The Impact of Androgen Deprivation Therapy on Men Diagnosed with Prostate Cancer: a Mixed-Method Analysis of Body Image, Masculine Identities, Exercise Habits and Coping Strategies.

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Language disclaimer:

Given that all the individuals who participated in the studies of this PhD were cisgender, the words "men" and "women" will be used throughout this thesis to refer to individuals identifying as such and who's assigned sex at birth is respectively "male" and "female". However, it is acknowledged that sex assigned at birth will not always correspond to an individual's gender identity (e.g., an individual identifying as a trans woman might still seek treatment for prostate cancer), in which case language should be adapted to meet PCa patients' identity. More research is needed to understand the experience of non-cisgender individuals seeking treatment for prostate cancer.

Abstract

Androgen Deprivation Therapy is one of the gold standard treatments for Prostate Cancer (PCa). By suppressing testosterone production, ADT slows down cancer growth, but can also lead to several side effects affecting bodily functions and appearance (e.g., weight gain, breast enlargement, fatigue, hot flushes, incontinence, erectile dysfunction). Such side effects may impact patients' body image and masculine self-esteem, but research in this area is still limited. Exercise may help counterbalance ADT side effects and enhance PCa patients' wellbeing, improving body image and masculine self-esteem outcomes too. However, adherence to exercise recommendations is low among PCa patients.

This PhD used a mixed methods approach to explore PCa patients' experiences with ADT, its impact on body image and masculine self-esteem, the potentially protective role of exercise and other coping strategies, as well as exercise barriers. Study 1 was based on 22 semi-structured interviews with PCa patients receiving ADT, who expressed appearance dissatisfaction focusing on body feminization. Participants exercised to counterbalance ADT side-effects and re-establish a sense of control and achievement. However, some men described being worried that their appearance and physical performance would be judged by others in public exercise settings.

Study 2 tested these themes quantitatively by comparing a group of PCa patients undergoing ADT (n = 60) to PCa patients who never received ADT (ADT-naïve) (n = 60), and a group of men who never received a PCa diagnosis (cancer-free) (n = 60) on body image and masculine self-esteem related outcomes. The cross-sectional study also tested several theoretical models on the association of high exercise frequency with low body image and masculine self-esteem concerns as well as the role of fear of negative appearance and physical performance evaluation as a potential exercise barrier. The results from Study 2 were mixed:

while ADT was associated with masculine self-esteem issues, the three groups did not significantly differ in their levels of body image issues and exercise frequency was not a significant predictor of any of the outcome variables.

The mismatch between the results of Study 1 and Study 2 informed the design of Study 3, a mixed methods exploratory study investigating different coping strategies applied by PCa patients (n = 97) to deal with ADT side effects and their association with body image and masculine self-esteem issues. The study found that acceptance was the most frequently reported coping strategy and that it was associated with positive body image and masculine self-esteem outcomes. Overall, the study found that the most frequently used coping strategies (i.e.., Acceptance and Active Coping) were also associated with positive body image and masculine self-esteem outcomes, while the least frequently used strategies (i.e., Self-Blame, Disengagement, Substance Use, Denial) were associated with negative outcomes.

In conclusion, while ADT seems to affect some PCa patients' body image and masculine self-esteem, the results of this PhD also suggest that many men manage treatment side effects well and engage in strategies that are effective when coping with the impact of such bodily changes. Various forms of exercise seemed to support some PCa patients to deal with the physical and psychological impact of ADT. However, more research is needed to fully understand the effect that different forms of exercise and different motivations to engage in exercise might have on PCa patients' wellbeing.

Acknowledgements

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Dissemination of this research

Gentili, C., McClean, S., Hackshaw-McGeagh, L., Bahl, A., Persad, R., & Harcourt, D (2021, July). A mixed methods study exploring the influence of coping strategies on positive body image, negative body image, and masculine self-esteem among prostate cancer patients undergoing ADT. Symposium presentation "Fostering Positive Body Image among Cancer Survivors". Online Appearance Matters 9, Bristol (UK).

Gentili, C., McClean, S., Hackshaw-McGeagh, L., Bahl, A., Persad, R., & Harcourt, D (2020, June). Exercise, body image issues and masculinity in prostate cancer (PCa): comparing PCa patients undergoing androgen deprivation therapy (ADT), to ADT-naïve PCa patients and age-matching controls. Poster presentation at British Psycho Oncology Society Conference, Edinburgh (UK).

Gentili, C., McClean, S., Hackshaw-McGeagh, L., Bahl, A., Persad, R., & Harcourt, D. (2019). Body image issues and attitudes towards exercise amongst men undergoing androgen deprivation therapy (ADT) following diagnosis of prostate cancer. *Psycho-oncology*, *28*(8), 1647-1653.

Gentili, C., Harcourt, D (2019, November). Psychological and social impact of cancer. An overview of our work. Keynote speaker presentation at "We Hear You" Conference, Frome (UK).

Gentili, C., McClean, S., Hackshaw-McGeagh, L., Bahl, A., Persad, R., & Harcourt, D (2019, July). Exercise and body image issues in prostate cancer: a mixed-methods study. Poster presentation at Division of Health Psychology Conference, Manchester (UK).

Gentili, C., McClean, S., Hackshaw-McGeagh, L., Bahl, A., Persad, R., & Harcourt, D (2019, June). Exercise, body image issues and masculinity in prostate cancer : comparing Pca patients undergoing ADT, to ADT-naïve PCa patients and age-matching controls. Oral presentation at the UWE HAS Post Graduate Students Conference, Bristol (UK).

Gentili, C., McClean, S., Hackshaw-McGeagh, L., Bahl, A., Persad, R., & Harcourt, D (2019, May). Body Image issues and attitudes towards exercise in men diagnosed with prostate cancer undergoing androgen deprivation therapy. Press Conference Presentation at American Urological Association Congress, Chicago (USA).

Gentili, C., McClean, S., Hackshaw-McGeagh, L., Bahl, A., Persad, R., & Harcourt, D (2019, May). Body Image issues and attitudes towards exercise in men diagnosed with prostate cancer undergoing androgen deprivation therapy. Podium Presentation at American Urological Association Congress, Chicago (USA).

Gentili, C., McClean, S., Hackshaw-McGeagh, L., Bahl, A., Persad, R., & Harcourt, D (2019, April). Psychological impact of ADT side effects: body image in Prostate Cancer and the role of exercise. Poster presentation at the European Association of Urology Congress, Barcelona (Spain).

Gentili, C., McClean, S., Hackshaw-McGeagh, L., Bahl, A., Persad, R., & Harcourt, D (2018, November). Impact of ADT on men’s body image: the role of exercise. Oral presentation at the International Psycho Oncology Society Conference, Hong Kong (HK).

Gentili, C., McClean, S., Hackshaw-McGeagh, L., Bahl, A., Persad, R., & Harcourt, D (2018, June). Body Image issues and attitudes towards exercise in men diagnosed with prostate cancer undergoing androgen deprivation therapy: preliminary findings. Poster presentation at Appearance Matters 8, Bath (UK).

Presentations have also been made at the Centre for Appearance Research, at the Centre for Public Health, and at the Psychology Faculty events (in 2017 2018, 2019, and 2020) at the University of the West of England (Bristol, UK). This work was also discussed during peer support group events at the local prostate cancer charity Prospect (2018). I was also featured on several pieces on the impact of ageing on body image in Telva Magazine Madrid (November 2019), CNN Style Hong Kong (February 2020), and Chatelaine Magazine Toronto (September 2020).

Thesis outline

Chapter 1. Prostate cancer incidence, screening, diagnosis, and treatment options: a focus on Androgen Deprivation Therapy (ADT).

Chapter 2. An overview of the psychological impact of prostate cancer and androgen deprivation therapy (ADT), focusing on body image, masculinity, and the role of exercise as a coping strategy to deal with ADT side effects.

Chapter 3. Methodological overview: a pragmatic mixed methods approach.

Chapter 4. Study 1: a qualitative exploration of body image issues and attitudes towards exercise in men undergoing Androgen Deprivation Therapy (ADT).

Chapter 5. Study 2: a quantitative cross-sectional study comparing a group of prostate cancer patients undergoing Androgen Deprivation Therapy (ADT) to ADT-naïve patients and cancer-free men on body image, masculine self-esteem, and exercise-related outcomes.

Chapter 6. Study 3: A mixed methods exploratory study of the influence of coping strategies no body image and masculine self-esteem in prostate cancer patients undergoing ADT.

Chapter 7. Discussion, final reflections, and conclusions.

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Chapter 1

Prostate cancer incidence, screening, diagnosis, and treatment options: a focus on Androgen Deprivation Therapy (ADT).

This PhD thesis explores the the association between exercise frequency, body image, and masculine self-esteem concerns among prostate cancer (PCa) patients' undergoing Androgen Deprivation Therapy (ADT). This work focuses on the role of exercise behaviour aimed at managing treatment side-effects as well as on exercise barriers encountered by PCa patients. This body of work analyses the role of masculine ideals, focusing on the effect of a hegemonic masculine ideal. Lastly, this PhD also explores how different coping strategies can influence body image and masculine self-esteem related outcomes. This first chapter provides a definition of prostate cancer and an overview of its incidence, screening procedures, diagnosis, and treatment, with a specific focus on ADT.

1.1. Prostate Cancer: an overview

Prostate cancer (PCa) is the carcinoma that occurs in the prostate. A carcinoma is a tumour in which the majority of the cancer cells incessantly divide from the surface tissues of organs or glands where they are placed. The prostate is a glandular part of the male reproductive system localized between the bladder and the penis, in front of the rectum (Figure 1.1).

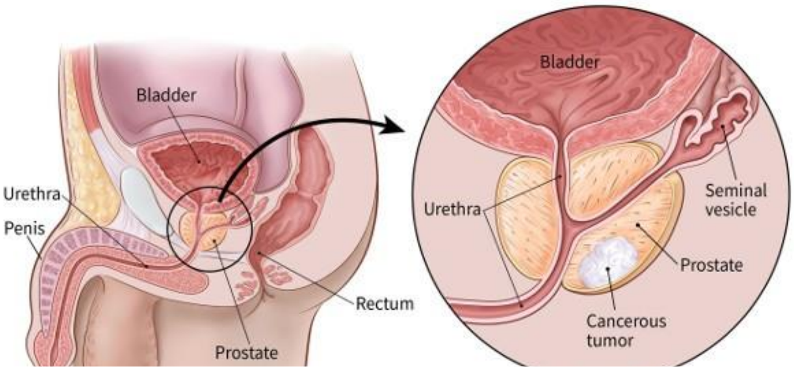

Figure 1.1. The prostate in the male reproductive system (from: https://www.cancer.org/cancer/prostate-cancer)

The prostate produces the seminal fluid, which allows the transportation of sperm after ejaculation through the urethra – which runs through the prostate. Patients diagnosed with PCa can experience symptoms like dysuria (i.e., difficult urination), increased urinary frequency, haematuria (i.e., blood in urine), dribbling, incomplete bladder emptying, excessive urinating at night, pain, bowel and urethra obstruction, and fatigue (Kunkel, Bakker, Myers, Oyesanmi, & Gomella, 2000).

1.1.1. Prostate Cancer Incidence

Prostate cancer (PCa) is the second most common cancer among men worldwide (Torre, Siegel, Ward, & Jemal, 2016) and it is now the most commonly diagnosed cancer in England (www.prostatecanceruk.org). It mostly affects men over 50, with the most common age at diagnosis ranging between 65 and 69 years old (Torre et al., 2016). According to Lloyd (2015), the lifetime risk of being diagnosed with PCa is 1 in 4 for Black men (23.5–37.2 %), 1 in 8 for White men (13.2%-15%), and 1 in 13 for Asian men (6.3–10.5 %) (Lloyd et al., 2015).

Because of the increasing screening and ageing of the baby-boomer generation, PCa incidence is increasing and expected to rise to 1.7 million new cases by 2030 worldwide (Center et al., 2012; Wallner et al., 2012). On a positive note, survival is also increasing in both Western and developing countries (Wong et al., 2016), with approximately 80% of patients living for at least 10 years after diagnosis (Chambers, Hyde, et al., 2017). According to Ward (2010), this might be due to early detection and improved treatment (Ward et al., 2010). Therefore, PCa survivors represent an increasing proportion of cancer survivors potentially needing supportive care.

1.1.2. Screening

Prostate Cancer screening aims to detect unsuspected and suspected tumours, allowing an early stage diagnosis and therefore a more favourable prognosis (Taitt, 2018). Screening options include the digital rectal exam (DRE) (manually detecting an enlarged prostate by inserting a finger into the rectum) and the prostate-specific antigen (PSA) blood test. PSA is considered an organ-specific marker as it is an enzyme almost solely produced by the prostate. In recent years, the U.S. Preventive Services Task Force confirmed the efficacy of PSA screening at reducing PCa mortality in some men (aged 55–69 years) (Taitt, 2018). However, PSA test cannot be considered a cancer-specific test, as elevated PSA can be caused by benign prostate hyperplasia as well (Taitt, 2018). Moreover, PCa can be diagnosed in patients despite absence of elevated PSA (Alberts, Schoots, & Roobol, 2015). The UK has not put in place a PCa screening program (due to the unreliability of PSA testing) (Graham, Kirkbride, Cann, Hasler, & Prettyjohns, 2014). However, in line with the Prostate Cancer Risk Management Programme free PSA tests are available through the NHS to any man aged 50 or over who requests it, after discussing the implications of taking the test with their General Practitioner (GP) (information available on the Government website). Similarly, the American Cancer Society recommends to request PSA screening at the age of 50, or 45 if from a black ethnic background or with a father suffering from PCa (Burford, Kirby, & Austoker, 2009).

Lastly, cystoscopy (which allows the visualization of the urinary track from inside the bladder) and trans-rectal ultrasonography (which creates a picture of the prostate using sound waves from a probe in the rectum) are alternative screening methods, though they are however used less frequently due to their invasiveness (Collins, Martin, Wynn-Davies, Brooman, & O'Reilly, 1997).

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* words highlighted in **blue** are included in the Glossary at the end of this chapter.

1.1.3. Diagnosis

Men with a PSA score higher than 10 and/or positive DRE usually undergo a biopsy to verify the diagnosis of PCa. A biopsy consists of the removal of prostatic tissue for microscopic examination. In the UK, most patients will undergo a trans-rectal ultrasound guided (TRUS) biopsy, where an ultrasound probe is inserted through the rectum to scan the prostate and guide the needle-sampling of prostatic tissue. The procedure happens under local anaesthetic. Alternatively, patients might undergo a trans-perineal biopsy, where a needle is inserted through the perineum to reach the prostate. This procedure is usually carried out under general anaesthetic. Both procedures can be preceded by a multi-parametric MRI (mpMRI) scan, which allows for the identification of which areas of the prostate might be affected by cancer tissue. The MRI scan allows the biopsy to be more precise and therefore reduces the number of necessary samples. Undergoing a biopsy might cause side-effects such as pain in the rectum and genital area, short-term bleeding, urinary tract infections, sepsis, acute urine retention, and temporary erectile dysfunction (Ahmed et al., 2017). Other common diagnostic exams are the Computerized Tomography (CT) scan (which checks cancer spread to nearby lymph nodes and bones), X-rays, bone scan, positron emission tomography (PET) scan (Cimitan et al., 2006).

1.1.4. Staging, prognosis, survivorship

While some types of prostate cancer grow slowly and may need minimal or even no treatment, others are aggressive and can spread quickly. Despite its limitations (Epstein et al., 2016) the Gleason grading system is frequently implemented to evaluate prognosis and plan therapy. Gleason scores range from 2 to 10, with higher numbers indicating greater risks and higher mortality (Table 1.1.) (Stark et al., 2009). In particular, the Gleason score is the sum of two grades referring to the two predominant cancer cell patterns in the prostate tissue sample (primary and secondary). The primary score refers to the area where cancer cells are most prominent in the sample. The secondary score refers to the area of prostate sample with the second highest concentration of cancer cells. Both primary and secondary scores range from 1 (well differentiated, lower risk) to 5 (poorly differentiated, higher risk). The Gleason score is the sum of the primary and secondary score and therefore ranges between 2 and 10. In particular, a Gleason score of 7 can be derived from different primary and secondary grades. A Gleason score of 7 composed of a primary score of 3 and secondary score of 4, indicates that the majority of cancer cells in the prostate have a score of 3 (lower risk), but some score 4 (higher risk). On the other hand, a Gleason score of 7 composed of a primary score of 4 and secondary score of 3 indicates that the predominant amount of cancer cells are poorly differentiated and higher risk, although some more differentiated and lower risk cells are also present (Stark et al, 2009).

Table 1.1. Gleason score and respective risk (Stark et al, 2009).

Gleason Score	**Risk**
≤ 6	Low
7 (3 + 4)	Intermediate Favourable - pattern 3 (favourable) is most prevalent but some amount of pattern 4 (unfavourable) is also observed.
7 (4 + 3)	Intermediate Unfavourable pattern 4 (unfavourable) is more prevalent than pattern 3 (favourable)
8-10	High

The TNM system is another method used to describe prostate cancer staging. This takes into consideration the size of the tumour (T), whether it has spread to any nearby lymph nodes

(N), and whether metastasis are present (M) (Cheng, Montironi, Bostwick, Lopez-Beltran, & Berney, 2012) (Table 1.2.).

Table 1.2. TNM staging system for prostate cancer.

T1 – Cancer present, but not detectable in DRE or on imaging.	
T1a	Found incidentally, less than 5 percent of sample malignant and low-grade.
T1b	Found incidentally, more than 5 percent of sample malignant and/or not low-grade.
T1c	PSA elevated, not palpable, found in needle biopsy
T2 – Tumour is palpable in DRE; organ confined	
T2a	Confined to half or less than half in one of the prostate’s two lobes.
T2b	Confined to more than one half of one lobe of gland but not both.
T2c	The tumour is in both lobes but within the prostatic capsule.
T3 – Locally extensive cancer.	
T3a	Penetration of prostate capsule on one or both sides.
T3b	Invasion into the seminal vesicle.
T4 – Tumour extension to other organs.	
T4a	Cancer that has invaded the bladder neck and/or rectum and/or external urinary sphincter.
T4b	Cancer that involves other areas near the prostate.
N – Lymph node involvement.	
NO	No cancer detected in the lymph nodes.
N1	Cancer spread to one or more lymph nodes measuring less than 2cm.
N2	Cancer spread to one or more lymph nodes measuring 2-5cm.
N3	Cancer spread to one or more lymph nodes measuring more than 5cm.

M – Metastasis to distant sites other than lymph nodes (cancer spread).	
MO	Cancer that is confined to the prostate, surrounding tissues and pelvic lymph nodes.
M1	Cancer that has spread beyond the pelvic area to bones, lungs, etc.

Estimated survival and mortality rates vary greatly depending on race, ethnicity, country, and presence of screening programs (Taitt, 2018). Nevertheless, despite PCa being the second most common cancer in men it has been estimated that PCa mortality represents only 6.6% of total male cancer mortality (Ferlay et al., 2018). Several studies showed a long survival span for PCa, with five-year relative survival approaching 100% for patients diagnosed at a localised stage in Germany and USA (Baade, Youlden, & Chambers, 2011), and death from PCa up to 20 years after diagnosis in Australia (Klaff, Rosell, Varenhorst, & Sandblom, 2016). This data indicates that many men will live with PCa for several years, highlighting the increasing necessity of investing resources to promote good quality of life during those years.

Given the high survival rates, in 2010 NHS Improvement put in place a Prostate Cancer Survivorship Initiative (as part of the larger National Cancer Survivorship Initiative (NCSI) (Richards, Corner, & Maher, 2011). The main aim of the Initiative was to increase the quality of life of people with a cancer diagnosis (and PCa specifically) (see https://www.worcsacute.nhs.uk/services/item/prostate-cancer-surviorship-initiative). NCSI recommends to offers PCa patients support via a Clinical Nurse Specialist (CNS), including a full assessment of aspects including finances, housing, emotional wellbeing, clarity and quantity of information received, physical assessment, and side-effects' impact (Ferguson & Aning, 2015). The Prostate Cancer Survivorship Initiative also ensures that PSA tests are available at local practices (rather than at general hospitals) and that patients can access regular events to engage with other men diagnosed with prostate cancer and learn about the new developments in PCa care (see https://www.worcsacute.nhs.uk/services/item/prostate-cancer-surviorship-initiative).

Similarly, in 2015 the UK National Institute for Clinical Excellence (NICE) (in collaboration with Prostate Cancer UK, Tackle Prostate Cancer UK, and Macmillan) published the Quality Standard for Prostate Cancer (https://www.nice.org.uk/guidance/qs91, published in 2015, updated in 2019). The quality standard has the objective of improving quality of life, need for care and support, premature death, and patient experience of hospital care. Additionally, in 2018 NICE and Prostate Cancer UK published the Best Practice Pathway (available here: https://prostatecanceruk.org/about-us/projects-and-policies/best-practice-pathway) (reviewed by the Clinical Reference Group (CRG)), aiming to guide healthcare professionals to deliver the best evidence-based practice for diagnosis, treatment and survivorship. In particular, the Support Pathway aims to outline the impact of potential side-effects that men can experience and provide guidance on best support practices for men to achieve a better quality of life, including managing treatment consequences (see Support Pathway policy: https://prostatecanceruk.org/media/2497116/03-support-pathway-jan-2018-final.pdf).

1.2. Prostate Cancer Treatment

Treatment plans for PCa depend on several factors, such as tumour size and stage, prediction of progression, potential comorbidities, patients' quality of life and life expectancy, and patients' choice (Byrne, 2005). The table below summarizes the main PCa treatments (Table 1.3.). However, the present body of work will focus specifically on Androgen Deprivation Therapy (ADT), which will therefore be addressed separately in section 1.2.1.

Table 1.3. PCa treatments

Active Surveillance	In case of localized and very low risk PCa, active surveillance is recommended by NICE guidelines in order to prevent avoidable treatment-related side-effects (Graham et al., 2014). Active surveillance is considered an effective strategy to maintain a good quality of life for those patients who are very unlikely to experience cancer progression and are more likely to die from non-cancer related causes (Newschaffer, Otani, McDonald, & Penberthy, 2000; Riihimäki, Thomsen, Brandt, Sundquist, & Hemminki, 2011). However, active surveillance has been associated with helplessness, anxiety and fear of cancer progression (Kunkel et al., 2000; Zeliadt et al., 2006).
Surgical Prostatectomy	Partial or radical surgical removal of the prostate is the main treatment option for localised or locally advanced PCa. This procedure can be performed robotically and is sometimes combined with radiation therapy in cases of recurrent PCa. The side-effects of surgical prostatectomy are several, including urinary and erectile dysfunction, which can persist long term after treatment (Choi, Nelson, Stasi, & Mulhall, 2007; Fujita, Landis, McNeil, & Pavlovich, 2009).
Radiation Therapy	Radiation therapy is often administered in combination with surgery and/or hormone therapy, either locally (for localized or locally advanced PCa) or in other parts of the body (in the case of advanced PCa) (Graham et al., 2014). When administered externally (i.e., External Beam Radiotherapy), high-energy X-ray beams targeted at the prostate from outside the body damage the cancer cells preventing further growth and spread. When administered internally (i.e., brachytherapy) a radioactive source is placed inside the prostate, either permanently (e.g., permanent seed brachytherapy, where a radioactive metal seed is permanently inserted in the prostate to slowly release a low level of radiation) or temporarily (e.g., temporary high dose rate (HDR) brachytherapy, where radioactive pellets are put into the

	prostate and then removed at the end treatment) (Grado et al., 1999). Since radiation is mostly absorbed by cells with higher metabolisms, radiotherapy aims to damage cancer cells, reducing tumour size and growth. Radiation toxicity can worsen previously experienced side-effects (e.g., gastrointestinal, rectal, urinary, and cutaneous related disorders) (Grado et al., 1999; Michaelson et al., 2008).
Radium-223	This internal radiotherapy treatment, also referred to as radioisotope treatment, is administered as a treatment for metastatic PCa spread in the bones. Radium-223 is an alpha-emitting radiotherapy drug with a similar composition to calcium which is absorbed by the bones, where it releases short distance-travelling radiation targeting cancer cells. After performing a PET scan, Radium-223 is delivered intravenously and can cause side-effects such as nausea, diarrhoea, vomiting, swelling of legs, and anaemia (Parker et al., 2013).
Chemotherapy	Chemotherapy is implemented for the treatment of advanced PCa, using cytotoxic drugs to interfere with cell fast mitosis, therefore damaging or stressing cancer cells, leading to apoptosis and death of cancer cells. Chemotherapy can be prescribed with a curative or palliative intent. This treatment can be given alone or in combination with hormone treatment. Chemotherapy is usually delivered intravenously but it can also be received orally. Chemotherapy can damage normal cancer cells which tend to divide rapidly, leading to side-effects such as alopecia, osteoporosis, inflammation of the digestive tract, reduced production of blood cells and consequent immunosuppression (Gilligan & Kantoff, 2002).

1.2.1. Androgen Deprivation Therapy

Androgen Deprivation Therapy (ADT) is a very well-established treatment for advanced PCa (Graham et al., 2014), received by almost 50% of patients (Chen, Hamstra, Sandler, & Zietman, 2014) and recommended by NICE UK. All of the different types of ADT aim to reduce androgen levels from the testes. In normal conditions, PCa cells react to testosterone with multiplication (Rashid & Chaudhary, 2004). Testosterone is the primary male sex hormone, playing a key role in the development of the male reproductive tissues, including the testes and the prostate, and promoting the development of secondary sexual characteristics. By inducing chemical castration in the patient and reducing their testosterone levels, ADT aims to slow down or interrupt PCa growth and spread (Sharifi, Gulley, & Dahut, 2005).

Multiple methods of ADT have been developed to treat patients with PCa. They can broadly be classified as either surgical or hormone-induced castration methods (Singer, Golijanin, Miyamoto, & Messing, 2008) (Table 1.4). This body of research focuses on hormone-induced castration, otherwise known as hormone therapy.

1.2.1.1. Hormone-induced ADT: side-effects

Any method of testosterone suppression is associated with a wide array of side-effects and changes in body composition. Many PCa patients undergoing ADT experience penile and testicular shrinkage (93%), erectile dysfunction (73.3% to 95%), lack of libido (58% to 91%), weight gain (70%), incontinence (25% to 69%), insulin resistance (65%), hot flushes (44% to 80%), osteoporosis (53.3% to 59.5%), fatigue (33% to 46.8%), breast enlargement (28.6%), breast tenderness (19%), loss of muscle mass (20% to 22.8%), increase of fat mass (14.4% to 22.8%), increased risk of cardiovascular diseases (21%), and heightened cholesterol (10.6%) (Bienz & Saad, 2015; Harrington, Schwenke, Epstein, & Bailey, 2014; Haseen, Murray, Cardwell, O’Sullivan, & Cantwell, 2010; Kopp et al., 2013; Michaelson et al., 2008; O'Connor

& Fitzpatrick, 2006; Shahinian, Kuo, Freeman, & Goodwin, 2006; Smith et al., 2007; Walker, Tran, & Robinson, 2013; Wassersug & Gray, 2011).

It is important to note that some side effects associated with ADT can overlap with side effects of other PCa treatments, that can be prescribed in combination with ADT. For example, both erectile dysfunction and incontinence are side effects associated with prostatectomy and radiotherapy. Similarly, lack of libido, weight gain, osteoporosis, and fatigue are side effects that can be provoked by chemotherapy as well (Table 1.3).

1.2.1.2. Prescription modality of hormone-based ADT

The European Association of Urology (EAU) guidelines advise ADT prescription both for patients with metastatic PCa, either as a stand alone treatment or in combination with other treatments (e.g., chemotherapy, radiotherapy), as well as for patients with localized PCa, either as a stand-alone treatment or in preparation for surgery (Morgia et al., 2016). For patients with advanced PCa, ADT is usually prescribed in a continuous manner for the remainder of a patient's life, either as a stand-alone treatment or in combination with other therapies (e.g., cycles of radiotherapy or chemotherapy) (Singer et al., 2008).

Table 1.4. Summary of the main ADT approaches from Singer et al (Singer et al., 2008).

Surgical castration	
Bilateral Orchiectomy	This surgery is performed under general, spinal or local anaesthesia and consists of the removal of both testicles through scrotal incision. This operation is associated with few risks (hematoma formation, infection, risk of anaesthesia). Prostatic testicles can be placed in the scrotum for aesthetic purposes, but this option is rarely chosen by patients. Bilateral orchiectomy reduces circulating oestrogens, but most importantly induces a drop of testosterone by more than 90% within 24 hours, representing an invasive but fast and effective way to achieve castration

	state. A series of studies series found that bilateral orchiectomy successfully decreased pain and improved functionality in patients with advanced PCa when compared to placebo. However, no survival advantage was observed when comparing early and delayed surgery. Despite being a convenient and inexpensive treatment when compared to hormone therapy, most PCa patients do not opt for surgery due to the permanent body alteration and irreversible side-effects (such as infertility, permanent loss of sexual interest. erection dysfunction, hot flashes, breast enlargement (gynecomastia), weight gain, loss of muscle mass, osteoporosis).
Hormone therapies	
Diethylstilbestrol (DES) Common brands: Stilboestrol.	DES is administered and results in the inhibition of testosterone production by the testis. Castration levels are reached within 2 to 4 weeks. DES also has a direct effect in tumour shrinkage by increasing oestrogen levels. DES tends to not cause hot flushes, but its use is often associated with breast enlargement. DES seems to be more effective than bilateral orchiectomy in terms of disease-specific survival rates, but seems to heighten the risk of adverse cardio-vascular events, affecting up to 33% of patients. However, DES in very low dosages (i.e., <1mg/day) might mitigate hot flashes and osteoporosis experienced during ADT.
Luteinizing hormone releasing hormone (LH-RH) agonists Common brands: Eligard, Lupron, Trelstar, Vantas, Zoladex	LH-RH agonists cause an initial increase in testosterone production for the first 1-2 weeks of treatment (i.e., “surge”), which is associated with an initial worsening of cancer symptoms (i.e., “flare phenomenon”). For this reason, LH-RH agonist treatment requires the pre-treatment with anti-androgens or oestrogens for a minimum of two weeks. After the “surge” period, LH-RH agonists lower and then interrupt testosterone secretion by the testis by downregulation on the HPT axis (hypothalamus, pituitary, testis axis). LH-RH has been found to be as effective as bilateral orchiectomy in achieving a castration state, without the cardiovascular risks associated with DES. The use of LH-RH agonist

	is associated with hypogonadism, hot flushes, loss of libido, and osteoporosis. The castration state induced by LH-RH agonist is reversible, meaning that if the administration is interrupted testosterone levels can return to their normal levels. For this reason, LH-RH agonist administration can be implemented for temporary or intermittent ADT. LH-RH agonists are usually administered with a subcutaneous injection either monthly, or every three or six months.
Luteinizing hormone releasing hormone (LH-RH) antagonist <u>Common brands:</u> Firmagon, Orgovyx.	LH-RH antagonists block LH production and reduce testosterone release. This allows an immediate decrease in testosterone levels, without any initial surge in testosterone or flare phenomenon of tumour symptoms. Pre-treatment can therefore be avoided for this type of ADT. LH-RH antagonists have been found to be as effective as LH-RH agonists at reducing PSA, but their use has been associated with heightened risk of anaphylactic reaction. LH-RH antagonist are also usually administered with a subcutaneous injection either monthly, or every three or six months.
Steroidal and Nonsteroidal Antiandrogens <u>Common brands:</u> Anandron, Androcur, Casodex, Diane-35, Eulexin, Nilandron.	Antiandrogens are administered orally and can be classified as either steroidal (e.g., Cyproterone Acetate) or nonsteroidal (e.g., Bicalutamide, Nilutamide and Flutamide). Also known as androgen antagonists or testosterone blockers, antiandrogens block androgen receptors, therefore preventing testosterone from mediating biological effects. Antiandrogens are administered in combination with LH-RH agonist to prevent testosterone surge and tumour flare but nonsteroidal antiandrogens can be used as a monotherapy as well.

Given the severe side-effects negatively affecting patients’ quality of life (QoL) (J. M. Harrington & Badger, 2009), an intermittent dosage strategy is sometimes implemented to both delay tumour progression and attenuate side-effects impact (i.e., Intermittent ADT, IADT). Intermittent ADT is advised only to patients suffering from severe side-effects, who would benefit from a significant increase in QoL (Higano, 2014). In this regard, benefits of IADT include increased libido and erectile function 4-6 months into the off-treatment phase and overall reduction of long-term side-effects associated with castration state, such as osteoporosis (Higano, 2003). Once ADT is interrupted, PSA levels should be checked every 1 or 2 months to ensure that they do not reach a threshold usually determined by pre-treatment PSA levels (Singer et al., 2008). If PSA reaches the established threshold, patients are advised to go back to continuous ADT (Higano, 2014).

1.3. Conclusion

Chapter 1 has presented a brief overview of PCa; in particular, it touched upon epidemiology, screening, diagnosis, and treatment. The chapter focused on ADT in particular as this treatment will be one of the main topics of study in this thesis. As presented in the following chapter (Chapter 2), this PhD focused on ADT because of its effects on body composition and functioning, which could lead to dissatisfaction with one's appearance and functionality. It focused on the impact of hormonal ADT specifically, since this represents the most common form of ADT and widely preferred ADT option by PCa patients (given its reversible nature when compared to orchiectomy) (NHS website; Perlmutter & Lepor, 2007).

Throughout the rest of this thesis, the terms "*hormonal treatment*" and "*ADT*" are used interchangeably and always refer to hormonal ADT. The following chapter presents an overview of the psychological outcomes associated with PCa and ADT in particular, as well as the rationale for the PhD and an overview of the studies composing this thesis (Chapter 2).

Chapter 2

An overview of the psychological impact of prostate cancer and androgen deprivation therapy (ADT), focusing on body image, masculinity, and the role of exercise as a coping strategy to deal with ADT side effects.

