were classified into two categories: low-moderate QoL (37.18%), where the median QoL was 50 (*IQR* 41.67-66.67), and high QoL (62.82%), where the median QoL was 83.33 (*IQR* 75-91.67). This is comparable to the reported global QoL score for this population in a previous study (*M* = 73.0, *SD* = 19.2) by Hinz et al. (2017). Additionally, normative data for the global QoL subscale (Scott et al., 2008) indicates that participants in this sample reported similar QoL to that of the general population (*Mdn* = 75, *IQR* = 58.3-83.3), and higher QoL than the referent cancer and prostate cancer populations (*Mdns* = 66.7, *IQRs* = 50-83.3). However, the wide confidence intervals suggest a high level of variance in QoL reported in this sample.

This study also found that the median functional scale score on the EORTC QLQ-C30-V3 in this group was 82.22 (*IQR* 66.67-93.33). The median symptom scale score on the EORTC QLQ-C30-V3 in this group was 12.82 (*IQR* 5.12-25.64). This is again comparable to the reported functional and symptom scale scores for this population in a previous study (*M* = 81.2, *SD* = 16.5 and *M* = 14.2, *SD* = 13.7 respectively), which found men's functioning to be slightly poorer compared to that of the general population (Hinz et al., 2017).

The current study therefore supports previous findings that, overall, people with prostate cancer report good global QoL (Ashley et al., 2015; Hinz et al., 2017). However, considering the significant proportion of those in the low-moderate QoL group, it is important to consider factors which may be associated with poorer QoL in this population. Understanding factors which contribute to the long-term psychological wellbeing of people with prostate cancer could aid the development and effectiveness of appropriate, person-centred interventions, improving outcomes of survivorship and QoL.

### 4.1.2 Demographic factors associated with QoL category

Demographic factors including age, ethnicity, relationship status, and employment status were not found to be associated with QoL category in this study. For education status, there were significant differences found across the QoL categories (Table 5). Unadjusted logistic regression models indicated that compared to participants who were educated to university degree level or higher, for people who had achieved up to an A-level the odds of being in the low-moderate QoL category were 3.88 times greater (Table 6). However, when entered into a fully adjusted logistic regression model this relationship became attenuated and non-significant. This suggests that there was no significant independent relationship between education status and QoL category in this population. Therefore, other risk factors need to be considered alongside education status.

### 4.1.3 Clinical factors associated with QoL category

Clinical factors including years since diagnosis, cancer stage, number of treatments, and exposure to treatments were not found to be associated with QoL categories in this study. There were trends in the data suggesting that exposure to hormone therapy was associated with poorer QoL and exposure to surgery was associated with higher QoL, in this population (Table 5).

### 4.1.4 Psychological needs associated with QoL category

Overall, the findings of this study suggest that participants in this sample reported comparable psychological wellbeing to that of the general population in terms of depression, anxiety, and QoL. Levels of body image dissatisfaction were comparable to that of mixed cancer samples, prominence and importance of masculinity concepts were comparable to those in a sample of men with chronic disease, and masculine self-esteem was comparable to those with prostate cancer in a previous validation study. Although in general the psychological wellbeing of prostate cancer survivors may be comparable to that of the general population, it is important to understand the individual factors which may contribute to variance in emotional wellbeing and

QoL in this group. Understanding factors which contribute to the long-term psychological wellbeing of people with prostate cancer could aid the identification of vulnerable groups, and the development and efficacy of person-centred interventions, improving outcomes of survivorship and QoL.

Significant differences were found across the QoL categories for the EORTC QLQ-C30-V3 subscales (Table 5), suggesting that participants with lower QoL experience more symptoms and have reduced levels of functioning.

For depression, the median score for the overall sample was 3 (*IQR* = 1-7), indicating that overall levels of depression were minimal in this group. Normative data sets (Kocalevent et al., 2013) indicate that general population mean responses to the PHQ-8 (*M* = 2.91, *SD* = 3.52) were similar to the levels of depression reported by participants in this sample; moreover, men in a similar age group (*M* = 2.13, *SD* = 3.26). However, there were significant differences found in depression scores across the QoL categories (Table 5), suggesting that participants with higher levels of depression experienced poorer QoL. Unadjusted logistic regression models indicated that for every unit increase in depression score, the odds of being in the low-moderate QoL category increased by 59% (Table 6). Depression score remained significantly and independently associated with being in the low-moderate QoL group compared to the high QoL group, when entered into a fully adjust logistic regression model. This suggests that increasing levels of depression was highly associated with lower QoL in this population, independent of all other factors measured in this study.

The median score for anxiety for all participants was 3 (*IQR* = 0-7), indicating that overall levels of anxiety were minimal in this group. Normative data (Löwe et al., 2008) indicates that participants in this sample reported similar levels of anxiety to that of the general population (*M* = 2.97, *95% CI* = 2.86-3.07). However, there were significant differences found in anxiety scores across the QoL categories (Table 5), suggesting that participants with higher levels of anxiety experience poorer QoL. Unadjusted logistic regression models indicated that for every unit increase in anxiety score, the odds of being in the low-moderate QoL category increased by 43%. However, when entered into a fully adjusted logistic regression model this relationship became attenuated and non-significant. This suggests that there was no significant independent relationship between anxiety and QoL in this population. Therefore, other risk factors need to be considered alongside anxiety.

For illness representations, the data presented in Table 5 show that in this group of prostate cancer survivors, stronger beliefs were held about the prostate cancer being chronic, having negative consequences, being controllable (both personally and slightly less so by their treatment), and having an emotional impact. Additionally, slightly weaker beliefs were held around having a good understanding about the prostate cancer, and about the prostate cancer being cyclical in nature. The findings also suggest that comparatively weaker beliefs were held about symptoms they are experiencing being attributed to the prostate cancer, and the prostate cancer being caused by personal, external or health factors. None of the IPQ-R subscales were associated with QoL in the fully adjusted model except for personal control (Table 6), which showed that for each unit increase in personal control the odds of being in the low-moderate QoL category decreased by 12%. This suggests that lower perceptions of personal control over the prostate cancer was highly associated with lower QoL in this population, independent of all other factors measured in this study.

For body image, the median score for the overall sample was 9 (*IQR* = 3-14), suggesting that overall participants in this sample reported moderately low levels of body image dissatisfaction. The body image score in this group was similar to that reported in a validation study by Hopwood et al. (2001) of mixed cancer patients (*M* = 8.62, *SD* = 5.02). However, there were significant differences found in body image scores across the QoL categories (Table 5), suggesting that participants with poorer body image experienced poorer QoL; however, this relationship was not maintained in the regression modelling.

For masculinity, the median score for masculinity as a whole for the overall sample was 52 (*IQR* = 35.25-70), suggesting that overall participants in this sample report moderate levels of masculinity. In terms of the masculinity subscales the data in Table 5 suggest that this sample of prostate cancer survivors view all components (strength/fitness, sexual priority / importance, family responsibilities emotional self-reliance and optimistic action) as reasonably prominent and important concepts of their masculinity. The scores on the masculinity subscales in this group were similar to those reported for the strength / fitness subscale (*M* = 3.71, *SD* = 0.81) sexual priority / importance subscale (*M* = 3.37, *SD* = 1.24), family responsibilities subscale (*M* = 4.25, *SD* = 0.91), emotional self-reliance subscale (*M* = 3.47, *SD* = 1.00) and optimistic action subscale (*M* = 3.71, *SD* = 0.74), in a validation study of men with chronic disease (Occhipinti et al., 2019). However, only the strength/fitness subscale remained significantly and independently associated with being in the low-moderate QoL group, when entered into a fully adjusted logistic regression model (Table 6).

For masculine self-esteem, the median standardised score for the overall sample was 40.63 (*IQR* = 18.75-56.25), indicating that overall participants in this group reported moderate levels of difficulty with masculine self-esteem. The masculine self-esteem in this group was comparatively higher to that reported in a validation study by Clark et al. (2003) of prostate cancer survivors (*M* = 75.1, *SD* = 5.02). There were significant differences in masculine self-esteem found across the QoL categories (Table 5), however, when entered into a fully adjusted logistic regression model this relationship became attenuated and non-significant.

Participants in the low quality of life category experienced higher levels of depression, higher levels of anxiety, poorer body image, lower prominence and importance of strength and fitness (as a component of masculinity), high prominence and importance of optimistic action (as a component of masculinity), and poorer masculine self-esteem. In terms of illness perceptions, higher scores for having a strong illness identity (attributing symptoms to be a consequence of their prostate cancer); higher scores for viewing prostate cancer as having a great effect on themselves and their family; higher scores for perceiving the condition as cyclical; higher scores for being greatly emotionally impacted by the prostate cancer; higher scores for attributing the cause of the prostate cancer to personal factors; lower scores for perceiving they have a high level of control over their prostate cancer; and lower scores for believing that prostate cancer treatments have been effective were associated with poorer QoL. Furthermore, higher depression score, lower perceptions of personal control, and lower prominence and importance of strength and fitness (as a component of masculinity) were identified as significantly and independently associated with lower QoL in this population. These will be discussed next, in the context of previous research.

## 4.2 Exploring the results in the context of previous research

### 4.2.1 Depression

This study found that having higher levels of depression was independently and significantly associated with lower QoL in this group of prostate cancer survivors. Previous research has explored depression in this group and highlighted how experiences of depression can impact on treatment adherence and outcomes. However, existing research has largely focused on describing the prevalence of clinical diagnoses of depression and depression symptoms in prostate cancer survivors (Brunckhorst et al., 2021; Watts et al., 2014), as well as factors which may make men with prostate cancer vulnerable to developing depression (Esser et al., 2020; Fervaha et al., 2021; Fervaha et al., 2019; Luckenbaugh et al., 2022). One previous study found a similar association between depression and QoL in prostate cancer survivors. They found that increased depression, along with psychological pain and perception of being a burden, mediated the association between poorer quality of life and suicide risk (Tripp et al., 2020). Whilst this highlights that depression may be an important factor in relation to QoL, there has been limited research looking directly at the relationship between depression and global QoL in prostate cancer survivors. Therefore, it is an important finding of this study that depression was significantly and independently associated with global QoL in this group.

The finding that depression level was significantly and independently associated with QoL in this group of prostate cancer survivors may be better understood within the context of chronic illness literature. Comorbidity of depression is common in people living with long-term illness (such as diabetes, HIV, arthritis, asthma, cancer, and heart disease), and impacts upon illness outcomes, ability to self-care, coping, treatment adherence, help-seeking, suicidality and QoL; as well as disease burden in health services (Di Benedetto et al., 2014; Gurhan et al., 2019; Prince et al., 2007; The King's Fund, 2012). According to The King's Fund (2012) people with chronic illness are 2-3 times more likely to suffer from mental health difficulties than the general population, and this is exacerbated by having multiple comorbidities. Furthermore, depression is likely to impact on ability to make lifestyle changes which may improve illness outcomes (Di Benedetto et al., 2014). Prince et al. (2007) suggest a bidirectional association between mental health conditions such as depression and long-term physical health conditions, due to an amalgamation of biological, psychosocial, environmental and behavioural factors (The King's Fund, 2012).

Chronic illness may increase vulnerability to developing depression due to increasing stress (due to the impact of the illness on day to day life and uncertainty about the future), symptom burden, disrupting relationships and roles, the impact of the treatment process, causing loss of ability, increasing social isolation, reducing ability to engage in leisure and occupational activities and evoking changes to self-image and perceived self-efficacy (Gurhan et al., 2019). Depression has been associated with poorer QoL in several chronic illness populations including kidney disease, COPD, respiratory diseases, and cardiovascular diseases (Blakemore et al., 2014; Dipak et al., 2020; Gurhan et al., 2019). The current study models similar associations, and extends existing research on depression in chronic illness, and its association with QoL, in the context of prostate cancer survivors.

The finding that depression level was significantly and independently associated with QoL in this group of prostate cancer survivors may also contribute to literature around depression in men. Depression is often posited as a more female mental health problem, due in part to the higher reported incidence of depression in women, but also male tendency to minimise illness, self-manage and avoid help-seeking (Ogrodniczuk & Oliffe, 2011). Previous research highlights that men in the US are diagnosed with depression half as frequently as women, though they are 3-4 times more likely to end their life through suicide (Swetlitz, 2021).

Research on experiences of depression in mixed cancer samples has previously found comparatively lower depression scores for men in comparison to women (Götze et al., 2019; Hinz et al., 2019). Swetlitz (2021) suggest that gender socialisation and adherence to masculine ideals (such as self-reliance, emotional control, and stoicism) impacts on how men express emotion and similarly depression. Furthermore, subscription to masculine ideals can increase vulnerability to depression, whilst also reducing help-seeking (Swetlitz, 2021). Gender role conflict theory suggests that harm can be caused when adherence to rigid gender roles leads to restricting, devaluing, or violating the self or others e.g., through chronic emotional control and lack of emotional expression (Holt, 2021; O'Neil, 2008). Deviating from these roles can lead to mental health difficulties in men through threatening masculinity (Holt, 2021).

Gender role conflict has been associated with psychological distress, including depression and anxiety, and reduced help-seeking in men (O'Neil, 2008). Stereotypical symptoms of depression, such as sadness and crying, are conflicting with masculine ideals (Martin et al., 2013). In illness, masculine ideals around physical and emotional strength, employment and provider status may be undermined (Apesoa-Varano et al., 2018). In an attempt to avoid deviating from traditional masculine norms, men may mask depression, avoid help-seeking, seek to reaffirm or reconstruct their masculinity concept and express depression differently to women (Apesoa-Varano et al., 2018). Male expressions of depression may include overworking, self-medicating (e.g., through substance misuse), risk taking, aggression and irritability (Apesoa-Varano et al., 2018; Martin et al., 2013; Swetlitz, 2021). Swetlitz (2021) suggests that potentially, male depression may go unrecognised and be influenced by gendered self-perceptions and stigmatisation. This includes men's perceptions of masculinity and how masculine ideals fit in with their identity and socio-cultural environment (Swetlitz, 2021). Furthermore, diagnostic tools for depression are largely based on studies focusing on female experiences of depression, and therefore Swetlitz (2021) suggests these tools can be a barrier to men's diagnosis of depression.

The findings of the current study highlight the association between depression and poorer QoL in this group of men with prostate cancer. Though further research is needed to understand the mechanisms through which this operates, the findings are particularly important considering the implications for illness outcomes, treatment adherence, coping, help-seeking, suicidality and QoL, and the potential for under-reporting of depression in men, as highlighted above. The results have potential implications for the need for routine assessment of depression in prostate cancer survivors, and interventions targeting depression to support increased QoL. This is particularly relevant, considering that depression may manifest differently in this group, and men may be reluctant to seek help. Though the overall level of depression in this group was minimal, this may still warrant further exploration considering the impact of masculinity on emotional expression, masking, and under-reporting of depressive symptoms (Otto et al., 2022), and the finding that those with higher depression (which may be missed in this group) experience poorer QoL.

### 4.2.2 Strength and fitness component of masculinity

This study also found that lower prominence and importance of strength and fitness (as a component of masculinity concept) was significantly and independently associated with poorer QoL in this group of prostate cancer survivors. Previous research has suggested that loss of or changes in perceived masculinity, and adherence to masculine ideals, can be a significantly debilitating side effect of prostate cancer and its treatments which reduces psychological wellbeing (Bowie et al., 2022; Langelier et al., 2019; Matheson et al., 2020). Although the findings of the current study support previous literature to some extent, overall masculinity was not significantly associated with QoL category univariately or in the multivariate model. This finding contributes to the literature around masculinity in men with prostate cancer, and could suggest that the prominence and importance of strength and fitness is encompassing of what men perceive as masculine in relation to QoL. The other masculine concepts (sexual priority/importance, family responsibilities, emotional self-reliance, and optimistic action) were potentially less important in identifying a sense of masculinity in association with QoL in this group.

Furthermore, although univariately problems with masculine self-esteem was significantly associated with poorer QoL, this significant relationship did not persist in the fully adjusted model, indicating that it was not significantly and independently associated with QoL category. This finding is contradictory to previous research (McAteer & Gillanders, 2019). However, research in this area is sparse, and the finding that it was univariately associated with QoL supports previous research to some extent. McAteer & Gillanders (2019) found that poor masculine self-esteem is significantly, directly associated with increased distress and poorer QoL in men with prostate cancer (McAteer & Gillanders, 2019). Furthermore, masculine self-esteem also moderated the association between cancer-related symptoms and psychological distress, though this was buffered by higher psychological flexibility (McAteer & Gillanders, 2019).

The finding that strength and fitness masculinity concept was significantly and independently associated with QoL may be further understood within the context of research around masculinity and exercise interventions for prostate cancer survivors. The current study suggests that increased prominence and importance of strength and fitness may be associated with improved QoL. Physical fitness has been associated with concepts of self-efficacy and QoL in adults, both in the general population and populations with chronic illnesses such as cancer (Bize et al., 2007; Medrano-Ureña et al., 2020). Exercise interventions for men with prostate cancer have been found to be beneficial in health promotion, improving physical side effects of the illness and its treatments, and improving QoL (Crawford-Williams et al., 2018; Rendeiro et al., 2021). Systematic reviews and meta-analyses have found that exercise can improve cancer-specific QoL, and fatigue up to 6 months post intervention, though there was notably poor adherence and attrition (Bourke et al., 2016; Vashistha et al., 2016).

Masculinity literature may offer insight into why exercise interventions may support QoL. Literature suggests that men may hold masculine ideals around the male body type being muscular, and showing physical prowess, strength, and dominance (Holmqvist Gattario et al., 2015). Previous research suggests that the side effects of prostate cancer and its treatment (e.g., feminisation of the body, urinary and sexual difficulties, penile shortening, hot flushes, adiposity, emotional changes, behavioural changes such as perceptions of loss of control, and psychological distress) result in the undermining of masculinity (Langelier et al., 2018; Langelier et al., 2019). This literature suggests these physical changes challenge traditional masculine ideals around what a man should look like and be capable of, which can impact on QoL in this group. Furthermore, Langelier et al. (2018) found that men with prostate cancer who were physically active reported higher levels of masculinity, better body image (which was also associated with higher masculinity) and higher QoL. Building on this, a later systematic qualitative review highlighted that exercise interventions improved outcomes related to masculinity, body image and self-identity in men with prostate cancer (Langelier et al., 2019). They suggest that prostate cancer survivors may try to reaffirm masculinity through working on their physical appearance and engaging in activities which increase their perceptions of control over the disease, and perceptions of self-efficacy and physical capability. Furthermore, previous research has suggested that physical strength is associated with masculine ideals about resilience, recovery and fighting disease in men with prostate cancer (Chambers et al., 2016; Wassersug et al., 2015).

In line with the current study, this previous research suggests that prominence and importance of strength and fitness is an important component of masculinity concepts in this group. Langelier et al. (2019) suggest that exercise (particularly in groups) generates masculinity and reconnection with pre-cancer identities through competitive training, distraction from cancer-related concerns, increasing sense of control, community building (allowing shared focus on new or different masculine traits) and social comparison. Exercise also promoted self-efficacy and identity changes, related to improved confidence and establishing a new identity (Langelier et al., 2019). However, it is worth noting the significant heterogeneity and small number of studies included in this review, as well as the lack of investigation of potential confounders such as demographic, clinical, or psychosocial variables.

The findings of the current study highlight the association between lower prominence and importance of strength and fitness (as a component of masculinity concept) and poorer QoL, in this group of prostate cancer survivors. This suggests that strength and fitness is a key component of how prostate cancer survivors construct masculinity in relation to QoL. Though further research is needed to understand the mechanisms through which this operates, the findings have potential implications for the development of interventions targeting strength and fitness promotion, including exercise interventions, to support reaffirmation of masculinity and increased QoL.

### 4.2.3 Perceptions of personal control

This study found that lower perceptions of personal control over prostate cancer was significantly and independently associated with poorer QoL. In line with the CSM of self-regulation, previous research suggests that individual illness perceptions and emotional responses, to disease and its treatments, influence how cancer survivors adapt to illness, the coping strategies they select and illness outcomes, including emotional wellbeing (Ashley et al., 2015; Cook et al., 2015; Leventhal et al., 1980; Traeger et al., 2009). When facing a chronic illness, loss of control (fuelled by inability to predict prognosis, treatment consequences, illness outcomes or future recurrence) can be a powerful source of psychological distress, which can undermine coping (Williams & Koocher, 1998). Perceptions of control have been associated with adjustment to chronic illness (Helgeson, 1992), and this relationship has also been found to be mediated by perceptions of self-efficacy (Jerant et al., 2008).