Being diagnosed and treated for PCa exposes patients to a wide variety of severe physical and psychological stressors that can have a negative impact on their lives. This PhD thesis focuses on the specific aspects of body image and masculine self-esteem in patients undergoing hormone-based ADT. This chapter discusses the most relevant findings on the topic published to date in order to support the rationale of these PhD studies. MEDLINE, PsychINFO, CINAHL Plus, Wiley Online Library, SCOPUS, and Google Scholar were searched using the following key words: body image, prostate cancer, ADT, Androgen Deprivation Therapy, hormonal therapy, prostatic carcinoma, embodiment, health-related quality of life, quality of life. Given the low numbers of studies investigating directly or indirectly body image in PCa patients undergoing ADT, both qualitative and quantitative studies were reviewed, regardless of study design. Before examining body image and masculine self-esteem during ADT, this chapter also presents a general overview of other common mental health and psychosocial issues faced by men diagnosed with PCa regardless of treatment.

2.1. Psychological impact of PCa and its treatment.

Given the high survival rates associated with PCa (Winter et al., 2017), the onset of psychological distress should be considered as a chronic condition which is likely to affect patients’ health throughout several years (Watts et al., 2014). In particular, depression and anxiety are two very common psychological issues experienced by patients with PCa (Pasquini

& Biondi, 2007). A meta-analysis by Watts et al (2014) reviewed 27 journal articles, resulting in a pooled sample size of 4494 patients on a variety of treatments (i.e., radical prostatectomy, radiotherapy, brachytherapy, surgical ADT, hormone-based ADT, chemotherapy, watchful waiting, and no therapy). The meta-analysis found that 17.27% of PCa patients reported significant depressive symptoms at pre-treatment. During treatment, depression prevalence rate would drop to 14.70% and then rise again to 18.44% at post treatment (Watts et al., 2014). Similarly, pre-treatment anxiety levels had a prevalence of 27.04% among PCa patients. During treatment, anxiety prevalence dropped to 15.09% and then rose again post-treatment to 18.49% (Watts et al., 2014). Similarly, a study by Anastasiou et al found that a small sample of 15 patients undergoing radical prostatectomy for localized PCa suffered from significantly more severe Post-Traumatic Stress Disorder (PTSD) symptoms when compared to a sample of 20 men undergoing the same surgery for benign prostate hyperplasia (BPH). In particular, PCa patients showed flashbacks connected to the moments of diagnosis and to the most invasive treatment procedures (Anastasiou et al., 2011). Overall, these results highlight how depression and anxiety levels are high after diagnosis, then decrease while patients undergo treatment, but rise again once the treatment is finished. Moreover, given that the prevalence of clinical depression and anxiety in cancer-free British men aged over 65 years is estimated to not be higher than 9% and 6%, respectively, these results highlight the significantly higher prevalence of mental health issues in patients diagnosed with PCa (Craig et al., 2008).

The fact that Watts et al’s (2014) meta-analysis found anxiety and depression levels rise again at the end of treatment is not surprising. A population-based, prospective cohort study by Smith et al estimated that up to 75% of an Australian sample of 495 men treated for PCa reported severe and persistent treatment-related side-effects and showed significantly worse sexual, urinary and bowel function when compared to age-matched controls (Smith et al., 2009). In particular, PCa patients on ADT reported poorest outcomes relating to sexual function, while men treated surgically reported the worst urinary function, and bowel function was poorest in patients who had external beam radiotherapy. Such side-effects are likely to impact on patients' mental health. For example, a cross-sectional survey conducted with 331 PCa patients in Australia a year post diagnosis found that 47% of them reported unmet psychological care needs (Hyde et al., 2017). In line with these results, Chambers et al (2017) found that in a sample of 1064 PCa survivors 6 years post diagnosis, 40% experienced significant and persistent health-related distress, worry, and low mood post diagnosis (Chambers, Ng, et al., 2017).

Suffering chronic side-effects affecting the body's functionality and sexuality, together with persistent psychological distress, can result in diminished quality of life (QoL) and loss of intimacy for both PCa patients and their partners (Chambers, Ng, et al., 2017; Chambers et al., 2013; Wootten, Abbott, Farrell, Austin, & Klein, 2014). Research highlighted how PCa diagnosis and treatment can diminish QoL of patients' partners and affect the quality of their relationship (Wootten et al., 2014). Loss of intimacy, sexual bother, financial struggle, and fear of reoccurrence are among the PCa-related issues faced by patients' partners (Badr & Carmack Taylor, 2009; Gray, Fitch, Phillips, Labrecque, & Fergus, 2000). Risk of suicide also increases after PCa diagnosis. For instance, a population-based study by Carlsson et al (2013) found that in a Swedish sample of 105,736 men diagnosed with PCa, risk of suicide was significantly higher 6 and 18 months post diagnosis when compared to a control sample of age-matching men, especially for patients with metastatic PCa (Carlsson et al., 2013).

These findings highlight how regardless of treatment protocols, PCa patients can experience significant physical, emotional and psychological changes throughout their cancer journey. When considering the increasing survival rates for PCa and the literature discussed here, it is clear how patients' psychological well-being needs to be at the forefront of their care plan, ensuring not only prolonged, but also high quality, survival.

2.2. Mental health issues in men undergoing ADT

When considering the psychological impact of PCa treatment, ADT is of particular interest. Although this thesis focuses on body image and masculine self-esteem issues, this section presents a brief overview of the negative psychological impact of ADT more broadly, in order to set the context in which said issues might arise.

PCa patients on ADT often have to face a series of bodily transformations that can deeply affect their psychological well-being (Chipperfield et al., 2013). Moreover, several studies suggest that ADT might have a direct negative impact on mood, anxiety, and cognitive functions (Shahinian, Kuo, Freeman, & Goodwin, 2006; Taylor, Canfield, & Du, 2009). Further studies report how men on ADT often experience emotional lability, irritability, and anger (Casey, Corcoran, & Goldenberg, 2012; Ng, Kristjanson, & Medigovich, 2006). Decreased physical and sexual functioning and changes to intimate relationships can result in feelings of hopelessness and isolation (Conn, Hafdahl, Porock, McDaniel, & Nielsen, 2006). Several studies highlighted how PCa patients undergoing ADT experienced a significantly worse decline in their Health-Related Quality of Life (HQoL) when compared to PCa patients receiving different treatments (Dacal, Sereika, & Greenspan, 2006). In particular, several longitudinal studies comparing PCa patients on ADT to patients who did not undergo ADT (ADT-naïve) found a significant decrease in physical function, lower energy levels, worsening of sexual functioning, decreased cognitive abilities, greater emotional distress, and overall significant worsening of patients' reported QoL in the ADT group (Alibhai et al., 2010; Alibhai, Gogov, & Allibhai, 2006; Basaria et al., 2002; Fowler, McNaughton Collins, Walker Corkery, Elliott, & Barry, 2002; Green et al., 2004; Herr & O'sullivan, 2000; Van Andel & Kurth, 2003).

Similarly, research found that ADT seems to be associated with clinically increased anxiety and depression levels. For example, a population-based study by Dinh et al (2017) analysed data from 78552 men diagnosed with PCa in the USA and found patients who received ADT (n = 33,882) experienced a higher 3-year cumulative incidence of anxiety compared with ADT-naïve patients (n = 44,670) (Dinh et al., 2017). However, the paper did not specify how anxiety was assessed and it is unclear whether this was on the basis of a clinical diagnosis. In line with these results, some studies suggested a link between ADT, sleep disturbances and development of symptoms of depression (Cherrier, Aubin, & Higano, 2009; Pirl, Siegel, Goode, & Smith, 2002). For example, Pirl et al. (2002) found a prevalence rate of 12.8% for major depressive disorder (assessed with SCID-I and Beck Depression Inventory) in a group of 45 PCa patients undergoing ADT in the U.S. This rate is 8 times higher than the general population in the U.S. (1.6%) and 32 times higher than the rate in men over 65 years (0.4%) (Pirl et al., 2002).

It is still not clear how much ADT might directly contribute to anxiety and depression through testosterone suppression and to what degree such symptoms might be caused by the strong impact that this treatment has on patients' QoL. Regardless, the evidence suggests that being on ADT represents a further risk factor for PCa patients' psychological well-being.

2.3. Body Image issues in prostate cancer: impact of ADT.

As presented above, research has widely investigated the impact that PCa diagnosis and ADT can have on patients' psychological well-being in terms of reported QoL, anxiety levels, and depression (Watts et al., 2014). In contrast, the impact that ADT can have on patients' body image remains under-investigated.

Body image can be defined as the subjective evaluation of one's body appearance and functioning (Menzel, Krawczyk, & Thompson, 2011). ADT side-effects include weight gain, loss of muscle mass, breast enlargement, penile and testicular shrinkage. Patients often have to embrace a body transformation that for many can feel like a “feminisation” of their body (Appleton et al., 2015; Chapple & Ziebland, 2002). Meanwhile, there is a growing amount of literature highlighting that the male body image ideal is centred on muscularity, especially in the upper body (McCreary, Sasse, Saucier, & Dorsch, 2004; Morry & Staska, 2001; J. Thompson & Cafri, 2007). Other studies have also highlighted the importance of leanness for male body image ideals, described as well-defined muscles, low body fat, and athletic shape (Smolak & Murnen, 2008). Considering the male body image ideal and the bodily changes provoked by ADT, it is evident how treatment side-effects might elicit negative body image. Negative body image can be defined as the negative subjective evaluations of one’s physical appearance (Menzel et al., 2011).

In particular, the way in which ADT-induced physical changes could elicit body image concerns may be explained by referring to the concept of thin ideal internalization (Thompson & Stice, 2001), which is part of the broader sociocultural model of body image, which addresses how widespread sociocultural appearance ideals can lead to body dissatisfaction (Tiggemann, 2011). In particular, the tripartite influence model (Thompson, Heinberg, Altabe, & Tantleff-Dunn, 1999), a popular framework of the sociocultural model of body image, proposes that perceived appearance pressures from family, friends, and the media can all contribute to body dissatisfaction. Thin ideal internalization is thought to mediate these relationships (Huxley, Halliwell, & Clarke, 2014). The concept of thin ideal internalization implies that those individuals holding an unattainable appearance ideal are at higher risk of body image dissatisfaction. In particular, the perceived discrepancy between one’s actual body and the thin-beauty ideal causes dissatisfaction and might encourage individuals to engage in unhealthy behaviours aimed at minimizing the discrepancy (such as food restriction and excessive exercising) (Vartanian, 2012). The sociocultural model of body image has been explored among both heterosexual and gay men, supporting a slightly revised version which includes muscularity ideal internalization (Tylka, 2011; Tylka & Andorka, 2012). Similarly, the impact of cancer diagnosis and ADT is likely to negatively impact those bodily and societal characteristics that are highlighted in the masculine body image ideal (such as being lean, strong and muscular). As a consequence, the discrepancy between PCa patients' body ideal and their body while going through their cancer journey could increase, causing body dissatisfaction.

A large body of literature in the general population highlights the way in which body image concerns are associated with several negative mental health outcomes, such as disordered eating and exercise patterns, heightened risk of social anxiety and depression, and also suicidal ideation (Tiggemann, 2004) ("Body image in adulthood", Mental Health Foundation, 2019). Despite evidence suggesting that PCa patients on ADT might develop body dissatisfaction and research highlighting the detrimental impact of negative body image on one's health, this topic is still largely under-represented in the literature.

2.3.1. Body image studies in males and older adults

Body image literature to date has mostly focused on predominantly young, white, and female populations (Tiggemann, 2004) and failed to "fully uncover the nuances of diversity and the ways that intersectionality informs older adults' embodied experience" (p. 504) (Clarke & Korotchenko, 2011). The reason for the strong focus of body image research on young female populations is rooted in the fact that historically men have been less exposed to appearance ideals, which tend to be less rigid for males than for females (Daniel & Bridges, 2013; Fredrickson & Roberts, 1997; Szymanski, Moffitt, & Carr, 2011). However, in order to fully explore and to understand body image issues in PCa patients undergoing ADT, it is necessary to gather information on the levels and characteristics of body image issues in a general population of age-matching men. This is indispensable in order understand which bodily characteristics are considered to be male appearance ideal and explore current knowledge about levels of body dissatisfaction in a PCa-free population of a comparable age. This will allow an informed evaluation of the magnitude of ADT-related body image issues.

Some studies have broadened the exploration of body image issues that have been predominantly researched from the perspective of younger women, to males and older populations (S. Chung, 2020). In this regard, while some research has found that males were on average less bothered by body image concerns and ageing when compared to females of the same age (McCabe & Ricciardelli, 2004; Oberg & Tornstam, 1999; Pope Jr et al., 2000), other studies found men were as concerned as or even more concerned than women about body weight (Abell & Richards, 1996; Harmatz, Gronendyke, & Thomas, 1985; McCabe & Ricciardelli, 2004; Smith, Handley, & Eldredge, 1998). Overall, body image issues in men seemed to be centred not only on leanness, but also on muscularity (Grogan & Richards, 2002; McCabe & Ricciardelli, 2004). Unfortunately, most of these studies are dated and also focused on relatively young samples (e.g., college students in their early 20s), making the findings difficult to generalize to an overall older population, such as PCa patients.

2.3.1.1. Studies on negative body image

Although body image studies targeting older males are still rare, a growing number of studies have investigated this topic, mostly applying qualitative methods. For example, Gough et al (2016) interviewed 30 men aged 30-69 (M_{age} = 52) living in larger bodies and participating in a weight management program. Participants highlighted their preoccupation with appearance, their experience of body self-consciousness, and the tendency to engage in social comparisons with regards to weight (Gough, Seymour-Smith, & Matthews, 2016). Similarly, a recent qualitative study by Hurd and Mahal (2019) conducted in depth interviews with 22 men aged 67–90 years asking participants about how they evaluated and felt about their appearance, health, physical abilities, and sexual functioning. While some older men reported weight satisfaction, others had been dissatisfied with their weight, identifying a higher weight with unattractiveness, and displaying fat phobic views (e.g., gaining weight equates to being lazy) (Hurd & Mahal, 2019). In line with these results, a qualitative study by Jankowski et al (2016) investigated the impact of ageing on older adults' body image. The study included 12 men aged 66–92 years (M = 79.38, standard deviation (SD) = 7.26), taking part in mixed-gender group discussions. Despite participants highlighting how appearance pressures tend to be stronger on ageing women, men also noted their need to take care of their appearance while ageing by looking clean and tidy at all times as a way to communicate personal identity, but also capability and social status (Jankowski, Diedrichs, Williamson, Christopher, & Harcourt, 2016). Similarly, a recent qualitative study by Bennett (2020) examined how 28 men aged 65–83 experienced age-related changes in their body image. The findings highlighted how participants were often ambivalent towards their ageing bodies, being both grateful for retaining functionality and unhappy or concerned for certain appearance changes. This study also found that participants engaged in social comparison towards others or their younger selves especially around weight concerns. Some participants referred to engaging in weight-control behaviours, such as physical activity and diet monitoring (Bennett, Hurd, Pritchard, Colton, & Crocker, 2020).

Accordingly to these qualitative findings, a quantitative study by Schuler et al (2004) examined the relationships among age, sex, exercise and body-image dissatisfaction in 175 older adults (101 women and 74 men, aged 50 to 98 years). The authors calculated body dissatisfaction comparing participants' choice for current and ideal body shape from a nine-figure body-silhouette scale and found that both older men and women had a desire for a thinner body shape independently of age (Schuler et al., 2004).

In addition to this, it seems that sexual orientation might also play a role in body image issues in older adults. Some qualitative research has found that older gay men might experience more severe body image concerns compared to their heterosexual counterparts (for example: (Lodge & Umberson, 2013; Slevin & Linneman, 2010). In both studies, participants reported strong pressures to maintain young-looking and sexually active bodies and attempting to adhere to such ageist body norms by engaging in physical activity and appearance management strategies, which is in line with results of studies on younger gay and bisexual men (e.g., Tran et al, 2020).

On the other hand, qualitative research has also highlighted how age can be a protective factor against body image issues: older individuals can become more invested in health rather than appearance and therefore be less susceptible to aesthetic societal norms (Hogan & Warren, 2012). While such findings seem in contradiction with the research results presented so far, it is important to note that the majority of the research conducted in this area adopted qualitative methods. Qualitative studies can reach a deep understanding of the subjective meanings attributed by participants to a specific condition, and all the qualitative studies presented so far reach samples that are considered appropriate for semi-structured interviews (Malterud, Siersma, & Guassora, 2016). However, qualitative results cannot be considered statistically representative at a population level (Bergman, 2008). While qualitative studies to date have highlighted the complexity of body image concerns in older age, more quantitative research is needed to reach a better understanding of how common body image issues might be in older age. Given the complexity of body image in older age, the following section will gather the results of studies focusing on positive body image in older men.

2.3.1.2. Studies on positive body image

Positive body image can be defined as “love and acceptance of one’s body (including aspects inconsistent with societally-prescribed ideals) and appreciation of its uniqueness and the functions it performs” (Tiggemann, 2015) (p. 168). Positive body image allows individuals to “(a) appreciate the unique beauty of their body and the functions that it performs for them; (b) accept and even admire their body, including those aspects that are inconsistent with idealized images;(c) feel beautiful, comfortable, confident, and happy with their body, which is often reflected as an outer radiance, or a “glow;” (d) emphasize their body’s assets rather than dwell on their imperfections; and (f) interpret incoming information in a body-protective manner whereby most positive information is internalized and most negative information is rejected or reframed” (Wood-Barcalow et al., 2010, p. 112). Positive body image has been associated with a broad conceptualization of beauty, adaptive appearance investment, and self-care behaviours (both health and appearance related) (Tylka & Wood-Barcalow, 2015; Tylka, 2018).

Filtering information in a body-protective manner. Research has found positive body image significantly associated with several aspects of psychological and physical health, and inversely correlated with mental health issues (Avalos, Tylka, & Wood-Barcalow, 2005; Tylka & Wood-Barcalow, 2015b). Importantly, positive body image should not be defined as the opposite of negative body image. These two psychological constructs are distinct and not alternative ends of the same spectrum (Tylka & Wood-Barcalow, 2015b). This means that an individual can potentially experience negative body image (e.g., dissatisfaction with the appearance of waist fat), while also experiencing some aspects of positive body image (e.g., feeling grateful for their body’s ability to still function despite age and illnesses) (Gentili et al., 2019; Tiggemann & McCourt, 2013). For this reason, research on older men’s experience of positive body image is necessary to reach a thorough understanding of body image in this group and consequently in PCa patients undergoing ADT.

Although research into the experiences of positive body image in males is scarce and mostly focused on younger populations, some data on older men is emerging. For example, a qualitative study by Bennet et al (2020), investigating the body image experiences of 28 men aged 65–83, found that participants often experienced what the authors called "body image ambivalence", suggesting that older men may experience both negative and positive body image. In particular, while participants expressed preoccupation for age-related appearance changes (with a specific focus on weight), they also highlighted their experiences of body acceptance. In particular, participants described accepting age-related bodily changes as part of the natural process of ageing, performing self-compassion and adapting expectations and activities to their current level of functioning. Moreover, participants engaged in appreciation for their current level of body functionality and health rather than focusing on their appearance (Bennett et al., 2020). Both body acceptance and body functionality appreciation (i.e., focusing on everything that the body can do rather than what it looks like) are a fundamental element of the positive body image experience (Alleva, Tylka, & Van Diest, 2017; Tylka & Wood-Barcalow, 2015a). Therefore, these findings suggest that positive body image can be experienced in older age.

These results are in line with quantitative research by Reboussin et al. (2000) which examined body satisfaction and its predictors among middle-aged and older adult men (n = 471) and women (n = 383) in the United States. Body satisfaction was measured with 9 items of a health-related quality of life questionnaire (the authors do not specify which questionnaire). The study found increased body satisfaction in 65–75-year-old men and women when compared to younger counterparts (Reboussin et al., 2000). Moreover, the study found that body satisfaction was more strongly predicted by satisfaction with functionality than satisfaction with appearance, highlighting that older adults may value body function more than body appearance.

Adding to this evidence, several studies have compared levels of positive body image in males and females and found that men tend to experience equivalent or higher levels of body appreciation when compared to women of the same age (Atari, 2016; Brown, Cash, & Mikulka, 1990; Gillen & Dunaev, 2017; He, Sun, Zickgraf, Lin, & Fan, 2020; Ibáñez, Chiminazzo, Sicilia, & Fernandes, 2017; Marta-Simões, Ferreira, & Mendes, 2016; Meneses, Torres, Miller, & Barbosa, 2019). Men might reach higher levels of body appreciation because they have been less exposed to appearance ideals, which tend to be less rigid for males than for females (Daniel & Bridges, 2013; Fredrickson & Roberts, 1997; Szymanski et al., 2011). Both identifying as male and being of older age might favour low appearance investment (Cash, Melnyk, & Hrabosky, 2004), which in turn can facilitate the engagement in positive body image practices (Malik, Grogan, Cole, & Gough, 2019).

Overall, these findings indicate that while females are typically more vulnerable to body image issues, males can be vulnerable to body dissatisfaction too, although more quantitative research is needed to corroborate the qualitative results. Moreover, while growing older can be associated with preoccupation with age-related appearance changes for some men, research also suggests that men can experience positive body image in older age. These mixed findings inform the investigation of body image experiences in PCa patients undergoing ADT. In particular, research in the PCa-free population suggests that patients are likely to experience a variety of psychological states related to both positive and negative body image, regardless of their age and gender.

2.3.2. Existing studies on body image in PCa undergoing ADT

A large amount of research has investigated the impact of several types of cancer and their treatments on appearance and functioning, and the potential negative effect of these changes on patients' body image (Lehmann, Hagedoorn, & Tuinman, 2015). Similarly to body image research in the cancer-free population, psycho-oncology research has mostly focused on female patients (Brandão, Schulz, & Matos, 2017; Kołodziejczyk & Pawłowski, 2019; Lewis-Smith, Diedrichs, Rumsey, & Harcourt, 2018; Miller et al., 2016). In particular, the majority of studies have focused on the impact of mastectomy and breast-sparing surgery on breast cancer survivors' body image (Fang, Shu, & Chang, 2013). Several studies have also explored the impact of head and neck cancer on appearance in both male and female patients (Fingeret et al., 2012), as well as investigating the negative effects of radiotherapy and chemotherapy on both appearance (e.g., hair loss, skin conditions, weight fluctuations, etc.) and functionality satisfaction (e.g., sexual issues, fatigue, etc.) (Heydarnejad, Hassanpour, & Solati, 2011). Results from research focusing on men has however suggested that male cancer patients might also suffer from body image issues as a consequence of cancer diagnosis and treatment (Burlew & Shurts, 2013; Harrington & Badger, 2009).

As previously stated, men diagnosed with PCa following ADT often face side-effects affecting their body appearance and functionality, which could foster body image issues both in terms of appearance acceptance (e.g., challenges accepting increase in body weights and breast enlargement) and functionality satisfaction (e.g., issues accepting fatigue and erectile dysfunction). However, a limited amount of research has investigated body image in PCa patients undergoing ADT, and this research has obtained mixed results.

Qualitative research found that ADT-induced bodily changes can foster feelings of feminized appearance, shame and discomfort around the changed post-cancer body. For example, Navon & Morag (2003) interviewed 15 PCa patients undergoing ADT in Israel, with the aim of detecting the main psychosocial difficulties they were facing. The study found that so-called “bodily feminization” was considered one of the main challenges associated with PCa diagnosis and ADT (Navon & Morag, 2003). Similarly, Kelly (2008) conducted a qualitative study with 14 men diagnosed with PCa in the United Kingdom to explore the embodiment and personal impact of PCa and found that participants were dealing with a sense of loss for their ability to function and for their masculine physical appearance prior diagnosis (Kelly, 2009). These findings are in line with the results of a qualitative study by Ervik & Asplund (2012). The authors interviewed 10 men (aged 58-83) with prostate cancer and receiving ADT in Norway, and explored participants’ experiences of bodily alterations throughout the course of the illness. The findings showed that hormone treatment has a significant influence on the bodies of prostate cancer patients: especially side-effects associated with body feminization like hot flushes and erectile dysfunction led to feelings of loss of identity on an existential level (Ervik & Asplund, 2012).

These qualitative results are also in line with some quantitative research. For example, a cohort study conducted by Fowler et al (2012) compared 234 PCa patients undergoing ADT to 855 ADT-naïve PCa patients in the US on several health-related outcomes, including body image related items designed from Clark et al’s work (Clark et al., 1997). The androgen deprived had significantly worse scores than those men who were not, including on body image outcomes (Fowler et al., 2002). Similarly, a quantitative study by Harrington (2009) compared a group of 87 PCa patients who received ADT at least once in their life with 45 ADT naïve patients on body image, administering the Body Image Scale (BIS) for cancer patients (Hopwood, Fletcher, Lee, & Al Ghazal, 2001). The authors found that patients who had been undergoing ADT showed significantly worse body image scores when compared to the ADT-naïve group (Harrington, Jones, & Badger, 2009). The same authors also found that, regardless of treatment, poor body image scores were associated with low QoL scores (measured with the Quality of Life Index (QLI) (Ferrans, 1996; Harrington & Badger, 2009).

The qualitative and quantitative findings presented so far highlight how ADT might have a negative impact on PCa patients' body image. However, some quantitative studies reported different results. For example, a longitudinal study by Taylor-Ford (2013) found that 74 PCa patients in the USA were satisfied with their body image (measured with the Body Image Scale from the Derogatis Sexual Functioning Inventory (Derogatis & Melisaratos, 1979). The study found that body satisfaction remained stable across three time points: prior to the start of patients' primary treatment as well as at 1 month and 2 years after treatment completion regardless of treatment type. However, the authors found that over time, body image was a significant predictor of change in QOL among PCa patients on ADT (Taylor-Ford et al., 2013). In line with these results, a study by DeFrank et al (2007) found that 104 PCa patients expressed positive body image significantly more frequently when compared to other male and female cancer patients (diagnosed with bladder (n =23), female breast (n =131), colorectal (n =84), endometrial (n =30), and melanoma (n =27)), independently from their treatment (DeFrank, Mehta, Stein, & Baker, 2007). Similarly, a quantitative pilot study by Langelier et al (2018) compared the body image scores of 26 PCa patients on ADT and 24 ADT-naïve PCa patients. The authors administered the Body Image Scale for cancer patients (Hopwood, 2001) and found no significant difference between the two groups. However, the study found that self-reported higher levels of aerobic exercise were associated with better masculine self-esteem (measured with the Masculine Self Esteem Scale (Clark et al., 2003)), as well as improved body image and QOL in all PCa patients, regardless of their treatment status (Langelier et al., 2018). Given the similarity of Langelier's study to the factors investigated in this body of work, this pilot represents a notable support to the rationale of this PhD. However, given its cross-sectional design and the reduced sample size, further research is needed to draw more definite conclusions on PCa patients' experience of body image while undergoing ADT.

Overall, the literature on body image issues and ADT obtained mixed findings. Most of the studies suggesting that ADT might be associated with body image issues applied qualitative methods (e.g.,Ervik & Asplund, 2012; Kelly, 2009). As previously mentioned, while qualitative methods can explore the deep subjective meanings that participants attribute to treatment side-effects, qualitative findings cannot be considered representative at a population level. On the other hand, quantitative results can be statistically generalizable but quantitative studies investigating the association between ADT and body image issues obtained mixed results. Therefore, the current state of the literature does not allow us to draw definite conclusions on the impact that ADT can have on PCa patients' body image, and more research is needed to further clarify the existing findings.

2.4. Hegemonic masculinity and masculine self-esteem: impact of prostate cancer and its treatment.

Masculinities can be defined as ways of being and being in the world that guide individuals identifying as men within a socio-cultural system (Connell, 2012). In Western societies, "being masculine" is still often stereotypically associated with attributes such as physical strength, sex drive, control of emotions, and ability to economically provide for the family (Ervik & Asplund, 2012; Gray et al., 2000; Oliffe, 2006). Such characteristics are typical of so-called *hegemonic masculinity*, which refers to the specific form of masculinity which idealizes toughness, self-sufficiency, lack of emotional sensitivity, physical and sexual strength (Wall & Kristjanson, 2005). Hegemonic masculinity ideals remain so valued in Western societies that the terms *masculinity* and *hegemonic masculinity* are often used interchangeably. Hegemonic masculinity ideals have been associated with negative mood, poorer social well-being, poorer health behaviours, higher health risks, and medical comorbidities (Burns & Mahalik, 2008; Campbell, Keefe, McKee, Waters, & Moul, 2012; Cecil, Mc Caughan, & Parahoo, 2010; Chambers, Chung, Wittert, & Hyde, 2017; Chapple & Ziebland, 2002). Similarly, a study by Burns and Mahalik (2008) found that prostate cancer patients who held hegemonic masculinity beliefs reported poorer mental health when compared to patients with less traditional views on masculinity (Burns & Mahalik, 2008).

Hegemonic masculinity ideals might be considered incompatible with being ill and vulnerable (for example a man with hegemonic masculine ideals might consider it inappropriate to ask their family for practical and emotional support during illness), and therefore threatened by PCa diagnosis and treatment (Araújo & Zago, 2019; Gray et al., 2000; Maliski, Rivera, Connor, Lopez, & Litwin, 2008). In a similar way as to the causation of negative body image, the impact of cancer treatment and diagnosis is likely to negatively affect those bodily and societal characteristics that are central to a hegemonic masculine ideal. In particular, patients can experience a loss of physical strength (with increased fatigue, loss of muscle mass, increase of fat mass, and breast enlargement), as well as suffering from erectile dysfunction and loss of sexual desire (Haseen, Murray, Cardwell, O'Sullivan, & Cantwell, 2010), as illustrated in the earlier section 1.2.1.1. in Chapter 1. PCa and ADT might also leave patients feeling deeply emotional and can affect their financial autonomy (Wright et al., 2019). Consequently, the discrepancy between patients' ideal and real embodiment of their masculinity might increase, causing a decrease in masculine self-esteem.

Masculine self-esteem can be defined as the subjective assessment of one's self-worth with respect to their masculinity ideal (Clark, Bokhour, Inui, Silliman, & Talcott, 2003). Numerous studies have shown that the diagnosis and treatment of PCa is likely to negatively impact patients' masculine self-esteem (Appleton et al., 2015). Research investigating the psychological experience of men diagnosed with PCa confirms that patients can experience feelings of loss for their masculine body (Kelly, 2009) and regret for deteriorated bodily functions (Cecil et al., 2010). In particular, a review by Chambers et al (2017) found that in both qualitative and quantitative studies erectile dysfunction provoked by PCa treatments was linked to diminished masculine self-esteem (Chambers, Chung, et al., 2017). Research also shows that PCa-induced reduction of masculine self-esteem is linked with negative psychological outcomes, such as distress (Cormie, Turner, Kaczmarek, Drake, & Chambers, 2015), depression, embarrassment, decreased self-worth, feelings of identity loss and stigmatization (Levy & Cartwright, 2015), poorer QoL (Chambers, Chung, et al., 2017), and relationship issues (Wootten et al., 2017; Zaider, Manne, Nelson, Mulhall, & Kissane, 2012). Moreover, cancer-related reduction in masculine self-esteem seems to be associated with negative physical outcomes. A longitudinal study by Hoyt et al. (2013) found that low masculine self-esteem at baseline predicted a decline in urinary, bowel, and sexual function three months later among 66 men who underwent radical prostatectomy and/or radiation therapy for localized PCa (Hoyt, Stanton, Irwin, & Thomas, 2013).

2.4.1. The impact of ADT on masculine self-esteem

These findings highlight the need to address masculine identity issues in men diagnosed and treated for PCa and to identify those patients more vulnerable to cancer-related reduction in masculine self-esteem. In this regard, research suggests that PCa patients following ADT might be particularly affected in their masculine self-esteem by treatment side-effects since, when compared to other treatments, ADT can have a particularly strong impact on body composition (Chipperfield et al., 2013; Fowler et al., 2002; Sharifi et al., 2005).

Qualitative research highlights the negative impact of ADT on masculine self-esteem, finding that ADT-induced bodily changes can foster body image issues and feelings of shame and discomfort for a feminized appearance (Ervik & Asplund, 2012; Gentili et al., 2019; Kelly, 2009; Navon & Morag, 2003). In particular, men on ADT seem to identify the cause of diminished masculine self-esteem in bodily changes such as weight gain, decreased muscle mass, breast enlargement, loss of libido and erectile dysfunction (Hamilton, Chambers, Legg, Oliffe, & Cormie, 2015; Keogh, Patel, MacLeod, & Masters, 2013; Walker, Tran, & Robinson, 2013). In particular, breast enlargement has been described by patients as particularly threatening to their masculine self-esteem (Casey et al., 2012; Harrington & Badger, 2009; Harrington, Jones & Badger, 2009). Some patients also report masculinity-related concerns around mood-swings and hot flushes, described as similar to menopausal symptoms (Hamilton et al., 2015). Feelings of decreased masculine self-esteem have also been associated with social isolation and decreased quality of life in this group of patients (Casey et al., 2012).

Although the number of quantitative studies exploring the impact of ADT on masculine self-esteem has been limited, quantitative findings seems to confirm qualitative results. A longitudinal study by Sharpley et al (2013) found that over time ADT-related side-effects such as breast changes and hot flushes predicted feelings of loss of masculinity in 1070 PCa patients over three years (Sharpley, Bitsika, & Denham, 2014). In line with these results, sexual problems provoked by ADT have been associated not only with poorer QoL (Benedict et al., 2014), poorer body image (Langelier et al., 2018; Saini et al., 2013), relationships problems (Badr & Carmack Taylor, 2009; Gray et al., 2000), and mood disturbances (A. Wootten et al., 2014), but also with diminished masculine self-esteem (Appleton et al., 2015; Bokhour, Clark, Inui, Silliman, & Talcott, 2001; Casey et al., 2012; Cecil et al., 2010).

However, while hegemonic masculinity ideals remain the most dominant and valued in Western societies, individuals can still adopt different models of masculinities. Indeed, masculinities are manifold (Araújo & Zago, 2019): men can reject the values of domination, physical strength, and sexual power, to embrace values such as connection to emotions, and interdependence instead (Elliott, 2016). Men who refuse hegemonic masculine ideals may likely be less negatively affected by ADT side-effects. In fact, the impact of ADT on features such as physical strength, sexual power and emotional control may not represent a threat to their core masculine identity. On the other hand, men holding a hegemonic ideal are likely to be impacted more negatively by hormonal treatment, as they might appraise a feminization of their body as strongly negative and undesirable. For men with a hegemonic masculine ideal, ADT side-effects might damage those core characteristics embodying their ideal masculine identity (Burns & Mahalik, 2008; Wassersug & Gray, 2011). This hypothesis is supported by a study by Alleva, Paraskeva, Craddock, and Diedrichs (2018), which collected data from a large British community sample of 439 men (M age = 39.13), and showed that individuals who conformed less to hegemonic masculine norms also showed higher levels of body appreciation.

Overall, these results indicate that PCa diagnosis and ADT might constitute a threat to patients' masculine self-esteem, which in turn can lead to more negative psychological outcomes. Such evidence highlights the need to understand if some PCa patients undergoing ADT might be particularly vulnerable in their masculine self-esteem due to treatment side-effects and hegemonic masculinity ideals. Together with the preliminary, but not exhaustive, evidence around the impact of ADT on men's body image, these results indicate the need for further research on the psychological impact of ADT and potentially effective coping strategies.

2.5. Exercise and its beneficial effects for PCa patients undergoing ADT.

Research to date suggests that some PCa patients undergoing ADT might be vulnerable to negative body image and low masculine self-esteem, but more research is needed to clarify some of the variable findings. Moreover, research is needed to investigate whether individuals with PCa might need support around body image and masculinity issues and, if so, in which form. In this regard, previous studies found that men diagnosed with PCa tend to not look for psychological support (M. K. Hyde et al., 2016). This might be related to adherence to stereotypical masculine models and reluctance to seek help (Galdas, Cheater, & Marshall, 2005). For this reason, focusing on practical strategies that might have a positive impact on the mental health could be a helpful way to support men diagnosed with PCa.

A potentially acceptable and effective way to promote mental health, reduce appearance-related concerns, and improve masculine self-esteem could be through exercise. Exercise is a subcategory of physical activity and consists of planned and structured bodily movements engaging skeletal muscles, resulting in energy expenditure and improvement of physical fitness (Caspersen, Powell, & Christenson, 1985). On the other hand, physical activity is defined as *any* bodily movement produced by skeletal muscles that require energy expenditure (World Health Organization). While this PhD focuses on the effect of exercise, it is important to note that a common limitation of exercise literature implementing self-report measures is that some participants can refer to their levels of physical activity instead. Moreover, some studies do use the term exercise and physical activity interchangeably (e.g., (Piercy et al., 2018). In this work, the term exercise is used to refer to structured bodily movements, while the term physical activity is used when referring to any bodily movement.

Studies in the general population indicate that exercise contributes to better QoL (Bize, Johnson, & Plotnikoff, 2007; Gill et al., 2013) and psychological well-being (Ströhle, 2009). In older adults, regular exercise can improve sleep quality and minimize the development and progression of chronic diseases (Paterson & Warburton, 2010; Reid et al., 2010), but also bring significant cognitive and psychological benefits such as reduced levels of clinical depression and anxiety (Bherer, Erickson, & Liu-Ambrose, 2013). Similarly, a meta-analysis by Netz et al (2005) confirmed the association between exercise, aerobic training in particular, and psychological well-being in older adults without clinical disorders (Netz, Wu, Becker, & Tenenbaum, 2005). In particular, older adults (above 65 to 85 years old) regularly engaging in exercise can experience enhanced physical fitness, but also better self-efficacy, and an improvement in several domains of QoL (Bherer et al., 2013).

Research in the general population confirms the positive effect of exercise in reducing body image concerns and enhancing positive body image (Hausenblas & Fallon, 2006). Some studies on younger adult samples (18-26 years old) have shown that body satisfaction, appearance satisfaction and physical self-efficacy increase after a training program or even after a single exercise session (Ginis, Eng, Arbour, Hartman, & Phillips, 2005; P. A. Williams & Cash, 2001). Similarly, a meta-analysis by Hausenblas and Fallon (2006) examined the impact of various forms of exercise on body image in 121 studies. The meta-analysis found that both individuals regularly taking part in exercise and participants taking part in exercise interventions showed significantly higher positive body image than non-exercisers (Hausenblas & Fallon, 2006).

While studies in the general population suggest that exercise might improve body image, there is a lack of recent studies investigating the effects of exercise on older men's body image specifically. In one of the few studies in this area, McAuley et al (2000) found that older men and women (n = 153; Mage = 65.5) experienced greater body esteem after a 6-month exercise intervention when compared to a control group (McAuley, Blissmer, Katula, Duncan, & Mihalko, 2000). Similarly, a study by Li et al (2002) found that a 6-month Tai Chi exercise program increased not only older adults' global self-esteem and body esteem, but also that these changes were mediated by an increase in appearance appreciation (Li, Harmer, Fisher, & McAuley, 2004). In line with these results, Gothe et al (2011) compared the effects of two 12-month exercise programs (walking vs. flexibility-toning-balance) in older adults (n = 179, *M*age = 66.38) and found that both programs were successful at increasing body esteem and that such increase was mediated by heightened appearance appreciation in both men and women (Gothe et al., 2011).

Taken together, these results indicate that exercise favours positive psychological outcomes, including positive body image. These outcomes are independent from exercise-provoked changes in body composition. In fact, psychological changes provoked by exercise have not been associated with exercise-related physical changes (Netz et al., 2005; Ruby, Dunn, Perrino, Gillis, & Viel, 2011). This indicates that exercise might be psychologically beneficial in itself (Netz et al., 2005). In particular, when interpreting the association between exercise and body image, it is important to consider exercise motivations. Research shows that individuals exercising for non-appearance related reasons (such as health preservation, enjoyment and socialization) present higher levels of body appreciation, independently from body weight and shape (Gilchrist, Pila, Castonguay, Sabiston, & Mack, 2018). Exercising for non-appearance related reasons can therefore be interpreted as an act of self-care, and as such inherently related to experiencing positive body image (Tylka & Wood-Barcalow, 2015a). Moreover, individuals exercising for non-appearance related reasons tend to exercise more regularly and in response to their bodily needs, prioritizing rest when needed (Gilchrist et al., 2018; Tylka & Wood-Barcalow, 2015a). In contrast, exercising for appearance related reasons has been associated with negative body image outcomes both in women and men (DiBartolo, Lin, Montoya, Neal, & Shaffer, 2007; Gast, Nielson, Hunt, & Leiker, 2015; Linardon & Mitchell, 2017; O'Hara, Cox, & Amorose, 2014; Prichard & Tiggemann, 2005; Strelan & Hargreaves, 2005).

2.5.1. Positive effects of exercise on body image and masculine self-esteem for PCa patients undergoing ADT.

The research cited above highlights how exercise can be effective at reducing body image concerns and improving positive body image in both younger and older adults. This suggests that exercise could also be an effective strategy to improve psychological well-being and body image in PCa patients. A meta-analyses by Mishra et al (2014) analysed the results from 40 exercise trials for a total of 3,694 participants with a variety of cancers (majority diagnosed with breast cancer), in a population aged between 39–70 years. The exercise trials prescribed strength/resistance training, walking, cycling, yoga, Qigong, Tai Chi, or some combination and 30 trials implementing aerobic exercise too. Length of the exercise intervention varied among trials, ranging from three weeks to one year, and the duration of individual exercise sessions ranged from 20 minutes to more than 90 minutes. The meta-analysis concluded that exercise programs not only had a beneficial effect on HRQoL, but also improved depression, sexual functioning, and body image among cancer patients (Mishra, Scherer, Snyder, Geigle, & Gotay, 2014).

Several exercise programs for PCa patients have been designed and tested, but the majority of them have focused on physical health-related outcomes and less on a psycho-social effects (Hackshaw-McGeagh et al., 2016; Thorsen, Courneya, Stevinson, & Fosså, 2008), like body image and masculine self-esteem (Demark-Wahnefried, 2017). In particular, many studies have supported the positive impact of exercise on several physical health outcomes in PCa patients. Regular engagement in aerobic, resistance and strength exercises (both in class settings and executed alone) seem to be associated with improved muscular and skeletal strength, enhanced cardiorespiratory fitness, decreased cholesterol, improved sexual functioning, reduced fatigue, and increased self-reported physical functioning in PCa patients (Baumann, Zopf, & Bloch, 2012; Cormie, Galvão, et al., 2015; Culos-Reed et al., 2010; Galvao, Taaffe, Spry, Joseph, & Newton, 2009; Moe et al., 2017; Segal et al., 2003; Thorsen et al., 2008; Winters-Stone et al., 2015). Some studies also found that regular high-intensity exercise can mildly reduce the incidence of advanced PCa, slightly reduce cancer progression, and potentially improve survival rates (Giovannucci, Liu, Leitzmann, Stampfer, & Willett, 2005; Kenfield, Stampfer, Giovannucci, & Chan, 2011). For these reasons, exercise is widely recommended to reduce the physical impact of PCa. For example, UK NICE guidelines state that patients who are starting or having ADT should be offered supervised resistance and aerobic exercise at least twice a week for 12 weeks (NICE guidelines 2014).

Despite being preliminary, some research evidence also supports the hypothesis that engaging in exercise might help PCa patients to reduce the negative impact of ADT on body image and masculine self-esteem. When looking at body image and masculine self-esteem specifically, a qualitative study by Kelly found that some PCa patients see exercise as a way to re-establish a sense of control over their bodies (Kelly, 2009). Similarly, studies confirm that exercise can help PCa patients' psychological state by giving them an active strategy to compensate for the feminizing ADT-induced muscle loss, increasing their physical self-efficacy (Bruun et al., 2014; Keogh et al., 2013; Keogh, Patel, MacLeod, & Masters, 2014). Craike et al (2011) also highlighted how for some patients exercise was helpful to manage stress and reduce appearance-related concerns (Craike, Livingston, & Botti, 2009). Similarly, a qualitative study by Hamilton et al (2015) found that exercise in a group-based setting contributed to the acceptance of sexual changes by helping men affirm strength-based aspects of their masculinity and through peer support (Hamilton et al., 2015). Moreover, a study by Langelier et al (2018) found that higher levels of aerobic exercise were associated with improved masculine self-esteem, better body image, and increased QoL in both PCa patients undergoing ADT and in ADT-naïve patients (Langelier et al., 2018). This is in line with a recent qualitative review by the same author, which found that exercise was associated with better body image and masculine self-esteem in PCa patients (Langelier et al., 2019). Lastly, a literature review by the same authors (Langelier, D'Silva, Shank, Grant, Bridel, & Culos-Reed; 2019) re-analysed and synthesized six qualitative studies examining the effect of exercise interventions on PCa patients' masculinity, body image, or personal identity (Bourke et al., 2012; Bruun et al., 2014; Cormie et al., 2013; Hamilton et al., 2014; Kronenwetter et al., 2005; Martin et al., 2015). The authors concluded that exercise supported PCa patients to improve their relationship with masculinity by providing a safe space for them to re-establish a sense of self-efficacy, reflect on the bodily changes they were experiencing, and re-focus on those traits connected to their gender identity that they valued. Exercise also seemed to provide distraction and a sense of control over cancer progression (Langelier et al., 2019). Despite the promising results, the review only included qualitative results, that cannot be generalized to the wider population of PCa patients. Moreover, the studies did not focus on ADT nor body image specifically. Therefore more quantitative research on the effects of exercise on PCa patients' body image and masculine self-esteem while undergoing ADT is needed.

Taken together, the results presented so far highlight how exercise can have a significant positive impact both on the physical and psychological health of PCa patients undergoing ADT (Graham et al., 2014; Rock et al., 2012). However, research shows that adherence to exercise recommendations among survivors is very low (Forbes, Blanchard, Mummery, & Courneya, 2015). A review by Thorsen et al. (2008) found prevalence rates of only 30-40% with respect to the medical advice (i.e., 150 min of moderate or 60 min. of vigorous aerobic exercise per week as advised by NICE guidelines)(Thorsen et al., 2008). With regard to resistance training prevalence, only 14% of PCa patients engage in one session of weekly resistance training (Keogh et al., 2010). Such low prevalence rates are concerning, considering the great benefits of exercise in counterbalancing ADT side-effects and potentially improving QoL, body image, and masculine self-esteem.

The perceived barriers to exercise in PCa patients have only been partially explored. Most studies identify time management, lack of encouragement from health professionals, lack of intention, fatigue, incontinence, and comorbidities as the main obstacles to regular exercise (Craike et al., 2009; Craike, Livingston, & Botti, 2011; Thorsen et al., 2008). Although these studies represent a preliminary exploration of the barriers to exercise among PCa patients, few of them have identified specific factors related to their health condition (e.g., Hackshaw-

McGeagh et al., 2017). In particular, no study has examined whether the ADT-induced bodily changes might contribute to the reluctance of PCa patients to engage in exercise. As previously stated, the strong ADT-induced side-effects on body composition might cause body image concerns. In this regard, previous studies highlighted how dissatisfaction with one's own appearance might cause fear of negative appearance evaluation (FNAE), which consists of worrying about being negatively evaluated for one's own physique (Brunet & Sabiston, 2009; Hart, Leary, & Rejeski, 1989) - both in women and men (Martin, Kliber, Kulinna, & Fahlman, 2006; McCreary & Saucier, 2009). In turn, FNAE has been identified as a major exercise barrier (Ball, Crawford, & Owen, 2000; Kruger, Lee, Ainsworth, & Macera, 2008). Studies have shown that people experiencing FNAE, tend to feel embarrassed about their body while exercising (Focht & Hausenblas, 2004; Sabiston, Pila, Pinsonnault-Bilodeau, & Cox, 2014), especially in mirrored environments such as gyms (Ginis, Jung, & Gauvin, 2003; Katula & McAuley, 2001). Individuals experiencing FNAE tend to not enjoy exercising and consequently lose motivation to engage in exercise (Brunet & Sabiston, 2009; Lantz, Hardy, & Ainsworth, 1997).

In conclusion, regular engagement in exercise could bring benefits to PCa patients, enhancing their physical and psychological health and improving body image and masculine self-esteem. However, the body image concerns that PCa patients experience could potentially contribute to developing FNAE, which might partially explain the low exercise rates in this clinical group. Paradoxically, even if exercise does have a positive impact on body image issues, FNAE might prevent PCa patients from experiencing exercise benefits. Having reviewed relevant literature, it appears that no study to date has investigated the effect of exercise on body image and masculine self-esteem in PCa patients undergoing ADT, while also considering body image related exercise barriers.

2.6. PhD rationale, objectives and studies overview

The literature presented so far highlights how PCa patients can face a variety of psychological challenges during their cancer journey. In particular, patients undergoing ADT might be vulnerable to negative body image. While most body image research to date has focused on young female populations, some preliminary results suggest that older men could be suffering from body image issues too. This supports the idea that body image issues should not be overlooked in PCa patients because of their demographic characteristics. Some preliminary studies have investigated body image in PCa patients undergoing ADT, suggesting that some men might face these problems during their cancer journey. However, despite having anecdotal evidence from clinicians that suggests they are aware that patients might be bothered by body image concerns and masculine self-esteem issues, published research has only partially touched upon the topic, usually from gender studies perspective. Therefore, body image issues in PCa patients undergoing ADT still require a thorough exploration from a body image standpoint. Moreover, it is still not clear whether some PCa patients undergoing ADT may be more vulnerable than others when it comes to developing negative body image.

The research questions that this PhD aimed to answer were the following:

- Are ADT-induced side-effects associated with body image and masculine self-esteem issues among PCa patients?
- And if so, what factors and coping strategies might alleviate such effects?
- Could exercise play a role in reducing body image and masculine-self esteem issues in men undergoing ADT?

This PhD aimed to

1.1. Better understand the impact of body image issues in PCa patients on ADT. Specifically, to investigate how body image issues in this population might relate to their masculine self-esteem, experience of illness and the process of ageing (Study 1, Study 2).

1.2. Explore whether some PCa patients undergoing ADT might be more vulnerable than others to developing negative body image. In particular, which characteristics might lead to either positive or negative body image (Study 2, Study 3).

The literature reviewed above suggests that undergoing ADT might lead to masculine self-esteem issues, which have been associated with negative physical and psychological health outcomes. However, it is still not clear which risk factors might lead to the development of masculine self-esteem issues in some PCa patients on ADT and what is the relationship between masculine self-esteem and body image in this population. Further aims of this PhD are therefore to:

2.1. Investigate the impact of masculine self-esteem issues and their relation with body image issues in men undergoing ADT (Study 1, Study 2).

2.2. Better understand which risk factors might contribute to the development of masculine self-esteem issues (Study 2, Study 3).

Most studies investigating the effect of exercise on PCa patients on ADT have focused on physical health outcomes. However, both literature in the general population of older adults and preliminary results of studies with PCa patients, suggest that exercise could represent a positive practical strategy to cope with ADT side-effects. Beyond its psychological benefits on mood and quality of life, exercise seems to also have positive effects on body image and masculine self-esteem (Langelier et al., 2019). However, despite the positive advantages of exercise, the adherence rate among PCa patients is low (Giovannucci et al., 2005). Studies investigating barriers towards exercise have not analysed potential body image-related barriers in PCa patients on ADT, while literature in the general population shows that worries such as Fear of Negative Appearance Evaluation can sometimes prevent individuals from engaging in regular exercise. Therefore, this PhD also aims to:

3.1. Further explore the impact of exercise on body image and masculine self-esteem in PCa patients undergoing ADT. In particular, to explore the meaning attached by patients to exercise behaviour in relation to illness, ageing, body image and masculine self-esteem (Study 1, Study 2).

3.2. Explore the role of body image related exercise barriers such as FNAE in PCa patients undergoing ADT. In particular, whether body image related worries might be present; if so, how they might influence patients' exercise behaviour and whether body image related worries might prevent individuals from exercising (Study 2).

2.6.1. Studies overview

The aims outlined in the previous paragraph have been addressed in this PhD through a programme of mixed methods research. Specifically:

Study 1 consisted of a preliminary qualitative exploration of body image and masculine self-esteem issues and attitudes towards exercise in men diagnosed with PCa undergoing ADT (Aims 1.1., 2.1., 3.1.). The application of qualitative methods allowed an in-depth exploration of this relatively unexplored field where there is a substantial lack of theory (Maxwell, 2008; Morse, 1991). The preliminary qualitative exploration informed the design and variable choices of Study 2.

Study 2 consisted of a quantitative study for which design and variables choices were informed by the results from Study 1. This study explored the presence of body image and masculine self-esteem related issues in PCa patients on ADT, in comparison to a group of PCa ADT-naïve patients, as well as a group of cancer-free men (Aims 1.1., 2.1.). Moreover, this study tested whether variables such as hegemonic masculinity ideals and appearance investment might favour the development of body image and masculine self-esteem issues (Aims 1.2., 2.2.). This study also quantitatively tested the associated between exercise frequency and body image and masculine self-esteem related variables (Aims 3.1.), and tested if body image related exercise barriers were mediating the effect of exercise on body image and masculine self-esteem related outcomes (Aim 3.2.).

Study 3 consisted of a mixed methods study in which design and variable choice was closely informed by the results of Studies 1 and 2. In particular, this study adopted both quantitative and qualitative methods to explore which coping strategies might be associated with various positive and negative body image outcomes and masculine-self esteem outcomes in PCa patients undergoing ADT (Aims 1.2., 2.2.). This study both deepens the results of the previous studies and broadens the exploration field to the topic of coping, opening possibilities for further research and intervention development. Given that Study 3 includes the exploration of coping strategies, which were not considered in Study 1 and 2, a separate and in-depth introduction explaining the rationale for coping strategies exploration is presented in Chapter 6 (paragraph 1).

2.7. Conclusion

This chapter has provided an overview of the literature on body image, masculine self-esteem, and exercise in PCa patients undergoing ADT and presented the PhD rationale, research questions, aims, and studies overview. Chapter 3 will discuss the ontological and epistemological stand on which this work was based, as well as the mixed methods approach that has been implemented throughout this PhD.

Chapter 3

Methodological overview: a pragmatic mixed methods approach.

Researchers and philosophers have developed a multitude of paradigms that can be defined as conceptual and practical "tools", used to solve specific research problems (Kaushik & Walsh, 2019). Each paradigm refers to a different series of assumptions around the nature of the world and its knowledge and therefore a different perspective on the ontology, epistemology, and methodology of research (Hall et al., 2003; Kaushik & Walsh, 2019). Ontology can be defined as the philosophical study of "being". Ontology explores concepts such as "becoming", "existing" and, most importantly "reality" (Goertz & Mahoney, 2012). The study of ontology is tightly related to the investigation of epistemology, which can be defined as the branch of philosophy that studies "knowledge" and in particular the origin, nature, methods, and limits of human understanding of the world (Hall, Mahoney, & Rueschemeyer, 2003). Epistemology is sometimes referred to as "philosophy of science" and provides philosophical grounding for defining what kind of knowledge is possible and how to ensure it is legitimate in the context of a research process (Maynard, 1994). Ontology and epistemology are complementary concepts, given that the definition of what "exists" (ontology), will determine if and how it can be understood (epistemology) (Crotty, 1998).

The definition and choice of an ontological and epistemological paradigm should stem not only from the existential and social positioning of the researcher, but also from the nature of the object of study itself, whether inherently subjective (e.g., the existential impact of cancer diagnosis) or potentially objective (e.g., determining mortality rate of PCa in a certain time and place) (Raddon, 2010). Defining a clear ontological and epistemological stand at the beginning of the research process is an essential step for the choice of the appropriate methodology. In fact, to be valid the methodologies used must be congruent with the ontology and epistemology stand adopted by the researcher (Fleetwood, 2005).

This chapter will illustrate the ontological, epistemological, and methodological stand of this PhD. In particular, the chapter discusses and justifies the adoption of a pragmatist approach. The chapter will also examine the implementation of a sequential exploratory mixed methods design and cross-sectional studies.

3.1. Ontological, epistemological, and methodological stand: a pragmatist approach.

This programme of research adopted a pragmatist ontological and epistemological stand. The word pragmatism derives from ancient Greek "*pragma*", action. Pragmatism as a philosophy postulates that human thoughts and actions are inherently connected. In fact, while an individual's beliefs are shaped by past experiences, any action undertaken in the present will cause consequences that will influence the system of thoughts held by the person (Kaushik & Walsh, 2019). Pragmatist ontology posits that reality is in a constant state of becoming, since it is systematically influenced by the actions of those experiencing the world (Goldkuhl, 2012; Maxcy, 2003; Morgan, 2014). Reality and knowledge are context-dependent, because the same action executed in different contexts will lead to different consequences, and therefore influence personal beliefs differently (Morgan, 2014). In line with pragmatist ontology, pragmatist epistemology postulates that given that each action has different consequences in different contexts and therefore shapes different beliefs for various individuals, no two world views can be identical (Kaushik & Walsh, 2019). However, pragmatic epistemology also conceives varying degrees of shared experiences and knowledge between people. If a belief is shared widely among a population, such belief will lead a large number of individuals to undertake similar actions in similar situations. The consequences of such actions are also likely to be interpreted with similar meanings, reinforcing both shared experiences and shared beliefs. Therefore, for pragmatist epistemology, knowledge can be both individually unique and socially shared (Kaushik & Walsh, 2019).

When applied to research, pragmatism allows the application of mixed methods. Pragmatic epistemology implies that while an objective reality can exist separate from human experience (Rorty, 1980), our only access to knowledge is grounded in individual perspective and context (Goles & Hirschheim, 2000; Kaushik & Walsh, 2019; Tashakkori, Teddlie, & Teddlie, 1998). Pragmatism conceives knowledge of the world to be socially constructed (Yefimov, 2004) and goes beyond the traditional philosophical dualism of objectivity and subjectivity (Tashakkori & Teddlie, 2010). Therefore, as a research paradigm pragmatism poses emphasis on empirically answering the research question rather than prioritizing the adoption of a stringent set of methods (Creswell & Clark, 2007; Kaushik & Walsh, 2019). As such, pragmatism welcomes any methodology that is deemed useful to fully answer the research question, including both deductive quantitative methods and inductive qualitative approaches (Morgan, 2007; Pansiri, 2005; Tashakkori & Teddlie, 2010; Yvonne Feilzer, 2010).

As such, the pragmatic “what works” approach has been criticised by some academics who consider its wide application problematic as it reduces the adoption of other theoretical methodologies that could potentially innovate the mixed methods field (S. Hesse-Biber, 2015). Similarly, the application of pragmatist epistemology has been criticized as a mere strategy to avoid hard epistemological issues to allow “methodological eclecticism” (Mutch, 2009). However, a pragmatist epistemology has the advantage of allowing the researcher to iteratively move from deduction to induction for the creation of hypotheses, models, and theories in relatively unexplored fields and therefore favouring the expansion of academic knowledge (Goldkuhl, 2012). As such, pragmatism favours the implementation of mixed methods (Morgan, 2014). In brief, the focus of pragmatism as a research paradigm is on the thorough investigation of the research question, rather than on the formal congruence of the different methods applied (Creswell, 2011).

3.2. Application of a pragmatist approach to this PhD thesis.

One of the aims of this PhD was to investigate body image issues and masculine self-esteem issues caused by ADT in PCa patients, and their relation to masculine self-esteem (Aim 1.1. and 2.1.). In line with the pragmatist epistemology approach, such research aims imply that while ADT side-effects exist independently from individuals' interpretation, their psychological, existential and social impact on body image and masculine self-esteem will depend on the meaning that patients might attach to them. For example, if a patient thought that their masculine identity was inherently dependent on being sexually active, suffering from erectile dysfunction as a result of ADT would affect their masculine self-esteem much more greatly than if they had attributed a different set of meanings to this side-effect.

A pragmatist approach supports the implementation of a qualitative approach, which was applied both in Study 1 (qualitative study based on semi-structured interviews, investigating the impact of ADT on body image and PCa patients' attitudes towards exercise) and partially in Study 3 (a mixed-methods online study investigating how PCa patients coped with the impact of ADT, using both validated questionnaires and open-ended questions). This method was considered the most appropriate to capture the subjectivity of the impact of ADT side-effects on body image and masculine self-esteem.

Moreover, this project aimed to investigate which characteristics might lead to negative body image and masculine self-esteem-related issues (Aims 1.2., 2.2.). Aiming to understand which PCa patients might be more vulnerable to such psychological issues implies the investigation of some characteristics traceable at a population level. Such a research objective is in line with the pragmatist epistemology which conceives lived experiences to be subjective but also socially shareable (Kaushik & Walsh, 2019). In line with the pragmatist approach, quantitative methods were implemented in both Study 2 and partially in Study 3. These research aims (aims 1.2., 2.2.) were focused on PCa population trends, and therefore would have been best answered through statistically valid quantitative methods. Similarly, the exploration of exercise also implemented qualitative and quantitative methods, in line with the pragmatist principle of adapting methods to the research question. In particular, this PhD also aimed to explore the meaning that PCa patients attached to exercise behaviour in relation to illness, ageing, body image and masculine self-esteem (Aim 3.1.) and also to test whether body image related worries might contribute to low exercise rates among this population (Aim 3.2.). While the former research question benefited from a qualitative approach given the focus on personal meanings given to exercise, the latter focused on investigating exercise barriers at a population level and therefore had to be addressed with quantitative analyses.

This PhD applied a mixed methods approach, since quantitative and qualitative approaches, in combination, provide a better understanding of research problems than when applied alone (Ivankova, Creswell, & Stick, 2006). A mixed methodology is in line with the pragmatist approach and is particularly advised when addressing research questions such as the ones at the basis of this PhD, which imply the understanding of complex trends and details (Ivankova et al., 2006). In particular, this PhD adopted a sequential exploratory mixed methods design, which allows, in line with the pragmatist approach, to develop hypotheses qualitatively first, and then strengthen, complement and deepen them with quantitative methods (Creswell & Clark, 2007, 2017).

3.3. The application of a sequential exploratory mixed methods design.

Given the scarce literature background and the lack of theory specifically around ADT-related body image and masculine self-esteem issues in men diagnosed with PCa, this PhD adopted a theory-free mixed-methods approach that aimed to formulate new hypotheses and empirical models. In particular, the lack of theories illustrating the impact of ADT on PCa patients' mental health (and on body image and masculine self-esteem in particular) meant that this PhD could not aim to corroborate and/or expand existing theories or models. Instead, this research programme had to further explore and expand the knowledge on the impact that ADT can have body image and masculine self-esteem. Such exploration would allow the formulation of new hypotheses to be tested at a population level and contribute to the future design and evaluation of models, theories, and interventions to support PCa patients undergoing ADT who might be struggling with body image and masculine self-esteem issues.

For these reasons, a mixed methods exploratory design was considered suitable. The sequential exploratory strategy implies an initial qualitative data collection, which is then followed by a second phase of quantitative data collection and analysis that builds on the results of the first qualitative phase (Creswell & Clark, 2007). The aim of this design is to qualitatively explore the phenomenon of interest to build hypotheses (inductive approach), which are then tested quantitatively to verify their generalizability at a population level (deductive approach) (Morgan, 2007). This approach is particularly useful for researchers aiming to explore an under-investigated field (such as ADT-induced body image and masculine self-esteem issues) but also expand their conclusions beyond qualitative findings (Morgan, 2014).

In the context of this PhD, Study 1 represented a preliminary qualitative exploration of the field. This study explored body image and masculine self-esteem issues and attitudes towards exercise in men diagnosed with PCa undergoing ADT (Aims 1.1, 2.1, 3.1). The application of qualitative methods allowed an in-depth analysis of this relatively unexplored field where there is a substantial lack of theory (Ivankova et al., 2006). The preliminary qualitative exploration informed the design and variable choices of Study 2, which aimed to quantitatively test the themes extracted from the data of Study 1. Specifically, this study compared a group of PCa patients undergoing ADT with a group of ADT-naive PCa patients and cancer-free men to test whether ADT was associated with body image and masculine self-esteem-related issues at a population level as well (Aims 1.1, 2.1). Study 2 also tested other hypotheses that were emerging from the findings of Study 1, specifically whether factors such as hegemonic masculinity ideals and appearance investment might favour the development of body image and masculine self-esteem issues (Aims 1.2, 2.2). Similarly, building from the findings of Study 1, Study 2 quantitatively tested the association between exercise frequency, body image and masculine self-esteem related variables and verified if body image related exercise barriers were mediating the effect of exercise on body image and masculine self-esteem related outcomes at a population level (Aims 3.1., 3.2.).

In the context of sequential designs, researchers have not reached an agreement on whether the quantitative secondary component can be interpreted independently from the primary qualitative one (Heath, 2020). While some claim that the secondary quantitative component should not be interpreted separately because it is supplementary to the qualitative one, others suggest that the quantitative component contributes to but is fundamentally independent from the qualitative findings (Heath, 2020; Hesse-Biber, Rodriguez, & Frost, 2015; Morse, 2016). While mixed methods have been considered useful for studying complex phenomena such as living with PCa, it is important to note that the integration of qualitative and quantitative results continues to be one of much debate among researchers (Morgan, 2007; Onwuegbuzie & Leech, 2005; Östlund, Kidd, Wengström, & Rowa-Dewar, 2011). This comes with disagreement on lexicon too, with authors using the same terms to indicate different concepts and vice-versa. Despite lack of agreement on the best integration techniques, we can say that qualitative and quantitative data can be integrated at different stages of the research process, be that during data collection, analysis or at the interpretative stage of the research (Kroll & Neri, 2009). Table

3.1 illustrates the main techniques that can be applied to integrate quantitative and qualitative datasets (Table 3.1).

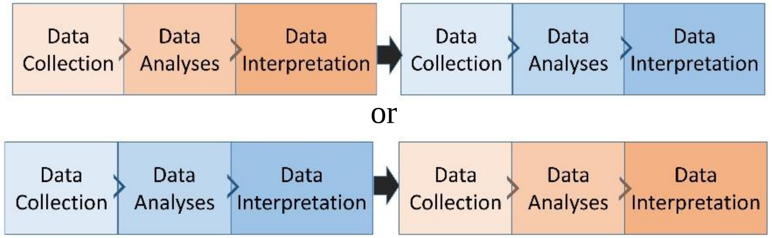
In this PhD work, the findings from Study 1 informed the design of Study 2, in accordance with the sequential exploratory mixed methods design (Figure 3.1). Therefore at this stage of the PhD, qualitative and quantitative data were integrated in accordance to the sequential technique (Table 3.1., first row) (Figure 3.1.). In particular, the analyses of the qualitative data (Study 1) produced findings that were consequently tested in the quantitative analyses (Study 2) to verify that they would be generalizable at a population level. Moreover, the qualitative analyses supported the formulation of new hypotheses, which were then tested quantitatively in Study 2 (Figure 3.1.).

The quantitative data collected during Study 2 was first analysed separately from Study 1. The quantitative results were interpreted in relation to the qualitative findings, applying the triangulation technique (Table 3.1., second row) (Figure 3.1). As we will go on to see, performing triangulation analyses allowed to highlight how the results from Study 1 and Study 2 were partially conflicting .In line with triangulation technique (Table 3.1, second row), the discrepancies between qualitative and quantitative results were analysed and used to inform the design of Study 3 (giving equal weight to quantitative and qualitative results). In particular, while Study 1 suggested that PCa patients on ADT were exposed to the development of body image and masculine self-esteem related issues, the results from Study 2 only confirmed that PCa patients undergoing ADT might be at risk of stronger masculine self-esteem issues but not body image issues. The analysis of the discrepancies between datasets led to the general conclusion that while at a population level body image issues might have not been detectable

Table 3.1. Overview of the main techniques to integrate qualitative and quantitative data.

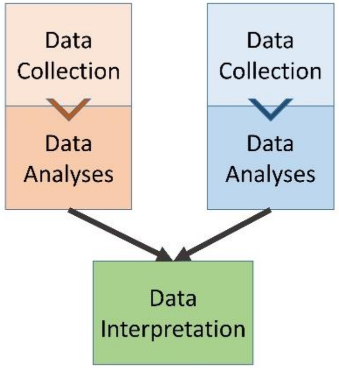
🟧 Qualitative 🟦 Quantitative

Sequential technique



When following the sequential technique, qualitative and quantitative data are analysed in a particular sequence (Östlund et al., 2011). The purpose is to use the results obtained with one method to inform the use of the other method (Onwuegbuzie and Teddlie, 2003). An example of sequential data analysis might be where a field is explored qualitatively to generate hypotheses that are subsequently tested quantitatively (Östlund et al., 2011). This technique of integration is particularly suitable for sequential mixed methods designs (Morgan, 2007).