The relationship between lower personal control illness perceptions and poorer QoL has similarly been identified in a previous meta-analysis and systematic review of mixed cancer (including prostate cancer) samples (Richardson et al., 2017). Research exploring illness perceptions in prostate cancer is in its infancy (Otto et al., 2022). However, in contrast to the findings of the current study, one cross-sectional survey found that perceptions of personal control were not associated with QoL in prostate cancer survivors (Traeger et al., 2009). This discrepancy in findings could potentially be explained by the differences in the target sample. In the study by Traeger et al. (2009), participants were those who had completed treatment for early-stage prostate cancer within the last 18 months. In the current study, participants were required to have received a diagnosis more than a year prior and may still have been undergoing treatment. Furthermore, the current study invited participants with a range of cancer staging. It is possible that personal control is associated differently with those more than one year post-diagnosis, who are still undergoing treatment and whose cancer is at a later stage. Additionally, a different standardised measure was used to assess QoL in the current study to that in the study by Traeger et al. (2009).

Previous research in mixed cancer samples and prostate cancer-specific samples has also found that other illness perception domains are associated with poorer QoL. These relationships were not significant in the current study. In mixed cancer (including prostate cancer) samples this includes perceptions of higher levels of illness identity, perceptions of the prostate cancer as being cyclical, negative consequence perceptions, greater emotional representations, lower perceptions of treatment control (Richardson et al., 2017). In prostate cancer specifically, this includes lower perceptions of treatment control, lower illness coherence, negative consequence perceptions, and more beliefs about personality or behaviour related causes of prostate cancer (Traeger et al., 2009). The current study supports this previous research to some extent, finding that higher levels of illness identity, negative consequence perceptions, perceptions of the prostate cancer as being cyclical, greater emotional representations, and more beliefs about personal causes of the prostate cancer were univariately associated with poorer QoL. However, when entered into a fully adjusted logistic regression model these relationships became non-significant. This suggests that although the findings indicate these domains were associated with QoL category, none were independently associated, and there was no significant direct relationship between these illness representation domains and QoL category in this population. This suggests that other factors, such as depression, lower prominence and importance of strength and fitness (as a component of masculinity) and perceptions of personal control over the prostate cancer were ultimately more highly associated with QoL in this group. Furthermore, the previous research also found that illness perceptions were associated with coping strategy (Richardson et al., 2017) and life stress (Traeger et al., 2009), the latter of which mediated the relationship between illness perceptions and QoL. It is possible that these factors were potential confounders or mediators which were not measured in the current study.

The concurrent finding that perception of personal control and lower prominence and importance of strength and fitness were both independently associated with QoL is noteworthy. Control is a key element of Western traditional masculine ideals, where men tend to be socialised to believe in their control to shape the world and their experiences (Canham, 2009). Canham (2009) highlights that being able to control events, the body and the self are also crucial to masculinity, and chronic illness, as well as natural decline due to aging, reduces ability to do this. For those who subscribe to such masculine ideas, conflict in ability to maintain masculinity and control can result in poorer psychological wellbeing (Canham, 2009)

Previous research suggests that, for prostate cancer survivors, perceptions of masculinity are impacted by a reduced sense of control (in relation to the future and emotional experiences), which is associated with poorer psychological wellbeing (Bowie et al., 2022; Matheson et al., 2020). Furthermore, regaining self-control has been found to be associated with reaffirming masculinity (Bowie et al., 2022). Additionally, as highlighted in section 4.2.2, previous research around exercise interventions for prostate cancer survivors suggests that exercise can improve QoL in this population. Langelier et al. (2019) propose that this is in part through the reaffirmation of masculinity, by increasing sense of control and promoting self-efficacy. However, considering the paucity of rigorous studies in this area, further research is needed to fully understand the relationship between personal control perceptions, strength and fitness masculinity concepts and QoL in this group.

The findings of the current study highlight the association between lower perceptions of control over the prostate cancer and poorer QoL. Though further research is needed to understand the mechanisms through which this operates, control perceptions may also be related to concepts of masculinity and self-efficacy. The results have potential implications for the need for routine assessment of perceptions of control, and how this relates to masculinity in prostate cancer survivors. There are potential implications for interventions targeted at increasing perceptions of personal control to support increased QoL.

### 4.2.4 Age

This study found that age was not associated with QoL category in this group of prostate cancer survivors. This contradicts findings from previous research which has identified younger age as a vulnerability factor for poorer psychological wellbeing (Lehto et al., 2017; Wilding et al., 2019), and QoL (Chambers et al., 2017). Additionally, older age has previously been associated with poorer functional QoL (Chambers et al., 2017). Chambers et al. (2017) suggest that symptom burden, uncertainty, and the psychological demands of living with cancer may have a greater impact on younger men and their life goals. Conversely, they suggest that poorer physical QoL in older men may reflect natural increases in comorbidity and physical decline due to aging.

However, there are differences between the current study and previous research which are important to consider and could explain the contradictory findings. Firstly, in the study which looked specifically at QoL, the mean age was younger than that of the current study (63.7 compared with 70.12 in the current study) and QoL was assessed using a different standardised measure (Chambers et al., 2017). The most recent data from Cancer Research UK suggests that the age of the current sample was in line with that of the national UK prostate cancer population (2016-2018), where most cases fall within the 70-74 age bracket (Cancer Research UK, 2022b). Other studies were conducted with different participant nationalities whose experience of prostate cancer and its treatments may differ from those in the UK (Lehto et al., 2017), and assessed psychological wellbeing and social distress rather than QoL specifically (Lehto et al., 2017; Wilding et al., 2019). A similar finding that age was not associated with QoL category in prostate cancer survivors was found by Dąbrowska-Bender et al. (2015). Dąbrowska-Bender et al. (2015) used the same standardised measure to assess QoL, and the mean age of participants was also closer to that of the current study (67.66).

### 4.2.5 Education status

This study also found that although univariately education level was significantly related to QoL category, this significant relationship did not persist in the fully adjusted model, indicating that it was not significantly *independently* associated with QoL category. This suggests that other risk factors need to be considered alongside education level. Although it was beyond the scope of the current project to conduct the stepwise analysis to see which variables account for the variation, this is potentially an interesting finding due to its comparison with socioeconomic status, which will be explored in further detail next.

The finding that education level was univariately associated with QoL supports previous research. For example, lower education level is suggested to be a vulnerability factor for both poorer psychological wellbeing (van Stam et al., 2017) and HRQoL (Chambers et al., 2017). In health research, education status is commonly used as a proxy for measuring socioeconomic status, as it easy to measure, generates good response rates, encompasses components of social opportunities for education, and is a strong predictor of future occupation and income (Galobardes et al., 2007). Education level may be particularly useful as a proxy for socioeconomic status in populations where occupation and income data is not available or appropriate, such as those who are retired (Galobardes et al., 2007). It may be that in the current study, the association between education level and QoL is reflective of differences in socioeconomic status. This is particularly relevant, considering the age of the participants in the current study, and that education is likely to be more related to socioeconomic status the further back in time you go, as the proportion of people going to university was much less. Recent government data highlights that participation in higher education has risen from 3.4% in 1950, 8.4% in 1970, 19.3% in 1990, to 33% in 2000 (Bolton, 2012). Previous research supports an association between socioeconomic status, and its proxies, and psychological wellbeing and QoL in prostate cancer survivors (Chambers et al., 2017; Wilding et al., 2019). Chambers et al. (2017) have previously highlighted the importance of socioeconomic disadvantage in reduced coping with the long-term negative effects of prostate cancer and its treatments. In light of the current findings, future research on the association between socioeconomic status and QoL in prostate cancer survivors may be valuable.

### 4.2.6 Anxiety

This study found that although univariately higher anxiety levels were significantly related to poorer QoL, this significant relationship did not persist in the fully adjusted model. This finding supports previous research to some extent. Previous research has explored anxiety in this group and highlighted how experiences of anxiety can impact on treatment adherence and outcomes. However, existing research has largely focused on describing the prevalence of clinical diagnoses of anxiety and anxiety symptoms in prostate cancer survivors (Brunckhorst et al., 2021; Watts et al., 2014), as well as factors which may make men with prostate cancer vulnerable to developing anxiety (Otto et al., 2022; Sharp et al., 2016). Previous research has found that higher levels of anxiety, and specifically prostate-related anxiety, is associated with poorer QoL in prostate cancer survivors (Erim et al., 2020). However, Erim et al. (2020) suggested that prostate cancer-related anxiety, and its impact on QoL was strongly associated with depression. Additionally, Wade et al. (2020) suggested that, alongside other factors, increased sense of control helped to mediate the impact of anxiety on psychological wellbeing. Furthermore, Sharp et al. (2016) suggest that loss of masculinity as a result of prostate cancer treatment side effects (particularly ADT) may be associated with poorer psychological wellbeing in prostate cancer survivors, including anxiety. It may be in the current study, that factors such as depression, lower prominence and importance of strength and fitness (as a component of masculinity) and perceptions of personal control over the prostate cancer, were ultimately more highly associated with QoL in this group, and account for more of the variation. However stepwise analysis to see which variables account for the variation is needed, in order to draw firm conclusions.

### 4.2.7 Body image

This study found that although univariately body image dissatisfaction was significantly related to poorer QoL, this significant relationship did not persist in the fully adjusted model. This finding supports previous research to some extent. Previous research in mixed cancer samples has highlighted the association between body image dissatisfaction and poorer QoL (Chow et al., 2019). However, body image research in prostate cancer is still in its infancy. The findings that body image dissatisfaction, although associated, is not independently associated with QoL in this group may be explained in the context of previous qualitative research. Such research suggests that body image difficulties in men with prostate cancer are closely related to perceptions of loss of masculinity, for example through experiencing feminisation of the body and sexual difficulties (Bowie et al., 2022; Gentili et al., 2019; Harrington et al., 2009; Langelier et al., 2018). Additionally, Bowie et al. (2022) suggested that experiencing a loss of ownership of the body could impact upon body image, which could be related to perceptions of control. Furthermore, in mixed cancer sample, previous research has identified a mediating role for body image on psychological wellbeing (Esser et al., 2018). It is possible that in the current study, factors such as lower prominence and importance of strength and fitness (as a component of masculinity) and perceptions of personal control over the prostate cancer, were ultimately more highly associated with QoL in this group, and account for more of the variation. However stepwise analysis to see which variables account for the variation is needed, in order to draw firm conclusions.

## 4.3 Strengths and limitations

### 4.3.1 Strengths

The use of an online survey to investigate the psychological needs of people with prostate cancer is a strength of this study. This design allows access to a population-based sample, which can generate a breadth of information. It allows for broad sampling of participant characteristics, including demographic, behavioural and life experience information, and supports inclusivity and generalisability of the findings. Additionally, the decision to circulate the survey through the support of cancer charities and organisations, and via various online platforms, meant that the survey was accessible to a wide portion of the intended population. Furthermore, this was a low cost and time efficient method, which allowed convenience for participants to respond at a time and place that suited them. Finally, given the impact of coronavirus on this patient group, the study design allowed opportunity to conduct this research via a methodology that did not require face to face contact.

Although this was an exploratory study, a strength of it is that a sufficiently large sample size was generated in order to estimate the variance around QoL. This was based on a sample size calculation, with a 95% level of confidence and margin of error of 3, using a previous survey which modelled a similar patient participant group and estimated the variance around QoL (McAteer & Gillanders, 2019). Exceeding the minimal sample size ensured that a sufficient number of participants was surveyed in order to accurately estimate the variance in QoL in the sample, and reduced the likelihood that the findings are due to chance.

A final strength of this study is that it used standardised outcome measures, which have been commonly used for research in health populations, including cancer (and specifically prostate cancer) populations. As highlighted in section 2.5.2, these measures have demonstrated good validity and reliability and, where indicated, they were adapted to ensure their suitability and utility. The BIS was adapted for use with people with prostate cancer, in order to make it more relevant and appropriate as indicated by previous literature (van den Driessche et al., 2016). Additionally, in order to enable rigorous analysis, the IPQ-R was subjected to factor analysis, as recommended by the authors (Moss-Morris et al., 2002).

### 4.3.2 Limitations

#### Methodological limitations

Although the strengths of using an online survey design were outlined in section 4.3.1, there are also important limitations to consider. Firstly, this type of design has implications for accessibility. The remote, anonymous nature of the online survey (meaning no direct contact with participants) meant that it was challenging to make adjustments for those who were unable to understand the content of the questionnaires independently. This means that some groups may have been unable to participate (such as those with cognitive impairment or who would require translation into a different language). Furthermore, participation in the survey required access to the internet and appropriate technology. This may raise accessibility issues for those with lower socioeconomic status, for those who have less online literacy, and for those with less social support to help them with such activities. This is particularly relevant considering the finding that lower education level (which is potentially a proxy for socioeconomic status) was univariately associated with poorer QoL.

A second limitation of this study was the risk of biases generated through the recruitment strategy. The use of cancer charities and organisations to recruit participants opens the study up to selection bias. Though online platforms were also used, these were often in association with online cancer communities, and it is likely that the majority of respondents were those who were already accessing these charities, organisations and communities. Therefore, this could reflect a sample of participants who were relatively well supported compared to the general population of prostate cancer survivors. Furthermore, the study may be at risk of self-selection bias. Research indicates that men may find it difficult to discuss topics which relate to concepts such as masculinity (Bowie et al., 2022), and are less open to describing their vulnerability (Burns & Mahalik, 2008). They may use coping strategies such as avoidance and concealment to manage their distress (Matheson et al., 2020), which may limit willingness to engage in such research. As participation in the survey is voluntary, the sample may reflect those more willing to give their time to a research survey, or potentially those less impacted by the difficult topics addressed in the survey and more willing to share their experiences.

Additionally, the use of a survey design did not allow for the collection of qualitative data. This could give opportunity to explore the unique experiences of individuals with prostate cancer, though would mean the results were less representative of the prostate cancer population.

An important limitation to consider is the lack of demographic diversity within the study sample. As highlighted in Table 5, the recruited sample was predominantly White, married, educated, and retired men. Furthermore, the current sample potentially reflected a less severe prostate cancer population, compared with the UK population overall. Public Health England (n.d.) report that in the UK 54% of men have localised (stage 1/2) prostate cancer, 16% have locally advanced (stage 3) prostate cancer and 30% have advanced (stage 4) prostate cancer. Comparatively, in the current study 39.1%, 25% and 13.5% reported localised, locally advanced, and advanced prostate cancer respectively. However, it is important to recognise that due to the high proportion of people who were unsure (22.4%) it is difficult to draw firm comparisons. This potentially reflects a sample who have a comparatively higher level of resources, including those with more social support, and potentially higher socioeconomic status, alongside belonging to the national majority culture, not having the day-to-day stress of working and having less severe illness. It is possible that had there been more variation in the sample, other factors may have been significantly associated with QoL either univariately or persisting in the fully adjusted model.

Of particular note is the low ethnic diversity of the sample. UK statistics data from 2013-2017 suggest that White people represent 87% of prostate cancer cases, with Asian, Black, Mixed/Multiple, other and 'not known' representing 1.8%, 3.1%, 0.4%, 0.9% and 7% respectively (Delon et al., 2022). The percentage of White participants represented in this sample is considerably higher (97.4%), suggesting that this group is overrepresented. It is possible that this reflects reduced access to cancer charities, organisations, and online communities for ethnic minority groups. However, it may also be that the recruitment strategy and study design itself was not optimal for prostate cancer survivors from ethnically minoritised groups. This is particularly relevant considering that ethnicity is a key risk factor for prostate cancer (Orchid, 2019). Black African / Black Caribbean men are at double the risk of getting prostate cancer than men from other ethnicities (Orchid, 2019), and may be more likely to develop depression (Parikh et al., 2021). Attempts were made to increase recruitment of participants from ethnically minoritised groups, through support from the Centre for Ethnic Health Research, approaching ethnic minority prostate cancer support groups, and linking in with notable dates and awareness days (such as national inclusion week and the play domino talk prostate campaign). Further research is needed to better understand the barriers for recruitment of participants from ethnically minoritised groups in such research.

The accessibility issues, potential selection biases and limited diversity of the sample highlighted above have implications for the generalisability of the findings, as some groups may not be sufficiently represented in the study.

Another methodological limitation of this study was the use of a cross-sectional design, meaning that causality cannot be inferred and a temporal relationship between the independent and outcome variables cannot be established.

### Procedural limitations

Alongside the methodological limitations highlighted above, there are important procedural limitations to consider, relating to the way the current project was designed specifically.

Firstly, participants were not asked to give any information relating to any comorbidity they were experiencing, or their pre-morbid mental and physical health. Previous research has highlighted that having comorbid conditions and receiving previous support for mental health difficulties are associated with poorer psychological wellbeing and QoL in prostate cancer survivors (Chambers et al., 2017; Wilding et al., 2019). Therefore, it is difficult to determine whether participant's responses reflected their psychological needs in relation to their experiences of prostate cancer, or other confounding variables. It is also not possible to establish baseline scores for the psychological needs measured, prior to their commencement of prostate cancer treatment.

Secondly, there are limitations in relation to the breadth of the analysis. Alongside exploring the relationship between demographic and clinical factors, and psychological needs and QoL, it would be valuable to explore how the demographic and clinical factors are related to the psychological needs of people with prostate cancer. Had there been more scope within the current project to do this, this would have been the next step in the analysis. Additionally, an important next step in this research would be to run complex cofounding models to explore the interactions between the variables and their association with QoL. Furthermore, although this study focused on global QoL as the outcome, it would be useful to re-run the regression models with the functional and symptom QoL subscales to see if the relationships identified with global QoL are mirrored. This may help direct specific areas for further research or inform specific interventions for improving QoL in people with prostate cancer.

### 4.3.3 Impact of Covid-19

It is important to recognise the potential impact of the timing of this research. Design and recruitment for the study were undertaken during the Covid-19 pandemic. It was designed with the pandemic in mind, and this context informed the decision for the survey to be recruited online, limiting face to face contact with individuals with prostate cancer who may be vulnerable to coronavirus. As such, no adaptations to the design were necessary, although strategies such as displaying posters in physical waiting rooms (e.g., those of clinics, cancer charities and organisations, support group meeting rooms), were not able to be utilised to support recruitment. It is possible that these strategies could have increased recruitment of participants not already accessing these charities, organisations and communities, though overall recruitment rate does not appear to have been affected. It may be that coronavirus restrictions positively impacted upon recruitment due to ‘stay at home’ policies. However, it is not possible to know this.

It is also not possible to know the impact that the Covid-19 pandemic had on participants completing the survey e.g., in relation to shielding, impact on treatment decision and procedures, impact on anxiety and uncertainty around prostate cancer, and the impact on support and access to usual coping strategies. It is possible that Covid-19 could have impacted upon the psychological wellbeing of prostate cancer survivors, however the impact of Covid-19 was not assessed and therefore no assumptions can be made.

## 4.4 Research implications for clinical practice

The findings of this study highlight numerous research implications for clinical practice. The data suggested that depression, perceptions of personal control over the prostate cancer, and prominence and importance of strength and fitness (as a component of masculinity) were significantly and independently associated with QoL in this group. Identifying factors which impact on the QoL of prostate cancer survivors serves to improve clinicians’ understanding of the psychological needs of people in this group. According to the findings of this study, targeting interventions to address depression, perceptions of personal control over the prostate cancer, and prominence and importance of strength and fitness (as a component of masculinity) may be important for improving QoL in this group.

Focusing on these factors may be important for clinical practice, in order to identify those who may be vulnerable to poorer psychological wellbeing, and in order to develop targeted, person-centred interventions which may improve QoL. However, further research would be needed in order to inform how these findings could be integrated into assessments and interventions, and support for clinicians involved in the care of prostate cancer survivors.

One area where these findings may be important is in the routine assessment of the psychological wellbeing of people with prostate cancer. The findings of this study suggest that depression, perceptions of personal control over the prostate cancer, and prominence and importance of strength and fitness (as a component of masculinity) were significantly and independently associated with QoL in this group. Routine assessment of these psychological needs in people with prostate cancer may be crucial to identifying those who are more vulnerable to experiencing poorer QoL, which can impact upon illness outcomes. As previous research has highlighted, men may find it difficult to discuss topics which relate to concepts such as depression and threats to masculinity (Bowie et al., 2022; Ogrodniczuk & Oliffe, 2011). They may be less open to seeking help or describing their vulnerability (Burns & Mahalik, 2008) and may use coping strategies such as avoidance, self-management, minimisation and concealment to deal with their distress (Matheson et al., 2020; Ogrodniczuk & Oliffe, 2011). This may limit their ability to acknowledge and disclose difficulties with their psychological wellbeing and QoL, without the support of professionals. Previous research suggests that men with prostate cancer find it challenging to discuss topics such as sexual dysfunction and loss of masculinity, when it is not bought up by medical professionals (Bowie et al., 2022). Therefore, clinicians should think carefully about routine assessment of such difficulties in this group.

Men may express distress such as depression in ways not targeted by current diagnostic tools or clinical assumptions (Apesoa-Varano et al., 2018; Martin et al., 2013), which could mean that depression in this group is overlooked (Swetlitz, 2021). It is important that clinicians do not rely solely on existing diagnostic tools, or on preconceived assumptions of ‘depressive’ presentations, when working with people in this group. Clinical resources could be developed for health professionals to aid routine assessment of the psychological needs of people with prostate cancer, though further research is needed before this is possible.

The findings of this study also have implications for contributing to the future development of targeted, person-centred interventions for people with prostate cancer. Currently, psychosocial interventions have mixed support for improving QoL, anxiety, and depression; with benefits not being maintained long-term (Crawford-Williams et al., 2018). However, research is sparse and lacks methodological rigour (Crawford-Williams et al., 2018). Therefore, understanding the factors which may contribute to the long-term psychological wellbeing of people with prostate cancer is important for designing appropriate interventions. This may include exercise interventions, which have been found to be beneficial in health promotion, improving physical side effects of the illness and its treatments, and improving QoL (Crawford-Williams et al., 2018; Rendeiro et al., 2021). Increasing the prominence of strength and fitness in people with prostate cancer may be important for reaffirming masculinity, which may have been undermined by prostate cancer and its treatments, through facilitating physical body changes and increasing perceptions of control, self-efficacy and physical capability (Langelier et al., 2018; Langelier et al., 2019).

The findings also highlight the importance of clinicians facilitating chances to regain control where possible for people with prostate cancer, in order to improve QoL. When facing a chronic illness, loss of control can be a powerful source of psychological distress, which can undermine coping (Williams & Koocher, 1998), adjustment to chronic illness (Helgeson, 1992), and masculinity (Bowie et al., 2022; Canham, 2009; Matheson et al., 2020). Regaining control has been found to be important in reaffirming masculinity (Bowie et al., 2022) and adjustment to chronic illness (Helgeson, 1992). Opportunities for facilitating increased perceptions of control may be through providing comprehensive information about prostate cancer and its treatments, in order to inform treatment decisions, and facilitating opportunities and thinking around other areas of life where control can be gained e.g., looking after physical health, caring for loved ones or gaining a sense of mastery and self-efficacy through another avenue such as exercise (Bowie et al., 2022; Langelier et al., 2018; Langelier et al., 2019).

The findings of this study may also contribute to the future development of educational materials for clinicians involved in the care of prostate cancer survivors. Such materials could provide both psychology professionals and non-therapy professionals with information relating to the long-term functional and psychological impact of prostate cancer and its treatments, including the psychological needs associated with poorer QoL in this group. This may support clinicians to develop appropriate language to facilitate conversations about these needs with prostate cancer survivors. It could also support clinicians to identify when a referral for further psychological input may be indicated.

Prostate cancer survivors themselves may also benefit from psychoeducational materials on the psychological impact of prostate cancer and its treatments. Prostate cancer survivors report unmet needs in relation to insufficient access to information about the long-term effects of treatment (Bowie et al., 2022; Paterson et al., 2015) and may experience illness uncertainty (Guan et al., 2020). Furthermore, men have previously perceived benefits to their perceptions of masculinity by regaining personal control over their prostate cancer through information gathering (Bowie et al., 2022). Psychoeducational resources could help to increase prostate cancer survivors' knowledge of their prostate cancer, and the psychological needs associated with this, reduce illness uncertainty, and improve perceptions of control.

In summary, the findings of this study suggest that depression, perceptions of personal control over the prostate cancer, and prominence and importance of strength and fitness (as a component of masculinity) may be important factors to consider for clinical practice. Assessment of these factors may help to identify those who are vulnerable to experiencing poor QoL. The development of interventions targeting these psychological needs may contribute to improving

QoL in this group. Furthermore, the findings could help to inform educational materials for psychological and non-therapy clinicians to help them to better support prostate cancer survivors. However, these implications should be considered in the context of the study limitations highlighted in section 4.3.2. There was a considerable lack of diversity within the sample, which contained predominantly White, married, educated, retired men who were over a year post-prostate cancer diagnosis. Respondents self-selected for the survey, expressing a willingness to report on their psychological needs, and competency for understanding and accessing the online survey. The lack of diversity has implications for the generalisability of the findings and further research would be necessary as a first step, to see how the findings could be integrated into assessment of people with prostate cancer, the development of targeted person-centred interventions and the development of educational materials to support clinicians with their understanding, language, approach, and ability to identify when referrals for further psychological support would be appropriate.

## 4.5 Implications for future research

This study highlights numerous avenues for future research. Firstly, as with the current study, the majority of research exploring the psychological needs of men with prostate cancer has been cross-sectional. Future research would benefit from use of a longitudinal design, which would aid understanding of the temporal and causal relationships between psychological needs and QoL in this group. For example, exploring how these psychological needs, and their association with QoL change over the prostate cancer journey from diagnosis, through treatment, to survivorship, would aid understanding of different vulnerable groups over the course of the disease.

Considering the lack of diversity within the sample, and in previous research in this area e.g., Crawford-Williams et al. (2018), future research should also explore the barriers to recruitment of participants from ethnically minoritised groups. The current study is not able to describe the psychological needs of prostate cancer survivors from ethnically minoritised groups, or their association with QoL. This is particularly important considering that ethnic minority status is a risk factor for health inequality, and poorer physical and mental health outcomes (World Health Organisation, 2010). Previous research has indicated that African American prostate cancer survivors are more likely to be diagnosed with depression, less likely to be prescribed antidepressants and more at risk of mortality associated with depression than White veterans (Parikh et al., 2021). Exploring the psychological needs of people with prostate cancer who are from an ethnic minority background would be a valuable avenue for future research.

Considering the limitations of the breadth of the analysis in the current study, it may be valuable to explore how demographic and clinical factors are related to the different psychological needs of people with prostate cancer. Additionally, an important next step in this area of research would be to run complex cofounding models to explore the interactions between the variables and their association with QoL. Furthermore, as this study focused on global QoL as the outcome, it would be useful to explore the association between demographic and clinical variables, and psychological needs on the functional and symptom QoL subscales to see if the relationships identified with global QoL are mirrored. Future research could also focus specifically on exploring the association between depression, prominence of strength and fitness (as a component of masculinity) and perceptions of personal control, and QoL in more depth. This would include exploring interaction effects and possible cofounders and mediators of the identified relationships.

An original area of interest for the current study, based on previous literature, was the impact of treatment type on global QoL. However, it was not possible to model the complexities of the treatment combinations in this sample using simple univariate and multivariate logistic regression modelling techniques. Based on the data from the current study, it could be possible to estimate a sample size to look at the impact of treatment on QoL in future research. A larger study, looking at treatment type would allow for how nuanced the experiences of treatments are in this group. This could contribute to the literature on how prostate cancer treatments impact on global QoL, and how treatment type interacts with other psychological needs such as depression, anxiety, illness perceptions, body image and masculinity.

Future research could explore the impact of cofounding or mediating variables on the association between psychological needs and QoL. Previous research has indicated a role for the mediating effects of coping strategies (Guan et al., 2020), self-efficacy (Jerant et al., 2008; Langelier et al., 2019), psychological flexibility (McAteer & Gillanders, 2019), and life stress (Traeger et al., 2009) on the psychological wellbeing of people with prostate cancer. Such research would further add to the understanding of the relationship between psychological needs and QoL in prostate cancer survivors.

## 4.6 Theoretical implications

The findings of this study may have potential theoretical implications. One area in which the findings of the current study may have theoretical implications is in understanding how men's psychological wellbeing may be impacted upon by illness in the longer-term. People with prostate cancer report lower satisfaction for psychosocial follow-up care than physical follow-up care (Watson et al., 2015). Research suggests that men find it difficult to discuss concepts such as threats to their masculinity with professionals (Bowie et al., 2020). Furthermore, discussion with an Associate Professor in Clinical Oncology during the design phase of this study confirmed that the psychological impact of illness for men is often overlooked and not asked about, due to the focus on treating the cancer at the time of contact with health services. The findings of this study suggest that in the longer-term, some prostate cancer survivors may be vulnerable to experiencing depression, perceptions of lower personal control, and lower prominence and importance of strength and fitness (as a component of masculinity), which impact upon their QoL. Previous research suggests that mental health difficulties, such as depression, in men are under-recognised (Ogrodniczuk & Oliffe, 2011), though impact on treatment adherence and illness outcomes (Brunckhorst et al., 2021; Maggi et al., 2019; The King's Fund, 2012; Watts et al., 2014). Gender socialisation and adherence to masculine ideals impacts on how men express emotion and similarly mask depression, whilst also reducing help-seeking (Apesoa-Varano et al., 2018; Swetlitz, 2021). Factors such as depression, perceptions of personal control, and prominence and importance of strength/fitness as a component of masculinity, may be particularly crucial to consider when understanding men and illness, and specifically men with prostate cancer in the longer-term. Psychological assessment of and interventions targeting these difficulties may be effective in improving the QoL of men experiencing illness such as prostate cancer.

The concurrent findings that lower perception of personal control and lower prominence and importance of strength and fitness were both independently associated with QoL is noteworthy and may pose questions for how we understand the impact of certain life events such as illness. The findings of the current study suggest that strength/fitness prominence and importance may be an important factor in how men construct masculinity in relation to QoL. Furthermore, it is understood that how people represent illness in their own minds is important for psychological wellbeing and QoL. The CSM of self-regulation suggests that an individual's illness perceptions and emotional responses towards the disease and its treatments, influence how they adapt to the disease, the coping strategies they select, illness outcomes, QoL and psychological wellbeing (Ashley et al., 2015; Cook et al., 2015; Leventhal et al., 1980; Richardson et al., 2017). Experiencing illness may be particularly impactful for those who value strength and being active, and those who value being in control. In illness, physical and functional side effects may impact on strength and fitness and the individual often does not have complete control over the outcomes and treatment decisions. Therefore, masculinity and perceptions of control may be undermined.

Finally, it may be that the impact of specific illness representations, as outlined by the CSM of self-regulation, may not be equal for all who are experiencing illness e.g., those of different genders. For people who highly subscribe to masculine ideals, the perception of control may be much more important than for those who do not. Control is a key element of Western traditional masculine ideals, and being able to control events, the body and the self are also crucial to masculinity (Canham, 2009). Chronic illness reduces the individual's ability to do this. For those who subscribe to such masculine ideas, conflict in ability to maintain masculinity and control may result in poorer psychological wellbeing (Canham, 2009). As indicated by previous research, it may be that perceiving something can be done about the illness allows it to be incorporated into concepts of self-identity and allows for masculinity to be reaffirmed (Bowie et al., 2022).

## 4.7 Conclusions

It has been acknowledged that research on the long-term consequences of prostate cancer survivorship is lacking, including research on global QoL, and factors associated with variation in this, subgroups which may be vulnerable to poorer wellbeing, and the psychological wellbeing of prostate cancer survivors (Chambers et al., 2017). To the awareness of the author, this was the first study to look at such a range of psychological needs and their impact on global QoL in this group. This study therefore provides a contribution to the literature around the psychological wellbeing of prostate cancer survivors, and in particular QoL and factors associated with variation in this. It also indicates avenues for future research, in order to better understand how factors such as depression, perceptions of personal control, and the prominence and importance of strength / fitness impact on the QoL of prostate cancer survivors, and how this understanding can be integrated into psychological interventions and education for non-therapy professionals.

This study aimed to describe the long-term psychological needs of men with prostate cancer, and explore the relationship between these needs and QoL in this group. Consistent with previous research the current study found that, overall, people with prostate cancer reported good global QoL and psychological wellbeing. Depression and anxiety scores for the overall group were minimal and comparable to that of the general population. However, considering the significant proportion of those in the low-moderate QoL group, this study recognises the importance of considering factors which may be associated with poorer QoL in this group.

In the current study, lower education level, higher levels of depression, higher levels of anxiety, poorer body image, lower prominence and importance of strength and fitness (as a component of masculinity), high prominence and importance of optimistic action (as a component of masculinity), and poorer masculine self-esteem, were univariately associated with poorer QoL. In terms of illness perceptions, higher scores for having a strong illness identity (attributing symptoms to be a consequence of their prostate cancer); higher scores for viewing prostate cancer as having a great effect on themselves and their family; higher scores for perceiving the condition as cyclical; higher scores for being greatly emotionally impacted by the prostate cancer; higher scores for attributing the cause of the prostate cancer to personal factors; lower scores for perceiving they have a high level of control over their prostate cancer; and lower scores for believing that prostate cancer treatments have been effective were univariately associated with poorer QoL. However, when entered into a fully adjusted logistic regression model, only the relationships between higher depression score, lower perceptions of personal control, and lower prominence and importance of strength and fitness (as a component of masculinity), and QoL persisted. This suggests that these factors were significantly and independently associated with lower QoL in this population. This finding contributes to the literature on the long-term psychological needs of prostate cancer survivors.

Further research is needed to understand the mechanisms through which the relationships operate. The findings are particularly important considering the implications for the impact of depression on illness outcomes, treatment adherence, coping, help-seeking, suicidality and QoL, and the potential for under-reporting and diagnosis of depression in men. Additionally, strength and fitness may be a key component of how prostate cancer survivors construct masculinity in relation to QoL, with exercise interventions providing an avenue for reaffirming masculinity. Personal control perceptions may also be related to concepts of masculinity and self-efficacy, in their association with QoL in this population.

Though the limitations of this study are recognised, this study contributes to the literature on the long-term psychological needs of people with prostate cancer, and in particular their relationship with QoL and factors associated with variation in this. Implications for clinical practice and future research have been discussed. It is hoped that the results of the current study will inform future research expanding the literature on the long-terms psychological needs and QoL in this group. Future research could explore how these findings could be integrated into assessments and interventions for prostate cancer survivors, and support for clinicians involved in their care. This could support understanding around the identification of vulnerable groups and when a referral for further psychological support is indicated. Future research in this area could also aid the development of interventions targeting these psychological needs, and psychoeducational resources for both clinicians and patients. This could consequently improve overall QoL for prostate cancer survivors.

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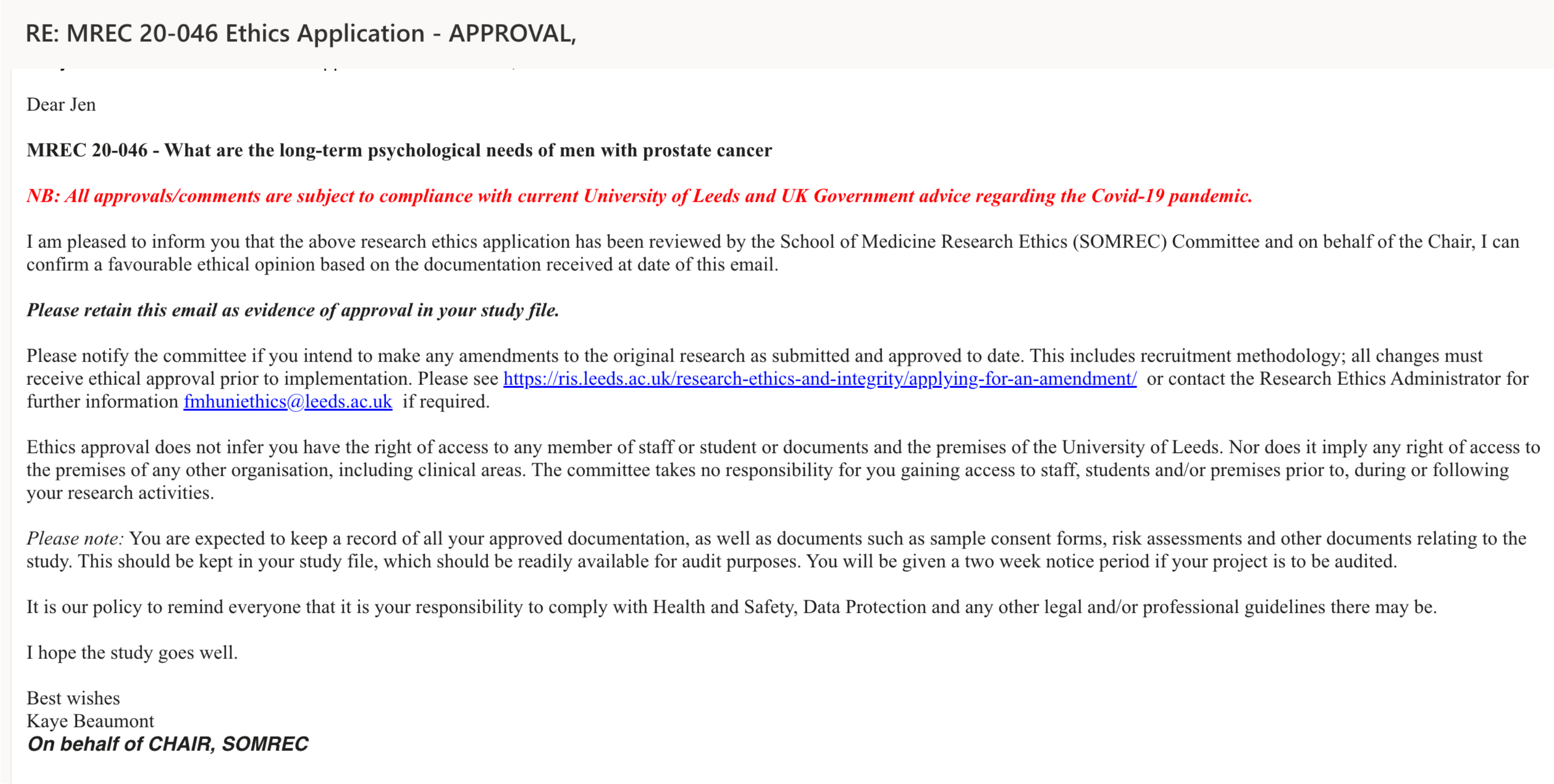
# Appendix A

## Ethical approval email



RE: MREC 20-046 Ethics Application - APPROVAL,

Dear Jen

**MREC 20-046 - What are the long-term psychological needs of men with prostate cancer**

***NB: All approvals/comments are subject to compliance with current University of Leeds and UK Government advice regarding the Covid-19 pandemic.***

I am pleased to inform you that the above research ethics application has been reviewed by the School of Medicine Research Ethics (SOMREC) Committee and on behalf of the Chair, I can confirm a favourable ethical opinion based on the documentation received at date of this email.

***Please retain this email as evidence of approval in your study file.***

Please notify the committee if you intend to make any amendments to the original research as submitted and approved to date. This includes recruitment methodology; all changes must receive ethical approval prior to implementation. Please see https://ris.leeds.ac.uk/research-ethics-and-integrity/applying-for-an-amendment/ or contact the Research Ethics Administrator for further information fmhuniethics@leeds.ac.uk if required.

Ethics approval does not infer you have the right of access to any member of staff or student or documents and the premises of the University of Leeds. Nor does it imply any right of access to the premises of any other organisation, including clinical areas. The committee takes no responsibility for you gaining access to staff, students and/or premises prior to, during or following your research activities.

*Please note:* You are expected to keep a record of all your approved documentation, as well as documents such as sample consent forms, risk assessments and other documents relating to the study. This should be kept in your study file, which should be readily available for audit purposes. You will be given a two week notice period if your project is to be audited.

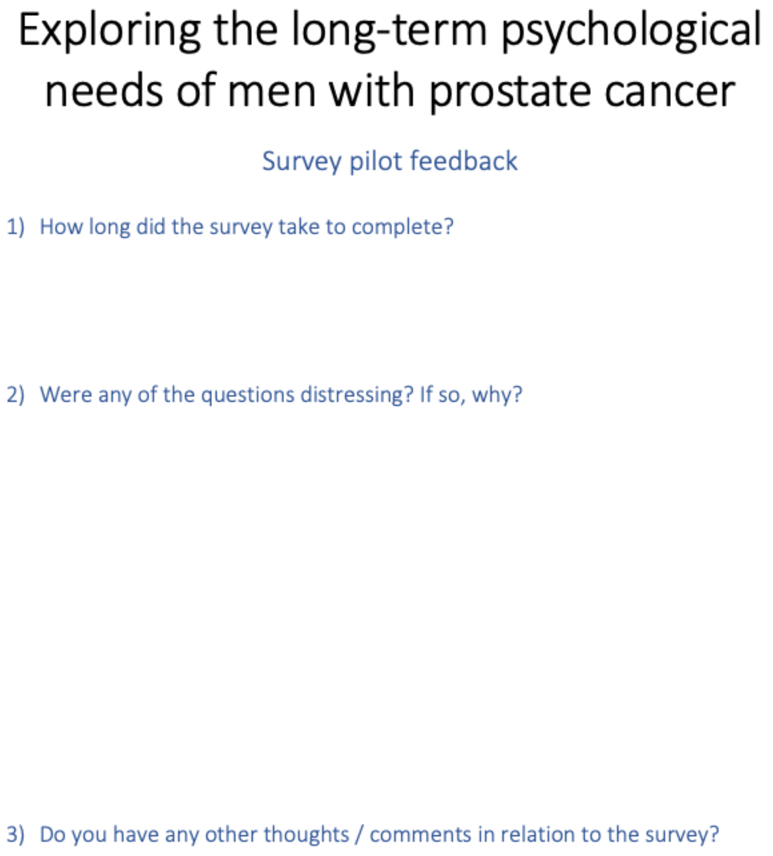
It is our policy to remind everyone that it is your responsibility to comply with Health and Safety, Data Protection and any other legal and/or professional guidelines there may be.