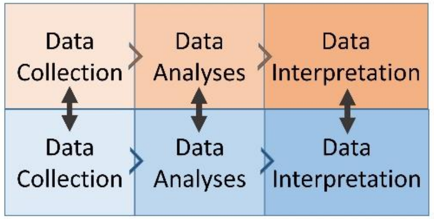
Parallel technique/Triangulation



Parallel data integration, also known as *Triangulation*, implies a separate collection and analysis of quantitative and qualitative data sets (Östlund et al., 2011). Triangulation indicates the process of studying a problem using different methods to gain a more comprehensive understanding (O’Cathain, Murphy, & Nicholl, 2010). The separate collection and analysis of qualitative and quantitative datasets produces two autonomous sets of findings. The two sets of findings are only integrated at the interpretation stage (O’Cathain et al., 2010). In particular, when applying the triangulation method, the researcher will need classify cases of:

- *Convergence*: the findings from each dataset agree (O’Cathain et al., 2010).
- *Complementarity:* the two datasets offer complementary information on the same issue.
- *Discrepancy or dissonance:* the findings from the two datasets seem to contradict each other. Looking for discrepancies between findings can represent a particularly informative process to better understand the research question and verify whether the qualitative findings could be generalizable at a population level (O’Cathain et al., 2010).
- *Silences*: theme or a finding might arise only in one dataset and not the other. Silence might be due to the different strengths of qualitative and quantitative methods and, like discrepancies, can be very helpful to better understand the study findings (O’Cathain et al., 2010).

Concurrent techniques



Concurrent techniques imply the integration of the two datasets already during the analytic stage of research (Östlund et al., 2011) . For example:

- *Following a thread*. The integration of qualitative and quantitative data happens at the analysis stage of the research process. When the researcher is analysing a factor (if in the quantitative dataset) or a theme (if in the qualitative dataset) that requires further exploration, then such factor or theme is further analysed in the other component (Moran-Ellis et al., 2006; O'Cathain et al., 2010). The technique has not been used frequently in the literature and although it offers the advantage of exploring a specific theme or factor in depth, it also poses the limitation of not detecting incongruences between datasets (O'Cathain et al., 2010) .
- *Quantification of qualitative data*. This strategy implies the codification of qualitative data into quantitative ones, in order to create a single comprehensive dataset (Driscoll, Appiah-Yeboah, Salib, & Rupert, 2007). A common technique is to consider the frequency at which a qualitative code occurs in the data, insert it in the dataset and consider it as an indication of significance of the qualitative code. A strong limitation of this technique is that while the frequency could indicate particularly influential codes, high frequencies can also simply indicate repetitive but not significant responses (e.g., PCa patients might frequently begin talking about their medical journey in order to get comfortable in the interview setting, before talking about body image and masculine self-esteem) (Driscoll et al., 2007).
- *Mixed methods matrix (focusing on each case).* A unique advantage of mixed methods studies is the possibility of analysing quantitative and qualitative data on the same set of cases. Therefore, all the data collected on each single case can be studied together, focusing attention on a single subject, rather than on variables or themes (O'Cathain et al., 2010). Qualitative and quantitative data for each case can be displayed in a matrix. This allows the researcher to notice commonalities between qualitative and quantitative data, as well as paradoxes and contradicting responses given by the same individual (O'Cathain et al., 2010). The main disadvantage of this technique is that it can be extremely time consuming when analysing bigger datasets.

in PCa patients undergoing ADT (quantitative component), there were still some individuals who developed a negative relationship with their body due to treatment side-effects (qualitative component) (Figure 3.1). Therefore, Study 3 aimed to investigate which coping strategies would be more effective for PCa patients to deal with ADT side-effects, resulting in positive body image and masculine self-esteem related outcomes.

Study 3 was designed on the preliminary conclusion that while at a population level most PCa patients might not develop body image issues as a result of ADT side-effects, at an individual level a minority of men do struggle with their body image because of hormone treatment-induced physical changes. Subsequently, Study 3 aimed to better understand which factors might contribute to the development of negative body image in some men on ADT and to a more functional adjustment in others, focusing on the role of coping strategies. In particular, while Study 3 was part of the overall sequential exploratory mixed methods design of the PhD, the design of this study mixed quantitative and qualitative methods in itself (Figure 3.1). Study 3 adopted a so-called “embedded” approach (Creswell, 2003), in which a primary database – in this case quantitative – guides the data collection and analyses, while a secondary database - in this case qualitative - is collected at the same time and provides support to the primary one. The secondary qualitative method was therefore “embedded” within the predominant quantitative method (Creswell, 2003).

Embedding one methodology into the other can help to achieve several research aims. In this research, the qualitative data collection was embedded in the quantitative database with the aim of clarifying quantitative data and seeking information around coping strategies at a more individual level and describe aspects that could not be quantified (Creswell, 2003). By using the two different methods, it was possible to gain informative perspectives from the two different types of data within the same study. For example, quantitative methods made it possible to collect information on how frequently different coping strategies are applied among

PCa patients undergoing ADT, while qualitative methods allowed to gain a deeper understanding of the personal meanings that each participant attributed to each coping strategy (Creswell, 2003). Within Study 3, the integration of quantitative and qualitative data was performed both via Triangulation (Table 3.1., second row) as well as through the concurrent integration technique of "Following a Thread" (Table 3.1., third row, first bullet point) (Figure 3.1.). A more comprehensive overview of Study 3 methods, rationale for measures choice, data analyses, data integration, and results can be found in Chapter 6.

To conclude, this PhD applied a sequential exploratory mixed methods design, where the first qualitative study informed the design of the following quantitative study, with the aim of verifying whether such qualitative results could be considered valid at a population level (Figure 3.1). Therefore, more weight was given to the qualitative component while designing Study 2 (applying a sequential technique) (Figure 3.1.). However, equal weight was given to the quantitative and qualitative components when interpreting the results of the first two studies together (through triangulation) (Figure 3.1.). The discrepancies between qualitative and quantitative results was analysed and used to inform the design of Study 3. Study 3 was a mixed methods study in itself, with a qualitative component embedded in the primary quantitative database, as illustrated in Figure 3.1.

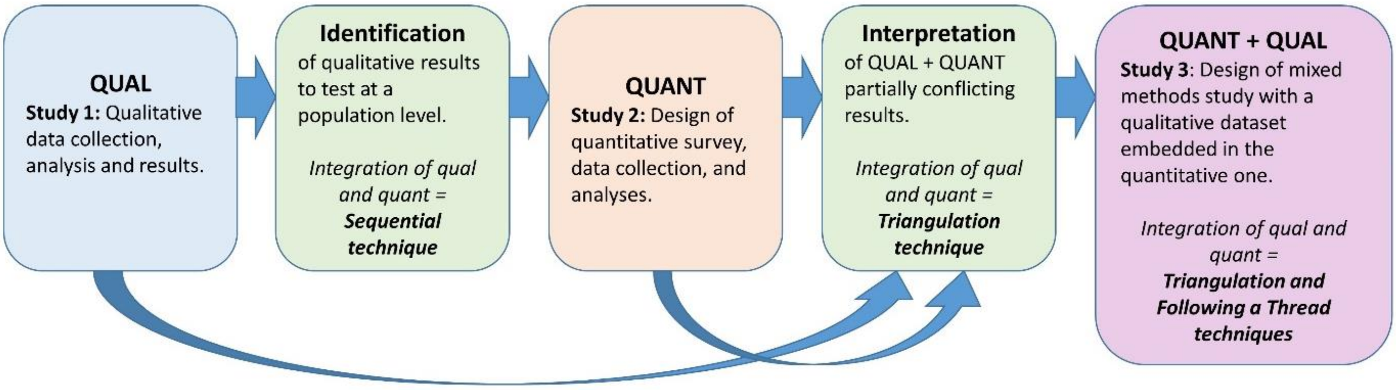


Figure 3.1. Overview of PhD sequential exploratory mixed-methods design

3.3.1. Limitations and challenges of mixed methods approaches.

Despite the numerous advantages of mixed methods, this research approach comes with its limitations. One of the main challenges within mixed methods research is the lack of universal guidelines on the integration of qualitative and quantitative data (Bressan et al., 2017; Hesse-Biber, 2015), which in turns makes assessing the quality of mixed methods research difficult. For example, a review by Bressan et al (2017) analysed five nursing mixed methods papers and found strong inconsistencies in the application of mixed methods and the way they are reported. In particular, the application of two sets of methods often means both methodological aspects have limitations and that reporting validity and reliability is uncommon (Bressan et al., 2017). The lack of clear reports on the application of mixed methods leads to limited guidance provided to new researchers in the field. Other academics moved similar critiques to the current application of mixed methods, highlighting how their formalization has mostly focused on the timings of qualitative and quantitative data collection, and not enough on the actual "mixing" of said data (S. Hesse-Biber, 2015). For example, a study by O'Cathain et al (2007) reviewed 81 mixed methods studies and found that only 28% were found to actively integrate qualitative and quantitative data (O'Cathain, Murphy, & Nicholl, 2007). The key feature of how the integration between qualitative and quantitative data was achieved is indeed often lacking in the literature (Andrew, Salamonson, & Halcomb, 2008; Zhang & Creswell, 2013), leaving once again new researchers without clear indications on how to perform the mixing. In order to ensure proper integration between qualitative and quantitative data, this PhD strictly designed the quantitative study (Study 2) on the findings of the qualitative exploration (Study 1). Similarly, Study 3 was designed on the basis of the triangulation of the results of Studies 1 and 2, and on the discrepancies between quantitative and qualitative findings specifically.

Another challenge posed by mixed methods research is the high resource expenditure, both in terms of skills and time. Mixed methods require a broad range of research skills and experience, in both quantitative and qualitative practices as well as in data integration (Bowers et al., 2013; Halcomb & Andrew, 2009). This can be challenging to achieve for a single researcher (Bishop, 2015; Halcomb, 2019) and for this reason this PhD strongly benefitted from the feedback of a supervisory team with a strong background in mixed methods research. Similarly, the collection of two different sets of data produces large datasets, which require more resources for time management and analyses – especially if conducted in fulfilment of a postgraduate degree (Halcomb & Andrew, 2009). In particular, sequential projects require a careful allocation of time for collection and analyses during the exploratory phase (in this PhD Study 1, qualitative semi-structured interviews, Figure 3.1). Not allocating the necessary time to perform the initial exploratory analyses can prevent the second data set from addressing the key issues (Bishop, 2015; Halcomb & Andrew, 2009). For these reasons, this PhD required careful time planning and management for the successful application of a sequential design. This was possible also thanks to the choice of running cross-sectional studies, which contributed to successful time management of the PhD research (discussed in section 3.4 of this chapter).

Lastly, the large volume of data generated by mixed methods might pose challenges for dissemination through publications, given the usually concise word limit of scientific papers. It is possible to publish qualitative and quantitative data separately, but the main limitation of this approach is that the integration between qualitative and quantitative data would not be accessible to readers, as only one aspect of the data would be published in each paper (Halcomb, 2019). This limit can also negatively affect the publication of non-significant findings, which would be particularly informative as a result of triangulation of qualitative and quantitative data (for example on interventions that are not proven to work and why) (Halcomb, 2019; Mannix, Wilkes, & Daly, 2015). To partially compensate on this issue, when publishing qualitative and quantitative results separately it is important to cross-reference papers referring to the same project (Halcomb, 2019). This is the strategy that was adopted for this PhD, publishing qualitative findings (Study 1) separately (Gentili et al., 2019), and referencing said paper when publishing the quantitative results (Study 2) (Gentili et al, 2021, *in preparation*).

Despite the challenges that a mixed methods approach posits to the researcher, the sequential exploratory mixed methods design was still the most appropriate choice for this PhD. In fact, this design allowed for the exploration of this under-investigated field - ADT-induced body image and masculine self-esteem issues in PCa patients - and the consequent generation and verification of new hypotheses at a population level. Given the incongruent results in the scarce quantitative literature currently published on the topic (for a complete overview, see section 2.3, Chapter 2), adopting a mixed methods approach and performing triangulation between findings allowed the in-depth analyses of emerging discrepancies between datasets and the utilization of such information for the design of Study 3. Further discussion on the advantages and challenges related to the implementation of a sequential exploratory mixed methods design in this PhD can be found in Chapter 7 (section 7.2).

3.4. Implementation of cross-sectional studies: advantages and limitations.

This PhD exclusively consists of cross-sectional studies. These can be defined as an observational study which analyses the data from a population or a representative group at a specific point in time (Levin, 2006). Cross-sectional studies allow for the collection of multiple outcomes simultaneously and are therefore relatively time efficient. While performing longitudinal studies to investigate the impact of ADT on PCa patients' body image and masculine self-esteem would be ideal, it was not feasible to incorporate this design within the constraints of the PhD.

Cross-sectional studies are mostly incorporated for descriptive purposes to identify the prevalence of a phenomenon in a population or to test associations between variables, for example between risk factors and the health outcomes of interest (Mann, 2003). The implementation of cross-sectional studies was therefore in line with the main aims of this PhD, namely investigating the association between ADT side-effects and body image and masculine self-esteem issues. Moreover, cross-sectional studies allow for the assessment of several outcomes and risk factors and can be useful in order to provide a base of evidence for hypotheses generation to test longitudinally (Levin, 2006). For this reason, several studies investigating similar topics in psycho-oncology generally and PCa specifically adopted a cross-sectional approach (Harrington & Badger, 2009; Harrington, Schwenke, Epstein, & Bailey, 2014; Langelier et al., 2018). The use of cross-sectional studies was appropriate for this PhD, as it allowed to test the influence of several variables on exercise behaviour, body image, and masculine self-esteem (Study 2), and to explore the relationship between several coping strategies and psychological outcomes, with the scope to generate new hypotheses (Study 3).

However, it is important to note that cross-sectional studies pose several disadvantages. For example, because cross-sectional studies collect information about one time point only, they are unable to infer information related to sequences of events (Levin, 2006). This limitation means that this PhD did not gather information about the evolution of ADT side-effects over time and did not monitor the fluctuations of body image and masculine self-esteem-related variables over time. This information would have allowed a better understanding of when PCa patients might be more psychologically vulnerable due to ADT administration and whether or not adjustment to side-effects might happen naturally over time. These data would have assisted the design of support tools targeted to the most critical treatment phases.

While cross-sectional designs can be used to an extent to infer causation - for example by comparing groups of participants who are overall statistically comparable apart from one factor (e.g., treatment plan) - it is still methodologically challenging to make sound causal inferences. Even when using regression models for data analysis, the absence of the time variable poses challenges when differentiating cause and effect from simple association. The results of cross-sectional studies can often be open to a number of explanations, which would be ruled out if time was included in the model (Levin, 2006). Moreover, given that cross-sectional studies give information about a specific point in time, it is possible that their results may lack replicability. This might happen because different studies may simply capture different points in time and therefore different circumstances. To control for this limitation, the studies in this PhD all involved participants at different ADT stages and included the variable "time since beginning of ADT" as a covariate in the analyses.

Despite their limitations, cross-sectional study designs were considered an appropriate choice to address this PhD's aims. As previously noted, despite the appropriateness of a cross-sectional design for this PhD, it is important to note that the results of these studies still represent preliminary knowledge which would benefit from further longitudinal testing.

3.5. Ethical implications

This PhD investigated sensitive topics (e.g., body image, masculine self-esteem, cancer treatment and diagnosis) and involved the participation of vulnerable adults (men diagnosed with PCa). This research posits the risk of emotional distress or emotional harm for participants. For this reason, men who were interested in participating were provided with a clear information sheet in advance (Appendixes A3.4, B3, C3), to ensure they were aware of what participation would imply for them. They were also asked to read and sign a consent form before taking part in any of the studies (Appendixes A3.5, B3, C3), were given the contact details of support organisations (including PCa specific support services), and advised to contact their GP or PCa team if taking part in the study raised any concerns about their physical or mental health (Appendix A3.4, B3, C3). Participants were reassured that choosing to take part or not would not influence the care they receive in any way. Lastly, participants could drop out at any time point during all the studies (without having to give a reason) and could ask to have their data withdrawn up to two weeks after their participation.

This PhD also implied the storage of sensitive data. The data was anonymized by renaming all the files with participation numbers. The files for each study were securely stored in an encrypted computer, only accessible by the principal investigator. At the end of each study, the data were kept in the same encrypted drive, for further future consultation.

3.6. Patients and Public Involvement

Patients and public involvement (PPI) in research is often defined as "research carried out with or by members of the public, rather than "to/about/for" them" (Involve website, FAQ) (Gordon, Dickinson, Offredy, & Smiddy, 2017). By applying PPI, patients and/or members of the public are invited to get involved in the research process not only as participants, but also as consultants on study aims, design, and processes (Gordon et al., 2017). PPI protocols are based on the recognition that non-academic knowledge of patients and members of the public can improve research quality (Gordon et al., 2017), acknowledging that their involvement contributes to the democratization of healthcare and ultimately to a reduction in health inequalities (Ocloo & Matthews, 2016) (Davies & Shields, 1999; Staniszewska, Herron-Marx, & Mockford, 2008).

On top of mutual learning between researchers and participants, PPI can also improve partnerships between academic staff and the public, with the potential of increasing the wider impact of research (Gordon et al., 2017). PPI can also support the definition of study aims and outcome measures, as well as recruitment strategies, publication and implementation of the results (Ocloo & Matthews, 2016).

In the UK, PPI in health and social care policy and research has been well established since 1997 (D. o. Health, 1997; Mockford, Staniszewska, Griffiths, & Herron-Marx, 2012), with a long series of initiatives encouraging individuals and communities to take part in the planning and development of services within the National Health Service (NHS) and within local NHS Trusts (Mockford et al., 2012). PPI can be applied in many different ways, ranging from consultation (in which involved patients/members of the public have limited power or decision-making authority) to shared leadership (in which involvement is characterised by shared power and responsibility) (Mockford et al., 2012; Ocloo & Matthews, 2016). Different levels of involvement are considered appropriate depending on the context and aim of the research project (Ocloo & Matthews, 2016; Tritter & McCallum, 2006). An overview of different PPI frameworks can be found in Table 3.2.

Table 3.2. PPI frameworks and aims (Greenhalgh et al., 2019)

Framework	**Aim**
Power-focused and community-based participatory research (CBPR)	Challenge power differentials between researchers and patients/public and focus on working with marginalized communities
Priority-setting	Involve patients/members of the public in order to set clear research priorities, translating them into defined and relevant research questions
Study-focused	Improve quality and efficiency of research materials and processes in order to maximize recruitment and retention in research trials
Report-focused	Guide the writing up and critical appraisal of research articles/ policy reports
Partnership-focused	Similarly to the power-focused frameworks, aims to guarantee transparency and accountability in researcher-public collaborations

Despite the wide range in objectives and level of involvement of different PPI frameworks (Table 3.2.), the “4Pi” national involvement standards designed by Faulkner et al (2015) provide a broad guidance to what constitutes good practice and meaningful involvement (Faulkner et al., 2015; Ocloo & Matthews, 2016). Specifically, Faulkner et al’s guidelines state:

1) *Principles*: PPI is underpinned by inclusive and non-discriminatory principles, as well as respect, transparency, and open-mindedness towards cultural differences

2) *Purpose*: the purpose of the PPI framework needs to be clearly defined and articulated so that patients and members of the public know what the goal of their involvement is;

3) *Presence*: the choice of who to involve has to be determined by the purpose of PPI;

4) *Process*: processes of involvement should be adapted to the specific project; for example PPI with consultation purposes will implement different processes than PPI with co-design purposes;

5) *Impact*: impact should be considered in a variety of ways, from recruitment reach, to participants’ satisfaction, as well as mutual learning between academics and service users.

It is important to point out that despite the growing evidence of PPI benefits in health psychology research (Coulter & Ellins, 2006; Gordon et al., 2017), several academics have identified criticisms and challenges related to this practice (Gordon et al., 2017; M. Taylor, 2002). For example, some have highlighted the difficulties in assessing PPI impact, as a result of the undefined conceptualization of the various PPI frameworks (e.g., Table 2.3) (Oliver et al., 2008; Staniszewska et al., 2011; Staniszewska et al., 2008). Other researchers have pointed out that it is not clear how and who to involve in PPI, and how this lack of clarity often results in the selection of “convenient” groups that are not diverse or representative (Ocloo & Matthews, 2016). Lastly, several researchers lament the lack of administrative and financial support for the implementation of PPI and its high cost in terms of time investment and emotional labour (for both the researchers and the patients/members of the public involved) (Boylan, Locock, Thomson, & Staniszewska, 2019).

Despite these challenges, the present PhD adopted *priority-setting* and *study-focused* PPI frameworks (Table 3.2) to inform the aims, design, quality of the materials, and recruitment plan of Study 2 (Chapter 5) and Study 3 (Chapter 6). In particular, some of the participants involved in the qualitative interviews of Study 1 (Chapter 4) were invited to give their feedback and contribute to the design of the following studies. PPI participants were selected on the basis of demographic diversity, willingness to be involved in future projects, and their gatekeeping role in their community. PPI allowed the definition of relevant research questions and the improvement of research materials and recruitment strategies. While the fact that Study 1 did not benefit from PPI represents a limitation, it is important to note that the qualitative exploration of the field allowed the researcher to build partnerships with local charities and community gatekeepers that allowed PPI to take place for the two following studies. More details on the specifics of each PPI session can be found in Chapter 5 (section 5.2.3.1.) and Chapter 6 (section 6.2.3.1.).

3.7. Conclusion

To conclude, this PhD research adopted a pragmatist epistemological approach, which conceives knowledge as socially constructed and dependent on individual context (Yefimov, 2004). Pragmatism prioritizes the choice of methods that are best suited to answer the research question. Therefore, a sequential exploratory mixed methods approach was adopted, where an initial qualitative study informed the variable choices and hypothesis of the following quantitative study. The incongruence of the studies' findings informed the design of the third mixed-methods study, in which qualitative data collection was embedded in the quantitative database (Figure 3.1). All the studies were cross-sectional, meaning that it was not possible to collect information on the evolution of ADT side-effects and to monitor the fluctuations of body image and masculine self-esteem through time. However, this design allowed three high-quality research studies to be completed within the timeframe of the PhD, answering several important research questions, investigating a wide variety of variables, and ultimately formulating new hypotheses for further investigation.

Chapter 4

Study 1: a qualitative exploration of body image issues and attitudes towards exercise in men undergoing Androgen Deprivation Therapy (ADT).

This chapter presents Study 1, which used semi-structured interviews with men diagnosed with PCa who received androgen deprivation therapy (ADT) to explore their individual experiences around treatment side-effects, body image, and exercise. It provides an introduction, the study methods, data analyses, results, discussion of the findings, and a reflexivity section. In particular, the methods section includes the design of the study and development of the interview topic guide, an overview of the recruitment strategies, description of the sample, and the interviewing process. The data analyses section includes a complete outline of and justification for the analyses technique. The results section includes the themes and subthemes extracted from the transcripts. The discussion analyses the results with respect to published literature and considers the strengths and limitations of the study. To conclude, the reflexivity section provides a detailed explanation of how my expectations, attitudes, and personal characteristics might have influenced the research process and results. Findings from this study have been published in the journal Psycho-Oncology (Gentili et al, 2019).

4.1. Introduction

Although PCa treatment options are improving outcomes for survival, each therapy is associated with side-effects. As discussed in Chapter 2, ADT is of particular interest because of its potential impact on body composition and psychological wellbeing. Only a few studies explored the impact that ADT could have on body image, often adopting a gender-studies perspective (rather than a more specific body image approach) and providing partial evidence that ADT could have a negative impact on patients' relationships with their bodies (see Chapter

2, section 2.3). However, there is still a lack of research investigating PCa patients' experiences and needs around body image issues. In general, previous studies found that PCa patients are often reluctant to seek psychological help (Hyde et al., 2017). This reluctance might be related to stereotypical views of masculinity where seeking help is considered inappropriate (Galdas et al., 2005). These results suggest that PCa patients might be reluctant to seek psychological help for body image issues as well. Therefore, patients might benefit from practical activities with a positive impact on psychological outcomes. Specifically, exercise could be an acceptable and effective way to reduce body image concerns in patients undergoing ADT, in addition to improving cancer-specific health outcomes (Bourke et al., 2016; Thorsen et al., 2008). Yet, adherence to exercise recommendations among PCa patients is very low (Forbes et al., 2015) (Chapter 2, section 2.5).

Research into perceived barriers to exercise in PCa patients has identified time management, fatigue, incontinence, but also limited resources, lack of expertise, and poor awareness of benefits (Craike et al., 2011; Keogh et al., 2014; Santa Mina et al., 2012). Within the general population, body image concerns have also been cited as an exercise barrier (Brudzynski & Ebben, 2010), but research has yet to investigate whether they might contribute to lack of exercise in PCa patients undergoing ADT.

The present study aimed to answer the following research questions:

- To what extent and how does ADT impact on PCa patients' body image and sense of masculinity?
- How do PCa patients undergoing ADT feel about exercise? Do they experience specific exercise barriers related to ADT side-effects and body image issues? Do they experience any psychological exercise benefit? If so, which ones?

4.1.2. Aims

Study 1 aimed to explore:

- the impact of ADT side-effects on PCa patients' body image and sense of masculinity;
- PCa patients' attitudes towards exercise and potential exercise barriers in relation to ADT side effects.

4.2. Methods

4.2.1. Design

In line with pragmatist principles, the present study adopted the methodology that best fitted the research questions presented above (Shah, Shah, & Khaskhelly, 2018). In particular, given the lack of knowledge around body image issues in PCa patients undergoing ADT, a qualitative approach was considered appropriate for the exploration of understudied topics (Morse, 2016) (Figure 4.1.). This study used semi-structured interviews that were conducted either face-to-face or via telephone, depending on participants' preference. The data was analysed with thematic analysis (Braun & Clarke, 2006) as the main goal of this study was to investigate the personal experiences of this group of participants and to inform the design of the following study (Heath, 2020).

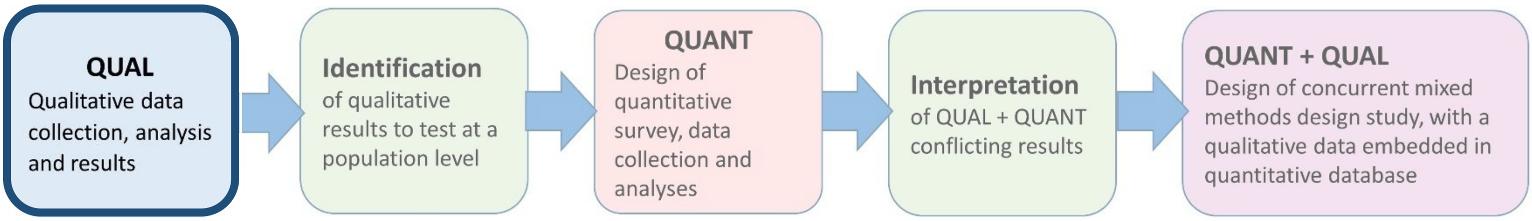


Figure 4.1. First phase of mixed methods exploratory design: qualitative exploration of the field.

4.2.2. Ethical approval

This study obtained ethical approval from the Research Ethics Committee of the Faculty of Health and Applied Sciences at The University of the West of England, Bristol (UWE REC REF No: HAS.18.01.080, Appendix A1).

4.2.3. Qualitative interview topic guide

The first topic guide draft was peer-reviewed by a fellow researcher experienced in conducting semi-structured interviews with men diagnosed with PCa (Appendix A2). The aim of this consultancy was to check whether the study questions were worded appropriately in order to allow participants to feel comfortable during the interview and to fully discuss their experiences with PCa and ADT. Moreover, the topic guide was adapted following the first five interviews, integrating the feedback provided by the participants at the end of their interview (Appendix 4.1).

4.2.4. Recruitment and sampling

The study was advertised with the title “My body after Prostate Cancer”, inviting men to take part in an interview focusing on body image changes of ADT and exercise. The inclusion criteria to be eligible for the study were having had a diagnosis of prostate cancer, having been prescribed ADT at some point in their life, not having any major physical injury that could prevent them from engaging in exercise, and being able to take part in an interview conducted in English.

Recruitment was performed through a variety of strategies:

- Time-location sampling. This recruitment strategy uses locations where potential participants tend to gather, which can be very useful when trying to reach a specific population (Marpsat & Razafindratsima, 2010; Semaan, 2010). Recruitment involved cancer and prostate cancer support organisations and charities (e.g., Maggie's Cheltenham, Tackle Prostate Cancer, Penny Brohn, Prospect Bristol). Each organization was contacted and invited to participate in the recruitment strategy of the study. If they were interested, they were provided with the information, flyer, and ethical approval of the study and asked which ways of recruitment would better fit their organization. Some organizations invited the principal investigator to their meetings to speak with their service users in person while others offered to distribute flyers to their members. Alongside these strategies, most of the organizations offered to promote the study through some form of online recruitment (e.g., publishing on their website, social media page, and newsletter). More details on the online recruitment strategies can be found in the last bullet point of this list. Men who were interested in participating, were encouraged to contact the principal investigator to receive further information and then arrange a date and time for the interview. Time-location sampling is a useful strategy to establish collaborations with key organizations in the field of study, as well as to improve research project credibility and acceptability for potential participants (Altpeter, Houenou, Martin, Schoster, & Callahan, 2011). Moreover, time-location sampling allows the researcher to successfully reach several potential participants from a specific population, such as men diagnosed with PCa undergoing ADT. However, a limitation is that this method tends to recruit participants who are already engaging with or seeking support from a specific service (Heath, 2020). Given that this study aimed to collect the experience of PCa patients with different levels of psychological support, this limitation was overcome by recruiting through different avenues, as mentioned in the following bullet-points.

- Snowball and chain referral sampling. In snowball referral, participants who have already taken part in the study identify other potential participants within their social group, who will then identify further potential participants (Atkinson & Flint, 2001; Etikan, Alkassim, & Abubakar, 2016). In this study, men who participated in the interview shared the information on the research and encouraged other men to contact the researcher. This happened both within groups of charities service users and online. This recruitment strategy allows the researcher to reach specific groups through the gatekeepers, who also contribute to prove the legitimacy of the project to new potential participants. Gatekeepers are those individuals who can grant or limit a researcher's access to a community. In this study, gatekeepers were charity workers as well as patients strongly involved in charity activities. However, it is important to note that since gatekeepers also ensure that members of their community are not exposed to harmful research (Coyne, 2010), they might also actively choose to not involve certain individuals in the research (Groger, Mayberry, & Straker, 1999), leading to a biased selection of the sample. To overcome this limitation, snowball sampling was adopted in combination with other strategies, namely time-location sampling and online recruitment. Another ethical consideration with snowball sampling is the potential disclosure of personal information that could happen when former participants are asked to contact other individuals who could be interested in the research (Sadler, Lee, Lim, & Fullerton, 2010). For this reason, all participants were asked to not disclose the content of their interviews with others, in order to maintain anonymity and confidentiality.
- Online recruitment. Web-based recruitment is considered an effective strategy to improve access to research since it expands recruitment to individuals in geographically different locations and can improve participation from ethnic minorities

(Heath, 2020; Wilkerson, Iantaffi, Grey, Bockting, & Rosser, 2014). However, it is also important to note that online recruitment might not reach individuals who do not have access to an internet connection or are not confident IT users. For this reason, online recruitment was paired with both snowball and time-location sampling. The study was advertised on social media. In particular, a short description of the study was posted on Facebook, both on the Centre for Appearance Research page, as well as on specific PCa self-help groups and through the pages of local and national Cancer Charities (e.g., Maggie's Cheltenham, Tackle Prostate Cancer, Penny Brohn, Prospect Bristol). This allowed to overcome one of the limitations of time-location sampling, namely recruiting only individuals who are already seeking help. By publishing information about the study on the charities' websites and social media platforms, individuals who were looking for information and not actively seeking help could be reached as well. Men who were interested in participating were encouraged to get in touch to receive the complete information sheet on the study and then arrange a date and time for the interview. The study was also advertised through a press release from the University of the West of England, which was visible to all UWE employee (Appendix A3.3.). Online support groups dedicated to ethnic and LGBTQ+ minorities existed on social media but most of them did not grant access to the principal investigator as a white cisgender researcher. This is understandable, given the higher discrimination and online bullying these groups tend to be exposed to, especially when interacting with white cisgender individuals (Hu, Chang, Lin, & Yen, 2019; Mason & Czapski, 2017).

While recruiting, it was important that the information provided on the research aim, methods, and data protection was as complete and clear as possible. In fact, given the sensitive topics that the study aimed to explore, a lack of clarity and understanding of the research might have resulted in resistance to participate (Clark, 2010). It was necessary that the social media posts, as well as the flyers and the information sheet, provided all the necessary information in the most transparent way, as well as a list of support sources for any PCa patients that might have needed help for ongoing distress (see Appendix A3 for social media post, flyer, and information sheet Study 1).

4.2.5. Participants

The recruitment was challenging but the application of different strategies resulted in the identification of twenty two potential participants. Two interviews were excluded from the analyses after the interview, as the recording quality was not sufficiently clear to allow transcription, leaving the transcripts of twenty participants for the analyses.

Sample size in qualitative research is often defined by achievement of so-called “data saturation”. Data saturation is broadly defined as information redundancy (Lincoln & Guba, 1985), the point at which no new information, codes or themes are yielded from data. Despite the large use of this concept in qualitative studies to justify the final sample size (Constantinou, Georgiou, & Perdikogianni, 2017; Greg Guest, Bunce, & Johnson, 2006; Gregory Guest, MacQueen, & Namey, 2012), its specific definition, validity, and utility are still object of debate (Braun & Clarke, 2019). The concept of data saturation if often criticized because it is not clear at which stage of the research process data saturation should be assessed, whether during data collection, following data familiarisation, or during data analysis itself (Braun & Clarke, 2019). For this reason, some academics suggest that the estimation of sample sizes for qualitative studies should follow a more pragmatic judgement, taking into consideration the scope and purpose of the project as well as its pragmatic constraints and analytic goals (Braun & Clarke, 2019; Sim, Saunders, Waterfield, & Kingstone, 2018). For Study 1, the data were analysed at the same time as data collection continued. This approach allowed the researcher to stop the data collection once the data provided a rich, complex and multi-faceted story about the impact of ADT on body image and masculine self-esteem in PCa patients and their attitudes towards exercise (Braun & Clarke, 2019; Sim et al., 2018).

Participants' ages were varied, ranging from 43 to 85 years ($M_{\text{age}} = 67.9$ years old, $SD = 9.99$). All participants were British, identified as white and heterosexual, mostly accessed higher education and lived with a supportive romantic partner (Table 4.1). Time since diagnosis ranged between three months and 15 years (Table 4.1). While the sample included a diverse range of ages, its homogeneity on the rest of the demographics (e.g., white, highly educated, living with a partner, already accessing support, etc.) represents a limitation of the study. This limitation is discussed in section 4.6.1. of this chapter and more specifically in Chapter 7 (section 7.4.). In order to guarantee the anonymity of all participants, pseudonyms were used in the analysis and reporting.

Table 4.1. Demographic characteristics of the sample for Study 1.

Pseudonym	Age	Marital status	Education	Treatment	Years since diagnosis	Interview
Marius	61	married	Bachelor's degree	surgery, radiotherapy, ADT	6	Face to face at university
Jacob	68	married	Doctoral degree	radiotherapy, brachytherapy, ADT	12	Face to face at his home
Robert	58	married	Master's degree	surgery, radiotherapy, ADT	3	Face to face at university
Paul	73	married	Bachelor's degree	surveillance, ADT, chemotherapy	15	Face to face at his home
Raphael	85	widowed	Grammar school	surveillance, ADT	4	Face to face at university
James	66	married	Master's degree	radiotherapy, ADT	12	Telephone
Elvio	73	married	Grammar school	surgery, radiotherapy, ADT	8	Face to face at his home
Matthew	83	divorced	Bachelor's degree	ADT	7	Face to face at university
Luca	43	married	Grammar school	ADT	4	Telephone
George	80	married	College	ADT	3	Face to face at university
Henry	74	married	Technical school	brachytherapy, ADT, radiotherapy	10	Telephone
Carl	70	married	Bachelor's degree	ADT	13	Telephone
Phil	75	married	Doctoral degree	radiotherapy, brachytherapy, ADT	3	Telephone
Eduard	65	engaged	Bachelor's degree	ADT, chemotherapy	1	Telephone
Michael	67	married	Technical school	ADT, chemotherapy	2	Telephone
Valerio	57	single	Grammar school	radiotherapy, ADT	5	Telephone
Ludvik	73	married	Master's degree	radiotherapy, ADT	0	Telephone
Alessandro	68	married	Master's degree	surgery, radiotherapy, ADT	3	Telephone
Richard	65	married	College	radiotherapy, ADT	1	Telephone
Peter	77	married	Grammar school	radiotherapy, ADT	1	Telephone
Marcello	59	married	College	ADT, chemotherapy	4	Telephone
Sander	54	married	Master's degree	surgery, radiotherapy, ADT	2	Face to face at university

Note. ADT = Androgen Deprivation Therapy

4.2.6. Procedure and interview process

Participants were invited to take part in a semi-structured interview touching upon themes such as ADT-induced bodily changes, body image issues, masculinity, exercise habits, attitudes towards exercise, and psychological effects of exercise (see *Topic Guide* in Appendix A4).

Some qualitative studies only rely on face to face interviews, which are often still considered the most desirable data collection method (Deakin & Wakefield, 2014). However, an increasing body of qualitative research has been employing a variety of data collection methods within single studies, in order to maximise participants' access. For example, some researchers have been combining face-to-face interviews with online video-calls, as well as telephone, and email interviews (Deakin & Wakefield, 2014; Dures, Rumsey, Morris, & Gleeson, 2011). For this study, participants could choose from several interviewing options, with the hope that this would improve their experience of the interview while also maximising the data collection target. Participants had the chance to choose between a face-to-face interview either in a quiet, comfortable, private meeting room at the university or at their home or a place of their choice, video-call, telephone call, or email. As displayed in Table 4.1, thirteen participants chose to be interviewed over the telephone, while nine chose to be interviewed face to face, and one participant opted to add an email to his telephone interview (Table 4.1).

Once participants made contact with the principal investigator either via email or telephone to participate in the study, they were sent the information sheet and consent form via email, to return on the day of the interview (either in person or electronically). The information sheet contained a list of services and organisations they could access for support, both specific for PCa as well as for general physical and mental health (see Appendix A3). Men participating in a telephone interview also gave verbal consent at the beginning of the call, which was recorded and then transcribed. Participants were given the opportunity to ask any question about the research process and were informed about their right to withdraw from the study at any time before and during the interview and within two weeks after the interview. Interviews lasted between 30 and 45 minutes, were audio recorded and then transcribed verbatim by the principal investigator. As a thank you, participants were given the chance to take part in a prize draw for a £70 Amazon voucher. The draw was incorporated in order to both compensate participants for their time, but also to avoid attracting participants solely on the basis of monetary compensation, which has been found problematic for data collection (O'Neil & Penrod, 2001). At the end of the study, all participants received an email with the results of the study and further thanks for taking part (Appendix A6).

4.3. Data analyses

The transcripts were analysed with the help of NVivo (Bazeley & Jackson, 2013), applying thematic analysis and the constant comparative method. Several forms of qualitative analysis were considered (e.g. grounded theory, narrative analysis) and thematic analysis was chosen since it can be applied without any pre-existing theoretical frameworks, and therefore in accordance to the pragmatic approach of this PhD (Braun & Clarke, 2006). Thematic analysis is an appropriate method to qualitatively investigate individual experiences (e.g., the impact of ADT on body image and masculinity), practices, feelings and motivations for doing something (e.g., exercise behaviours and subjective meanings associated with exercises) (Braun & Clarke, 2006). Moreover, the flexibility of thematic analysis makes it an ideal qualitative method to apply in relatively unexplored research fields, such as the exploration of body image issues in PCa patients undergoing ADT (Braun & Clarke, 2013).

Thematic analyses allows the researcher to define patterns of meaning across participants (Braun & Clarke, 2006). After familiarising with the data, thematic analysis employs a process of initial coding across the entire dataset. Those codes are then organized and used to build themes. The researcher should then proceed to review and rename the themes, constantly moving back and forward in the entire data set, until reaching a comprehensive and meaningful output. The writing of the output is considered an integral part of the analyses process, and not just as the final stage of the research. The six phases of thematic analysis that was performed on the data is described by Braun and Clarke (2006) and can be found in Table 4.2.

Table 4.2. The six phases of thematic analysis (Braun & Clarke, 2006)

1) Familiarization with the data Transcribing the data from the interviews, reading and re-reading the transcripts, writing down initial ideas and patters.
2) Generating initial codes Systematically coding significant patters across the entire dataset, reviewing the codes by collating text relevant for each code together. Building a preliminary codes map (Appendix A4).
3) Building the themes Collecting the codes into bigger themes, collating together all the text relevant for each theme using NVivo.
4) Reviewing the themes Checking if the themes are meaningful in relation to the text and the codes that are being collated together. Define a structure of the themes with a theme map (Appendix A5).
5) Defining the name of the themes Define the relationship and structure between and within themes, decide on a name and short description for each theme.
6) Producing the final report Selection of vivid quotes, final analyses of selected quotes in relation to the initial research questions and the broader literature.

The application of thematic analyses allowed for the identification of broad themes relevant to participants' experience with ADT, body image, masculinity, and exercise. The six phases of thematic analysis as described above in Table 4.2. were adhered to familiarising with the data, developing preliminary codes first and then broader themes (see Appendix A4 for codes map and Appendix A5 for themes map).

Mixing different data collection modalities (face-to-face interview, telephone interview, email), resulted in different levels of depth of the data. In particular, in this study telephone interviews provided much richer data than face-to-face interviews. While face-to – face interviews were strongly influenced by the age, gender, and nationality gap between me and the participants, phone-based interviews allowed me to keep my identity more neutral (e.g., not disclosing my age) and also helped participants to remain more anonymous (e.g., by not showing their physical identity). These characteristics favoured the disclosure of personal and sensitive information, ultimately resulting in richer qualitative data. The process of reflexivity, "owning one's perspective" (Elliott et al, 1999), is a key quality criteria for thematic analysis. The researcher's expectations, values, and personal characteristics will inevitably shape data collection and analyses. It is therefore necessary to engage in reflexivity, in order to clarify the researcher's perspective on the data. A thorough discussion of the social and personal factors that might have influenced data collection can be found in the reflexivity section of this chapter (section 4.6.2) and in the reflexivity chapter (Chapter 7, section 7.3.1).

Thematic analysis was conducted by the first author with the support of the supervisory team during the phases 4 (reviewing the themes), 5 (defining the names of the themes) and 6 (writing the final report).

4.4. Results

Thematic analysis resulted in three main themes:

- Theme 1: Body image issues as body feminization issues;
- Theme 2: The compromise of exercise;
    - Compromising exercise and side-effects: between compensation and barriers;
    - Psychological implications of exercise: between empowerment and fear of evaluation.
- Theme 3: Coping with a new body.
    - Reluctant body acceptance;
    - Talking about it: it is certainly important, but is it “manly enough”?

Most participants started their interviews talking about the broader context of their diagnosis and focused on the specific topics of ADT side-effects, body image, and exercise later on.

4.4.1. Theme 1: body image issues as body feminization issues.

Participants experienced several ADT-induced bodily changes, some of which had a distressing impact on their masculine identity. These changes often led participants to experience their body as inherently different from how it was prior to diagnosis, which they often wanted to return to.

> *“I should say as a patient all you want to do is going back to what you were. You want to go back.”* (Robert, 58 years old)

Breast enlargement was the bodily change mentioned most often, identified by those who had experienced it as distressing, embarrassing, and feminizing. The majority of men who had not experienced breast enlargement described their hope that they never would.

> "*I suppose you sort of feminize (…) because obviously you get breast enlargement (…) It's embarrassing. I remember having the grandkid saying shouting to his sister "my grandad got boobies!" which is not nice you know…*" (Carl, 70 years old)

> *"I did fear (…) that I would start to grow, although it is ridiculous really, that I would start to grow breasts."* (Marius, 61 years old)

Embarrassment for breast enlargement brought some participants to conceal this bodily change, mostly with baggy clothing but also through surgical breast reduction.

> "*The breasts were one of the biggest embarrassments to me, so as I said a baggy t-shirt helped"* (Henry, 74)

> *"I said, doctor "Can you do something about these?" (referring to breasts) (laughs) he agreed to put me (…) forward to have breast reduction. So I had breast reduction. Emh.. and that was okay. It sorted it, it worked, you know my breasts reduced. That was an embarrassment to me, if you want.. in terms of body image. I don't always take my shirt off, but you know when you are on holiday… you go swimming, whatever.. I wasn't satisfied. Given the opportunity, I asked if I could have them removed and I had them removed. In retrospect, it was more painful than I expected"* (Jacob, 68 years old)

Increased body fat was also concerning for many participants, who defined weight gain as undesirable aesthetically and functionally, and described their bodies as less masculine, less attractive and less capable of performing physically and sexually. Most participants would therefore try to engage in both dieting and exercise with the aim of losing weight.

> *“(...) I am looking fatter as well as feeling fatter (…) I want to continue doing some of the vigorous exercise I have enjoyed in the past and I don’t want to be carrying all this extra weight”* (Edward, 65*)

> *“The only way I’m going to lose weight is if I’m going to stop eating. So I did stop for about two weeks, (…) I needed to get sort of my head straight and lose some weight.”* (Richard, 65)

In this regard, many participants were concerned about loss of functionality due to muscle-wastage and fatigue. This change often led to feelings of distress, frustration, lowered physical self-efficacy, and sense of loss.

> *“Now my energy levels aren’t as great as they used to be. So I can still walk (…) 8 to 10 miles a day…. Whereas before it was 15 to 20. But those days have gone now and I found that very sad.”* (James, 66)

> *“Especially my arms… I’m thinking my muscles disappeared!”* (Marcello, 59)

> *“The tiredness limits to some extend what I can do. I used to go walking distance and that… I can’t do as much, I get tired (…) I have to restrict what I can do (..)”* (Phil, 75)

ADT often caused penile-shrinkage, erectile dysfunction, and loss of libido. Although sexuality was not specifically included in the topic guide, sexual issues emerged as one of the most upsetting side-effects, strongly contributing to loss of masculine self-esteem.

> “*I mean I must admit penis has shrunk a bit.. it shorten a bit… which can be slightly awkward at times…”* (Phil, 75)

> “*I think you lose all… you lose a lot if your libido… and…. Emh….. you… you have erectile dysfunction and things like that… (…) Which are all sort of problems and I*

** The numbers represent participants’ age in years*

> *think…. These are contributing to your body image you know… (…)… an extra problem to contend with"* (Henry, 74)

> Answering the question: "How do these sexual issues make you feel?": *"It's upset… is uncomfortable, it's upset. (…) Obviously the physical side of our relationship is not totally fulfilled but… there are various ways around that (…) we talk about it…"* (James, 66)

ADT also caused mood swings that were interpreted by many patients as a further feminization of their identity.

> *"I did become very tearful and emotional about silly things…Which again is strange from a man… from a manly point of view…"* (Henry, 74)

Altogether, ADT-induced changes contributed to a sense of bodily feminization and had a negative and distressing impact on participants' masculine self-esteem. Bodily feminization and femininity overall were conceptualised as negative, disturbing and threatening. Some participants coped with the discomfort with humour and sometimes sexist jokes.

> *"I feel very much emasculated at the moment…"* (Eduard, 65)

> *"I was somehow convinced that I was turning into a woman. So that's what it is and (…) just from a manly point of view that it is… quite… disturbing…."* (Henry, 74)

> *"And… of course the standard joke about hormone therapy was the fact that because it is a female thing, the worse side-effect is that you spend money in things you don't need. Being a female thing (laugh)"* (Elvio, 73)

The ADT-provoked bodily changes induced feelings of loss for the body as it was prior to diagnosis and, for some participants, a loss of their identity as male. Some described frustration towards their current body, changed in its appearance and functioning. Some men expressed regret for not appreciating their bodies more when they were cancer-free.

> *"Why should I worry too much about myself? But yet… at the same time I know my own identity and my own identity is not to be overweight with breasts."* (Sander, 54)

> *"I took my body pretty much for granted, I'm afraid."* (Jacob, 68)

4.4.2. Theme 2: the compromise of exercise

4.4.2.1. Compromising exercise and side-effects: between compensation and barriers.

Most participants reported regularly engaging in light exercise, often walking and cycling, but also Pilates and light weight lifting. Exercise was identified as an effective strategy to compensate ADT side-effects. In particular, participants expressed preoccupation with ADT-induced fat increase and many of them engaged in exercise to reduce weight.

> *"I read up about the side-effects from these hormones and I did… I do what you would consider an awful lot of exercise at the gym…"* (Richard, 65)

> *"Certainly regular exercise does help to keep your weight down…"* (Ludovick, 73)

Beyond compensating for side-effects, exercise was conceptualised as a strategy to compensate or slow down cancer growth in general.

> *"If you don't exercise your cancer will grow. Your body needs exercise."* (Carl, 70)

> *"I do get a lot of information about cancer and they do say that exercise is a very good thing to try and ... to inhibit your cancer and you know… to help you survive it"* (Henry, 74)

However, men referred to how side-effects could represent an exercise barrier itself. Specifically, men who were working full-time and struggling with fatigue found engaging in exercise very difficult.

"I am working full time, and you are tired after work. It is difficult to fit exercise in your day…" (Marius, 61)

"The moment you start going back to normality, gets… it does get more difficult to get the energy… to put the exercise in…" (Robert, 58)

Therefore, exercise represented an effective strategy to compensate for ADT side-effects, but it was only accessible when the side-effects were not too severe.

"It can be self-perpetuating… if you feel tired and you don't exercise, you stay tired. The exercise actually increases your energy level… but sometimes it depends… there are days where literally I need to sit down" (Peter, 77)

4.4.2.2. Psychological implications of exercise: between empowerment and fear of evaluation.

Participants described how exercising helped them to focus on what their body could still do, giving them a sense of achievement and reinforcing their body functionality, physical self-efficacy and body confidence.

"That makes me feel good inside, the fact that I have done it! And I can push myself a little bit harder the next time" (Richard, 65 years old)

"Even now I'm still improving." (Michael, 67 years old)

"If you are able to exercise, it makes you feel like if you haven't given up on life yet… you can still do these things (…) the fact that you say -well yes I can still do it!-" (Peter, 77)

Moreover, participants associated exercise with a sense of renewed control over their bodies, and in particular over their illness. In this regard, exercise helped them reduce health-related anxiety.

> *"So you get that sort of positive buzz from the fact that you are under still a little bit of control over your body…your cancer is incurable. I don't know how long I have got but it's just gratifying and reassuring that I can still do things"* (Michael, 67 years old)

> *"You know it is feeling that you….that I can… That I can take back some control over what is happening to my body…."* (Eduard, 67)

> *"It makes you feel as if you are taking control again… it gives you control of your body, it gives you belief that you can actually do things"* (Sander, 54)

However, for some participants exercise implied an exposure of one's bodily appearance and physical performance, for example in gyms or swimming pools. Such exposure made some men feel vulnerable to other people's judgment.

> *"Unfortunately with the walking machine you got somebody else in front of you or next to you and you still think - Oh they are quicker! Especially when you have people on either side of you were going twelve times faster! And you are like what am I doing here??"* (George, 80 years old)

> *"I wouldn't like to be in a situation where I slow the group down."* (referring to walking groups specifically for men with PCa, organised by charities) (James, 66)

> *"I went to the gym regularly and did a lot of swimming. So my body appearance was on view (...) which slightly embarrassed me, you know the changes (...) probably because of my body image I didn't do any swimming for some time…"* (Henry, 74)

> *"It was quite a shock to discover the physical changes in my body's appearance. My testicles and scrotum shrank so that I looked like a pre-pubescent 60-year-old teenager. I also lost most of my chest and thigh hair and with the loss of pubic hair from the radiotherapy I had to avoid the changing room at the gym at all costs! (...) I am now very conscious of my "Casodex breasts" that again I was not fully prepared for…"* (Robert, 58)

In this regard, a participant referred to avoid group exercise settings, especially if attended by people without a diagnosis of prostate cancer, in order to avoid comparing himself to others and worry about his physical performance:

> Interviewer: *"You mentioned that you used to walk in groups while now you prefer to walk with your wife only. Is it right?"*
>
> Sander: *"Yes… yes."*
>
> Interviewer: *"Is there any particular reason why you made this change?"*
>
> Sander.: *"Ern…….(long pause). Well……. I suppose… mh….it's hard to explain really. (pause). I would… I wouldn't like to be in a situation where I slow the group down. So……but I'm not sure how realistic that sort of is (…)I sort of become less sociable on those groups…"*
>
> Interviewer: *"Mh…"*
>
> Sander*: "So…..uh…….(pause). I still have a little bit of me which is envious of people who aren't affected by cancer."*
>
> Interviewer: *"Right."*
>
> Sander: *"I have not got totally rid of that… I mean it is not as bad as it was and…. I think walking in a group of healthy people… well… not all of them will be healthy. I know…. I am making conversation and… I feel like I don't want to be bothered."* (Sander, 54)

Most participants reported to exercise in private settings (total mentions = 17), referring to activities such as walking alone or with a partner (mentioned 8 times), gentle home workouts (mentioned 5 times), gardening (mentioned 2 times), and cycling (mentioned 2 times). On the other hand, only a minority of participants (total mentions = 4) referred to still exercise in public settings like the gym (mentioned 3 times) and park runs (mentioned once). The strong preference for private exercise settings could be interpreted in relation to the fact that participants expressed preoccupation to be judged for their appearance and physical performance in public exercise settings. However, it is important to note that only one participant (Sander, 54) explicitly linked his preference to walk only with his wife to the fact that group exercise settings exposed him to comparison and preoccupation. Since the preference to exercise in private settings could be due to a variety of reasons (e.g., more privacy but also more accessibility), this interpretation should be further investigated with quantitative methods.

In conclusion, exercise seemed to enhance participants' body confidence and reduce health-related worry. However, fear of negative evaluation for body appearance and functioning seemed to prevent some men from enjoying exercise environments, potentially reducing the positive psychological effects of exercise.

4.4.3. Theme 3: coping with a new body.

Although not explicitly prompted by the topic guide, during the interviews many participants referred to the strategies they had adopted to cope with ADT side-effects, health-related anxiety and low mood.

4.4.3.1. Reluctant body acceptance.

Many participants referred to the side-effects caused by ADT as “the price to pay for life” and therefore expressing the inevitability of the bodily changes they were experiencing. For some participants, highlighting the essential function of the treatment allowed them to put the bodily changes in perspective, favouring a somewhat reluctant acceptance of the situation. However for others identifying ADT as the price to pay for life evoked a feeling of resignation towards an inevitable condition.

> *“Well…. If you don’t take the drugs or the treatment, you have a very high rate of chances of dying so you know… you gotta… do you wanna take the short term pain for the long term gain?”* (Valerio, 57)

> *“With this drug, I know it could fail at any time but it gives us some… some future. You know… We are all mortal, you are going to die somewhen,[sic]. I’m going to die somewhen… I mean I’m closer to mortality than you are but… it gives you…. It… because we have a certain period it means we can talk about “well what are we going to do next year”… Because there is a good chance that you know… that I’m still going to be around.”* (James, 66)

> *“That saved my life. But my body isn’t the same anymore.”* (Marius, 61)

In this respect, some participants tried to accept their bodily changes as part of the general process of ageing. They thought they would have been more bothered at a younger age, when their expectations around bodily appearance and functioning were higher. However, during the interviews younger men did not explicitly refer to their young age as an aggravating factor for body image concerns.

> "*I'm 73 and I have had the hormones, I have had the chemo, and everything else, all within the last two and a half years…So is it the hormones? Is it the chemo? Or is it old age?"* (Paul, 73)

> *"You know particularly a man younger than me could have problems with his sex life. We have been married… well just over 44 years"* (Ludvik, 73)

> *"I think in my case age is coming into it. I talked to some of the other members* (of the group which the man attended) *who were younger and they are full of worries and worries (...) I look at myself in the mirror and I think well you are not the handsome guy you used to be but never mind…. at 80 what do you expect?"* (George, 80)

Some participants also referred to not being particularly bothered by appearance-related bodily changes induced by ADT because they focused on the importance of health and body functionality rather than their looks. Low appearance investment tends to play a protective role against body image concerns (Jarry, Dignard, & O'Driscoll, 2019).

> *"I'm mostly concerned about the (loss of) function, I don't care about the aesthetics I don't go around naked!"* (Paul, 73)

> *"You find out you going around looking like Mr Universe becomes a bit less important (...) there are more important things in life than physical appearance"* (Marcello, 59)

However, some participants also expressed the view that being dissatisfied with one's body is inherently emotional, silly and feminine. This suggests that while some participants were not invested in appearance, others might have felt it was not appropriate for them to have body image concerns. Their masculine self-esteem was therefore threatened not only by the bodily changes induced by ADT, but also by the preoccupation associated with such changes. This conception of body image issues suggests that some participants might hold so-called hegemonic masculinity ideals, which refer to a specific form of masculinity which idealizes toughness, self-sufficiency, lack of emotional sensitivity, physical and sexual strength (Wall & Kristjanson, 2005)

> *"You know actually I never put myself as a young female (laugh)… I never I never sort of regarded it as a body image issue… you know (…)I don't think of myself as having a body image"* (Jacob, 68)

> *"Well that most of the men… I mean it's not considered sort of too much of a manly thing to talk about it (...) whereas you know we may not talk about it, I'm sure secretly we are very concerned about it you know (...)we all recognize that the ladies are far more open and they can discuss with each other you know… problems and things like that. But I think that men are far more reluctant to do that"* (Henry, 74)

To conclude, participants gave different meanings to the concept of accepting the bodily changes induced by ADT. While some focused on the importance of treatment to survive and on other aspects of their body and their lives that they valued more than appearance, others accepted the changes as part of the process of ageing. A proportion of participants described body image issues as a stereotypically female problem, which therefore could not touch them and was inappropriate to talk about regardless.

4.4.3.2. Talking about it: it is certainly important but is it "manly enough"?

Many participants referred to finding it difficult to ask for and receive social and psychological support, especially from other men. In particular, men who had not been through PCa themselves were often described as not understanding or willing to understand.

> "*Even though probably most of them* (men who have not been diagnosed with prostate cancer) *will have to face up to it one day, still they're not interested. Psychologically speaking that was one of the bigger barriers that I had to face. They see you. They know*

> *what you've had. They don't necessarily know what you've done. But when they stand in front of you, (...) they think is nothing. They just assume that… they just assume that it is nothing. Cause they think it's not really nothing to worry about"* (Marius, 61)

Some participants also referred to a struggle to find support from other men diagnosed with PCa themselves, finding it difficult to open up to each other about their cancer journey.

> *"I found the meetings to be quite depressing. I wouldn't go away feeling supported. Although I suppose they were all trying to do their best for each other…no doubt about that but…I always came away feeling a bit depressed"* (Marius, 61)

> *"I'm a bit weary of other people with prostate cancer… I think… Emh… I have met a couple of prostate pals in the radiotherapy corner, cause we were there every day for seven weeks and (...) so I have met a couple of them (...). I don't think that helps really, because usually I think they are not doing as well as I am (...) I find myself more introspective really"* (Robert, 58)

At the same time, some highlighted how support groups were very important to encourage men to open up in a safe environment.

> *"That's one of the good things about our support group, cause it encourages men to talk about problems yeah… and you can compare your situation with other guys situation and you (...) recognize that you are not unique…and everybody perhaps. Many other guys have the same sort of problem so… in a funny sort of way I think that helps quite a lot (...) it is reassuring to talk to other guys who have the same sort of problems, same sort of concerns, I think that does help."* (Henry, 74)

Some participants also referred to the tendency of men not to talk about their feelings and share their vulnerability, as opposed to female counterparts who in their opinion were more used to openly talking and supporting each other.

> “*We all recognize that the ladies are far more open and they can discuss with each other you know… problems and things like that. I think that men are far more reluctant to do that.” (*Henry, 74)

> *“On Facebook there’s a (...) closed group for men who have been diagnosed with prostate cancer obviously… an advanced one… and then there’s the women there who’s husbands have been going through or partners or sons or fathers…mh… and I tend to see on it that there’s many of the women who do the talking… and then man tend to sort of bury their head and not say anything and just sort of watch. But I’d just come along and put a word about the sexual problems and people were saying well done you know… I wish my husband had talked about (...) I wonder what he is thinking, I wander what he feels.. I wonder what we could do but he won’t talk about it… you know…”* (Sander, 54)

Most participants found their main psychological support to be from female partners, as well as female counsellors and female health care professionals. Sometimes participants expressed the idea that only women were willing to listen and emotionally support them.

> *“There is no empathy from anybody. The only people I had talked to are professional people. (...) The only people I could talk to were counsellors. And they were women. I can only assume that men really aren’t interested.”* (Marius, 61)

In summary, while most participants recognized the importance of talking to others about their cancer journey, many individuals struggled to open up to other men specifically – despite the presence of safe spaces offered by PCa specific charities. Instead, they found support from their female partners or female counsellors, who they described as naturally more nurturing.

4.5. Discussion

This qualitative study explored the impact of ADT- related side-effects on PCa patients' body image and masculine self-esteem. Participants' attitudes and barriers towards exercise were also explored, as a potential strategy to compensate ADT side-effects, enhance health, and improve body confidence. The results supported and expanded previous findings, representing a contribution to this relatively unexplored field.

In line with previous literature, most of the participants referred to ADT-induced bodily changes as distressing because they were considered feminizing (Ervik & Asplund, 2012; Navon & Morag, 2003). The combination of weight gain, breast enlargement, functionality loss, penile shrinkage and erectile dysfunction left participants with a body that was perceived as profoundly different from the one they had prior to diagnosis. Most of the participants were bothered by these changes both from an aesthetic and functional point of view. Moreover, these changes often represented a threat to their masculine self-esteem and participants often expressed feelings of regret for not appreciating their masculine healthy body more in the past.

It is important to note that the degree and type of impact the ADT-induced bodily changes has on participants' masculine self-esteem also depends on their personal conception of what it means to be masculine. In particular, many participants seemed to refer to a hegemonic masculine ideal, which idealizes toughness, self-sufficiency, lack of emotional sensitivity, physical and sexual strength. Despite referring to this masculinity model, some men mentioned the negative aspects it entails (e.g., discouraging men from talking about their emotions). Hegemonic masculinity ideal remains the most dominant and valued in Western societies, but individuals can still adopt different models of masculinities. In fact, masculinities are manifold and it is possible to reject the values of domination, physical strength, and sexual power, to embrace values such as connection to emotions, and interdependence instead. Men holding a hegemonic ideal seemed to be more negatively affected by hormonal treatment, as they identified the ADT-induced bodily changes as a feminization and therefore as a fundamentally undesirable and troubling process. For men with a hegemonic masculine ideal, ADT side-effects seemed to damage those core characteristics embodying their ideal masculine identity. In support of this interpretation of the data, a study by Alleva, Paraskeva, Craddock & Diedrichs (2018) found that in a British community sample of 439 men (Mage = 39.13) body appreciation was inversely correlated with conformity to masculine norms (Alleva, Paraskeva, Craddock, & Diedrichs, 2018). Similarly, a study by Wassersug et al (2011) found that the quality of life of patients undergoing ADT differed dramatically between individuals identifying as men diagnosed with PCa and male-to-female transsexual individuals going through the same treatment for their sex confirmation procedure. Despite experiencing the same sexual issues and bodily changes in appearance and functionality, the transsexual group coped better with the side-effects. This was not surprising given the very different medical contexts in which ADT was administered. The authors suggest that the results support the possibility for men diagnosed with PCa undergoing ADT to better cope with the treatment side effects by restructuring their concept of masculinity (Wassersug & Gray, 2011). These indicate the need to further explore the influence that masculinity ideals might have on body image and masculine self-esteem for PCa patients undergoing ADT. For this reason, this was investigated further in Study 2 (Chapter 5).

Exercise is recommended to PCa patients as an effective strategy both to increase survival and reduce cancer re-occurrence (Thorsen et al., 2008). Participants who regularly engaged in exercise referred to doing so in order to both improve their health and compensate for some of their ADT side effects. In line with previous literature (Kelly, 2009; Langelier et al., 2018; Langelier et al., 2019), exercise not only helped participants to improve their mood and energy levels, but also gave them a sense of achievement and control over their body. For many, being able to exercise was a comforting demonstration of their abilities and strength despite cancer. This suggests that exercise could be an effective and acceptable strategy for PCa patients undergoing ADT to focus on the functionality that their body still has despite cancer. Focusing on what their body can still do might also help PCa patients to increase their body confidence and facilitate acceptance of their appearance (Alleva, Martijn, Jansen, & Nederkoorn, 2014). For this reason, the following study further explored the relationship between exercise and body image outcomes in PCa patients on ADT.

In line with previous studies (Keogh et al., 2014), participants who were suffering from ADT-induced fatigue and working full time particularly struggled to exercise. However, time and energy management were not the only barriers to exercise identified through the qualitative analyses. This study expands previous literature by highlighting how fear of negative evaluation might partially explain the low exercise rates in this clinical group. Some participants were also concerned about being judged by other men, both for their bodily appearance (especially for breast enlargement) and physical performance. In this regard, most participants reported to prefer private exercise settings compared to public or group exercise environments, with one participant explicitly linking his preference to walking alone with his wife to the fact that group exercise settings exposed him to fear of negative evaluation for appearance and physical performance. Fear of negative evaluation might partially explain both the preference for private exercise settings as well as the low exercise rates that research usually finds in this clinical group (Forbes et al., 2015). This interpretation is in line with results from studies conducted in the general population, finding that certain exercise settings tend to elicit fear of negative evaluation and self-presentation concerns (e.g., dressing rooms, swimming pools, gyms with mirrors, exercise classes emphasizing weight loss, but also high impact exercise classes), which in turn can result in negative emotions and lower engagement in exercise (Brudzynski & Ebben, 2010; Focht & Hausenblas, 2003, 2004; Ginis et al., 2003;

Katula & McAuley, 2001; Martin et al., 2006; Raedeke, Focht, & Scales, 2007). Even if exercise does have a positive impact on body image issues, fear of negative evaluation (being judged negatively by others) might prevent PCa patients from engaging regularly in exercise and therefore from experiencing exercise benefits. Therefore, Study 2 further explored the role of fear of negative evaluation in PCa patients undergoing ADT (Chapter 5).

During the interviews, participants often touched upon the strategies and thought processes that helped them cope with the bodily and life-style changes induced by ADT and PCa diagnosis. In particular, several participants referred to ADT as the price to pay for life and therefore to be accepting its side-effects given the possibility of living longer. While for some participants, highlighting the life-saving function of ADT was helpful to cope with its side-effects, others mentioned deeply missing their cancer-free body and having no choice but accept ADT in order to stay alive. Acceptance can be defined as a coping strategy that aims at changing the emotional impact of a negative event, when it is not possible to change the negative event itself (Brandtstädter, Wentura, & Rothermund, 1999). From the interviews, it was possible to identify two different forms of acceptance with regards to ADT side-effects, which Nakamura and Orth (2005) defined as active acceptance and resigning acceptance. Active acceptance implies the acknowledgement of a negative situation and a drive to deal with it constructively. Actively accepting ADT implies avoiding wasting energies to control what cannot be changed, and still engaging with positive behaviours and pursing life goals where possible (e.g., exercise, focusing on family and friends, etc.). While resigning acceptance is also characterised by the interruption of control attempts where the situation cannot be changed, this strategy is often also accompanied by negative expectations about the future and loss of hope which could lead to a general passivity and feelings of sorrow (e.g., "There is no other choice") (Nakamura & Orth, 2005). The fact that participants wanted to talk about the strategies they engaged in to cope with cancer diagnosis and ADT (despite not being present in the original topic guide), highlighted the need to further explore this topic. Exploring the influence of different coping strategies on body image and masculine self-esteem outcomes became the focus of Study 3 (Chapter 6).

Expectations on bodily function and appearance played a role in how well men accepted the side-effects of ADT. For example, older men seemed to be able to accept their body condition more easily, since they could anticipate similar issues at that stage in life regardless of PCa and ADT. On the other hand, older participants highlighted how, if they were younger, they might have set higher expectations on their body appearance and functioning and for this reason they might have felt more upset about treatment side-effects. This is in line with research highlighting how age can be a protective factor against body image issues, as older individuals can become less appearance invested and less susceptible to appearance societal norms (Ålgars et al., 2009; Hogan & Warren, 2012; Tiggemann, 2004).