I hope the study goes well.

Best wishes
Kaye Beaumont
***On behalf of CHAIR, SOMREC***

## Appendix B

## Feedback form for Patient and Public Involvement Group



# Exploring the long-term psychological needs of men with prostate cancer

Survey pilot feedback

1) How long did the survey take to complete?

2) Were any of the questions distressing? If so, why?

3) Do you have any other thoughts / comments in relation to the survey?

# Appendix C

# Data cleaning Diary

| **Variable** | **Action** |
|---|---|
| Age | Participant 665145-665136-79928091 changed age to 70 (average of other participants as 23 clearly an error - later reports that believes prostate cancer due to aging to support this) |
| Relationship status | Participant 665145-665136-81779001 Changed relationship status other living together with a long-term partner to in a relationship |
| Employment status | Participant 665145-665136-82893513 changed employment status other (I may be retired but I am volunteering for various organisations probably working harder than before I retired) to retired |
| | Participant 665145-665136-83943640 changed employment status other taking a break from work to disabled, not able to work |
| Years diagnosed | Participant 665145-665136-79921805 - for column 8: Approximately how many years ago were you diagnosed with prostate cancer? Changed 2018 to 3 |
| | Participant 665145-665136-81175839 changed years since diagnosis to 2 from 2 years |
| | Participant 665145-665136-81179980 changed years since diagnosis to 5 from 5 years |
| | Participant 665145-665136-81490452 changed years since diagnosis to 1.5 from 18 months |
| | Participant 665145-665136-81502190 changed years since diagnosis to 2.5 from 2.5yrs |
| | Participant 665145-665136-82897602 changed years since diagnosis to 4 from 4 years |
| | Participant 665145-665136-82899329 changed years since diagnosis to 11 from 11q |
| | Participant 665145-665136-82899329 changed years since diagnosis to 6 from almost 6 years ago |
| | Participant 665145-665136-82902642 changed years since diagnosis to 16 from 16 years |

| | |
|---|---|
| | Participant 665145-665136-82904882 changed years since diagnosis to 2 from 2 years |
| | Participant 665145-665136-82920431 changed years since diagnosis to 8 from 8 years |
| | Participant 665145-665136-82921073 changed years since diagnosis to 8 from Oct 2013 |
| | Participant 665145-665136-82921808 changed years since diagnosis to 5 from five years |
| | Participant 665145-665136-82922960 changed years since diagnosis to 3 from March 2018 |
| | Participant 665145-665136-82926926 changed years since diagnosis to 10 from 10 years |
| | Participant 665145-665136-82929512 changed years since diagnosis to 2 from Feb 2019 |
| | Participant 665145-665136-82948658 changed years since diagnosis to 10 from almost 10 years |
| | Participant 665145-665136-82950705 changed years since diagnosis to 5 from 5 years |
| | Participant 665145-665136-82952817 changed years since diagnosis to 1.5 from 18 months |
| | Participant 665145-665136-82957991 changed years since diagnosis to 13 from 13 years ago |
| | Participant 665145-665136-82982389 changed years since diagnosis to 2 from 1.75 (31/10/2019) |
| | Participant 665145-665136-82998089 changed years since diagnosis to 5 from 5 years approximately |
| | Participant 665145-665136-83028485 changed years since diagnosis to 4 from 2017 |
| | Participant 665145-665136-83113211 changed years since diagnosis to 1.5 from 18 months |
| | Participant 665145-665136-83132338 changed years since diagnosis to 3 from 2018 |
| | Participant 665145-665136-83130908 changed years since diagnosis to 5.5 from 5 1/2 |
| | Participant 665145-665136-83142591 changed years since diagnosis to 17 from 17 years ago |

| | |
|---|---|
| | Participant 665145-665136-83197148 changed years since diagnosis to 2 from 2 years ago |
| | Participant 665145-665136-83219017 changed years since diagnosis to 11 from 11 years |
| | Participant 665145-665136-83346041 changed years since diagnosis to 16 from 16years |
| | Participant 665145-665136-83540885 changed years since diagnosis to 8 from 8 years |
| | Participant 665145-665136-83925118 changed years since diagnosis to 1.5 from 1.5 years |
| | Participant 665145-665136-84042367 changed years since diagnosis to 6 from August 2015 |
| | Participant 665145-665136-84392820 changed years since diagnosis to 8 from 7yrs 8months |
| Treatment | Participant 665145-665136-79919531, changed '9. What type of treatment are you currently having for your prostate cancer? (please select multiple if appropriate)' from 'Other' to 'Active Surveillance' as detail provided was PSA annual after surgery |
| | Participant 665145-665136-80840366 changed treatment Other - treatment finished now just following tests to Active Surveillance |
| | Participant 665145-665136-82028384 changed treatment other PSA to Active Surveillance |
| | Participant 665145-665136-82993307 changed treatment other observation to Active Surveillance |
| | Participant 665145-665136-82906410 changed treatment other - None - Occasional psa test on request to active surveillance |
| | Participant 665145-665136-83036423 changed treatment other - annual review to active surveillance; changed treatment other brachytherapy to radiotherapy |
| | Participant 665145-665136-80935892 changed treatment other brachytherapy to radiotherapy |
| | Participant 665145-665136-81302968 removed treatment other - high dose brachytherapy as covered by radiotherapy |
| | Participant 665145-665136-81180943 removed treatment other Abiraterone as this is a type of hormone therapy for advanced |

| | |
|---|---|
| | prostate cancer where other HT is not effective, therefore covered by hormone therapy |
| | Participant 665145-665136-81179980 removed treatment other Enzalutamide as this is a type of hormone therapy for advanced prostate cancer where other HT is not effective, therefore covered by hormone therapy |
| | Participant 665145-665136-84042367 removed treatment other xtundi 2 tablets daily as this is Enzalutamide, a type of hormone therapy for advanced prostate cancer where other HT is not effective, therefore covered by hormone therapy |
| | Participant 665145-665136-82986311 Changed treatment other Zoladex to hormone therapy as hormone drug |
| | Participant 665145-665136-81490452 changed treatment other None, because of Covid, apparently to treatment other None |
| | Participant 665145-665136-82892998 changed Other treatment completed to Other None |
| | Participant 665145-665136-83423007 changed other - finished treatment to other none |
| | Participant 665145-665136-82898853 changed Other no treatment to Other None |
| | Participant 665145-665136-84008709 Changed other treatment no treatment at present but undergoing scans again to other None |
| | Participant 665145-665136-82925798 Changed treatment other prostate removed to surgery |
| | Participant 665145-665136-83943640 changed current treatment other Recovering- surgery in 2018 and Radiotherapy in 2020 to radiotherapy and previous treatment surgery and radiotherapy to surgery; as dates provided show timeline of treatments. |
| | Participant 665145-665136-82950550 Changed treatment other (incontinence pads) to treatment other (None) |
| | Participant 665145-665136-83871677 Changed Previous treatment Other (none diagnosed with no symptoms then immediate surgery) to surgery; changed current treatment Surgery,Radiotherapy to radiotherapy as responses indicate timeframe for treatments |
| | Participant 665145-665136-81734570 changed treatment other signed off to other none |

| | |
|---|---|
| | Participant 665145-665136-81415708 changed post-surgery PSA to active surveillance instead of other |
| | Participant 665145-665136-82717484 Changed treatment other PSA to Active Surveillance, removed treatment other HDR brachytherapy as covered by radiotherapy |
| | Participant 665145-665136-82902954 changed treatment other (None - My surgery was 3 years ago; I'm not currently having treatment but option missing) to other none |
| | Participant 665145-665136-82902642 Changed treatment other following open surgery in2005 annual psa test to active surveillance |
| | Participant 665145-665136-82904456 removed treatment other high dose brachytherapy as covered by radiotherapy |
| | Participant 665145-665136-82906498 Changed treatment other monitoring to Active Surveillance |
| | Participant 665145-665136-82950718 changed treatment other (Just PSA monitoring after treatment 3-4yrs ago) to active surveillance |
| | Participant 665145-665136-83038296 Changed treatment other (post-surgery) to other none |
| | Participant 665145-665136-83021557 changed treatment other annual PSA to Active Surveillance |
| | Participant 665145-665136-83113211 changed treatment other (nothing) to other (none) |
| | Participant 665145-665136-83211491 changed treatment other (no treatment) to other (none) |
| | Participant 665145-665136-83197210 changed treatment other (None, treatment complete) to other (none) |
| | Participant 665145-665136-83315728 changed treatment other zoladex to hormone therapy |
| | Participant 665145-665136-83906546 Changed treatment other (6 monthly PSA check) to active surveillance |
| | Participant 665145-665136-84600989 changed treatment other (None. I have been discharged) to other (none) |
| | Participant 665145-665136-84600989 changed treatment other (prostatectomy) to surgery |

| | |
|---|---|
| | Participant 665145-665136-83211491 changed treatment other brachytherapy to radiotherapy |
| | Participant 665145-665136-82893513 Changed treatment other (Annual PSA test) to active surveillance |
| | Participant 665145-665136-79921805 changed treatment other (None as successful prostatectomy in 2018) to other (none) |
| | Participant 665145-665136-79990117 Changed treatment other prostatectomy July 2020 to surgery |
| | Changed all Treatment Other (None) to its own category (None) as high number (24) |
| | Changed all Treatment Other (Chemotherapy) to its own category (Chemotherapy) as high number (11) |
| Illness Representations (IPQ-R) | Participant 665145-665136-79944540 changed stiff joints and sore eyes related to prostate cancer answer to No, as they had reported that they had not experienced the symptom |
| | Participant 665145-665136-79928091 changed wheeziness related to prostate cancer answer to No, as they had reported that they had not experienced the symptom |
| | Participant 665145-665136-80877598 changed breathlessness and sleep difficulties related to prostate cancer answer to No, as they had reported that they had not experienced the symptom |
| | Participant 665145-665136-81779001 changed stiff joints related to prostate cancer answer to No, as they had reported that they had not experienced the symptom |
| | Participant 665145-665136-82904882 changed sleep difficulties related to prostate cancer answer to No, as they had reported that they had not experienced the symptom |
| | Participant 665145-665136-82996844 changed wheeziness related to prostate cancer answer to No, as they had reported that they had not experienced the symptom |
| | Participant 665145-665136-83057305 changed loss of strength related to prostate cancer answer to No, as they had reported that they had not experienced the symptom |
| | Participant 665145-665136-83102232 changed pain, nausea, and weight change related to prostate cancer answer to No, as they had reported that they had not experienced the symptom |

| | |
|---|---|
| | Participant 665145-665136-83211491 changed fatigue related to prostate cancer answer to No, as they had reported that they had not experienced the symptom |
| | Participant 665145-665136-83132338 changed pain, nausea, breathlessness, fatigue, stiff joints, sore eyes, upset stomach, dizziness, loss of strength, sore throat and wheeziness related to prostate cancer answer to No, as they had reported that they had not experienced the symptoms |
| | |
| | Participant 665145-665136-82920431 reported agree that prostate cancer will last a short time, but also agreed that it would be permanent, that it will last a long time, and that they will have it for the rest of their life. Agreed with supervisors to take first response as correct and recode the contradictory responses as the opposite coding |
| | Participant 665145-665136-82897602 strongly agree that prostate cancer will last a short time, but also strongly agreed that it would be permanent, that it will last a long time, strongly disagreed that it would pass quickly, and strongly agreed that they will have it for the rest of their life. Agreed with supervisors to take first response as correct and recode the contradictory responses as the opposite coding |
| | Participant 665145-665136-82926926 reported agree that prostate cancer will last a short time, but also agreed that it would be permanent, that it will last a long time, disagreed it would pass quickly and agreed that they will have it for the rest of their life. Agreed with supervisors to take first response as correct and recode the contradictory responses as the opposite coding |
| | Participant 665145-665136-82952817 reported strongly agree that prostate cancer will last a short time, but also strongly agreed that it would be permanent, agreed that it will last a long time, strongly disagreed it would pass quickly and agreed that they will have it for the rest of their life. Agreed with supervisors to take first response as correct and recode the contradictory responses as the opposite coding |
| | Participant 665145-665136-82986311 reported strongly agree that prostate cancer will last a short time, but also strongly |

| | |
|---|---|
| | agreed that it would be permanent, that it will last a long time, strongly disagreed it would pass quickly and strongly agreed that they will have it for the rest of their life. Agreed with supervisors to take first response as correct and recode the contradictory responses as the opposite coding |
| | Participant 665145-665136-83113211 reported agree that prostate cancer will last a short time, but also agreed that it would be permanent, that it will last a long time, strongly disagreed it would pass quickly and agreed that they will have it for the rest of their life. Agreed with supervisors to take first response as correct and recode the contradictory responses as the opposite coding |

# Appendix D

## Treatment category frequencies

| Level | Treatment combination | n (%) |
|---|---|---|
| Current treatment | Active Surveillance | 70 (44.9) |
| | Hormone Therapy | 37 (23.7) |
| | None | 22 (14.1) |
| | Surgery | 9 (5.8) |
| | Active Surveillance, Hormone Therapy | 4 (2.6) |
| | Hormone Therapy, Other | 3 (1.9) |
| | Radiotherapy | 2 (1.3) |
| | Chemotherapy | 2 (1.3) |
| | Other | 2 (1.3) |
| | Active Surveillance, Radiotherapy | 1 (0.6) |
| | Active Surveillance, Radiotherapy, Hormone Therapy | 1 (0.6) |
| | Radiotherapy, Hormone Therapy | 1 (0.6) |
| | Active Surveillance, Other | 1 (0.6) |
| | Hormone Therapy, Chemotherapy | 1 (0.6) |
| Previous treatment | Surgery | 31 (19.9) |
| | Radiotherapy, Hormone Therapy | 26 (16.7) |
| | Active Surveillance | 16 (10.3) |
| | Radiotherapy | 13 (8.3) |
| | Surgery, Radiotherapy, Hormone Therapy | 11 (7.1) |
| | Active Surveillance, Radiotherapy, Hormone Therapy | 11 (7.1) |
| | Surgery, Radiotherapy | 11 (7.1) |
| | Hormone Therapy | 10 (6.4) |
| | Surgery, Radiotherapy, Hormone Therapy, Chemotherapy | 3 (1.9) |
| | Active Surveillance, Surgery, Radiotherapy, Hormone Therapy | 3 (1.9) |
| | None | 2 (1.3) |
| | Radiotherapy, Hormone Therapy, Chemotherapy | 2 (1.3) |
| | Active Surveillance, Surgery | 2 (1.3) |
| | Radiotherapy, Other | 2 (1.3) |
| | Hormone Therapy, Chemotherapy | 2 (1.3) |
| | Other | 2 (1.3) |
| | Surgery, Radiotherapy, Hormone Therapy, Other | 1 (0.6) |
| | Radiotherapy, Hormone Therapy, Other | 1 (0.6) |

| | | |
|---|---|---|
| | Active Surveillance, Surgery, Radiotherapy | 1 (0.6) |
| | Active Surveillance, Hormone Therapy | 1 (0.6) |
| | Surgery, Hormone Therapy | 1 (0.6) |
| | Active Surveillance, Other | 1 (0.6) |
| | Hormone Therapy, Other | 1 (0.6) |
| | Surgery, Other | 1 (0.6) |
| | Chemotherapy | 1 (0.6) |
| Overall treatment exposure | Active Surveillance,Radiotherapy,Hormone Therapy | 25 (16) |
| | Active Surveillance,Surgery | 20 (12.8) |
| | Radiotherapy,Hormone Therapy | 13 (8.3) |
| | Surgery | 13 (8.3) |
| | Active Surveillance | 11 (7.1) |
| | Surgery,Radiotherapy,Hormone Therapy | 11 (7.1) |
| | Hormone Therapy | 9 (5.8) |
| | Active Surveillance,Radiotherapy | 8 (5.1) |
| | Active Surveillance,Surgery,Radiotherapy | 7 (4.5) |
| | Active Surveillance,Radiotherapy,Hormone Therapy,Surgery | 6 (3.8) |
| | Surgery,Hormone Therapy | 3 (1.9) |
| | Radiotherapy | 3 (1.9) |
| | Surgery,Radiotherapy,Hormone Therapy,Chemotherapy | 3 (1.9) |
| | Hormone Therapy,Chemotherapy | 3 (1.9) |
| | Surgery,Radiotherapy,Hormone Therapy,Other | 3 (1.9) |
| | Radiotherapy,Hormone Therapy,Chemotherapy | 2 (1.3) |
| | Active Surveillance,Other | 2 (1.3) |
| | Surgery,Radiotherapy | 2 (1.3) |
| | Active Surveillance,Hormone Therapy | 2 (1.3) |
| | Other | 1 (0.6) |
| | Radiotherapy,Hormone Therapy,Other | 1 (0.6) |
| | Active Surveillance,Surgery,Other | 1 (0.6) |
| | Active Surveillance,Hormone Therapy,Other | 1 (0.6) |
| | None | 1 (0.6) |
| | Hormone Therapy,Other | 1 (0.6) |
| | Radiotherapy,Hormone Therapy,Chemotherapy,Other | 1 (0.6) |
| | Active Surveillance,Radiotherapy,Hormone Therapy,Chemotherapy | 1 (0.6) |
| | Active Surveillance,Radiotherapy,Other | 1 (0.6) |
| | Active Surveillance,Radiotherapy,Hormone,Chemotherapy,Other | 1 (0.6) |

# Appendix E

# Selected SPSS output

## E.1 Sensitivity analysis

Related-Samples Wilcoxon Signed Rank Test

IPQ consequence unchanged subscale score, IPQ consequence changed subscale score

**Statistics**

| | | IPQ consequence unchanged subscale score | IPQ consequence changed subscale score |
|---|---|---|---|
| N | Valid | 156 | 156 |
| | Missing | 0 | 0 |
| Percentiles | 25 | 15.00 | 15.25 |
| | 50 | 18.00 | 18.00 |
| | 75 | 20.00 | 21.00 |

**Hypothesis Test Summary**

| | Null Hypothesis | Test | Sig. |
|---|---|---|---|
| 1 | The median of differences between IPQ consequence unchanged subscale score and IPQ consequence changed subscale score equals 0. | Related-Samples Wilcoxon Signed Rank Test | .005 |

**Related-Samples Wilcoxon Signed Rank Test Summary**

| | |
|---|---|
| Total N | 156 |
| Test Statistic | 45.000 |
| Standard Error | 8.016 |
| Standardized Test Statistic | 2.807 |
| Asymptotic Sig.(2-sided test) | .005 |

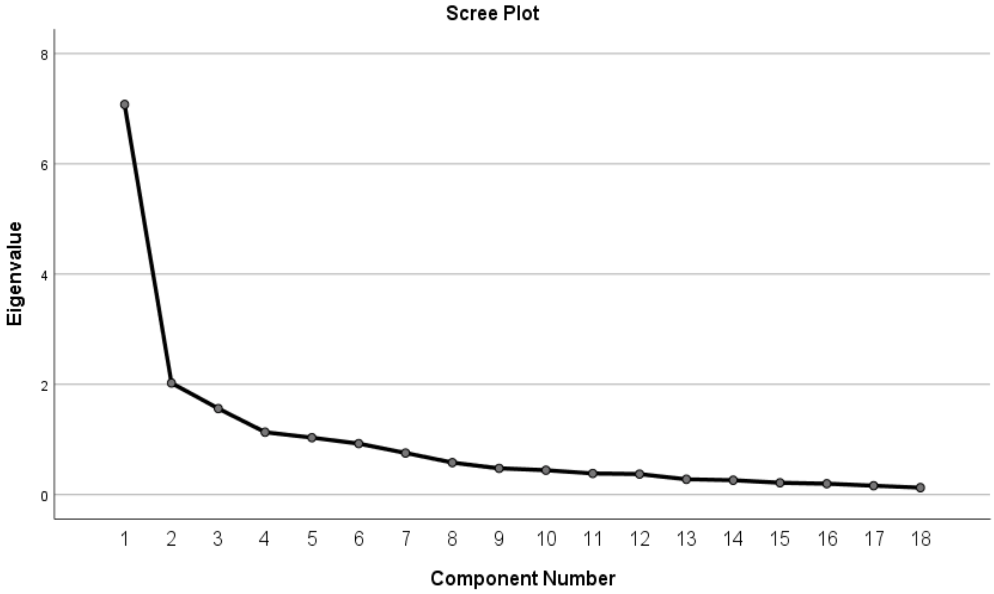
## E.2 Principal components analysis for the causal section of the IPQ-R

**KMO and Bartlett's Test**

| | | |
|---|---|---|
| Kaiser-Meyer-Olkin Measure of Sampling Adequacy. | | .875 |
| Bartlett's Test of Sphericity | Approx. Chi-Square | 1603.841 |
| | df | 153 |
| | Sig. | .000 |

**Total Variance Explained**

| | Initial Eigenvalues | | | Extraction Sums of Squared Loadings | | |
|---|---|---|---|---|---|---|
| Component | Total | % of Variance | Cumulative % | Total | % of Variance | Cumulative % |
| 1 | 7.076 | 39.311 | 39.311 | 7.076 | 39.311 | 39.311 |
| 2 | 2.024 | 11.243 | 50.554 | 2.024 | 11.243 | 50.554 |
| 3 | 1.562 | 8.676 | 59.229 | 1.562 | 8.676 | 59.229 |
| 4 | 1.132 | 6.290 | 65.519 | | | |
| 5 | 1.033 | 5.740 | 71.260 | | | |
| 6 | .926 | 5.143 | 76.403 | | | |
| 7 | .755 | 4.193 | 80.597 | | | |
| 8 | .581 | 3.226 | 83.823 | | | |
| 9 | .476 | 2.645 | 86.468 | | | |
| 10 | .442 | 2.456 | 88.924 | | | |
| 11 | .383 | 2.130 | 91.054 | | | |
| 12 | .372 | 2.067 | 93.121 | | | |
| 13 | .278 | 1.545 | 94.666 | | | |
| 14 | .260 | 1.447 | 96.113 | | | |
| 15 | .215 | 1.196 | 97.309 | | | |
| 16 | .197 | 1.095 | 98.404 | | | |
| 17 | .161 | .897 | 99.301 | | | |
| 18 | .126 | .699 | 100.000 | | | |



Extraction Method: Principal Component Analysis.[a]

a. 3 components extracted.