In this regard, participants who implied they had a low appearance investment seemed to not be greatly affected by ADT-induced bodily changes, as they chose to focus on other important aspects of their health and life. This result is consistent with a large amount of literature finding that low appearance investment is a protective factor against body image issues (Jarry et al., 2019; Sherman, Woon, French, & Elder, 2017). Moreover, focusing on aspects such as health and body functionality (i.e., everything that the body can (still) do) is considered a core element of a positive body image attitude towards one's body (Alleva et al., 2017; Tylka & Wood-Barcalow, 2015b). In contrast, some participants referred to body image issues as a stereotypically female problem, and as such not relevant for men nor appropriate to talk about. This suggests that expressing body image concerns was perceived as socially undesirable because it was not seen to be masculine for some of the participants. This finding could be interpreted in light of the hegemonic masculine stereotype, which glorifies the lack of emotional vulnerability in men and is associated with the tendency of not requesting or accepting psychological support (Keohane & Richardson, 2018; Wahto & Swift, 2016). This highlights the need to further explore the relationship between hegemonic masculinity, appearance investment, and body image concerns, which are explored quantitatively in Study 2 (Chapter 5). This preliminary finding also suggests the need to create safe spaces in which PCa patients prescribed ADT could express their body image concerns to other men.

In line with this result, several participants expressed their discomfort in talking to other men about their condition. While they all thought that talking about a difficult situation is an important resource for coping with it, many felt it was not possible to be vulnerable with other men, whether they were also diagnosed with PCa or not. Some participants expressed the idea that their female partners, friends, health care professionals, and counsellors were more nurturing, overall better listeners and more able to talk about sensitive topics. Western gender norms have been describing men in emotionally negative terms since the eighteenth century, for example assuming men would be more selfish, cruel, and emotionally unavailable (Grenz, 2005). On the other hand, women have been stereotypically constructed as emotionally available and keen to take responsibility for a relationship (Grenz, 2005). This results in the common assumption (that some consider even an empirical fact) that women are better listeners (Grenz, 2005). Men strongly identifying with stereotypical gender norms might avoid being emotionally vulnerable with other men and be more inclined to opening up to women instead.

4.6. Considerations on the research process.

4.6.1. Limitations of the study.

This study has some limitations. Firstly, the sample was composed only of white individuals who had high educational levels and identified as heterosexual men. The scarce variation of the sample not only negatively affects qualitative results (Palinkas et al., 2015) but also fails to represent a diversity of voices in this research, excluding the most disadvantaged

PCa patients. Conducting this study in the very first months of my arrival in the UK meant that I was not fully aware of the racial and social composition of British society nor did I fully understand the implications between race, gender, sexuality, social economic status and health inequalities in this country. While the recruitment strategies adopted for this study successfully resulted in a sample diverse for ages and locations within the UK, they still did not manage to reach individuals with different backgrounds. For example, I did not realise that the charities through which most of the participants were reached, had mostly White service users. To address this issue, the following two studies focused their recruitment online, since web-based is considered an effective strategy to improve access to research to individuals with a variety of backgrounds (Heath, Williamson, Williams, & Harcourt, 2018; Wilkerson et al., 2014). However, it is important to note that online recruitment still poses issues when trying to reach individuals who might not have a reliable access to the internet. Upon reflection, recruitment strategies could have been further diversified by distributing flyers in locations not specifically dedicated to cancer patients (e.g., barbers, churches, gyms, etc.) in order to make contact with participants who were not already seeking help. Flyers could have also been distributed in locations that might have been of easier access for men from ethnic and LGBTQ+ minority groups (e.g., neighbourhoods with high density of ethnic minorities households, and areas with high proportions of LGBTQIA social networks, etc.). The challenges to reach a diverse sample will be further discussed in Chapter 5 (Study 2), Chapter 6 (Study 3), and Chapter 7 (Reflexivity Chapter). In Chapter 7, section 7.4 will specifically focus on discussing the implications of lack of diversity in psycho-oncology studies focusing on PCa.

As the first key study of this research programme, Study 1 adopted qualitative methods to explore ADT impact in depth and generate hypotheses. However, it is important to note that this approach does not provide information around potential differences in body image issues between PCa patients undergoing ADT and ADT-naïve patients, nor it can guarantee that the issues raised by participants are unique to men diagnosed with PCa and following hormonal therapy. For this reason, Study 2 compared a group of PCa patients undergoing ADT to a group of ADT-naïve patients and a group of cancer-free men.

One of the inclusion criteria of the study was "not having any limitation that does not allow oneself to exercise". This criteria was added because one of the major topics to explore was indeed exercise. Following discussions with my supervisory team, we thought it would have been appropriate to only interview participants who could engage in exercise. Upon reflection, the inclusion and exclusion criteria could have been revised to encourage people living with motor impairment disabilities to take part. In fact, this study only included people living in fully abled bodies, missing the chance to capture the lived experience of individuals living with a motor disability, PCa, and ADT, and their perceived barriers to engaging in various form of disability-friendly exercise.

All the PCa patients who participated in the study were already physically active or at least were interested in exercise. This might have happened because the study advert explicitly mentioned exercise (see Appendix A3). The study did collect the perspective of men who might not have been interested in exercise at all. This represents a limitation, as this information would have been relevant to shed light on other barriers to exercise that men diagnosed with PCa and undergoing ADT might perceive. To overcome this issue the following studies aimed to reach participants with different levels of engagement with exercise.

It is also important to note that information on participants' cancer stage was not collected. This choice was motivated by the fact that clinical advisors highlighted how cancer stage is sometimes not known by patients and can also represent a triggering question, which might have prevented participants from feeling comfortable throughout the interview.

However, the lack of information on participants' cancer stage did not allow for a comparison on the results of PCa patients experiencing different moments of their cancer journey.

Lastly, the interviews were offered solely in English. Due to limited resources it was not possible to hire translators to open the interviews to languages other than English. This represents a limitation as the study was not accessible to individuals from ethnic minorities in the UK only speaking languages different from English.

4.6.2. Researcher-researched identities: reflections on cultural, age, and gender differences.

Reflecting on my first attempt at drafting the topic guide, I can see how my expectations on the study and the interviews shaped the initial phrasing of my questions. In particular, I expected participants to be familiar with the concept of body image and used to talking about their psychological processes. Going through the first couple of interviews, I soon realized that my wording was not necessarily the most appropriate to connect with the participants. For some of them body image was a completely new term, and therefore needed to be broken down (e.g., "The way you feel and think about your body"). Similarly, other participants were new to an interview setting focusing solely on their thoughts and emotions. In fact, some of them expected the discussion to focus on their medical path instead. In these cases broad questions on the participant's psychological state were not effective at establishing a meaningful communication, as they were perceived as too broad and overwhelming (e.g., "How do you feel about your treatment?" "I haven't really thought about this", Elvio, 73). I had to adapt the questions so that we could start exploring body image and masculine self-esteem from a common starting point, and then develop the conversation moving forward (e.g., "ADT provoked breast enlargement" "Did weight gain bother you?" "Oh yes it did" "In which way?" "What do you mean?" "Was it a problem aesthetically or functionally for example? Or maybe something else?” Luca, 43). Some participants did not have access to a quiet and private room in their homes and sometimes did not expect the interviews to focus on their emotional state while undergoing ADT. After realising the potential mismatch in expectations, I made sure to ask the following participants to have a quiet space where they felt comfortable talking about their feelings without being interrupted.

At the time in which I conducted these interviews, I was a 27 year old Italian woman and had only been living in the UK for a few months. Although I had spent several years abroad for my education and had had the chance to perfect my English, I still had to overcome several cultural and linguistic barriers. Sometimes it was challenging to fully understand interviewees who were speaking in local dialects or using expressions I was not familiar with. Apart from being as focused as possible during the interviews, I also had to be confident in asking them to repeat themselves if I did not understand something. This process could be stressful, as I had to ensure I was fully following the conversation with each participant while worrying about not appearing unprofessional because of my foreign accent (especially given the politically charged anti-immigration sentiment due to Brexit during the years in which this PhD programme took place, between 2017 and 2020) . Similarly, I initially found it challenging to read and interpret some transcripts. While some methodological literature advises against conducting qualitative research in a second language altogether (MacLean, Meyer, & Estable, 2004), going through the data repeatedly for a year and then again after three years spent in the UK allowed me to better understand the nuances of participants’ responses. In fact, being more immersed in a British context helped me to better comprehend participants’ communication style while also critically reflecting on the cultural differences in health management between the UK and my home country, Italy.

Another challenge during the interviews was the expectations that participants had around my age. Some expected me to be older, rather than in my late twenties. The age gap might have discouraged some participants from opening up to me, thinking that I would not be able to empathise with their perspective. Especially in the face-to-face interviews, unmet expectations around age were sometimes evident through comments such as “ Oh but you are just a student!”, which challenged me to maintain a professional outlook from participants’ perspective. To overcome this difficulty, my supervisory team and I decided to focus on telephone interviews as the primary method of data collection. Choosing this data collection method was really helpful in bridging the age gap between participants and me, as they could not guess my age based on my appearance and would therefore judge my ability to empathise with them solely on the quality of the conversation. In qualitative literature, telephone interviews are often seen as a less desirable option when compared to face-to-face as they might make the responded uncomfortable while discussing sensitive issues (e.g., they do not allow the interviewer to observe the interviewee’s body language) (Groves, 1979; Novick, 2008). However, other authors have reported interviewees feeling more comfortable with telephone interviews when discussing sensitive issues because they were less concerned about their identity being disclosed and any potential humiliation that could follow speaking to someone face-to-face, (Chapple, 1999; Heath et al., 2018).

Lastly, during the interviews I had to manage the gender gap between participants (all identifying as men) and myself (identifying as a woman). Some participants seemed hesitant opening up regarding sensitive topics to me. In particular, during several interviews participants would briefly touch upon sexual issues and then change the conversation to another topic. When this happened I sometimes had to reassure them that if they wanted to talk about sexual issues, this was a safe and confidential space.

> “Participant: *“I don’t know how much you want to talk about it, I will be guided by your questions”*

CG: *"Yes of course…"*

Participant: *"I don't want to sort of embarrass you.."*

CG: *"No absolutely not, don't worry about that…Yes so tell me, I know that hormonal therapy can cause some sexual problems and some sexual issues for many patients. And of course this affects the relationship one has with his own body, cause that's part of the body of course. Did you have a similar experience as well?"*

Participant: *"Yeah… yes I did. I don't want to go into it too deeply if you don't want me to"*

CG: *"Give me the details that you want you to give. This is my job so I'm not going to get embarrassed. Tell me whatever you feel comfortable with."*

However as previously stated, several participants referred to finding talking to women more comfortable and reassuring, as they had experienced a lack of empathy from other men.

> *"There is no empathy from anybody. The only people I had talked to are professional people. (…) The only people I could talk to were counsellors. And they were women. I can only assume that men really aren't interested."* (Marius, 61)

This suggests that some patients might have actually felt more comfortable being interviewed by a female researcher rather than by a male. In this regard, a similar study by Chapple and Ziebland (2002), interviewed 52 men with PCa to explore their embodied experience with cancer. Participants were given the choice of speaking to either a female or male researcher, and only one patient chose to be interviewed by a male (Chapple & Ziebland, 2002). On the other hand, as a female researcher I faced the difficulty of witnessing some slightly sexist considerations and humour during the interviews and made sure to avoid challenging them. This was necessary in order to maintain the interaction entirely focused on participants' experience and avoid a disruption of the communication flow.

4.7. Conclusions and following steps

This qualitative study confirmed and expanded previous literature. ADT side-effects seemed to impact upon participants' body image. In particular, the treatment-induced bodily changes seemed to affect participants because they were conceptualised as being feminizing. ADT side-effects also seemed to negatively affect participants' masculine self-esteem. Informed by these results, the next study quantitatively investigated the impact of ADT on PCa patients' body image and masculine self-esteem, by comparing a group of PCa patients on ADT to a group of ADT-naïve patients and a group of cancer-free men. Moreover, given the emphasis that participants had put on the feminizing effect of ADT, the next study investigated whether masculinity ideals might influence the effect that ADT seems to have on PCa patients' masculine self-esteem. In particular, Study 2 tested whether participants with a strong hegemonic masculinity ideal might be even more affected in their masculine self-esteem by ADT side-effects, compared to patients with a more flexible conceptualisation of what it means to be masculine.

For the participants of Study 1, engaging in exercise seemed to be an effective strategy to compensate ADT side-effects. More importantly, exercise seemed to give them a sense of achievement and control over the changes of their body due to cancer. Exercise seemed to improve their physical self-efficacy and their body functionality. However, worrying about being judged for one's appearance and physical performance prevented some participants from enjoying, and thus engaging in, exercise, especially if in a public setting. This led some participants to exercise alone or drop exercise completely, therefore missing out on its positive psychological and physical effects. For this reason, Study 2 also examined the effect of fear of negative appearance and physical performance evaluation on participants' levels of exercise engagement.

In conclusion, this first qualitative study explored the field and provided a preliminary understanding of the impact of ADT on PCa patients' body image, their attitudes and perceived barriers towards exercise, and its potential psychological benefits. Following a sequential exploratory mixed methods design, some hypothesis were developed from the qualitative findings of this study, which were then quantitatively tested in Study 2 which is presented in the next chapter.

Chapter 5

Study 2: a quantitative cross-sectional study comparing a group of prostate cancer patients undergoing Androgen Deprivation Therapy (ADT) to ADT-naïve patients and cancer-free men on body image, masculine self-esteem, and exercise-related outcomes.

This chapter presents Study 2, which builds on the findings from Study 1 and quantitatively compared a group of men diagnosed with PCa and undergoing Androgen Deprivation Therapy (ADT) to PCa patients who never received ADT (ADT-naïve) and men who had never received a PCa diagnosis (cancer-free) with regards to body image, masculine self-esteem, and exercise related outcomes.

5.1. Introduction

5.1.1. ADT and body image issues: qualitative and quantitative results.

Study 1 found that men diagnosed with prostate cancer (PCa) following ADT often face side-effects which could foster body image and masculine self-esteem issues (Gentili et al., 2019). Results from Study 1 are in line with previous research suggesting that ADT-induced bodily changes can foster feelings of feminised appearance, shame and discomfort around the changed post-cancer body, and loss of masculine self-esteem (Ervik & Asplund, 2012; Gentili et al., 2019; Kelly, 2009; Navon & Morag, 2003). Masculine self-esteem is defined as the subjective assessment of one’s self-worth with respect to their masculinity ideal (Clark et al., 2003). These findings suggest the need to address body image issues in men diagnosed and treated for PCa and to identify those patients who could be more vulnerable to cancer-related body image concerns. However, most of these studies applied qualitative methods. As discussed in Chapter 2, quantitative studies on the impact of ADT on patients’ body image obtained mixed results (DeFrank et al., 2007; Harrington & Badger, 2009; Langelier et al., 2018; Taylor-Ford et al., 2013) (Chapter 2, section 2.3). While qualitative methods can capture the personal and existential meanings that individuals attribute to a given situation, qualitative data cannot be considered generalizable (Malterud et al., 2016) and therefore cannot be used to assess the needs of PCa patients at a population level to design targeted interventions.

Given the mixed quantitative results currently available, further investigation is necessary to determine whether findings from Study 1 could be generalizable to the wider population of PCa patients undergoing ADT. Moreover, quantitative studies so far only compared PCa patients on ADT with ADT-naïve patients. Study 2 also aimed to include an age-matched control group of men who were never diagnosed with cancer, in order to better understand the relative risk of body image issues associated with PCa diagnosis in general and hormone therapy specifically.

5.1.2. The impact of prostate cancer and ADT on masculine self-esteem: the influence of the hegemonic masculine ideal.

Numerous studies have shown that the diagnosis and treatment of PCa is likely to negatively impact patients' masculine self-esteem (Appleton et al., 2015). Research investigating the psychological experience of men diagnosed with PCa confirms that patients can experience feelings of loss for their masculine body (Kelly, 2009) and regret for deteriorated bodily functions (Cecil et al., 2010). In turn, PCa-induced reduction of masculine self-esteem is linked with negative psychological outcomes, such as distress (Cormie, Turner, et al., 2015), depression, embarrassment, decreased self-worth, feelings of identity loss and stigmatization (Levy & Cartwright, 2015), poorer QoL (Chambers, Ng, et al., 2017), sexual bother and relationship issues (Wootten et al., 2017; Zaider et al., 2012).

These findings highlight the need to address masculine self-esteem issues in men diagnosed and treated for PCa and to identify those patients who could be more vulnerable to cancer-related reduction in masculine self-esteem. Both quantitative and qualitative research suggests that PCa patients following ADT might be particularly affected in their masculine self-esteem by treatment side-effects (Ervik & Asplund, 2012; Gentili et al., 2019; Sharpley et al., 2014), suggesting that hormone therapy could be a risk factor for lowered masculine self-esteem during PCa.

Moreover, as previously noted when considering the impact of ADT on masculine self-esteem it is important to take into consideration the specific masculinity ideals patients might hold. Findings from Study 1 suggested that participants held hegemonic masculinity ideals and, when comparing the changes induced by ADT to such ideals, they often described feelings of loss regarding their identity as men (Gentili et al., 2019).

While a hegemonic masculine ideal remains the most dominant and valued in Western societies, it is important to note that masculinities are manifold (Araújo & Zago, 2019) and some individuals reject hegemonic values, to embrace a more flexible and emotionally available idea of masculinity instead (Elliott, 2016). Those men refusing hegemonic masculine ideals could be less negatively affected by ADT side-effects. The impact of ADT on features such as physical strength, sexual power and emotional control might not represent a threat to their core masculine identity, while for men with a hegemonic masculine ideal, ADT side-effects might damage those core characteristics embodying their desired masculine identity (Burns & Mahalik, 2008; Wassersug & Gray, 2011).

When considering the impact of ADT on masculine self-esteem, research so far has not taken into consideration the influence of various masculinity ideals. For this reason, Study 2 investigated both the impact of ADT and hegemonic masculine ideals on PCa patients' masculine self-esteem.

5.1.3. Exercise as a strategy to cope with body image issues and masculine self-esteem issues.

As presented in Chapter 2 (paragraph 2.5.1), the majority of trials evaluating exercise programs for PCa patients have focused on physical health-related outcomes and less on psycho-social impacts (Hackshaw-McGeagh et al., 2016; Thorsen et al., 2008), such as body image and masculine self-esteem (Demark-Wahnefried, 2017). However, some preliminary evidence supports the hypothesis that engaging in exercise might help PCa patients to reduce the negative impact of ADT on body image and masculine self-esteem. Some qualitative studies found that exercise can represent an active strategy to compensate for the feminizing ADT-induced muscle loss, increasing their physical self-efficacy (Bruun et al., 2014; Keogh et al., 2013, 2014), reducing appearance-related concerns (Craike et al., 2009), and supporting men to affirm strength-based aspects of their masculinity (Hamilton et al., 2015). Similarly, a quantitative study by Langelier et al (2018) found that higher levels of aerobic exercise were associated with improved masculine self-esteem and better body image in both PCa patients undergoing ADT and in ADT-naïve patients (Langelier et al, 2018). The studies that explored the effect of exercise on PCa patients' body image and masculine self-esteem while undergoing ADT are either qualitative or small quantitative studies. Therefore, more quantitative research employing big sample sizes is needed to further explore and corroborate said preliminary findings.

In terms of exercise barriers, Study 1 found that some PCa patients undergoing ADT struggled to exercise because they worried that their appearance and their ability to exercise (e.g. fear of negative physical performance evaluation) would be judged by others. As a consequence, they preferred to exercise alone or not exercise at all (Gentili et al., 2019). This result is in line with results from studies conducted in the general population, finding that certain exercise settings tend to elicit fear of negative evaluation and self-presentation concerns (e.g., dressing rooms, swimming pools, gyms with mirrors, exercise classes emphasizing weight loss, but also high impact exercise classes), which in turn can result in negative emotions and lower engagement in exercise (Brudzynski & Ebben, 2010; Focht & Hausenblas, 2003, 2004; Ginis et al., 2003; Katula & McAuley, 2001; Martin et al., 2006; Raedeke et al., 2007).

However, more quantitative research is needed to determine whether fear of negative evaluation for appearance and physical performance might be an exercise barrier for PCa patients undergoing ADT at a population level. For these reasons, Study 2 focused on the role of fear of negative appearance and physical performance evaluation as an exercise barrier for men diagnosed with PCa undergoing ADT.

5.1.4. Aims and hypotheses

The present study aimed to compare PCa patients on ADT, with ADT naïve patients and age-matched cancer-free men to examine body image, masculinity, and exercise and investigate causal relationships between these variables.

Specifically, this study tested the following hypotheses:

H.1. PCa patients on ADT will present higher body image concerns, lower functionality appreciation, higher fear of negative evaluation (both for physical performance and appearance), and more masculine self-esteem issues when compared (in order) to ADT-naïve PCa patients and age-matched cancer-free men.

H.2a. Being on ADT will predict more masculine self-esteem issues and this relationship will be moderated by hegemonic masculinity ideals, i.e., this association will hold true only for patients with high scores on hegemonic masculinity stereotype (Figure 5.1.).

H.2b. Being on ADT will predict higher fear of negative evaluation for appearance and physical performance (Figure 5.1.).

H.2c. Being on ADT will also predict higher body image issues and this relationship will be moderated by appearance investment, i.e., this association will hold true only for patients highly invested in their appearance (Figure 5.1.).

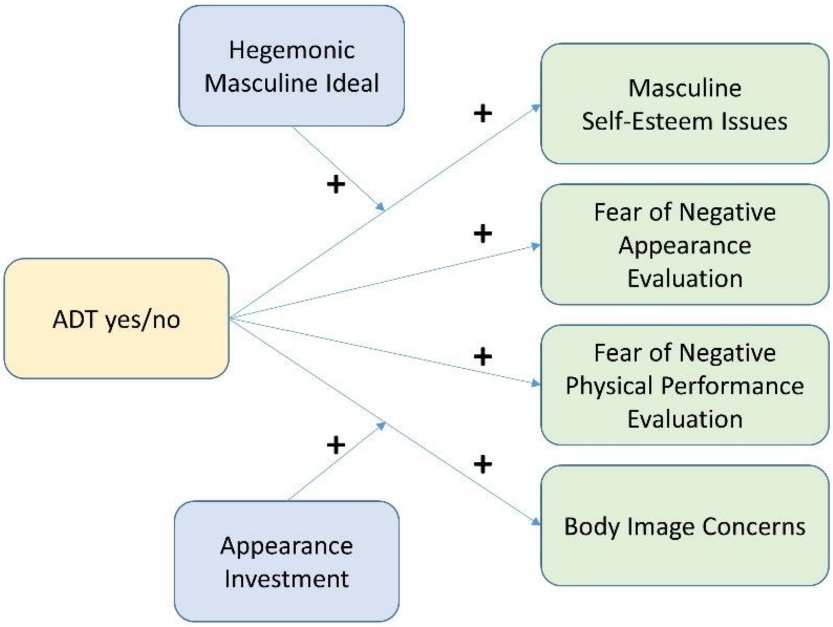


Figure 5.2. Study 2, hypotheses 2a,b,c.

H.3a. For the group of PCa patients undergoing ADT, high levels of fear of negative appearance evaluation will predict higher body image concerns, lower functionality appreciation, and more masculine self-esteem issues. These relationships will be mediated by exercise frequency, with fear of negative appearance evaluation predicting lower exercise frequency. In turn, exercise frequency would predict lower body image concerns, higher functionality appreciation, and lower masculine self-esteem issues (Figure 5.2.). This hypothesis was only tested in the group of PCa patients undergoing ADT.

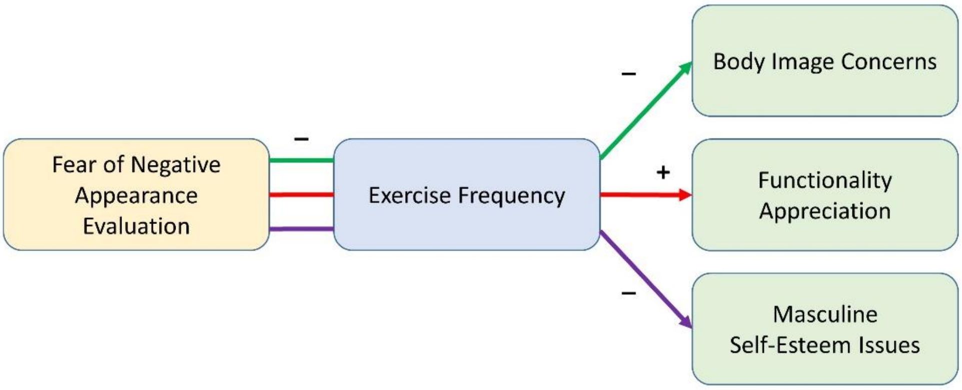


Figure 5.2. Study 2, hypothesis 3a

physical performance evaluation will predict higher body image concerns, lower functionality appreciation, and more masculine self-esteem issues. These relationships will be mediated by exercise frequency, with fear of negative physical performance evaluation predicting lower exercise frequency. In turn, exercise frequency would predict lower levers of body image concerns, higher levels of functionality appreciation, and lower masculine self-esteem issues (Figure 5.3.). This hypothesis was only tested in the group of PCa patients undergoing ADT.

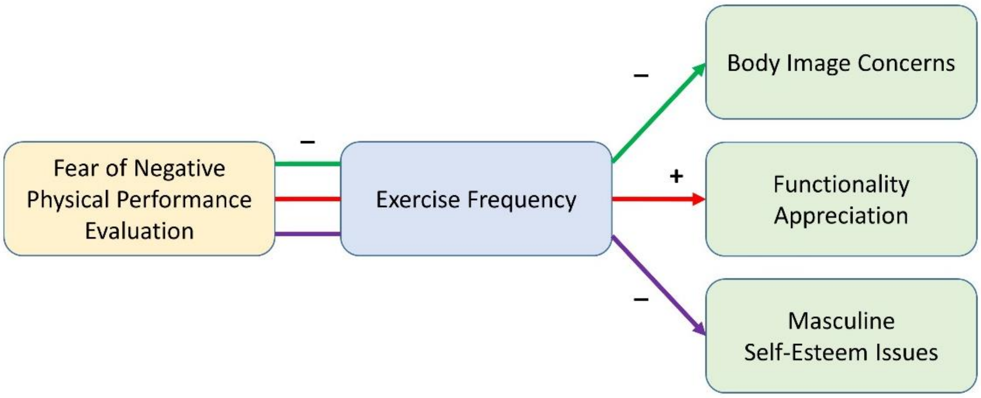


Figure 5.3. Study 2, hypothesis 3b

5.2. Methods

5.2.1. Design

In line with the sequential exploratory mixed methods design, Study 2 applied a quantitative design building on the results of the first qualitative study (Creswell & Clark, 2007). The aim of Study 2 was to test quantitatively whether the results from Study 1 would be generalizable at a population level (Morgan, 2007) (Figure 5.4).

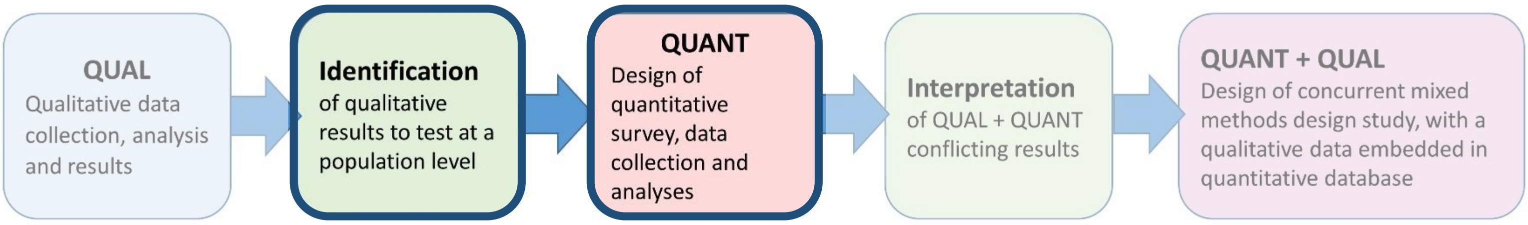


Figure 5.4. Building Study 2 design on the results of Study 1, testing qualitative results quantitatively.

In particular, this study applied a cross-sectional comparative design. The recruitment resulted in a group of 60 PCa patients undergoing ADT, with 60 ADT-naïve PCa patients, and 60 cancer-free men, and compared body image and masculine self-esteem scores of the three groups with each other (Hypothesis 1). Hypothesis 2 only compared the ADT and the ADT-naïve group (Fig. 5.1.), while Hypothesis 3 required analyses on the ADT group scores only (Fig. 5.2., Fig.5.3.).

5.2.2. Ethical approval

This study obtained ethical approval from the Research Ethics Committee of the Faculty of Health and Applied Sciences at The University of the West of England, Bristol (UWE REC REF No: HAS.18.10.049, Appendix B1).

5.2.3. Survey

5.2.3.1. Patients and Public Involvement

Three men diagnosed with PCa who had participated in Study 1 were invited to review and provide feedback on the study information, consent form, questionnaires, online platform, and recruitment strategy. These individuals were chosen given their willingness to be involved in future research, as well as for their diversity in age, recruitment environments, as well as for their role of community gatekeepers. The aim of this public involvement was to check whether the study information and questionnaires were appropriate, that the survey would not be too burdensome for participants, and that the planned recruitment strategy was acceptable. All three patients responded positively to the invitation (Appendix B2), but only two provided feedback via email, while one stopped engaging in the correspondence. Minor changes were made to the survey wording and visual format, following their feedback. The complete survey can be found in Appendix B3.

5.2.3.2. Body Image Concern measures

Since the study sample was composed of both men who had been diagnosed with PCa and men who had never been diagnosed with cancer (cancer-free men), body image concerns were assessed using both a cancer-specific measure and a questionnaire validated in the general population. Both questionnaires were administered to all the groups. Thanks to this strategy it was possible to capture both cancer-specific body image issues (e.g., scarring, loss of sexual confidence, etc.) as well as more general body image concerns (e.g., satisfaction with how clothes fit). When administering cancer-specific questionnaires to cancer-free men, all the phrasing referring to cancer diagnosis was modified in order to meet the specific experiences of the respondents.

Body Image Scale (BIS) (Hopwood et al, 2001). The BIS is a 10-item scale developed in collaboration with the European Organisation for Research and Treatment for Cancer (EORTC), which measures body image issues in cancer patients (e.g., "Since cancer treatment/diagnosis, how much have you felt dissatisfied with your appearance?"). The items were adapted for the cancer-free group (e.g., "In the past year, how much have you felt dissatisfied with your appearance?"). Participants responded using a Likert scale ranging from 0 (not at all) to 3 (very much).The global score is obtained by adding up all the item scores, with higher scores indicating more severe body image issues. The internal consistency of BIS was excellent for the patients groups (α = .916), and good for the cancer-free group (α = .870).

Appearance Evaluation (AE) Subscale from the Multidimensional Body-Self Relations Questionnaire (MBSRQ) (Cash, 2015). The AE subscale from the MBSRQ measures feelings of physical attractiveness or unattractiveness. The AE subscale is composed of 7 items (e.g., "I like my looks just the way they are."), rated on a five-point Likert scale (1= *very dissatisfied,* 5= *very satisfied*). The AE subscale global score consists of the mean of the items score, with higher scores indicating more satisfaction with one's looks and lower scores indicating stronger appearance dissatisfaction. The AE subscale presented a good internal consistency both for the patient groups (α = .825) and for the cancer-free group (α = .836).

5.2.3.3. Functionality Appreciation measures

Functionality Appreciation Scale (FAS) (Alleva et al., 2017). The FAS is a 7-item questionnaire assessing how much respondents feel appreciation for what their body can do (e.g., "I am grateful for what my body helps me to do"). The global score consists of the sum of all the item scores, with higher scores reflecting greater levels of functionality appreciation. Participants rate how much they agree/disagree with each item on a 5-point Likert scale (1 = strongly agree, 5 = strongly disagree). The internal consistency was excellent for the patient groups (α = .914) and good for the cancer-free group (α = .871).

5.2.3.4. Appearance Investment measures

Appearance Orientation (AO) subscale of the Multidimensional Body-Self Relations Questionnaire (Cash, 2015). The AO is a 12-item subscale from the (MBSRQ), measuring the cognitive and behavioural investment in one's appearance (e.g., "Before going out in public, I always notice how I look"). Respondents are asked to indicate the degree to which they agree with each statement on a 5-point Likert scale (1 = definitely disagree, 5 = definitely agree). The AO subscale global score consists of the mean of the item scores, with higher scores indicating stronger appearance investment. The AO subscale internal consistency was excellent for the patient groups (α = .912) and good for the cancer-free group (α = .901).

5.2.3.5. Fear of Negative Evaluation measures

Fear of Negative Appearance Evaluation Scale (FNAE) (Lundgren, Anderson, & Thompson, 2004). The FNAE scale is a 6-item questionnaire assessing one's preoccupation for being judged by others on appearance (e.g., "I am concerned of what other people think of my appearance"). Participants are asked to rate the extent to which they agree with each state on a 5-point Likert scale (1 = not at all, 5 = extremely). The global score consists of the sum of all the item scores. The FNAE scale presented an excellent internal consistency for both the patient groups (α = .919) and for the cancer-free group (α = .935).

Fear of Negative Physical Performance Evaluation for Physical Performance (FNPPE) (Adaptation of Fear of Negative Appearance Evaluation Scale). Since the results from Study 1 highlighted how some participants preferred not to exercise or to only exercise alone in order to not be judged for their fitness level, a validated scale measuring worry about being judged by others for one's physical skills whilst exercising had to be identified. The following validated scales were considered for inclusion in the study:

1) Physical Self-Perception Profile questionnaire (Fox & Corbin, 1989), which is used to assess participants' physical self-perceptions. The inventory with 30 items consists of five physical self-perception scales: perceived sport competence, physical condition, attractive body, physical strength, and physical self-worth. In particular, the Sport Competence Subscale and Physical Condition Subscale were considered for inclusion. The questionnaire was not used, despite being validated, because a close analyses of the items highlighted how the subscales were mostly measuring participants' judgment of their ability to engage in sports rather than their worry about being judged by others for their fitness level when in an exercise setting (for Sport Competence Subscale and Physical Condition Subscale items list, see Appendix B5.1).