### Pattern Matrix[a]

| | Component | | |
|---|---|---|---|
| | 1 | 2 | 3 |
| IPQ_Cause_Stress | .903 | | |
| IPQ_Causes_Mental_attitude | .871 | | |
| IPQ_Causes_Emotional_state | .843 | | |
| IPQ_Causes_Personality | .837 | | |
| IPQ_Causes_Overwork | .830 | | |
| IPQ_Causes_Family_problems | .827 | | |
| IPQ_Causes_Behaviour | .492 | | .365 |
| IPQ_Causes_Germ_Virus | | .852 | |
| IPQ_Causes_Altered_Immunity | | .815 | |
| IPQ_Causes_Pollution | | .781 | |
| IPQ_Causes_Accident_Injury | | .660 | |
| IPQ_Causes_Chance | | | |
| IPQ_Causes_Ageing | | | .704 |
| IPQ_Causes_Alcohol | | | .687 |
| IPQ_Causes_Smoking | | .385 | .624 |
| IPQ_Causes_Poor_medical_care | | | .557 |
| IPQ_Causes_Diet | .374 | | .411 |
| IPQ_Causes_Hereditary | | | .320 |

Extraction Method: Principal Component Analysis.
Rotation Method: Oblimin with Kaiser Normalization.[a]
a. Rotation converged in 6 iterations.

## Structure Matrix

| | Component | | |
|---|---|---|---|
| | 1 | 2 | 3 |
| IPQ_Causes_Emotional_state | .887 | .329 | .389 |
| IPQ_Cause_Stress | .875 | | |
| IPQ_Causes_Mental_attitude | .874 | | .344 |
| IPQ_Causes_Personality | .872 | .353 | .330 |
| IPQ_Causes_Overwork | .855 | .406 | |
| IPQ_Causes_Family_problems | .806 | .339 | |
| IPQ_Causes_Behaviour | .656 | .337 | .552 |
| IPQ_Causes_Diet | .572 | .359 | .566 |
| IPQ_Causes_Germ_Virus | .301 | .862 | |
| IPQ_Causes_Altered_Immunity | .312 | .831 | |
| IPQ_Causes_Pollution | .384 | .822 | |
| IPQ_Causes_Accident_Injury | .421 | .731 | |
| IPQ_Causes_Chance | | | |
| IPQ_Causes_Alcohol | .368 | .382 | .743 |
| IPQ_Causes_Ageing | | | .645 |
| IPQ_Causes_Smoking | | .433 | .634 |
| IPQ_Causes_Poor_medical_care | .382 | | .626 |
| IPQ_Causes_Hereditary | | | .360 |

Extraction Method: Principal Component Analysis.
Rotation Method: Oblimin with Kaiser Normalization.

## Component Correlation Matrix

| Component | 1 | 2 | 3 |
|---|---|---|---|
| 1 | 1.000 | .329 | .343 |
| 2 | .329 | 1.000 | .154 |
| 3 | .343 | .154 | 1.000 |

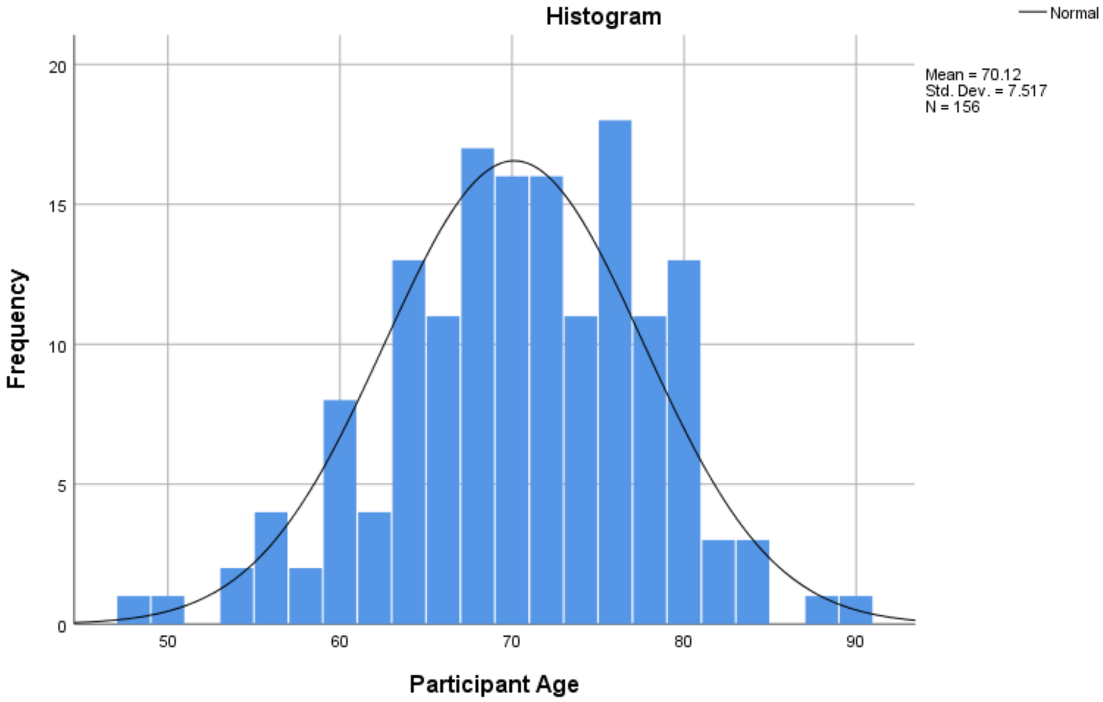
Extraction Method: Principal Component Analysis.
Rotation Method: Oblimin with Kaiser Normalization.

## E.3 Descriptive statistics to examine the distribution of the data

### Tests of Normality

| | Kolmogorov-Smirnov[a] | | | Shapiro-Wilk | | |
|---|---|---|---|---|---|---|
| | Statistic | df | Sig. | Statistic | df | Sig. |
| Participant Age | .069 | 156 | .068 | .990 | 156 | .357 |

a. Lilliefors Significance Correction



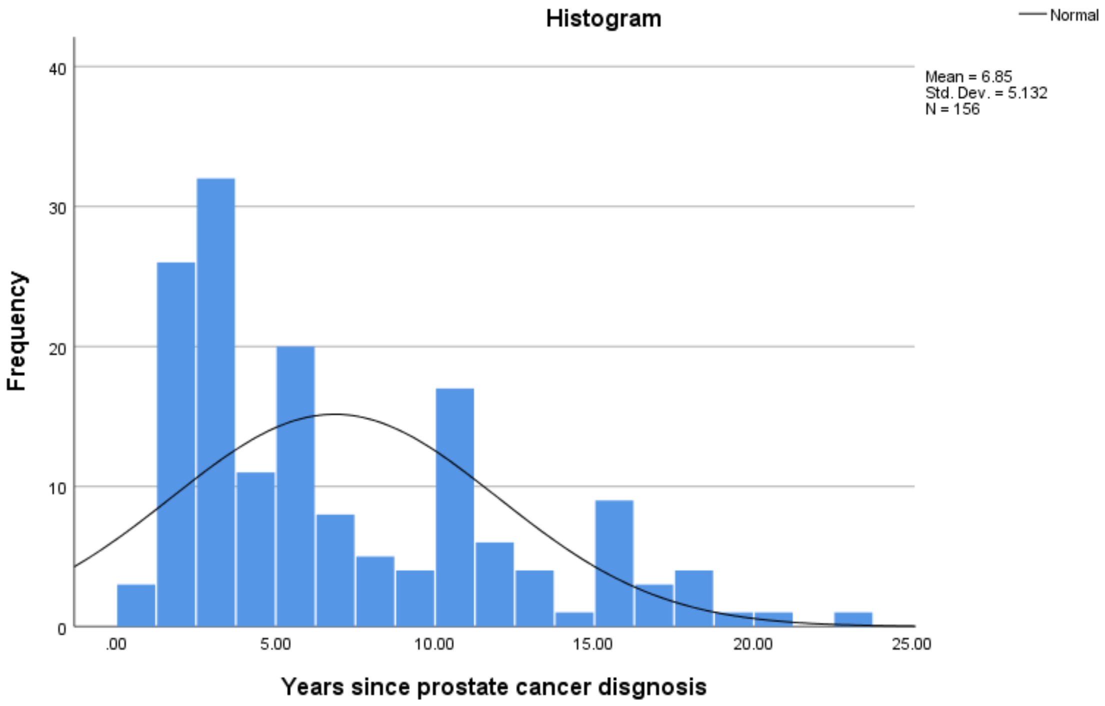
### Tests of Normality

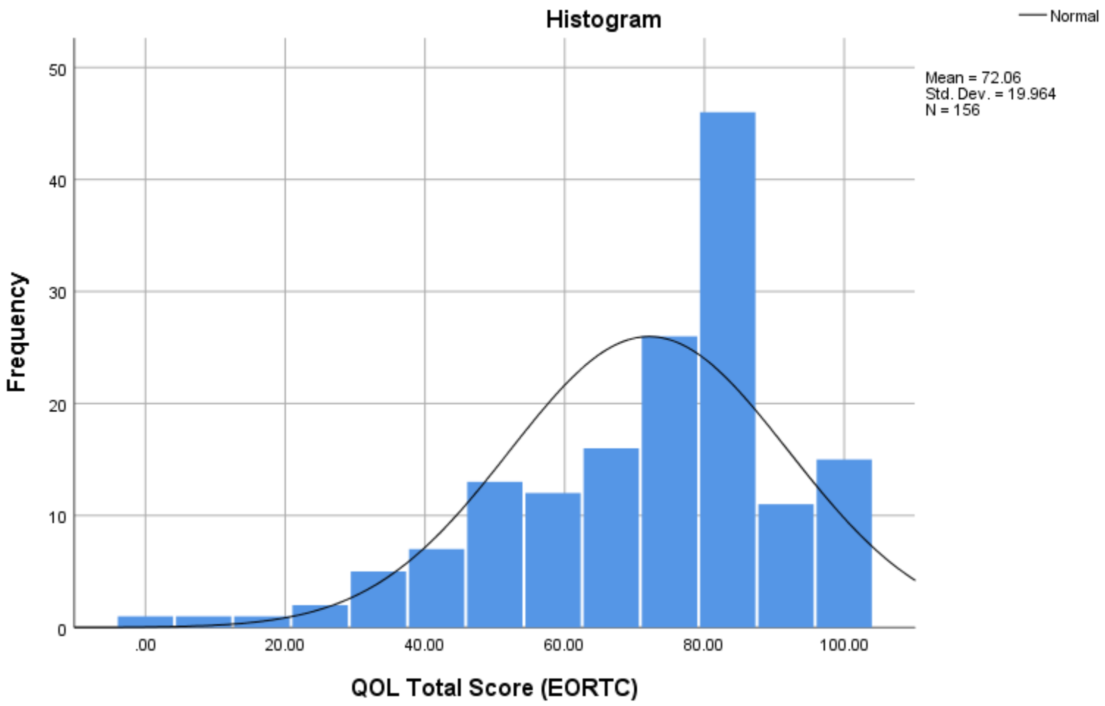
| | Kolmogorov-Smirnov[a] | | | Shapiro-Wilk | | |
|---|---|---|---|---|---|---|
| | Statistic | df | Sig. | Statistic | df | Sig. |
| Years since prostate cancer diagnosis | .173 | 156 | .000 | .876 | 156 | .000 |
| QOL Total Score (EORTC) | .187 | 156 | .000 | .913 | 156 | .000 |
| QOL Functional Subscale Score (EORTC) | .160 | 156 | .000 | .894 | 156 | .000 |
| QOL Symptom Subscale Score (EORTC) | .145 | 156 | .000 | .880 | 156 | .000 |
| Depression raw score (PHQ8) | .201 | 156 | .000 | .840 | 156 | .000 |
| Anxiety raw score (GAD7) | .186 | 156 | .000 | .837 | 156 | .000 |
| IPQ identity subscale score | .180 | 156 | .000 | .865 | 156 | .000 |

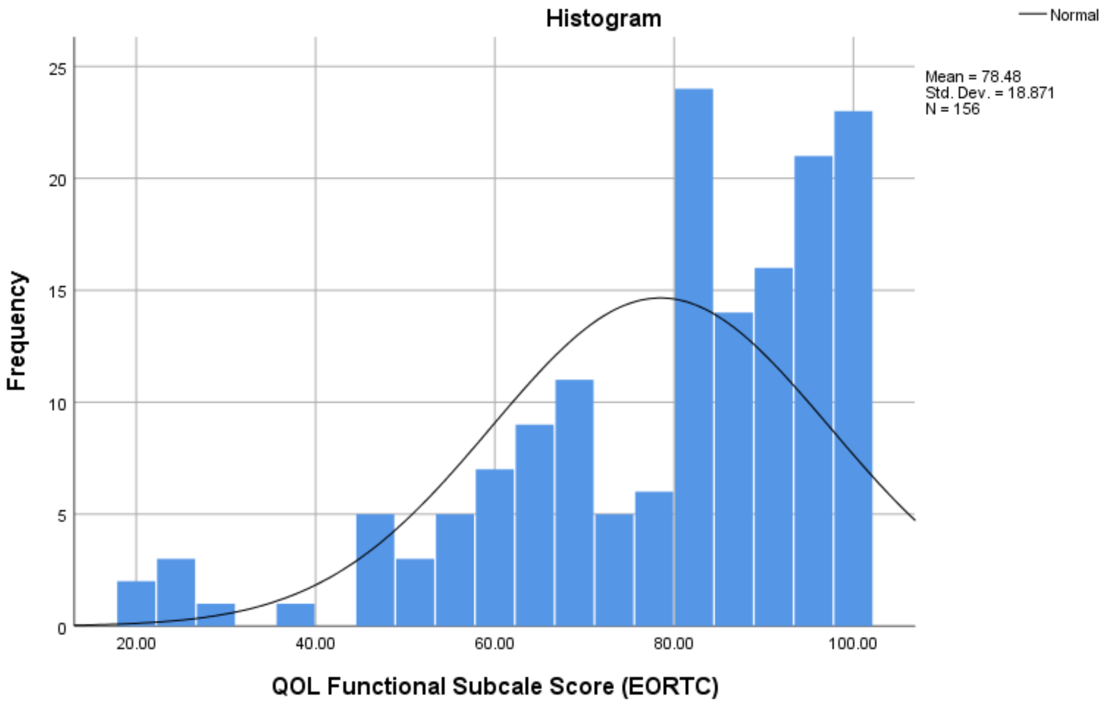
| | | | | | | |
|---|---|---|---|---|---|---|
| IPQ timeline (acute / chronic) subscale score | .242 | 156 | .000 | .797 | 156 | .000 |
| IPQ consequence unchanged subscale score | .089 | 156 | .004 | .980 | 156 | .021 |
| IPQ consequence changed subscale score | .102 | 156 | .000 | .980 | 156 | .021 |
| IPQ personal control subscale score | .142 | 156 | .000 | .943 | 156 | .000 |
| IPQ treatment control subscale score | .130 | 156 | .000 | .954 | 156 | .000 |
| IPQ illness coherence subscale score | .160 | 156 | .000 | .959 | 156 | .000 |
| IPQ timeline cyclical subscale score | .163 | 156 | .000 | .917 | 156 | .000 |
| IPQ Emotional representations subscale score | .102 | 156 | .000 | .977 | 156 | .009 |
| Body Image Scale raw score | .098 | 156 | .001 | .937 | 156 | .000 |
| Masculinity raw score (MCD-I) | .069 | 156 | .070 | .983 | 156 | .049 |
| Masculinity Strength / Fitness subscale score (MCD-I) | .146 | 156 | .000 | .947 | 156 | .000 |
| Masculinity Sexual Priority / Importance subscale score (MCD-I) | .136 | 156 | .000 | .898 | 156 | .000 |
| Masculinity Family Responsibilities subscale score (MCD-I) | .163 | 156 | .000 | .878 | 156 | .000 |
| Masculinity Emotional Self Reliance subscale score (MCD-I) | .129 | 156 | .000 | .943 | 156 | .000 |
| Masculinity Optimistic Action subscale score (MCD-I) | .057 | 156 | .200* | .979 | 156 | .015 |
| Masculine self-esteem raw score (MSE) | .082 | 156 | .012 | .962 | 156 | .000 |
| Masculine self-esteem standardised score (MSE) | .082 | 156 | .012 | .962 | 156 | .000 |

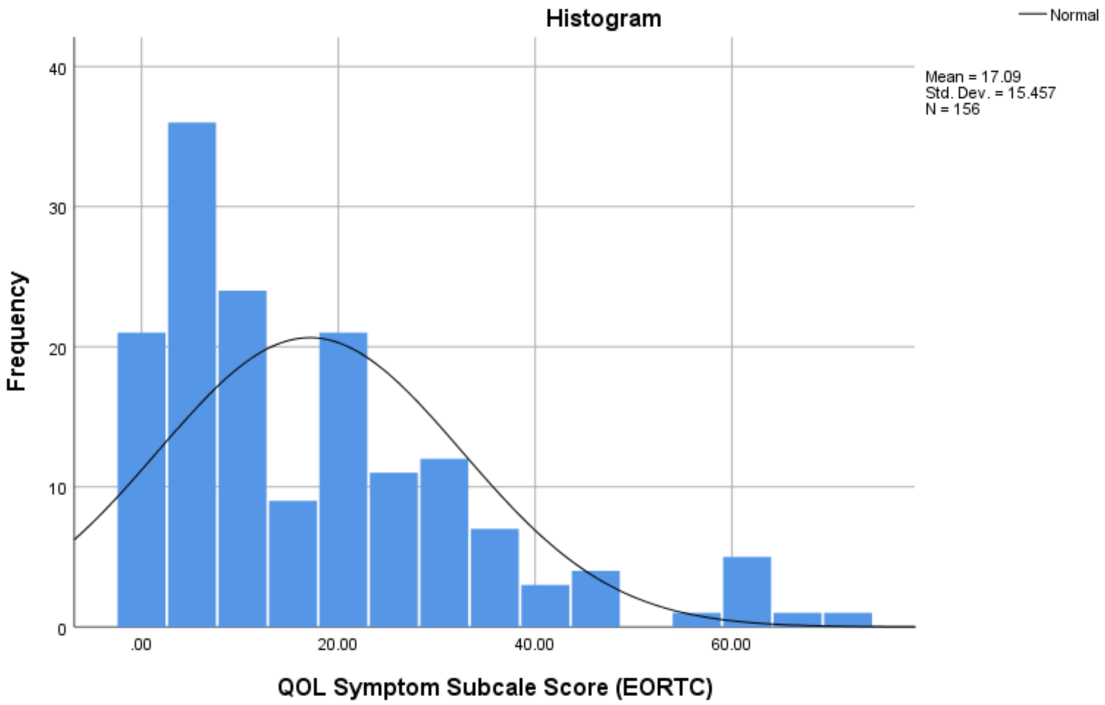
*. This is a lower bound of the true significance.

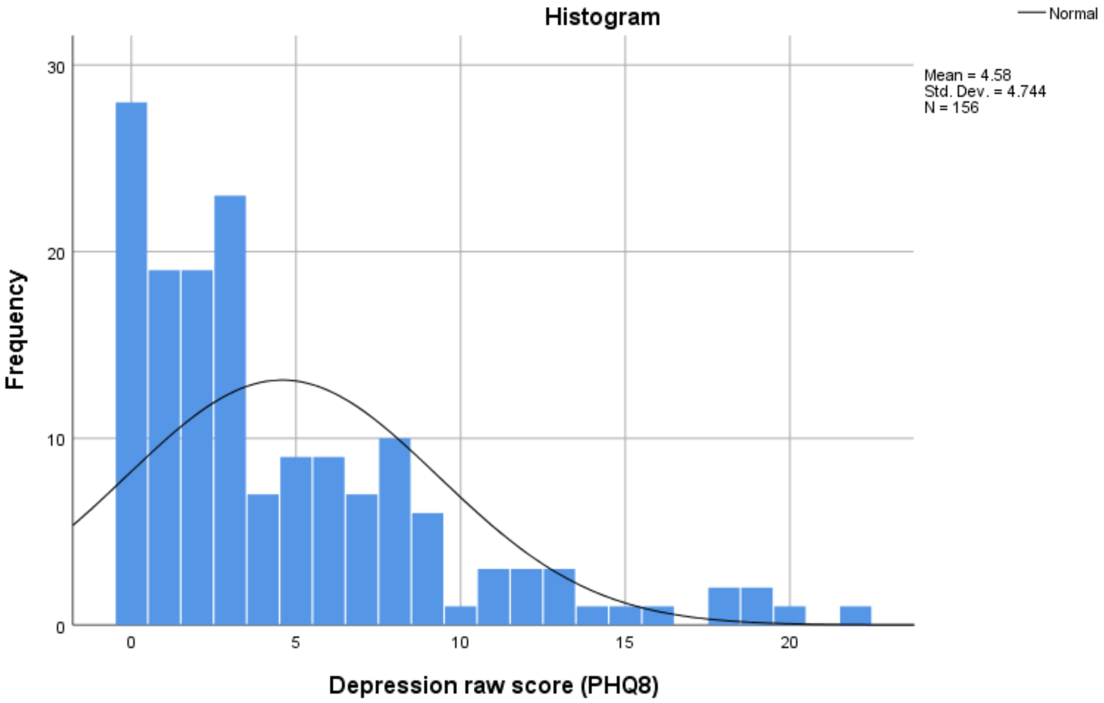
a. Lilliefors Significance Correction

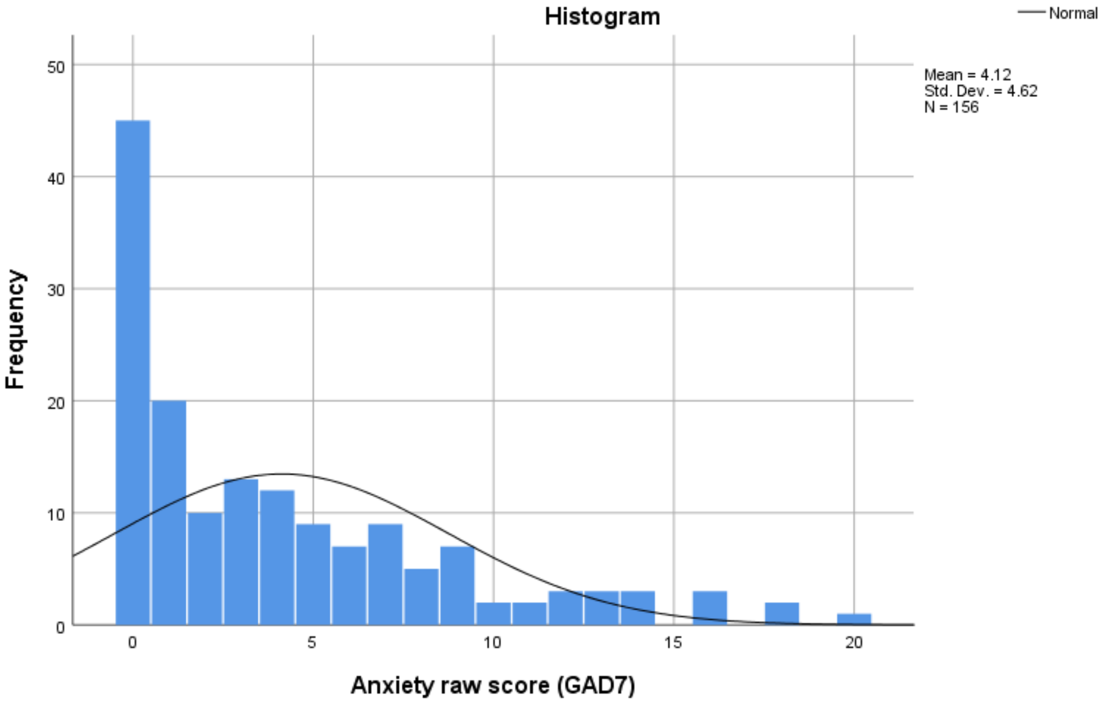

Histogram
Normal
Mean = 6.85
Std. Dev. = 5.132
N = 156
Frequency
0
10
20
30
40
.00
5.00
10.00
15.00
20.00
25.00
Years since prostate cancer disgnosis

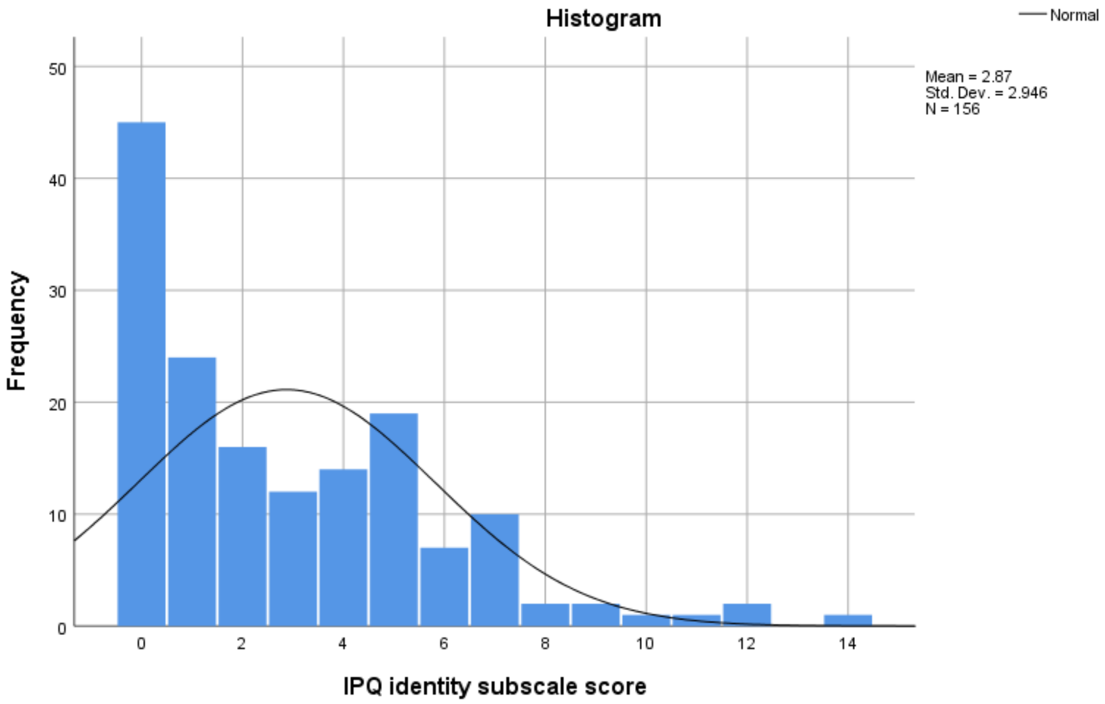

Histogram
Normal
Mean = 72.06
Std. Dev. = 19.964
N = 156
Frequency
0
10
20
30
40
50
.00
20.00
40.00
60.00
80.00
100.00
QOL Total Score (EORTC)

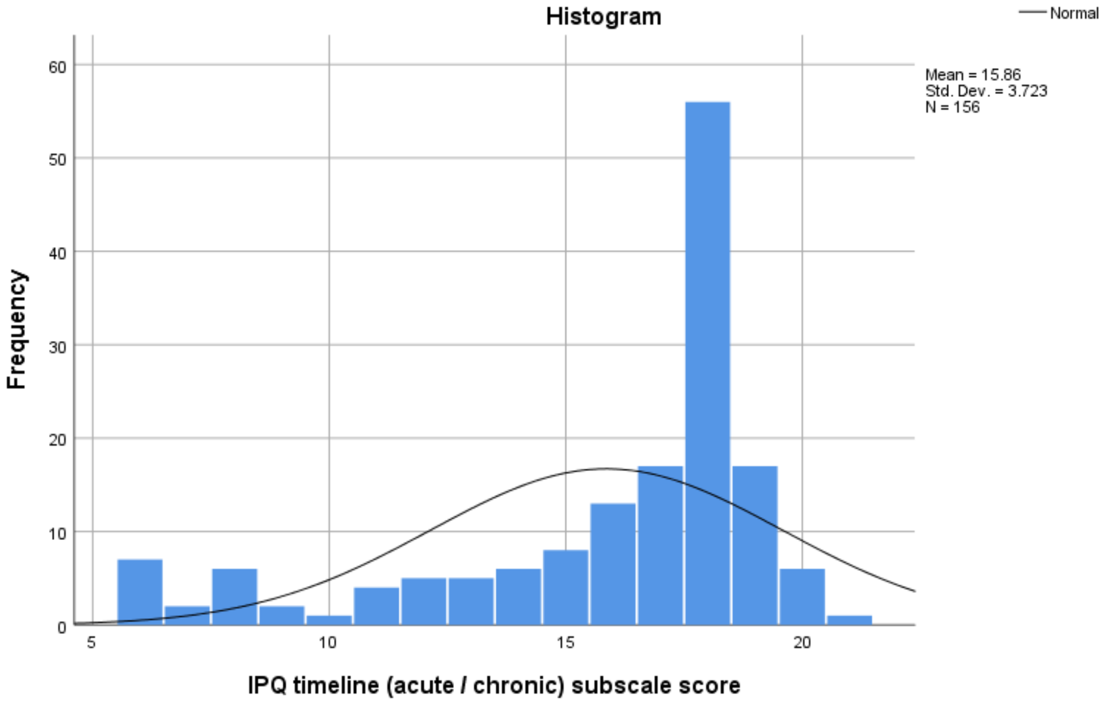

Histogram
Normal
Mean = 78.48
Std. Dev. = 18.871
N = 156
Frequency
25
20
15
10
5
0
20.00
40.00
60.00
80.00
100.00
QOL Functional Subcale Score (EORTC)

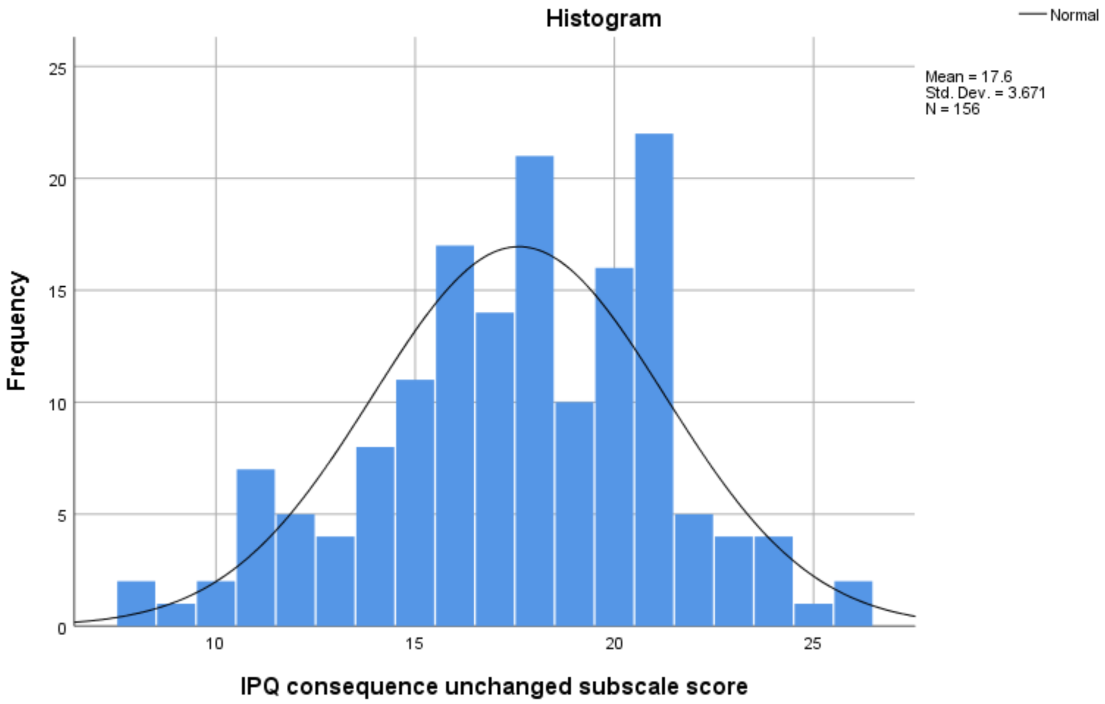

Histogram
Normal
Mean = 17.09
Std. Dev. = 15.457
N = 156
Frequency
40
30
20
10
0
.00
20.00
40.00
60.00
QOL Symptom Subcale Score (EORTC)

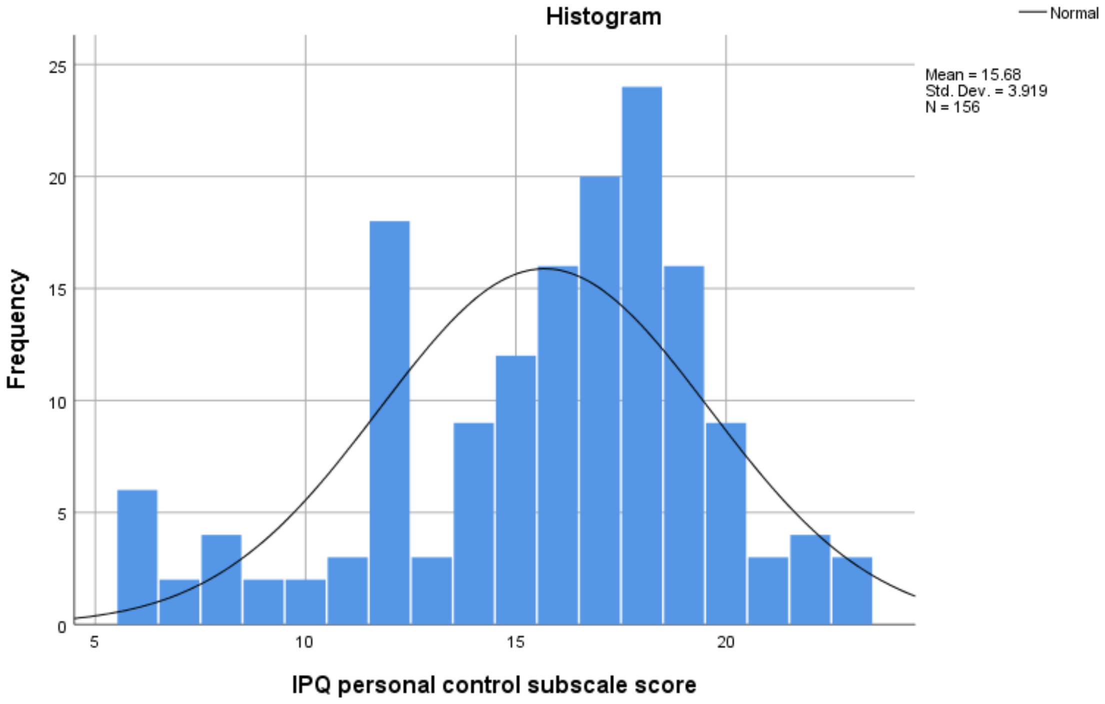

Histogram
Normal
Mean = 4.58
Std. Dev. = 4.744
N = 156
Frequency
30
20
10
0
0
5
10
15
20
Depression raw score (PHQ8)

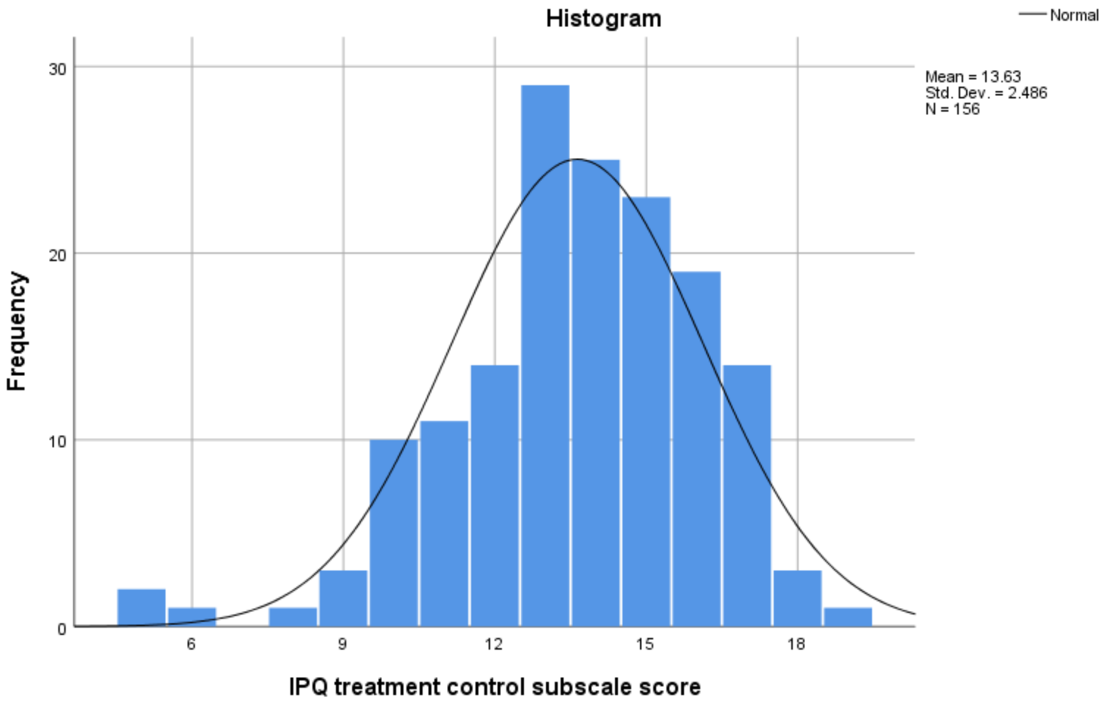

Histogram
Normal
Mean = 4.12
Std. Dev. = 4.62
N = 156
Frequency
50
40
30
20
10
0
0
5
10
15
20
Anxiety raw score (GAD7)

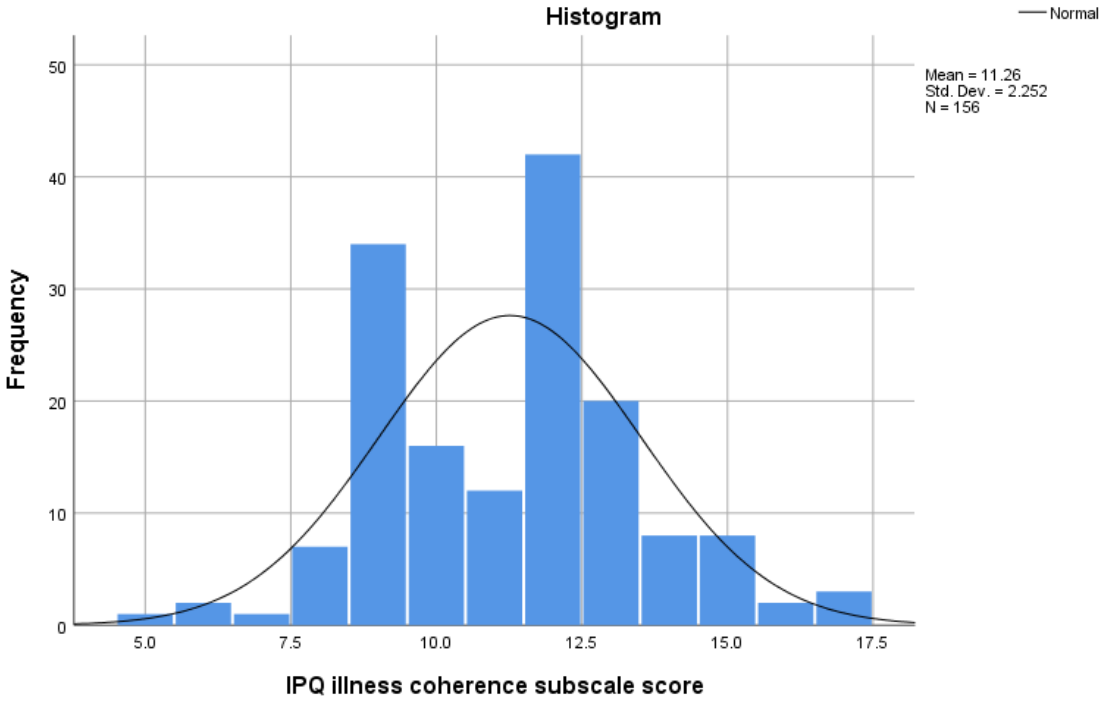

Histogram
Normal
Mean = 2.87
Std. Dev. = 2.946
N = 156
Frequency
0
10
20
30
40
50
0
2
4
6
8
10
12
14
IPQ identity subscale score