2) The Basic Psychological Needs in Exercise Scale (Vlachopoulos & Michailidou, 2006) is a domain-specific self-report instrument assessing whether the needs of autonomy, competence, and relatedness are satisfied in exercise. In particular, the Competence and Relatedness subscales were considered for inclusion as they partially capture the self-assessment of fitness and ability to relate to others in exercise settings (for Competence and Relatedness subscale items list, please see Appendix B5.2). However, the combination of these

two subscales was still not specific enough to capture the factor that had emerged from Study 1, namely the worry of being judged by other people for one's own level of physical fitness while in a public exercise setting.

Since, to the best of the author's knowledge, there was no validated scale measuring fear of negative evaluation focusing on levels of fitness while in an exercise setting, an ad hoc measure was designed for this study: the Fear of Negative Physical Performance Evaluation Scale (FNPPE). The FNPPE scale is an eight-item self-report measure assessing participants' worry about being judged by others for their physical skills whilst exercising. The scale was constructed by modifying the Fear of Negative Appearance Evaluation Scale (Lundgren et al., 2004) (Table 5.1 and Table 5.2.). The novel items were developed to capture preoccupation about judgement related to physical performance, (e.g., "I am concerned of what other people think of my ability to exercise"). The items are rated on a 5-point Likert scale (1 = not at all, 5 = extremely) and the global score consists of the sum of all the item scores. The FNPPE scale internal consistency was excellent for the patient groups (α = .920) and good for the cancer-free group (α = .898). Given the promising internal consistency scores, future studies should carry on the validation of the scale.

Table 5.1. Items of the Fear of Negative Physical Performance Evaluation Scale.

I am concerned of what other people think of my ability to exercise.				
1	2	3	4	5
not at all	slightly	moderately	very	extremely
It bothers me if I know someone is judging my physical performance.				
1	2	3	4	5
not at all	slightly	moderately	very	extremely
I worry that other people will find my body not strong and athletic enough.				
1	2	3	4	5
not at all	slightly	moderately	very	extremely

In an exercise setting, I wonder if others find me slower or weaker.

1	2	3	4	5
not at all	slightly	moderately	very	extremely

I am afraid other people will notice my physical weaknesses.

1	2	3	4	5
not at all	slightly	moderately	very	extremely

I am reluctant to exercise because of a fear of being judged by people.

1	2	3	4	5
not at all	slightly	moderately	very	extremely

Table 5.2. Fear of Negative Appearance Evaluation Scale Items (Lundgren et al., 2004)

I am concerned about what other people think of my appearance.

1	2	3	4	5
not at all	slightly	moderately	very	extremely

It bothers me if I know that someone is judging my physical shape.

1	2	3	4	5
not at all	slightly	moderately	very	extremely

I worry that people will find fault with the way I look.

1	2	3	4	5
not at all	slightly	moderately	very	extremely

When I meet new people, I wonder what they think of my appearance.

1	2	3	4	5
not at all	slightly	moderately	very	extremely

I am afraid other people will notice my physical flaws.

1	2	3	4	5
not at all	slightly	moderately	very	extremely

I think that other's people opinion on my appearance are too important to me.

1	2	3	4	5
not at all	slightly	moderately	very	extremely

5.2.3.6 Masculinity Measures

Masculine Self-Esteem Scale (*MSES) (Clark et al., 2003).* The MSES is an 8-item questionnaire specifically developed for PCa patients, assessing the subjective evaluation of physical and mental components of masculine self-esteem (e.g., “Since cancer treatment/diagnosis, how much have you felt no longer a whole man?”) on a 5-point Likert scale (1 = never, 5 = always). The items were adapted for the cancer-free group (e.g., “In the past year, have you ever felt like no longer a whole man?”). MSES global score consists of the sum of all the item scores, with higher global scores representing lower masculine self-esteem and more severe psychosocial distress. The MSES presented a good internal consistency for both the patient groups (α = .869) and the cancer-free group (α = .867).

Hegemonic Masculinity Ideals Scale (currently in validation) (HMIS). While testing the theoretical model, it was important to control for hegemonic masculinity ideals. Specifically, the analyses had to test whether participants who held a hegemonic masculine ideal might have been more severely affected in their masculine self-esteem and body image as a consequence of ADT side-effects. A literature review revealed only one validated questionnaire measuring conformity to masculine norms, the Conformity to Masculine Norms Inventory (Mahalik et al., 2003). However, after a detailed analysis of the questionnaire items, it was evident how the questionnaire measured the respondent’s adherence to stereotypical personality traits (e.g., “I tend to keep my feelings to myself”), rather than their beliefs on what being masculine in society means (regardless of their traits) (see Appendix B6 for Conformity to Masculine Norms Inventory items). Therefore, a five-item measure investigating whether participants held a hegemonic masculine ideal was developed for this study (Table 5.3). The aim of this measure was to investigate what participants thought being masculine meant in the society where they lived, regardless of their current personality traits. This study was interested in understanding whether participants’ masculine ideal might influence their judgment of their embodiment of masculinity and therefore affect their masculine self-esteem and body image. The items were developed in accordance with the hegemonic model theory, in which being male is centred around competitiveness, sexual and athletic power, control and stoicism (Beauchamp, Carron, McCutcheon, & Harper, 2007). The questionnaire was then reviewed by the PPI group, to ensure that the phrasing of the items was clear. Participants rated the items on a 5-point Likert scale (1 = disagree, 5 = agree) and the global score was calculated by summing all the item scores. Higher global scores indicate a stronger hegemonic masculine ideal. The HMIS presented an acceptable internal consistency for the both the patient groups ($\alpha = .648$) and for the cancer-free group ($\alpha = .793$). Given the acceptability of HMIS scale internal consistency, further research should carry on the validation of the scale.

Table 5.3. Hegemonic Masculinity Ideals items.

Directions for participants:

Indicate the degree to which you agree with the following statements:

Items

I think in society being masculine means…

1. Being physically strong
2. Being sexually active
3. Being emotional (Reversed item)
4. Being vulnerable (Reversed item)
5. Dealing with problems alone

Scoring method:

1 = disagree
2 = somewhat disagree
3 = neither agree nor disagree
4 = somewhat agree
5 = agree

5.2.3.7. Exercise frequency

Godin Leisure-Time Exercise Questionnaire (G-LTEQ) (Shephard, 1997). The G-LTEQ assess average weekly exercise frequency. Specifically, the questionnaire assesses the frequency of strenuous, moderate, and light activities performed for more than 15 minutes (e.g., "Considering a 7-day period (a week), how many times on average do you do the following kinds of exercise for more than 15 minutes during your free time? Strenuous exercise (heart beats rapidly), like running, jogging, etc.?"). Global scores are calculated by multiplying the weekly frequency of strenuous exercise by 9, moderate exercise total by 5, light exercise by 3 and summing them. Higher scores indicate higher weekly exercise frequency. The G-LTEQ internal consistency was poor for the patient groups (α = .569) and acceptable for the cancer-free group (α = .685). The G-LTEQ is widely used to assess exercise frequency among cancer patients (Santa Mina, Guglietti, Alibhai, Matthew, Kalnin, Ahmad, Lindner, & Trachtenberg, 2014). However the internal consistency of the global score is rarely reported in studies focusing on PCa patients (e.g., Culos-Reed et al., 2010) and the measure is used to classify participants in categories (i.e., meeting exercise guidelines vs not meeting exercise guidelines) (e.g., Langelier et al., 2018; Santa Mina et al., 2014). Looking at the items of the G-LTEQ, the low internal consistency might be due to the fact that the global score combines items measuring strenuous, moderate, and light exercise. Moreover, self-assessment of exercise is a notoriously challenging measure to collect, given the tendency of participants to not be accurate when reporting their engagement with exercise, potentially further decreasing scores internal consistency (Verplanken & Melkevik, 2008).

5.2.4. Recruitment and survey distribution

Participants were invited to take part in a 20-min survey titled "A Survey on Men's Health", aiming to improve psychological support available for PCa patients. The study advertisement did not mention body image and exercise specifically in order to attract a wide audience of participants, with a diverse level of investment on body image issues and exercise, in order to collect data that could be as ecologically valid as possible. The advertisement clearly stated that the men who had never received a PCa diagnosis were also encouraged to participate (Appendix B4). Recruitment happened mostly online, in order to improve access to research. As previously mentioned, online recruitment can reach individuals in geographically different locations and potentially improve participation from ethnic minorities (Heath, 2020; Wilkerson et al., 2014).

In particular, this study was advertised via a sponsored post which included the description of the study and the Qualtrics link (the secure online platform where the study survey was available) to access the survey (please see Appendix B4 for study advertisement). The advertisement was distributed via Facebook , since this social media is the most frequently used by PCa patients (Struck et al., 2018). In particular, the advertisement was posted on:

- several groups dedicated to prostate cancer peer support and men's health;
- Centre for Appearance Research Facebook page;
- University of the West of England Facebook page;
- A Facebook page dedicated to the study (Appendix B4.1.).

The study was also advertised on Twitter, through the Centre for Appearance Research account and through through the University of the West of England's press office.

Moreover, the study information and Qualtrics link was published through the pages of local and national Cancer Charities (e.g., Maggie's Cheltenham, Tackle Prostate Cancer, Penny Brohn, Prospect Bristol, Prostate Cancer Research Centre, The Blue Ribbon Foundation). Each organization was contacted and asked if they would be willing to promote the study. If they were interested, they were provided with detailed information, a flyer, and ethical approval of the study and asked to promote the survey in a way that suited them best, for example by adding a link on their website, social media page, or newsletter. As for Study 1, publishing information about the study on the charities' websites and social media platforms meant that individuals who were looking for information and not actively seeking a therapeutic intervention could be reached as well.

As previously stated, a limitation of online recruitment is that this strategy does not reach individuals who might not have access to an internet connection or are not confident IT users. For this reason, online recruitment was paired with time-location sampling, distributing paper questionnaires at PCa-specific events (although this strategy only resulted in two participants completing the survey).

Men who were interested in taking part were asked to follow a link (Qualtrics, 2018) to a secure online survey. Firstly, participants were asked to read an information sheet. Then they would read a consent form and tick a box to declare their consent, before completing some preliminary screening questions. Only men between 35 and 75 years old, without a diagnosis of dementia or psychosis, and able to exercise were included in the study. The age inclusion criteria were introduced to minimize the age differences between the control group and the two groups of PCa patients. Since PCa occurs more frequently among men over 50, with the most common age at diagnosis ranging between 65 and 69 years old (Torre et al., 2016) not applying age inclusion criteria would have implied a higher risk of recruiting non-comparable groups. As mentioned in section 5.2.6., the recruitment strategy aimed to reach a cancer-free group of a similar age as the other two groups. This was done both by applying age limits throughout the recruitment and by excluding, post data collection, participants in the control group who were below the age of 44 in order to match the minimum age of the other two patients groups, minimizing the age difference between groups (Table 5.4.). Despite these preventive measures, the control group was still significantly younger than the ADT and ADT-naïve groups (Table 5.4.). Age differences between groups are discussed in detail in section 5.2.6.

Individuals with a cancer diagnosis different from prostate cancer were also excluded from the study. Participants not meeting the inclusion criteria of the study were directed to a separate page, thanking them for their willingness to participate and explaining that they were not eligible to take part in the survey. After completing the screening questions, participants were automatically directed to the study questionnaires.

5.2.5. Procedure

Firstly, participants were asked to create a personalized code in order to let them identify their anonymous response in case they decided to withdraw from the study within two weeks of completion.

Participants were then asked to fill out a demographics questionnaire, which directed them either to a patient survey stream (for patients on ADT and ADT-naïve patients) or to a control survey stream (for the cancer-free group). Creating two separate survey streams allowed the control group to be directed to the questionnaires that had been adapted to suit a non-cancer group (Appendix B3). Order effect was controlled for by randomizing the questionnaires administration sequence in Qualtrics. At the end of the survey, participants were provided with a list of services they could contact if they were worried about their physical and/or mental health. The survey stream dedicated to the ADT and ADT-naïve groups also included PCa-specific support services (Appendix B3). The survey took an average of 16.6 minutes to complete (SD = 7.61 minutes).

Participants were offered the chance to enter a lottery to win £70 online shopping vouchers. To do so, they had to leave their email address in a separate online sheet, in order to that their survey responses remained anonymous. Once the study was concluded, a summary of the study results was sent to the charities that helped with recruitment and shared on the dedicated Facebook page (Appendix B10 and B10.1).

5.2.6. Participants

The survey reached 312 participant, of which 219 answered the preliminary screening questions. Of these 219, 211 gave their consent to partake the survey and met the inclusion criteria: 63 PCa patients on ADT, 64 ADT-naïve PCa patients, and 84 cancer-free men (Figure 5.5.). Of these 211, 203 completed the entire survey (60 in the ADT group, 60 in the ADT-naïve group, and 83 in the cancer-free group) (Figure 5.5.), with an overall completion rate of 96%. The recruitment was interrupted after reaching the target of a minimum of 60 participants per group, as the power analyses performed with G*power confirmed that this sample size is adequate in order to detect medium and small effect sizes on the main MANOVA analysis ($1-\beta = .95$, $\alpha = .05$). Participants under the age of 44 years in the control group were excluded from the analyses, in order to match the minimum age of the other two patients groups and minimize the age difference between groups (Table 5.4.).

The recruitment aimed to reach a cancer-free group of the same age as the other two groups, both by applying age limits as inclusion criteria and by excluding participants in the control group who were below the age of 44, as mentioned above. Despite having these strategies in place, the cancer-free group was still significantly younger than the ADT and ADT-naïve groups. A one-way ANOVA revealed a significant difference in age between the three groups $F(2,177)=28.97$, $p<.001$. Post-hoc comparisons run using the Tukey HSD test revealed that the cancer-free group mean age ($M=56.45$, $SD=8.05$) was significantly lower when compared both to the ADT ($M=64.37$, $SD=7.12$, $p<.001$) and the ADT-naïve group ($M=65.23$, $SD=5.46$, $p<.001$), while the ADT and ADT-naïve group did not significantly differ from each other (Table 5.4.).

Most participants were British and American. Despite focusing the recruitment strategy online with the aim of reaching a more diverse sample than Study 1, the three groups were mostly composed of white participants, although some men identifying as Asian (n = 1), Black (n = 1), and from Multiple Ethnic groups (n = 2) partook in the survey (Table 5.4.). Similarly, most participants identified as heterosexual, with a smaller proportion of participants identifying as gay (n = 3) or bisexual (n = 3). Most participants across all 3 groups declared to be in a supportive romantic relationship and to live with their partner (Table 5.4.). Participants' areas of residence equally varied between urban, suburban, and rural (Table 5.4.). The sample was overall highly educated, with the majority of participants having a college, bachelor, or masters' degree (Table 5.4.). Despite reaching a slightly more diverse sample than the group of participants interviewed for Study 1, Study 2 still presents a rather homogeneous sample, with the majority of participants belonging to rather privileged groups (e.g., white, highly educated, living with a partner, already accessing support, etc.). This limitation is discussed in section 5.6 of this chapter and more specifically in Chapter 7 (section 7.4.).

When considering the PCa groups only, an independent sample t-test revealed a significant difference in time in months since diagnosis between the ADT-naïve (*M*=41.13, *SD*=31.67) and the ADT group (*M*=53.37, *SD*=51.55), *t*(118)=-1.56, *p*<.01. This difference was expected, as ADT tends to be prescribed at a more advanced stage of prostate cancer, thus often further from diagnosis. The majority of patients in the ADT group had received at least another treatment in addition to ADT, mostly radiotherapy, followed by radical prostatectomy, and chemotherapy. Most patients in the ADT-naïve group received only one treatment, the most frequently reported being radical prostatectomy (Table 5.4.).

Table 5.4. Demographic data, Study 2

	ADT (*n* = 60)	**ADT-naïve (*n* = 60)**	**Cancer-free (*n* = 60)**
Age (years) M(SD)	64.37 (7.12)**^{a}	65.23 (5.46)**^{b}	56.45 (8.05)**^{ab}
Age range (years)	47 - 74	48 - 74	44 - 74
Nationality % (n)			
American	36.7% (22)	21.7% (13)	5% (3)
Australian	-	3.3% (2)	-
British	56.8% (34)	65% (39)	85% (51)
Canadian	1.7% (1)	3.3% (2)	-
Croatian	1.7% (1)	-	-
Dutch	-	-	1.7% (1)
German	-	-	1.7% (1)
Irish	3.3% (2)	3.3% (2)	-
Italian	-	1.7% (1)	-
New Zealander	-	-	1.7% (1)
Northern Irish	-	-	1,7% (1)
Swedish	-	-	1.7% (1)
Rather not say	-	1.7% (1)	1.7% (1)
Ethnicity			
Asian/Asian British European/Asian American	-	-	1.7% (1)
Black/African/Caribbean British/	-	1.7% (1)	-
Multiple ethnic groups	3.3% (2)	-	3.3% (2)
White	95% (57)	98.3% (59)	93.4% (56)
Rather not say	1.7% (1)	-	1.7% (1)
Sexual Orientation			
Bisexual	1.7% (1)	1.7% (1)	1.7% (1)
Heterosexual	91.7% (55)	96.7% (58)	91.7% (55)
Homosexual	5% (3)	-	6.7% (4)

Rather not say	1.7% (1)	1.7% (1)	-
Supportive romantic relationship			
Yes	73.3% (44)	81.7% (49)	80% (48)
No	21.7% (13)	15% (9)	17% (10)
Rather not say	5% (3)	3.3% (2)	3.3% (2)
Living Situation			
with Partner	70% (42)	85% (51)	68.3% (41)
Alone	21.7% (13)	11.7% (7)	18.3% (11)
with Children or Relatives	5% (3)	3.3% (2)	3.3% (2)
Other	1.7% (1)	-	8.3% (5)
Rather not say	1.7% (1)	-	1.7% (1)
Living Area			
Rural	31.7% (19)	30% (18)	21.7% (13)
Urban	35% (21)	26.7% (16)	28.3% (17)
Suburban	33.3% (20)	43.3% (26)	21.7% (13)
Rather not say	-	-	1.7% (1)
Education			
Vocational/ Technical school	8.3% (5)	16.7% (10)	11.7% (7)
High school equivalent	6.7% (4)	11.7% (7)	13.3% (8)
Grammar school	5% (3)	11.7% (7)	8.3% (5)
College	25% (15)	13.3% (8)	23.3% (14)
Bachelor’s degree	18.3% (11)	21.7% (13)	21.7% (13)
Master’s degree	20% (12)	18.3% (11)	11.7% (7)
Doctoral degree	10% (6)	5% (3)	6.7% (4)
Other	6.7% (4)	1.7% (1)	3.3% (2)
Time since diagnosis in months *M(SD)*	53.37(51.55)*	41.13(31.67)*	N/A

ADT duration in months *M(SD)*	33.44 (42.64)	N/A	N/A
Number of treatments			
None	-	15% (9)	N/A
1	10% (6)	73.3% (44)	N/A
2	53.3% (32)	11.7% (7)	N/A
3	30% (18)	-	N/A
4	6.7% (4)	-	N/A
Treatments (other than ADT)			
Active surveillance	11.7% (7)	30% (18)	N/A
Brachytherapy	13.3% (8)	8.3% (5)	N/A
Chemotherapy	26.7% (16)	-	N/A
External beam radiotherapy	55% (33)	13.3% (8)	N/A
Radical prostatectomy	35% (21)	75% (45)	N/A
Radium-223	3.3% (2)	-	N/A

Note. The table reports the demographic data of the ADT, ADT-naïve, and cancer-free group. The table also includes the results of a one-way ANOVA performed on age (in years) between the three groups, and the results of an independent sample t-test performed on time since diagnosis (in months) between the ADT and ADT-naïve group.

ADT = Androgen Deprivation Therapy; M = mean; SD = standard deviation.

** $p<.001$ * $p<.01$

a: The cancer-free group mean age (*M*=56.45, *SD*=8.05) was significantly lower when compared the ADT group (*M*=64.37, *SD*=7.12, *p*<.001)

b: The cancer-free group mean age (*M*=56.45, *SD*=8.05) was significantly lower when compared the ADT-naïve group (*M*=65.23, *SD*=5.46, *p*<.001)

The mean age of the ADT and ADT naïve group did not significantly differ.

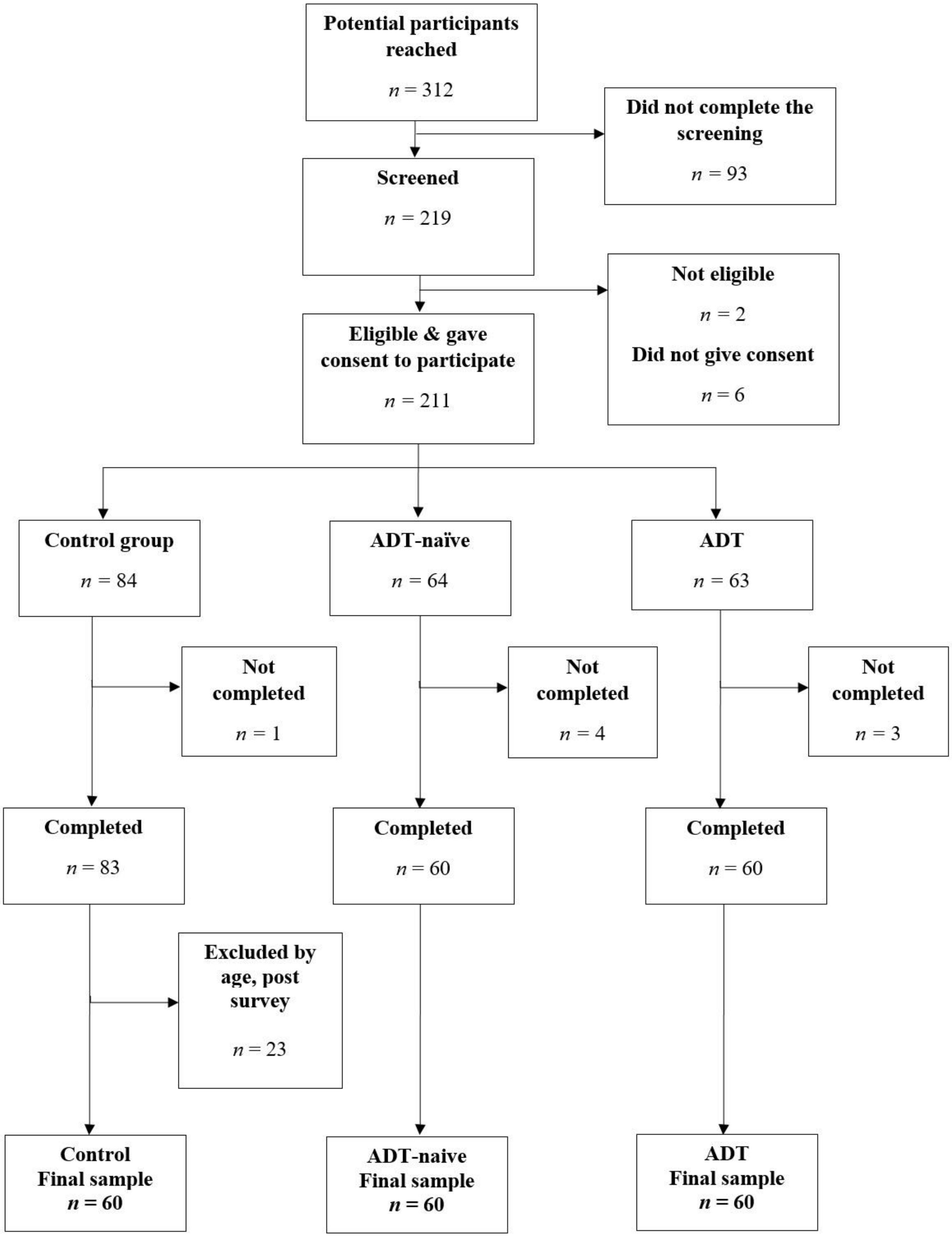


Figure 5.5. Participants' flowchart, Study 2

5.3. Data analyses

All the analyses were performed with SPSS25 ©.

The first hypothesis (H.1.) was tested by performing a MANOVA, with the three-level group factor as the independent variable and BIS, AE subscale, FAS, MSES, FNAE, and FNPPE global scores as dependent variables. Specifically, a MANOVA was performed instead of multiple ANOVAs in order to reduce multiple testing error rate; moreover, in case of correlating dependent variables, the former test has greater statistical power and allows to assess patterns between multiple dependent variables.

The second hypothesis was tested on the two patients groups only. The first section of the hypothesis (H.2a.) was tested by performing a multiple regression with PROCESS macro, which applies an ordinary least square or logistic regression-based path analytic framework. Treatment (ADT yes/no) was included as the independent variable, HMIS scores as a moderator, and MSES scores as the dependent variable. Similarly, the second part of the hypothesis (H.2b.) was tested performing two regression analyses with treatment (ADT yes/no) as the independent variable, and FNAE and FNPPE scores as dependent variables respectively. The last section of the hypothesis (H.2c.) was also tested by performing two multiple regressions with treatment (ADT yes/no) as the independent variable, AO subscale scores as a moderator, and BIS and AE subscale scores as dependent variables respectively (Figure 5.1.).

The third hypothesis was tested on the ADT group only. The first part of the hypothesis (H.3a.) was tested by performing four multiple regressions analyses with the SPSS extension PROCESS Macro, with FNAE as the independent variable, G-LTEQ scores as a mediator and BIS, AE, FAS, and MSES scores as dependent variables respectively (Figure 5.2.). Similarly, the second part of the hypothesis (H.3b.) was tested by performing another four multiple regression analyses with FNPPE as the independent variable, G-LTEQ scores a mediator, and BIS, AE, FAS, and MSES scores as dependent variables respectively (Figure 5.3.).

5.4. Results

5.4.1. Preliminary analyses

Participants across the three groups presented mean levels of body image concerns and appearance investment when comparing their scores on the BIS, AE, and AO scale to the questionnaires score ranges (Table 5.5 reports the means and standard deviations for all measures). On the other hand, participants across all groups presented high levels of functionality appreciation, with average FAS scores being close to the upper end of the scale score range. Participants across groups presented low levels of fear of negative evaluation both for appearance and physical performance, with the average scores being close to the lower end of the scales' score ranges. When considering masculine self-esteem issues, the ADT group presented slightly higher scores when compared to the other two groups, slightly higher than the mid score range for the MSES scale. On the contrary, the ADT-naïve and cancer-free group presented scores falling on the mid-point of the MSES score range. Participants across all groups scored high on hegemonic masculine ideals, presenting scores close to the upper end of the HMIS score range. Lastly, participants across all three groups reported mean levels of exercise frequency, with their scores falling on the mid-point of the G-LTEQ score range. However, the mode of the G-LTEQ was lower compared to the mean (Table 5.5.) across all three groups (ADT group G-LTEQ Mo = 44; ADT-naïve G-LTEQ Mo = 57; Control G-LTEQ Mo = 43.00), indicating a positively skewed distribution. This suggests that the mean of the G-LTEQ might have been inflated by a minority of participants highly engaged in exercise when compared to the rest of the sample.

Table 5.5. Means and SD for all variables for all groups

	Possible Score Range:	**ADT (n= 60)**	**ADT-naïve (n= 60)**	**Cancer-free (n= 60)**
BIS M(SD)	0 - 30	19.30 (6.78)	19.30 (7.09)	17.72 (5.32)
AE M(SD)	1 - 5	3.17 (0.72)	3.35 (0.70)	3.17 (0.70)
FAS M(SD)	7 – 35	28.00 (5.11)	28.81 (4.54)	28.51 (4.72)
AO M(SD)	1 - 5	3.10 (0.74)	2.87 (0.86)	2.90 (0.78)
FNAE M(SD)	6 - 30	10.77 (4.38)	11.12 (5.45)	10.49 (4.45)
FNPPE M(SD)	6 - 30	9.69 (4.11)	9.95 (5.36)	9.68 (3.80)
MSES M(SD)	8 - 40	18.26 (5.96)	16.15(5.58)	16.42 (5.33)
HMIS M(SD)	5 - 25	16.26 (4.52)	16.57 (3.05)	15.36 (4.11)
G-LTEQ M(SD)	0 - 119	63.20 (27.07)	66.85 (22.77)	70.55 (27.77)

Note. The table reports the mean scores for all the measures in the ADT, ADT-naïve, and cancer-free group. BIS = Body Image Scale; AE = Appearance Evaluation Subscale; FAS = Functionality Appreciation Scale; AO = Appearance Orientation Subscale; FNAE = Fear of Negative Appearance Evaluation; FNPPE = Fear of Negative Physical Performance Evaluation; MSES = Masculine Self Esteem Scale; HMIS = Hegemonic Masculinity Ideals Scale; G-LTEQ = Godin Leisure Time Exercise Questionnaire; ADT = Androgen Deprivation Therapy.

For exploratory purposes, correlations were run between all the variables for each group separately (Tables 5.6, 5.7, 5.8). The tests detected significant correlations between most of the body image related questionnaires, across all groups. This was expected, given that the body image questionnaires aim to measure closely related factors.

Interestingly, MSES scores (masculine self-esteem) significantly correlated with several body image questionnaires across the three groups. In particular, MSES scores significantly and positively correlated with BIS and FNPPE scores across all groups (Tables 5.6, 5.7, 5.8), and with FNAE scores in both patients groups (Tables 5.6, 5.7). MSES also significantly and negatively correlated with AE and FAS scores across all groups (Tables 5.6, 5.7, 5.8). Overall, these correlations seem to indicate that masculine self-esteem issues could be associated with higher levels of body image issues and fear of negative evaluation for both appearance and physical performance, and lower appearance and functionality appreciation.

HMIS scores significantly and positively correlated with BIS scores both in the ADT-naïve and control group (Tables 5.7, 5.8). HMIS also significantly and positively correlated with FNAE scores in ADT group (Tables 5.6). Moreover, HMIS scores significantly and positively correlated with both FNPPE and MSES scores in both the ADT and ADT-naïve group (Tables 5.7, 5.8). Although the results were slightly mixed across groups, the correlations indicated the tendency of hegemonic masculinity ideals to be associated with poorer body image outcomes and more masculine self-esteem issues.

G-LTEQ scores significantly and positively correlated with FAS scores in both the ADT-naïve and the control group (Tables 5.7, 5.8). Exercise frequency also significantly and negatively correlated with FNPPE in the ADT-naïve group only (Tables 5.7). Interestingly, G-LTEQ scores significantly correlated with AO and FNAE scores in both the ADT-group and in the control group, but while the correlation was negative in the ADT-naïve group, the two variables were positively associated in the control group (Tables 5.7, 5.8). Lastly, exercise scores were significantly and negatively associated with MSES scores in the ADT-naïve group only (Tables 5.7).

Table 5.6. Correlations between variables in the ADT group

	BIS	AE	FAS	AO	FNAE	FNPPE	MSES	HMIS	G-LTEQ
BIS	1	-.604**	-.222	.160	.497**	.552**	.787**	.148	.008
AE		1	-.001	.153	-.294*	-.457**	-.433**	-.021	.156
FAS			1	-.123	-.059	-.140	-.335*	-.114	.096
AO				1	.364**	.268*	.155	.244	.065
FNAE					1	.620**	.252**	.345**	.036
FNPPE						1	.678**	.311*	-.208
MSES							1	.280*	-.211
HMIS								1	.014
G-LTEQ									1

Note. The table reports the results of Pearson's correlations between all the measures, performed in the ADT group. BIS = Body Image Scale; AE = Appearance Evaluation Subscale from the MBSRQ; FAS = Functionality Appreciation Scale; AO = Appearance Orientation Subscale; FNAE = Fear of Negative Appearance Evaluation; FNPPE = Fear of Negative Physical Performance Evaluation; MSES = Masculine Self Esteem Scale; HMIS = Hegemonic Masculinity Ideals Scale; G-LTEQ = Godin Leisure Time Exercise Questionnaire;

ADT = Androgen Deprivation Therapy.

** p < .01 * p < .05

Table 5.7. Correlations between variables in the ADT-naïve group.

	BIS	AE	FAS	AO	FNAE	FNPPE	MSES	HMIS	G-LTEQ
BIS	1	-.661**	-.388**	..216	599	.433**	.597**	.296*	-.212
AE		1	.582**	.072	-.294*	-.292*	-.563**	-.145	.090
FAS			1	.035	-.304*	-.275*	-.468**	-.157	.382**
AO				1	.310*	.234	-.089	.154	-.278*
FNAE					1	.700**	.561**	.255	-.309*
FNPPE						1	.479**	.092	-.319*
MSES							1	.101	-.069
HMIS								1	-.187
G-LTEQ									1

Note. The table reports the results of Pearson's correlations between all the measures, performed in the ADT-naïve group. BIS = Body Image Scale; AE = Appearance Evaluation Subscale from the MBSRQ; FAS = Functionality Appreciation Scale; AO = Appearance Orientation Subscale; FNAE = Fear of Negative Appearance Evaluation; FNPPE = Fear of Negative Physical Performance Evaluation; MSES = Masculine Self Esteem Scale; HMIS = Hegemonic Masculinity Ideals Scale; G-LTEQ = Godin Leisure Time Exercise Questionnaire;

ADT = Androgen Deprivation Therapy.

** p < .01 * p < .05

Table 5.8. Correlations between variables in the control group.

	BIS	AE	FAS	AO	FNAE	FNPPE	MSES	HMIS	G-LTEQ
BIS	1	-.639**	-.254	.022	.526**	.587**	.805**	.283*	.084
AE		1	.405**	.153	-.420**	-.476**	-.439**	-.247	.128
FAS			1	.117	-.304*	-.324*	-.351**	-.194	.256*
AO				1	.351**	.202	.119	-.083	.316*
FNAE					1	.806**	.216	.583**	.261*
FNPPE						1	.631**	.203	.118
MSES							1	.301*	.142
HMIS								1	.060
G-LTEQ									1

Note. The table reports the results of Pearson's correlations between all the measures, performed in the control group. BIS = Body Image Scale; AE = Appearance Evaluation Subscale from the MBSRQ; FAS = Functionality Appreciation Scale; AO = Appearance Orientation Subscale; FNAE = Fear of Negative Appearance Evaluation; FNPPE = Fear of Negative Physical Performance Evaluation; MSES = Masculine Self Esteem Scale; HMIS = Hegemonic Masculinity Ideals Scale; G-LTEQ = Godin Leisure Time Exercise Questionnaire;
ADT = Androgen Deprivation Therapy.
** p < .01 * p < .05

5.4.2. Hypothesis 1

A MANOVA compared PCa patients on ADT to ADT-naïve patients, and age matching cancer-free men on body image-related variables, namely body image issues (BIS, AE subscale scores), functionality appreciation (FAS scores), masculine self-esteem (MSES), and fear of negative appearance and physical performance evaluation (FNAE and FNPPE scores).