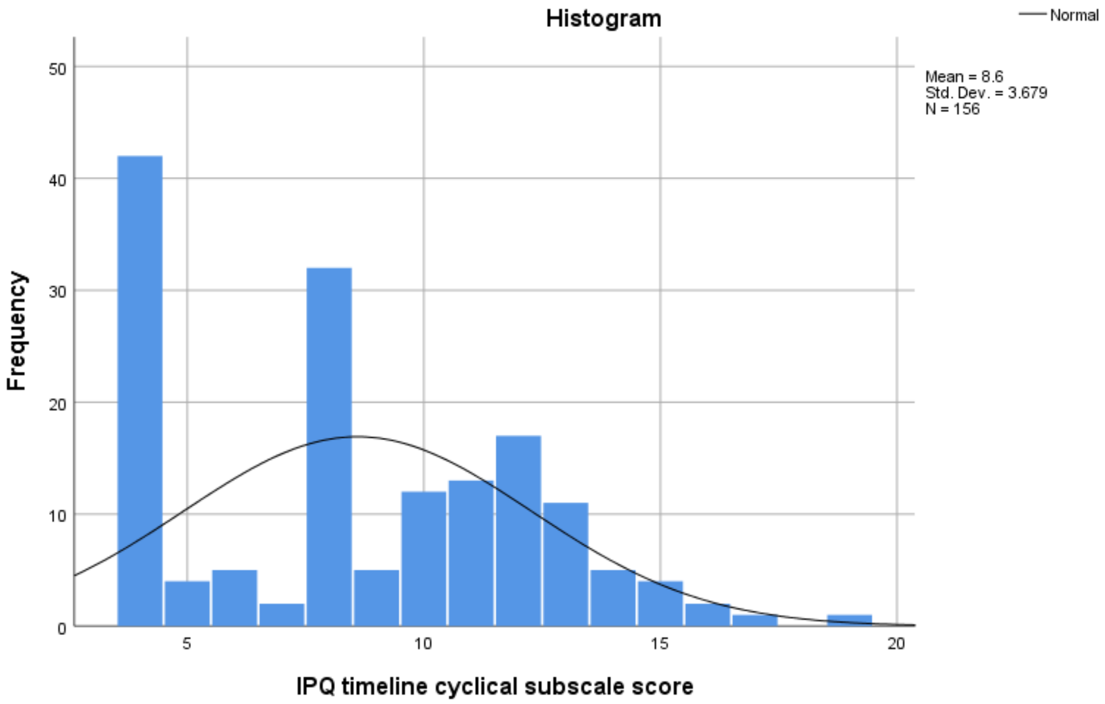

Histogram
Normal
Mean = 15.86
Std. Dev. = 3.723
N = 156
Frequency
0
10
20
30
40
50
60
5
10
15
20
IPQ timeline (acute / chronic) subscale score

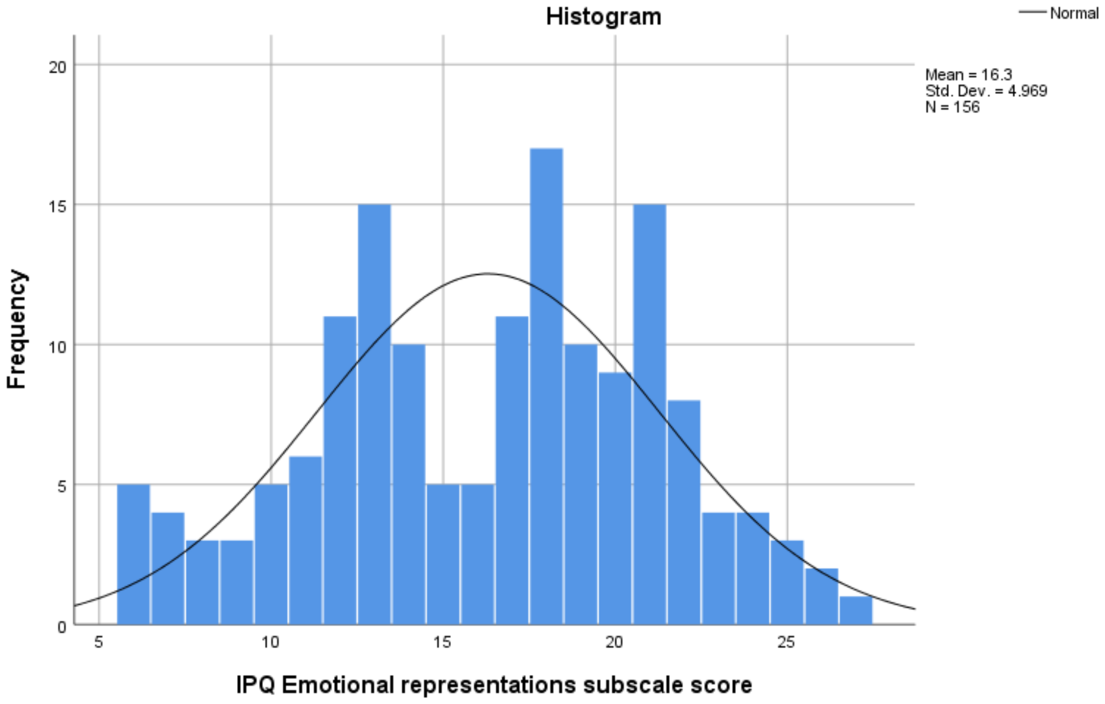

Histogram
Normal
Mean = 17.6
Std. Dev. = 3.671
N = 156
Frequency
0
5
10
15
20
25
10
15
20
25
IPQ consequence unchanged subscale score

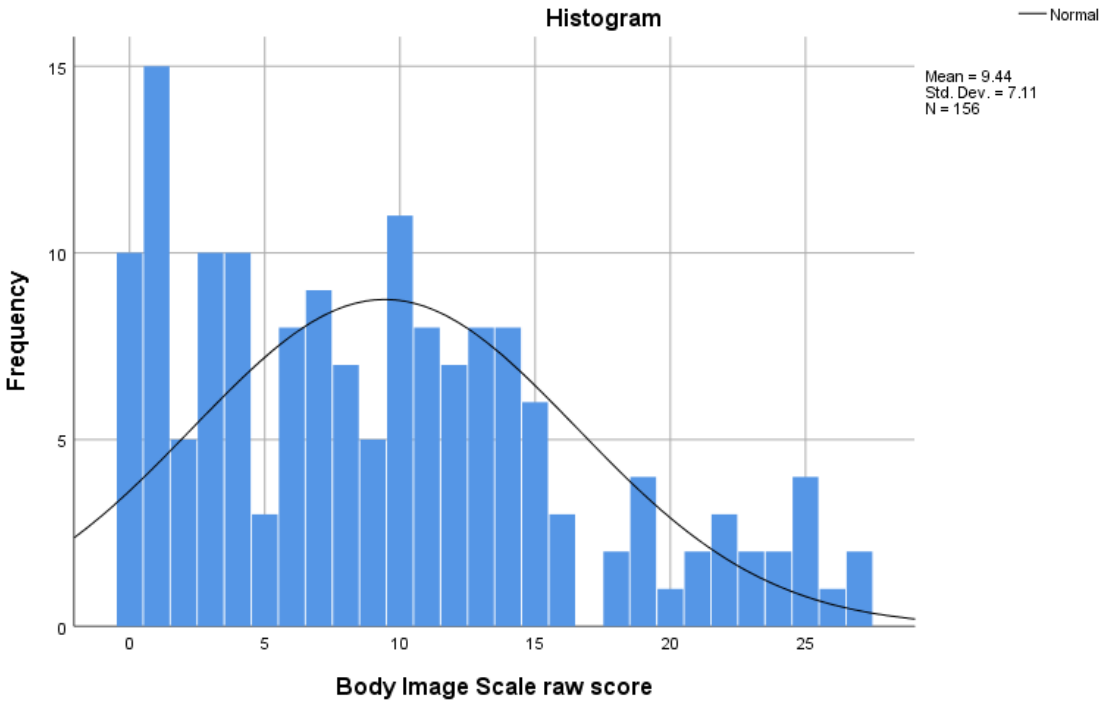

Histogram
Normal
Mean = 15.68
Std. Dev. = 3.919
N = 156
Frequency
0
5
10
15
20
25
5
10
15
20
IPQ personal control subscale score

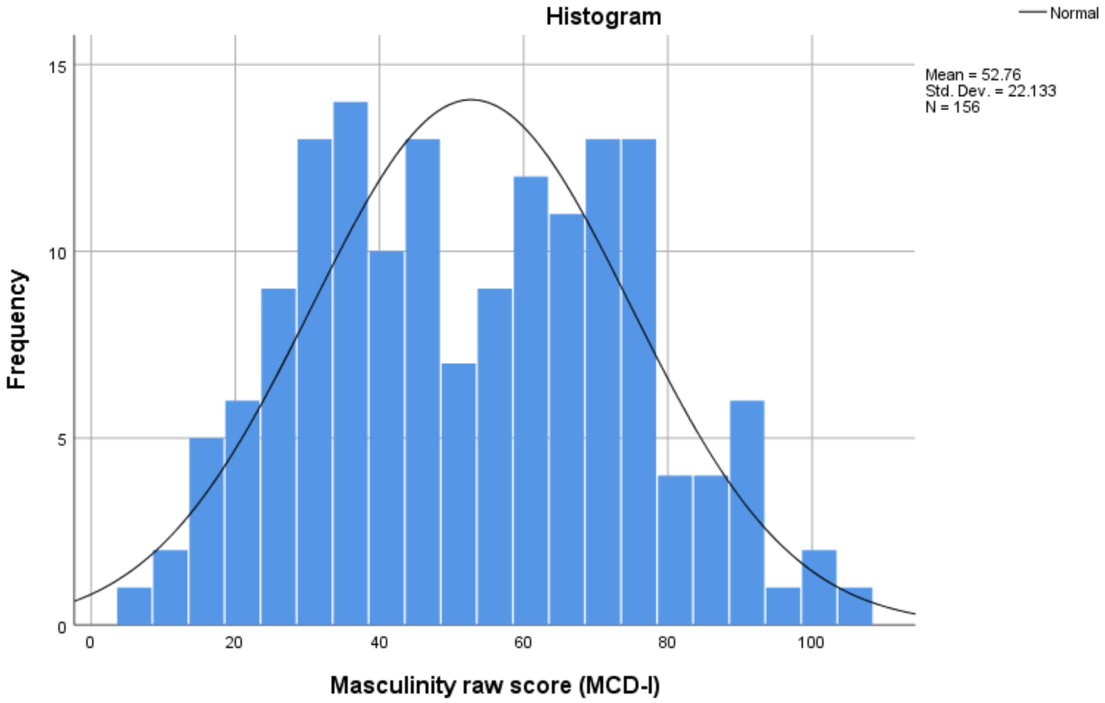

Histogram
Normal
Mean = 13.63
Std. Dev. = 2.486
N = 156
Frequency
30
20
10
0
6
9
12
15
18
IPQ treatment control subscale score

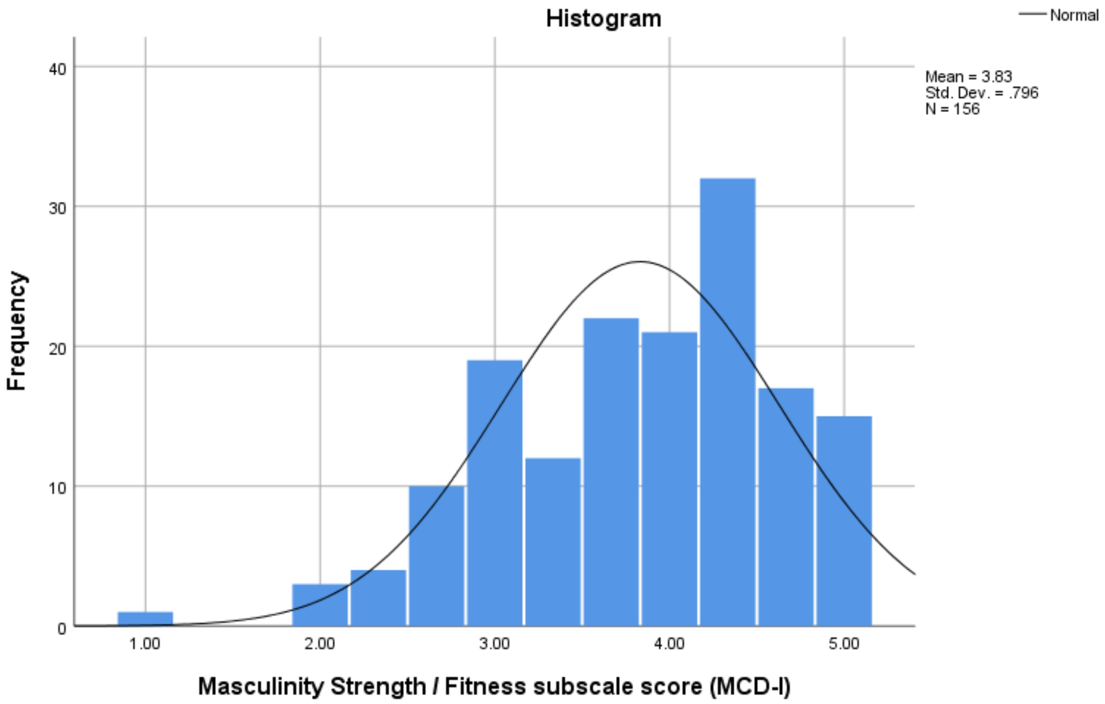

Histogram
Normal
Mean = 11.26
Std. Dev. = 2.252
N = 156
Frequency
50
40
30
20
10
0
5.0
7.5
10.0
12.5
15.0
17.5
IPQ illness coherence subscale score

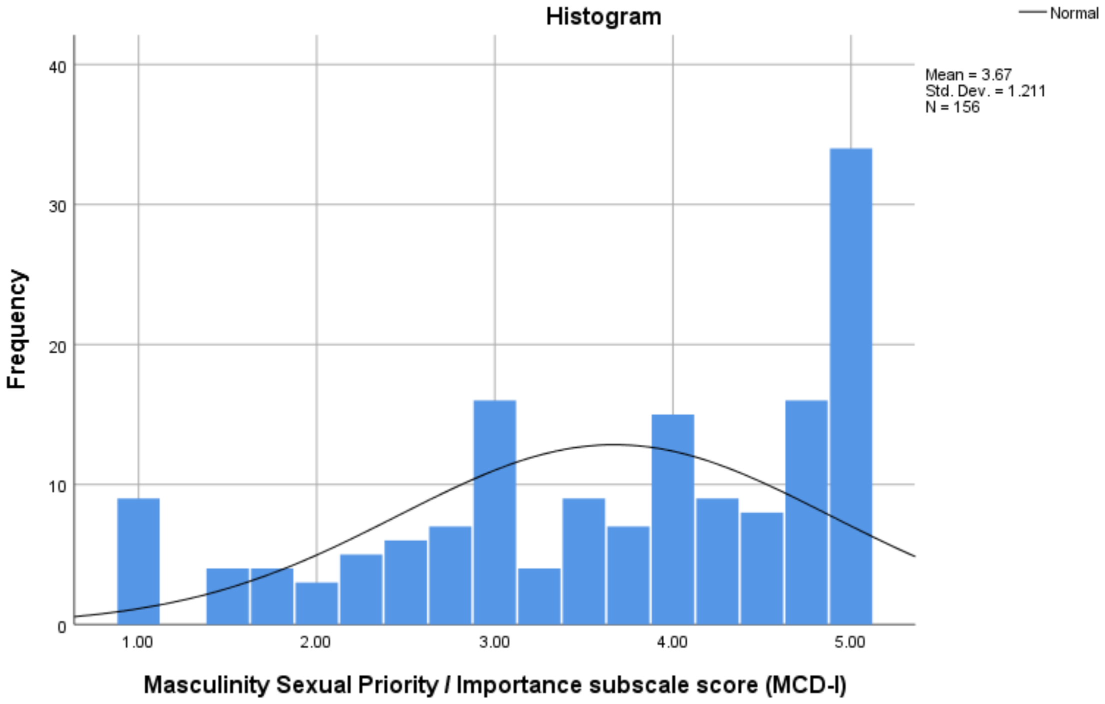

Histogram
Normal
Mean = 8.6
Std. Dev. = 3.679
N = 156
Frequency
0
10
20
30
40
50
5
10
15
20
IPQ timeline cyclical subscale score

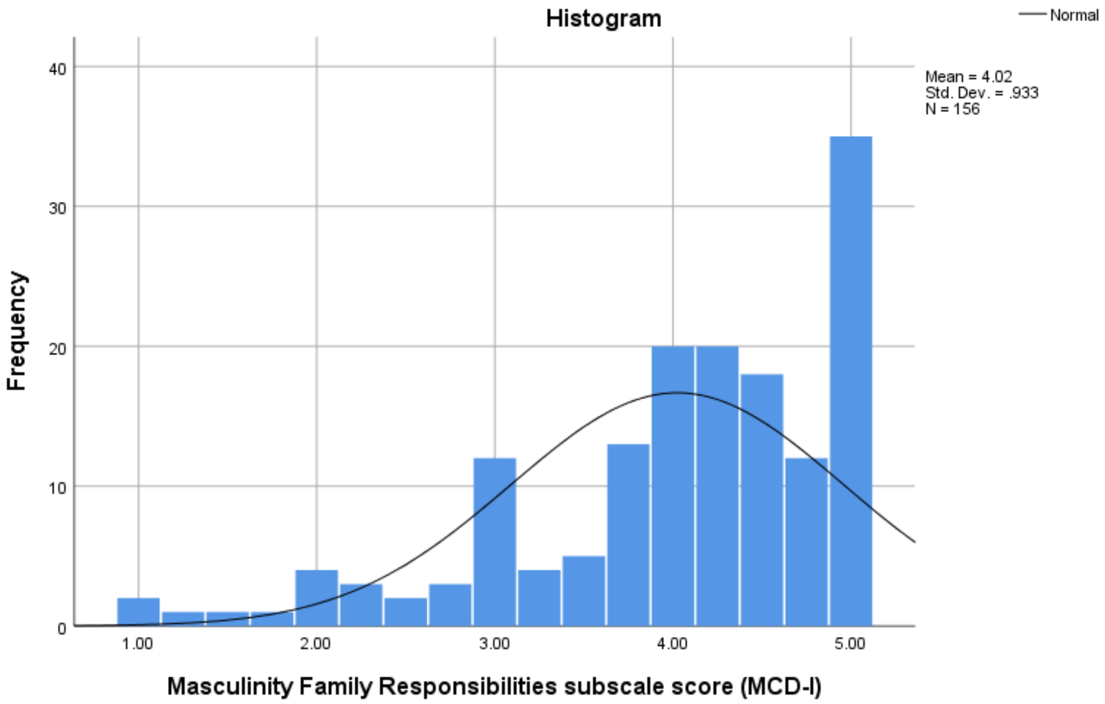

Histogram
Normal
Mean = 16.3
Std. Dev. = 4.969
N = 156
Frequency
0
5
10
15
20
5
10
15
20
25
IPQ Emotional representations subscale score

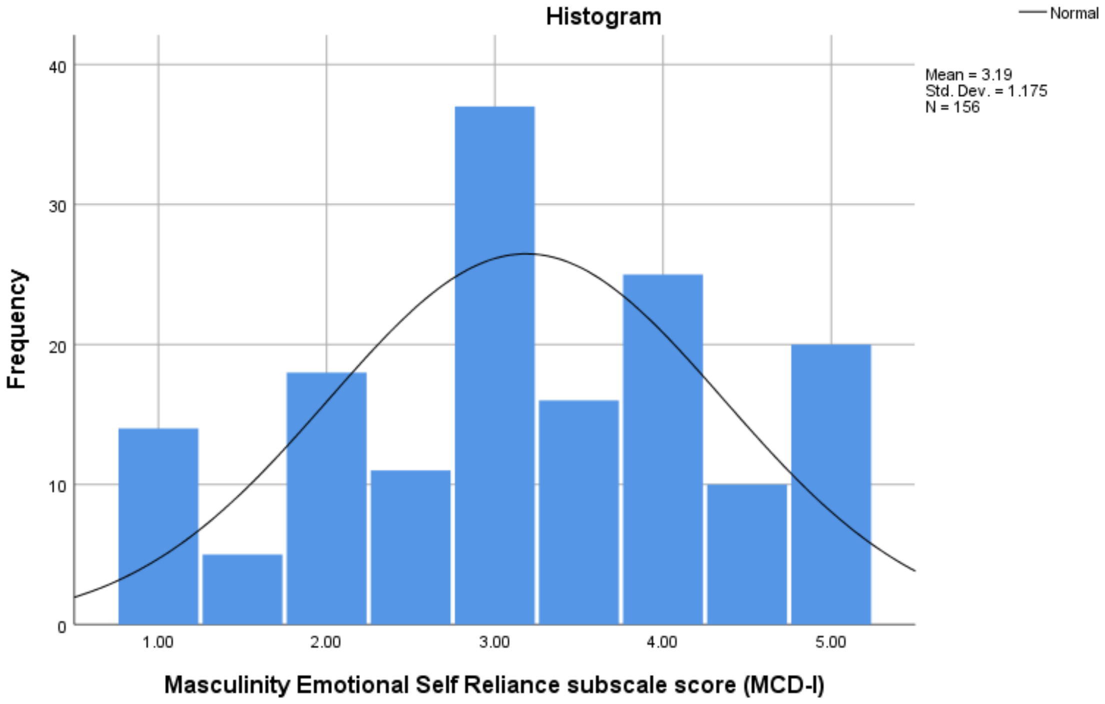

Histogram
Normal
Mean = 9.44
Std. Dev. = 7.11
N = 156
Frequency
15
10
5
0
0
5
10
15
20
25
Body Image Scale raw score

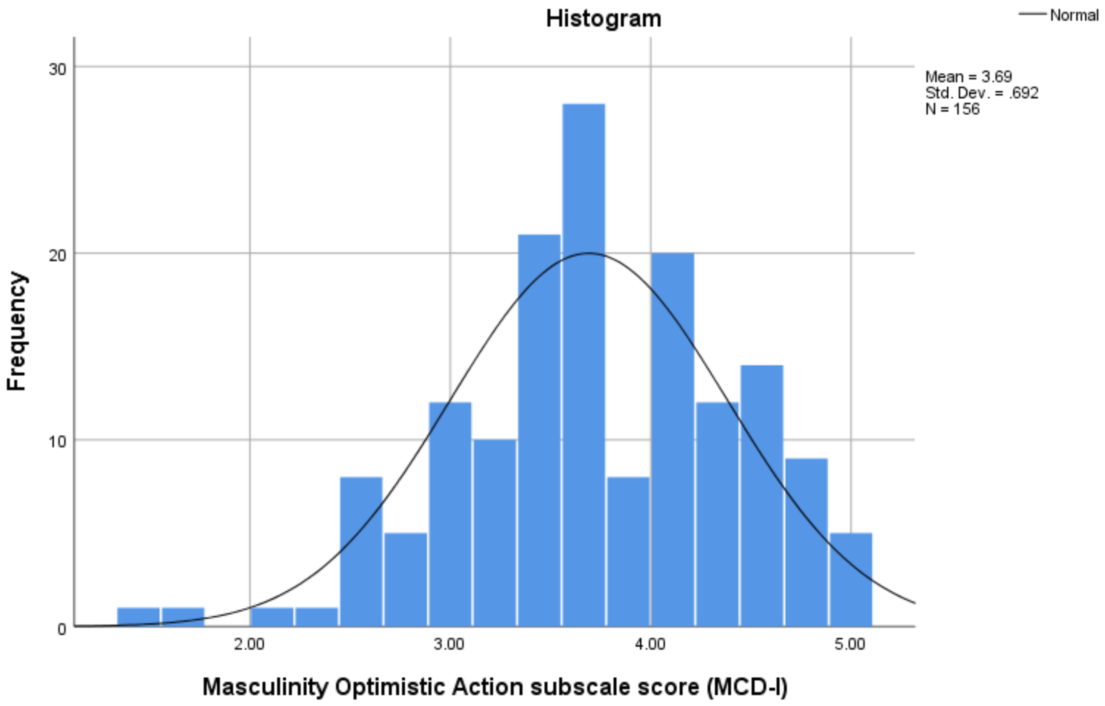

Histogram
Normal
Mean = 52.76
Std. Dev. = 22.133
N = 156
Frequency
15
10
5
0
0
20
40
60
80
100
Masculinity raw score (MCD-I)

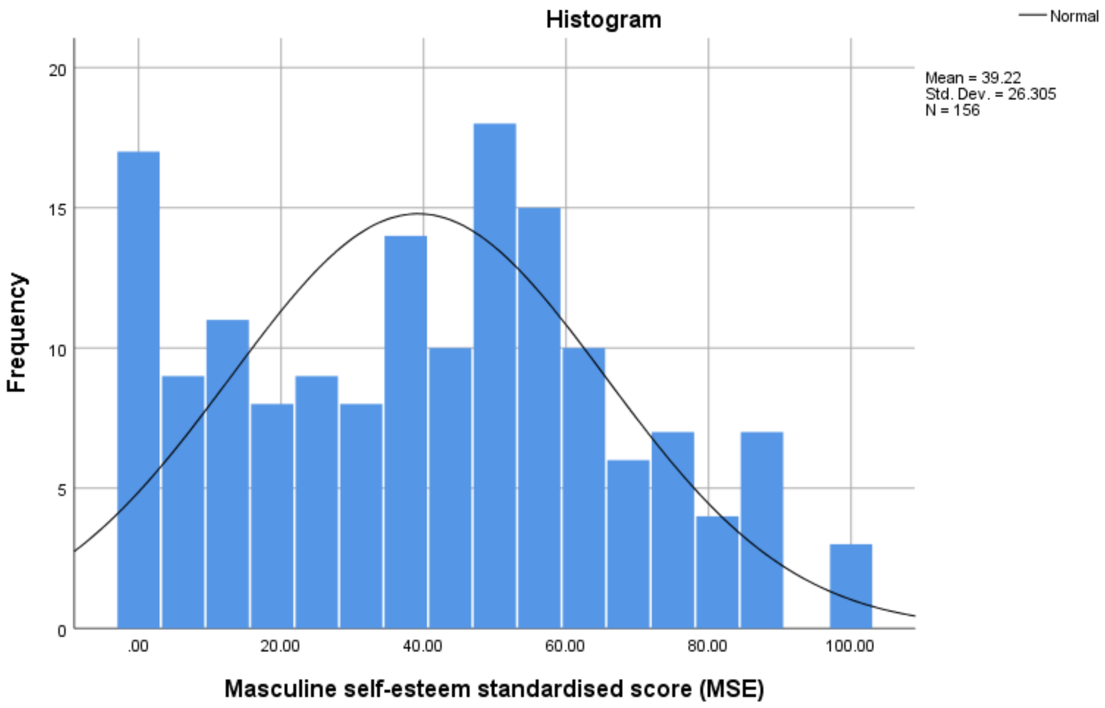

Histogram
Normal
Mean = 3.83
Std. Dev. = .796
N = 156
Frequency
40
30
20
10
0
1.00
2.00
3.00
4.00
5.00
Masculinity Strength / Fitness subscale score (MCD-I)


Histogram
Normal
Mean = 3.67
Std. Dev. = 1.211
N = 156
Frequency
40
30
20
10
0
1.00
2.00
3.00
4.00
5.00
Masculinity Sexual Priority / Importance subscale score (MCD-I)


Histogram
Normal
Mean = 4.02
Std. Dev. = .933
N = 156
Frequency
0
10
20
30
40
1.00
2.00
3.00
4.00
5.00
Masculinity Family Responsibilities subscale score (MCD-I)


Histogram
Normal
Mean = 3.19
Std. Dev. = 1.175
N = 156
Frequency
0
10
20
30
40
1.00
2.00
3.00
4.00
5.00
Masculinity Emotional Self Reliance subscale score (MCD-I)

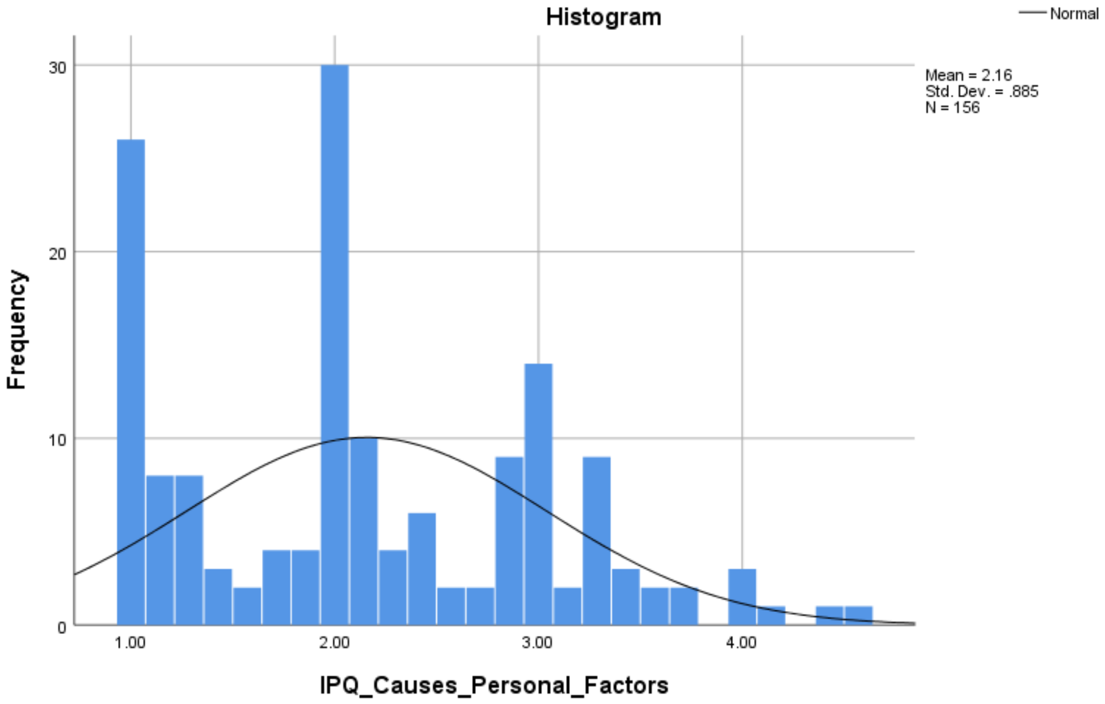

Histogram
Normal
Mean = 3.69
Std. Dev. = .692
N = 156
Frequency
30
20
10
0
2.00
3.00
4.00
5.00
Masculinity Optimistic Action subscale score (MCD-I)

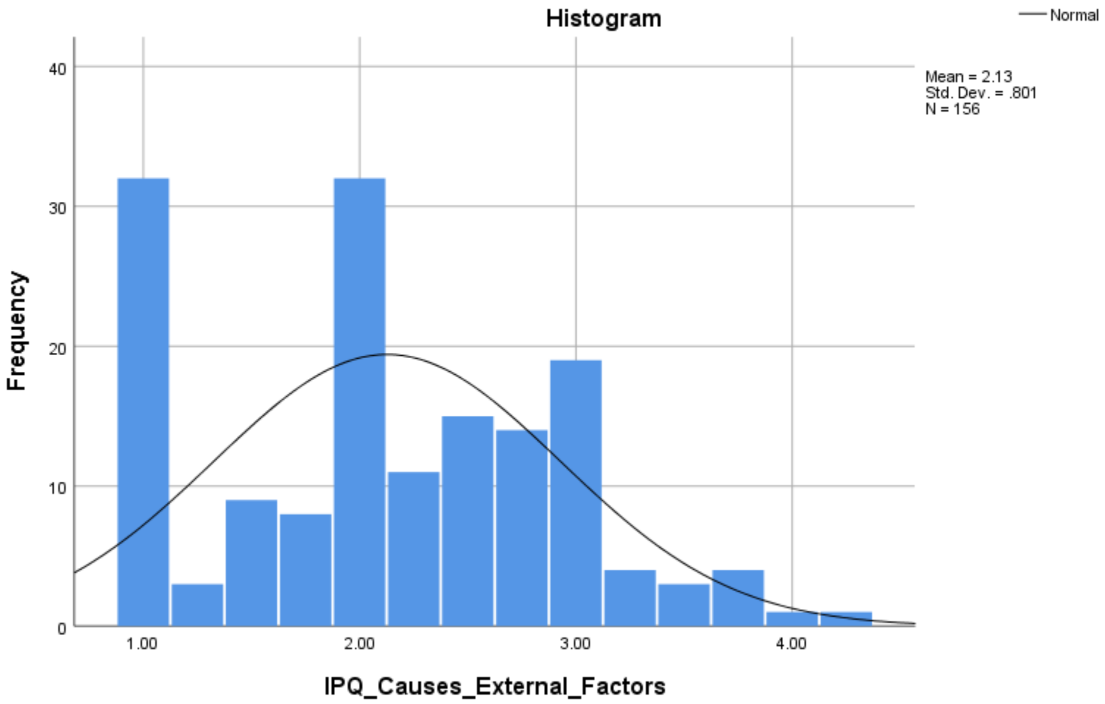

Histogram
Normal
Mean = 39.22
Std. Dev. = 26.305
N = 156
Frequency
20
15
10
5
0
.00
20.00
40.00
60.00
80.00
100.00
Masculine self-esteem standardised score (MSE)

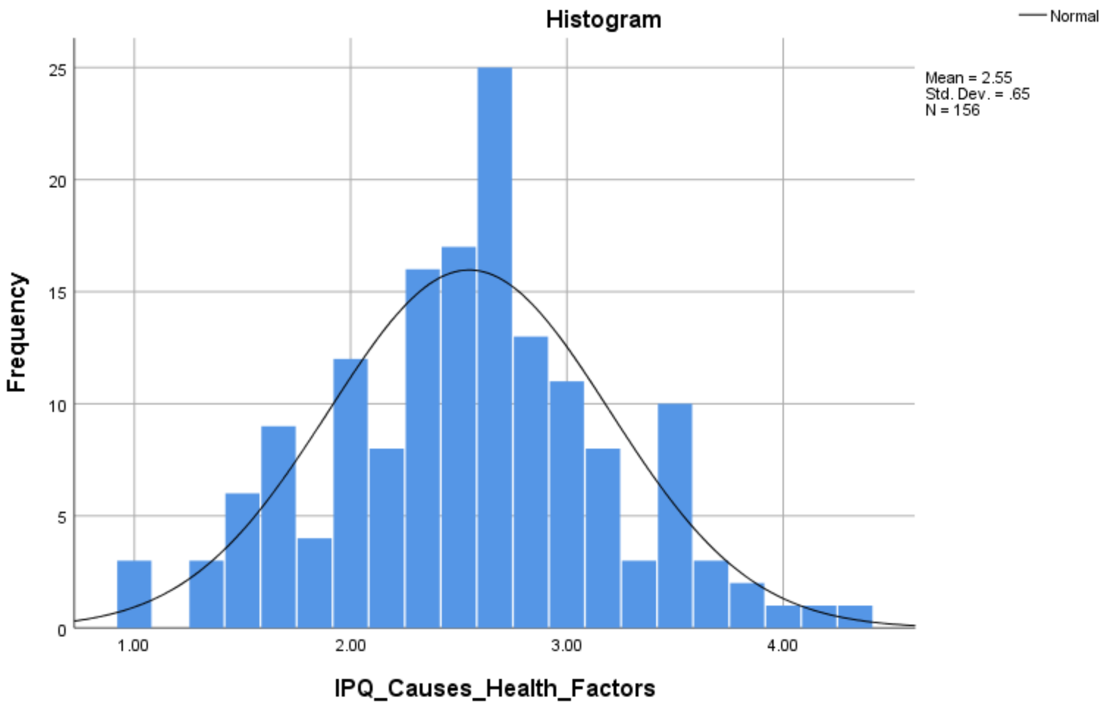
**Tests of Normality**

| | Kolmogorov-Smirnov[a] | | | Shapiro-Wilk | | |
|---|---|---|---|---|---|---|
| | Statistic | df | Sig. | Statistic | df | Sig. |
| IPQ_Causes_Personal_Factors | .115 | 156 | .000 | .936 | 156 | .000 |
| IPQ_Causes_External_Factors | .125 | 156 | .000 | .941 | 156 | .000 |
| IPQ_Causes_Health_Factors | .088 | 156 | .005 | .987 | 156 | .146 |

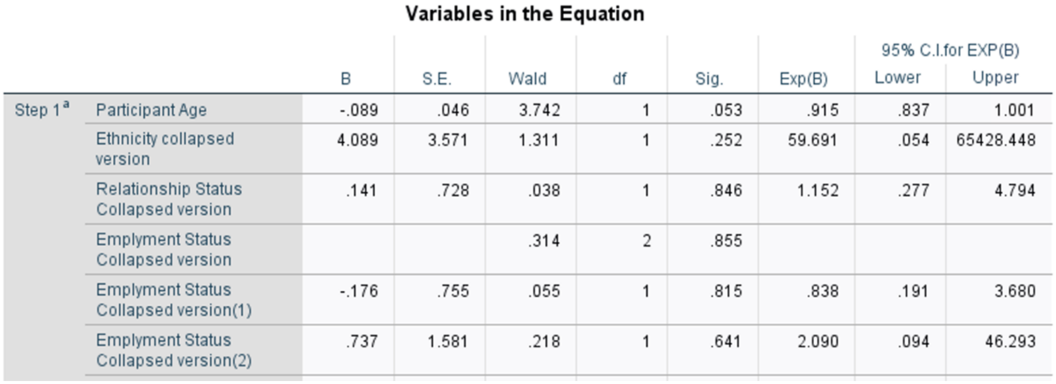
a. Lilliefors Significance Correction




Histogram
Normal
Mean = 2.13
Std. Dev. = .801
N = 156
Frequency
40
30
20
10
0
1.00
2.00
3.00
4.00
IPQ_Causes_External_Factors


Histogram
Normal
Mean = 2.55
Std. Dev. = .65
N = 156
Frequency
25
20
15
10
5
0
1.00
2.00
3.00
4.00
IPQ_Causes_Health_Factors

## E.4 Regression output including ethnicity variable



**Variables in the Equation**

| | | B | S.E. | Wald | df | Sig. | Exp(B) | 95% C.I.for EXP(B) | |
|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | Lower | Upper |
| Step 1[a] | Participant Age | -.089 | .046 | 3.742 | 1 | .053 | .915 | .837 | 1.001 |
| | Ethnicity collapsed version | 4.089 | 3.571 | 1.311 | 1 | .252 | 59.691 | .054 | 65428.448 |
| | Relationship Status Collapsed version | .141 | .728 | .038 | 1 | .846 | 1.152 | .277 | 4.794 |
| | Emplyment Status Collapsed version | | | .314 | 2 | .855 | | | |
| | Emplyment Status Collapsed version(1) | -.176 | .755 | .055 | 1 | .815 | .838 | .191 | 3.680 |
| | Emplyment Status Collapsed version(2) | .737 | 1.581 | .218 | 1 | .641 | 2.090 | .094 | 46.293 |

# Appendix F

## Single treatment exposure variables by QoL category

| | | | Quality of Life Categories | | |
|---|---|---|---|---|---|
| | | | Low-moderate QoL | High QoL | |
| **Variable** | **Level** | **All (n=156)** | **N=58 (37.18)** | **N=98 (62.82)** | **P value** |
| AS only | No | 145 (92.9) | 53 (36.55) | 92 (63.45) | 0.54[a] |
| | Yes | 11 (7.1) | 5 (45.45) | 6 (54.55) | |
| Radiotherapy only | No | 153 (98.1) | 57 (37.25) | 96 (62.75) | 1.00[a] |
| | Yes | 3 (1.9) | 1 (33.33) | 2 (66.67) | |
| Hormone therapy only | No | 147 (94.2) | 55 (37.41) | 92 (62.59) | 1.00[a] |
| | Yes | 9 (5.8) | 3 (33.33) | 6 (66.67) | |
| Surgery only | No | 143 (91.7) | 56 (39.16) | 87 (60.84) | 0.13[a] |
| | Yes | 13 (8.3) | 2 (15.38) | 11 (84.62) | |
| Chemotherapy only | No | 156 (100) | 58 (37.18) | 98 (62.82) | - |
| | Yes | 0 (0) | 0 (0) | 0 (0) | |
| Other treatment only | No | 155 (99.4) | 57 (36.77) | 98 (63.23) | 0.37[a] |
| | Yes | 1 (0.6) | 1 (100) | 0 (0) | |
| No treatment | No | 155 (99.4) | 57 (36.77) | 98 (63.23) | 0.37[a] |

| | | | |
|---|---|---|---|
| Yes | 1 (0.6) | 1 (100) | 0 (0) |

[a] $p$ values derived from Pearson’s Chi$^2$ tests