All MANOVA assumptions were met (see Appendix B7 for complete MANOVA assumptions testing), with the exception of multivariate normality. With the exception of AE sores, none of the dependent variables were normally distributed (Table 5.9.). This was expected, since most of the dependent variables are salient to the condition of living with cancer. The sample consisted of two thirds cancer patients and one third of cancer-free men, which likely affected normality. However, MANOVA is robust against violation of normality when sample size is equal across groups (Von Eye & Bogat, 2004).

Table 5.9. Normality testing for all dependent variables across groups

	Shapiro Wilk's	df	*p*
BIS	.955	165	.000
AE	.986	165	.096
FAS	.938	165	.000
FNAE	.865	165	.000
FNPPE	.818	165	.000
MSES	.968	165	.001

Note. The table reports the results of Shapiro Wilk's test, which tests the null-hypothesis that the population is normally distributed. BIS = Body Image Scale; AE = Appearance Evaluation Subscale from the MBSRQ; FAS = Functionality Appreciation Scale; FNAE = Fear of Negative Appearance Evaluation; FNPPE = Fear of Negative Physical Performance Evaluation; MSES = Masculine Self Esteem Scale; ADT = Androgen Deprivation Therapy.

The multivariate test result revealed a non-significant effect of group, Pillai's Trace = .07, F (10, 330) = 1.21, ***p***= 28, partial η^2 = .035. Accordingly, the univariate F tests and the post-hoc contrasts revealed non-significant differences between groups on any of the outcome variables (Table 5.10, 5.11).

Table 5.10. Post hoc multiple comparisons between groups.

		Mean Difference	Standard Error	Sig.
BIS	Control vs ADTnaive	-1.6125	1.26038	.409
	Control vs ADT	-1.6056	1.27000	.417
	ADT-naïve vs ADT	.0069	1.19850	1.000
AE	Control vs ADTnaive	-.1709	.13682	.426
	Control vs ADT	.0042	.13786	.999
	ADT-naïve vs ADT	.1751	.13010	.372
FAS	Control vs ADTnaive	-.3583	.92721	.921
	Control vs ADT	.4583	.93429	.876
	ADT-naïve vs ADT	.8167	.88168	.625
FNAE	Control vs ADTnaive	-.7208	.93202	.720
	Control vs ADT	-.3800	.93913	.914
	ADT-naïve vs ADT	.3408	.88626	.922
FNPPE	Control vs ADTnaive	-.3458	.87642	.918
	Control vs ADT	-.0855	.88311	.995
	ADT-naïve vs ADT	.2603	.83339	.948
MSES	Control vs ADTnaive	.2458	1.09084	.972
	Control vs ADT	-1.8628	1.09917	.210
	ADT-naïve vs ADT	-2.1086	1.03728	.108

Note. The table reports the results of Tukey HSD test. BIS = Body Image Scale; AE = Appearance Evaluation Subscale from the MBSRQ; FAS = Functionality Appreciation Scale; FNAE = Fear of Negative Appearance Evaluation; FNPPE = Fear of Negative Physical Performance Evaluation; MSES = Masculine Self Esteem Scale; ADT = Androgen Deprivation Therapy.

5.4.3. Hypothesis 2

Before testing Hypothesis 2, linear regression assumptions were tested considering only the ADT-naïve and ADT group (see Appendix B8 for complete assumptions testing). All regression assumptions were met (e.g., linear relationship between independent and dependent variable, sufficient sample size, no outliers, no multicollinearity, no auto-correlation, homoscedasticity), apart from the assumption of multivariate normality. None of the dependent variables presented a normal distribution across the ADT and ADT-naïve group, with the exception of AE scores (Table 5.12). Given the sufficient sample size, the data was not transformed in order to avoid bias in the model estimates (Schmidt & Finan, 2018).

Table 5.11. Normality testing for all dependent variables in ADT and ADT-naïve groups for hypotheses 2a,b,c.

	Shapiro Wilk’s	Df	*p*
BIS	.928	118	.000
AE	.987	118	.314
FNAE	.861	118	.000
FNPPE	.798	118	.000
G-LETQ	.972	118	.015
MSES	.966	118	.004

Note. The table reports the results of Shapiro Wilk’s test, which tests the null-hypothesis that the population is normally distributed. BIS = Body Image Scale; AE = Appearance Evaluation Subscale from the MBSRQ; AO = Appearance Orientation Subscale; FNAE = Fear of Negative Appearance Evaluation; FNPPE = Fear of Negative Physical Performance Evaluation; MSES = Masculine Self Esteem Scale; HMIS = Hegemonic Masculinity Ideals Scale; G-LTEQ = Godin Leisure Time Exercise Questionnaire; ADT = Androgen Deprivation Therapy.

5.4.3.1. Hypothesis 2a

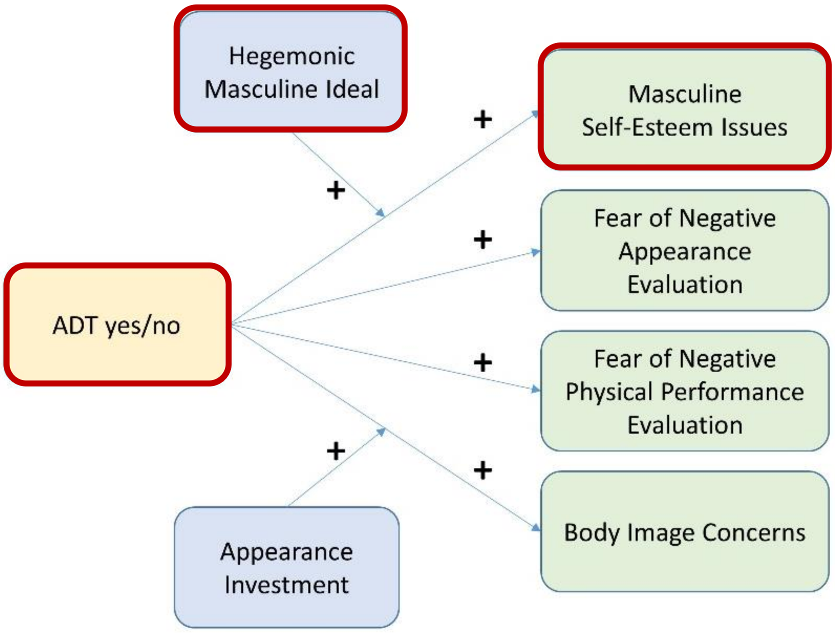


Figure 5.1-bis. Hypothesis 2a

After verifying multiple regression assumptions, the bivariate variable ADT treatment (no = 0, yes = 1) significantly predicted MSES scores, $\beta = 2.12$, t (116) = 1.98, $p < .05$, and explained a significant proportion of the variance in MSES scores R^2=.033, $F(1,116) = 3.94$ (Figure 5.6). After controlling for the demographic variables of age, length of ADT treatment, sexual orientation, and ethnicity, none of these variables significantly contributed to the model (Table 5.13). The significant result of the regression analysis and the positive beta indicates that being on ADT significantly predicted higher MSES scores, suggesting that patients on ADT suffered from more issues related to their masculine self-esteem.

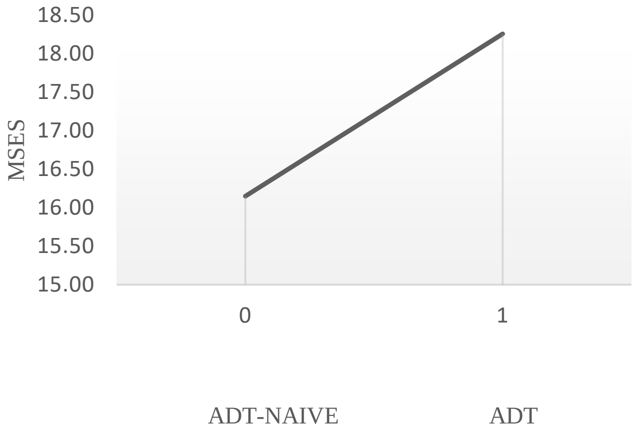


Figure 5.6. Being on ADT significantly predicted higher MSES scores.
Note. MSES = Masculine Self Esteem Scale; ADT = Androgen Deprivation Therapy.

Table 5.12. Controlling for demographic variables when testing regression ADT → MSES.

	β	t (116)	p	R^2	F (1, 116)
Age (in years)	-.16	-1.89	.06	.06	3.8
Time on ADT (in months)	-.009	-.47	.64	.004	.221
Sexual orientation	-.42	-.56	.58	.035	2.11
Ethnicity	.84	.475	.63	.035	2.06

Note. The table reports the results of four multiple regressions run with ADT (yes/no) as independent variable, MSES scores as dependent variable, and controlling for each of the variables in the table respectively.

HMIS scores were centred to the mean to correct for collinearity. The linear regression was then run with HMIS centred scores as independent variable and MSES scores as dependent variable, finding that HMIS significantly predicted higher MSES scores, β =.415, t (116) =

3.05, $p < .01$, and explained a significant proportion of the variance in MSES scores $R^2 = .074$, $F(1,116) = 9.303$. After controlling for the demographic variables of age, length of ADT treatment, sexual orientation, and ethnicity, age significantly contributed to the model $\beta = -.19$, t (116) = -2.32, $p < .05$ (Table 5.14). The significant result of the regression analysis and the positive beta indicates that higher HMIS significantly predicted higher MSES scores, meaning that those participants strongly identifying with hegemonic masculine ideals also suffered from more severe masculine self-esteem issues when compared to participants not identifying with hegemonic masculine ideals. Moreover, when controlling for age it was found that masculine self-esteem issues decreased with age, with younger patients more vulnerable to low masculine self-esteem.

Table 5.13. Controlling for demographic variables when testing regression HMIS → MSES.

	β	*t* (116)	*p*	*R*^{2}	*F (1, 116)*
Age (in years)	-.19	-2.32	.02*	.116	7.53
Time on ADT (in months)	-.01	-.51	.61	.094	2.48
Sexual orientation	-.53	-.71	.48	.078	4.89
Ethnicity	.945	.55	.58	.077	4.77

Note. The table reports the results of four multiple regression run with HMIS scores as independent variable, MSES scores as dependent variable, and controlling for each of the variables in the table respectively.

The moderation model was then tested with PROCESS macro, with ADT treatment (no = 0, yes = 1) as independent variable and HMIS scores (centred to the mean) as a moderator. The overall model was significant $p < .01$ and explained a significant proportion of the variance in MSES scores $R^2 = .114$, $F\ (3,114) = 9.303$. Both ADT ($\beta = 2.25$, t (114) = 2.19, $p < .05$) and HMIS scores ($\beta = .55$, t (114) = 2.31, $p < .05$) significantly predicted MSES scores. The positive betas indicate that both the variables predicted more severe issues related to masculine self-esteem. However, the interaction term between independent variable and moderator did not significantly contribute to the model ($\beta = -.18$, t (114) = -.63, $p = .53$). The lack of interaction effect disconfirms the hypothesis of HMIS moderating the relationship between ADT and MSES scores. This means that even if hegemonic masculine ideals are associated with worse masculine self-esteem, HMIS effect on masculine self-esteem is independent from the effect of ADT. When comparing simple effects, HMIS scores explain a larger proportion of variance ($R^2 = .074$) in MSES scores than ADT ($R^2 = .033$), suggesting that HMIS might be the stronger predictor of MSES scores.

5.4.3.2. Hypothesis 2b

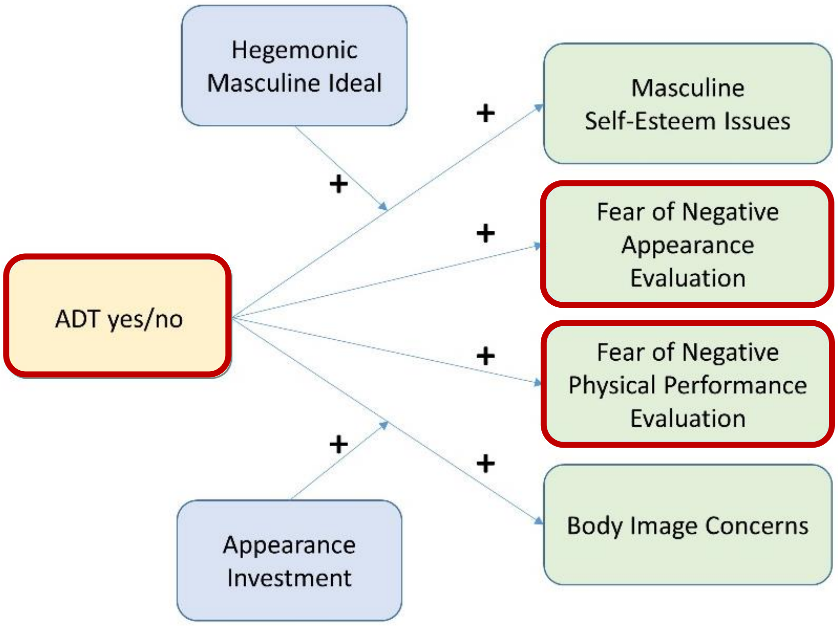


Figure 5.1-bis. Hypothesis 2b

Two regression analyses were run to test whether being on ADT significantly predicted higher levels of fear of negative appearance and physical performance evaluation. Contrary to the original hypothesis, ADT did not significantly predict any change in FNAE scores R^2=.001, *F*(1,117)=.125, *p*=.72, t(117)= -.35, *β*=-*.32*, nor in FNPPE scores R^2=.001, *F*(1,117)=.064, *p*=.80, t(117)=-.25, *β*=-*.22*.

5.4.3.3. Hypothesis 2c

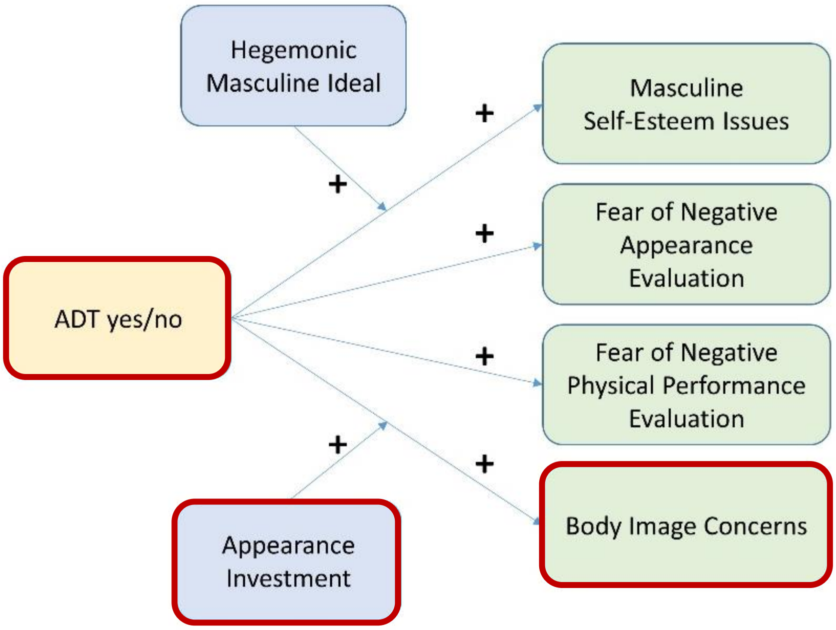


Figure 5.1-bis. Hypothesis 2c

Two regression analyses were run to test whether being on ADT significantly predicted body image issues, measured with BIS and AE scores. Contrary to the study's hypothesis, ADT did not significantly predict any change in BIS scores R^2=.00, *F*(1,116)=.00, *p*=.99, t(116)=-.005, *β*=-*.007* nor in AE scores R^2=.015, F(1,116)=1.7, *p*=.18, t(117)=-.12, β=-.17. The relationship between ADT and body image issues was also not significantly moderated by appearance investment (AO scores), for neither BIS scores R^2=.01, F(3,114)=.471, p=.70 nor AE scores R^2=.038, F(3,114)=1.5, p=.21.

5.4.4. Hypothesis 3

Hypothesis 3 was tested in the ADT group only. Before testing hypotheses 3a, b, and c, linear regression assumptions were checked considering the ADT group only. All regression assumptions were met (e.g., linear relationship between independent and dependent variable, sufficient sample size, no outliers, no multicollinearity, no auto-correlation, homoscedasticity), apart from the assumption of multivariate normality (see Appendix B9 for complete assumption testing). None of the dependent variables were normally distributed, apart from AE and MSES scores (Table 5.15). Given the sufficient sample size, the data was not transformed in order to avoid bias in the model estimates (Schmidt & Finan, 2018).

Table 5.14. Normality testing for all dependent variables in the ADT group only for hypotheses 3a,b,c.

	Shapiro Wilk's	df	*p*
BIS	.928	58	.002
AE	.992	58	.959
G-LETQ	.951	58	.020
MSES	.968	58	.123
FAS	.908	58	.000

Note. The table reports the results of Shapiro Wilk's test, which tests the null-hypothesis that the population is normally distributed. BIS = Body Image Scale; AE = Appearance Evaluation Subscale; G-LTEQ = Godin Leisure Time Exercise Questionnaire; MSES = Masculine Self Esteem Scale; FAS = Functionality Appreciation Scale.

5.4.4.1. Hypothesis 3a

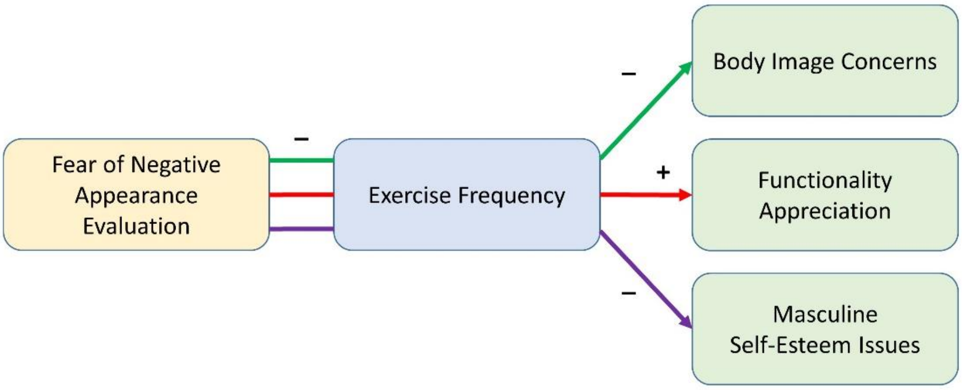


Figure 5.2-bis. Hypotheses 3a

Three regression analyses tested whether FNAE scores would predict BIS, MSES, and FAS scores and whether these relationships would be mediated by G-LTEQ scores. In line with the study's hypothesis, FNAE would significantly predict higher BIS scores R^2=.24, F(1,56)=18.34, p<.001, t(56)= 4.3, β=.77. Contrary to the initial hypothesis, this relationship was not mediated by exercise frequency, since FNAE scores did not significantly predict G-LTEQ scores (equation 1 in Table 5.16) and, in turn, G-LTEQ scores did not significantly predict BIS scores (equation 2b in Table 5.16).

Accordingly to the hypothesis, FNAE scores significantly predicted higher MSES scores R^2=.27, F(1,56)=21.27, p<.001, t(56)= 4.6, β=.72. Contrary to the hypothesis, this relationship was not mediated by exercise frequency, since FNAE scores did not significantly predict G-LTEQ scores (equation 3 in Table 5.16). However, in line with the hypothesis, G-LTEQ scores significantly predicted lower MSES scores (equation 4b in Table 5.16)

FNAE scores also did not significantly predict FAS scores, which did not support the hypothesis R^2= 003, F(1,56)= 189, p=.*66*, t(56)=-.435, β= -.068. This relationship was not mediated by G-LTEQ scores (equations 5 and 6 in Table 5.16).

5.4.4.2. Hypothesis 3b

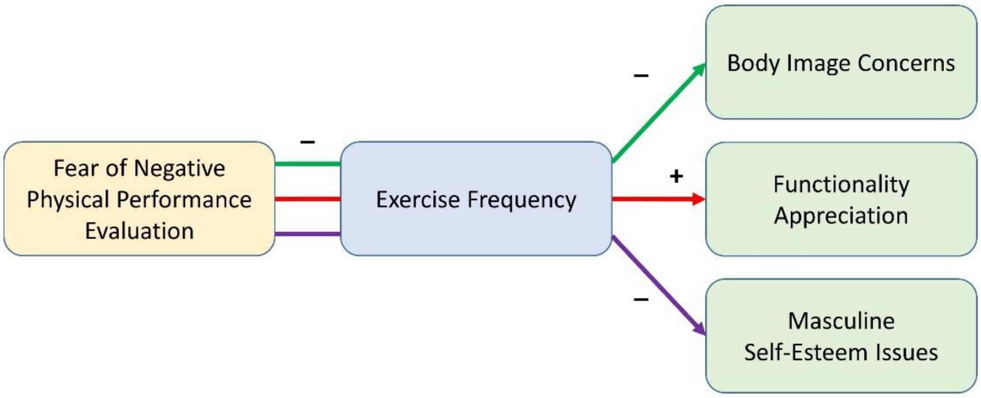


Figure 5.3-bis. Hypotheses 3b

Three regression analyses were run to test the hypothesis that FNPPE scores would predict BIS, MSES, and FAS scores and that these relationships would be mediated by G-LTEQ scores. In line with the initial hypothesis, FNPPE scores significantly predicted higher BIS scores R^2=.30, F(1,56)=24.55, p<.001, t(56)= 4.95, β=.91. However, G-LTEQ scores did not significantly mediate this relationship (equations 7 and 8 in Table 5.16).

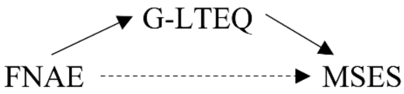
FNPPE scores also significantly predict higher levels of MSES R^2=.46, F(1,56)=47.66., p<.001, t(56)= 6.9, β=.98. However, this relationship was not mediated by G-LTEQ scores (equations 9 and 10 in Table 5.16).

FNPPE scores did not predict FAS scores, disconfirming the study's hypothesis, R^2= 016, F(1,56)= .93, p=.34, t(56)= -.963, β= -.16. This relationship was not significantly mediated by G-LTEQ scores (equations 11 and 12 in Table 5.16).

Table 5.15. Complete equations for testing Hypothesis 2a and 2b with multiple regression modelling. Tested in the ADT group only.

Hypothesis 3a

(1) (X → Me)	R^2=.001, *F*(1,56)=.074, *p*=.78, t(56)=.27, *β*=.22
(2) (X, Me → Y)	R^2=.25, *F*(2,55)=9.0, **_p_< .001**
(2a) (X → Y)	**_p_<.001**, t(55)= 4.2, *β*=.77
(2b) (Me → Y)	**_p_ = .93**, t(55)= -.08, *β*= -.002

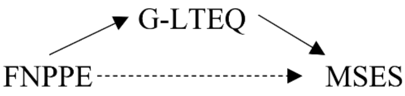


(3) (X → Me)	R^2=.001, *F*(1,56)=.074, **_p_=.78**, t(56)=.27, *β*=.22
(4) (X, Me → Y)	R^2= .33., *F*(2,55)= 13.44, **_p_<.001**
(4a) (X → Y)	**_p_<.001**, t(55)= 4.8, *β*= .726
(4b) (Me → Y)	**_p_<.05**, t(55)= 4.8, *β*= -.05

(5) (X → Me)	R^2=.001, *F*(1,56)=.074, **_p_=.78**, t(56)=.27, *β*=.22
(6) (X, Me → Y)	R^2=.013, *F*(2,55)=.36 , **_p_=.70**
(6a) (X → Y)	**_p_=.7**, t(55)= -.46 , *β*= -.07
(6b) (Me → Y)	**_p_=.47**, t(55)= .73 , *β*= .02

Hypothesis 3b

(7) (X → Me)	R^2=.04, *F*(1,56)=2.53, **_p_=.12**, t(56)= -1.6, *β*= -1.368
(8) (X, Me → Y)	R^2=.32, *F*(2,55)=13, **_p_<.001**
(8a) (X → Y)	**_p_<.001**, t(55)= 5.09, *β*=.95
(8b) (Me → Y)	**_p_ = .26,** t(55)= 1.13, *β= .032*



(9) (X → Me)	R^2=.04, *F*(1,56)=2.53, **_p_=.12**, t(56)= -1.6, *β*= -1.368
(10) (X, Me → Y)	R^2=.46, *F*(2,55)=23.9, **_p_<.001**
(10a) (X → Y)	**_p_<.001**, t(55)= 6.57, *β*= .96
(10b) (Me → Y)	**_p_=.47**, t(55)= -.72, *β*= -.016

(11) (X → Me)	R^2=.04, *F*(1,56)=2.53, **_p_=.12**, t(56)= -1.6, *β*= -1.368
(12) (X, Me → Y)	R^2=.021, *F*(2,55)= .60, **_p_=.55**
(12a) (X → Y)	**_p_ =.412**, t(55)= -.82 , *β*= -.14
(12b) (Me → Y)	**_p_=.6**, t(55)= -.53 , *β*= .01

Note. The table reports the results of multiple regression analyses testing hypothesis 2a and 2b. FNAE= Fear of Negative Appearance Evaluation Scale; FNPPE= Fear of Negative Physical Performance Evaluation; G-LTEQ= Godin Leisure Time Exercise Questionnaire; BIS = Body Image Scale; MSES = Masculine Self Esteem Scale; FAS = Functionality Appreciation Scale; X= independent variable; Me= mediator; Y= dependent variable.

5.5. Discussion

5.5.1. Hypothesis 1

The present study compared PCa patients undergoing ADT with ADT-naïve patients and a group of age-matched cancer free men. Contrary to the hypothesis, there was no significant difference between groups on any of the body image scales, nor for functionality appreciation, masculine self-esteem, fear of negative appearance and physical performance evaluation. This is in contrast with the hypothesis that PCa patients on ADT would present the worst body image related outcomes and with some of the literature suggesting that ADT side-effects could be associated with body image and masculine self-esteem issues. As previously mentioned, the majority of the studies finding that patients undergoing ADT struggle with their body image tend to adopt qualitative methods (e.g.,(Ervik & Asplund, 2012; Gentili et al., 2019; Kelly, 2009; Navon & Morag, 2003), while quantitative studies present mixed findings (e.g.,(Langelier et al., 2018). This pattern suggests that while the ADT-induced bodily changes might foster feelings of negative body image in some men, this might not necessarily be the case for the majority of patients.

In this regard, several studies in the general population suggest that individuals identifying as males tend to be less vulnerable to body image issues (Ålgars et al., 2009). While for centuries and in several cultures women have been experiencing strong pressures to adhere to certain beauty ideals, men have not been exposed to such aesthetic norms so systematically

(Daniel & Bridges, 2013; Fredrickson & Roberts, 1997; Szymanski et al., 2011). This suggests that identifying as male could be associated with lower appearance investment (Cash et al., 2004). In turn, low appearance investment could act as a protective factor against body image issues for some PCa patients, even when faced with such radical bodily changes as those induced by ADT. For example, a study by Sabiston et al. (2010) administered the MBSRQ (Cash, 2015) to a sample of 469 women with breast cancer (Mean age 57.1, SD = 7.9) and 385 women without breast cancer (Mean age 55.4, SD = 13.5). While scores on the Appearance Evaluation scale of Sabiston's sample between 1.6% and 3.8% higher than the AE scores in this study's sample, both women with and without breast cancer presented higher AO (appearance investment) scores than PCa patients in this study (Sabiston et al., 2010). In particular, the survey found that breast cancer patients had a mean score of 3.39 (SD = 0.60) on the AO subscale, compared to an AO means of 3.10 (SD = 0.74) in the ADT group and 2.87 (SD = 0.87) in the ADT-naïve group in this study. Similarly, women without breast cancer scored an average of 3.48 (SD = 0.61) on the AO subscale, while cancer-free men in this study presented a mean AO score of 2.90 (SD = 0.78). These comparisons highlight that male PCa patients in this study presented AO scores between 5.8% and 12% lower than the ones of the breast cancer patients in Sabiston et al's sample. This descriptive comparison supports the interpretation that the appearance investment of the men who participated in this study is overall low and potentially lower than the appearance investment of both women with and without cancer of a similar age. However, it is important to take this comparison with caution, since it is only descriptive and not statistically valid. Future studies should statistically compare male and female cancer patients as well as cancer-free samples on appearance investment and body image outcomes.

Another factor to consider when interpreting these findings, is age. Research showed that while women often remain dissatisfied with their bodies as they get older, body image issues tend to dissipate with age in men (Malik et al., 2019). In addition to identifying as male, older age is also associated with lower appearance investment (Ålgars et al., 2009; Tiggemann, 2004). In this regard, it is important to note that the majority of men in the two patient groups were in their sixties and early seventies, while most of the cancer-free men were in their fifties and potentially more invested in their appearance due to younger age. Comparing PCa patients on ADT to a slightly younger group of cancer-free men might have therefore masked the difference in body image dissatisfaction between the groups. Due to this limitation, it is not possible to draw definite conclusions on whether PCa patients undergoing ADT do or do not suffer from more severe body image issues when compared to ADT-naïve patients and cancer free men of the same age group. Moreover, when testing Hypothesis 2 and taking in consideration only PCa patients on ADT and ADT-naïve patients, ADT significantly predicted masculine self-esteem issues but not body image issues. Future studies should therefore be even more rigorous in the selection of age-matching cancer-free men when applying this design.

The present study did not consider the role that different coping strategies might play in protecting some individuals from developing body image issues as a consequence of ADT side-effects. An understanding of the nature and effectiveness of coping strategies adopted by PCa patients to deal with ADT could inform supportive interventions for those who struggle to manage the impact of treatment side-effects, and potentially explain the mixed findings within the existing research. For this reason, the next study in this thesis (Study 3, Chapter 6) investigated the relationship between coping strategies, body image and masculine self-esteem issues, with the further aim of identifying strategies that could help those PCa patients undergoing ADT who suffer from body image and masculine self-esteem issues.

5.5.2. Hypothesis 2

5.5.2.1. Hypothesis 2a

According to the study's hypothesis, ADT was significantly associated with higher MSES scores, indicating stronger issues associated with masculine self-esteem. This is in line with previous literature investigating sexual issues and masculine self-esteem in patients on ADT (E. Chung & Brock, 2013), confirming that ADT side-effects are likely to have a negative impact on patients' masculine self-esteem and potentially on sexual wellbeing. Since a PCa-induced reduction of masculine self-esteem is linked with both negative psychological and physical health outcomes (Chambers, Hyde, et al., 2017; Cormie, Turner, et al., 2015; Hoyt et al., 2013; Levy & Cartwright, 2015; Wootten et al., 2017; Zaider et al., 2012), these findings highlight the need for interventions supporting PCa patients on ADT who are dealing with the psychological impact of their treatment.

Moreover, those patients with a strongly hegemonic masculine ideal presented higher MSES scores, indicating that patients' masculinity ideal can have a direct effect on their mental health, with a hegemonic masculinity model being detrimental for patients' masculine self-esteem. To the best of the author's knowledge, this is the first study investigating the impact of a hegemonic masculine ideal on PCa patients' masculine self-esteem. This result could be interpreted in a similar way to the thin ideal internalization theory, which states that those individuals holding an unattainable appearance ideal are at higher risk of body image dissatisfaction (Thompson & Stice, 2001). Thin ideal internalization theory suggests that the perceived discrepancy between one's actual body and the thin-beauty ideal causes dissatisfaction and might encourage individuals to engage in unhealthy behaviours aimed at minimizing the discrepancy (Vartanian, 2012). The association between hegemonic masculine ideal and low masculine self-esteem in PCa patients could be interpreted in a similar way. The impact of cancer treatment and diagnosis is likely to negatively impact those bodily and societal characteristics that are central to a hegemonic masculine ideal (such as being strong, muscular, sexually active, and financially autonomous). As a consequence, the discrepancy between patients' ideal and real embodiment of their masculinity will increase, causing a decrease in self-esteem. On the contrary, those patients scoring low on HMIS showed better masculine self-esteem, suggesting that different masculinity models might represent a protective factor for PCa patients. Age was a significant control variable in the analysis, suggesting the younger men might be more vulnerable to low masculine self-esteem. This is in line with previous literature, finding PCa patients more vulnerable to body dissatisfaction at a younger age, when expectations around sexual performance and autonomy are higher (Gentili et al., 2019). These results suggest that masculinity beliefs might be important targets to include in interventions for men adjusting to PCa, with specific attention to younger patients (Campbell et al., 2012). Moreover, future research should further explore how patients with different models of masculinity cope with diagnosis and treatment of PCa.

Lastly, a moderation model was run with ADT (yes/no) as independent variable, HMIS scores as a moderator, and MSES scores as a dependent variable, in order to test for the interaction between ADT and hegemonic masculine ideal. The aim of this analysis was to test whether the effects of ADT and hegemonic masculinity ideal would interact, therefore putting those patients following ADT and holding such ideals at risk of even more severe masculine self-esteem issues. Interestingly, while in the moderation model both the independent variables had a significant effect, the interaction did not – disconfirming the hypothesis of a moderation effect. When analysing the effect of the two predictors separately, HMIS showed a stronger predictive value on MSES scores than ADT, indicating that those hegemonic masculine ideals might be a stronger risk factor for masculine self-esteem issues than ADT in itself.

These results suggest that while ADT still represents a potentially detrimental factor to PCa patients’ masculine self-esteem, hegemonic masculinity ideals represent a much stronger threat to patients’ well-being, regardless of their treatment plan. Therefore, while researchers and health care professionals should still focus on minimising the negative impact of ADT side-effects, a reformulation of hegemonic masculinity ideals is essential to support specifically younger men to adapt to the changes provoked by PCa diagnosis and treatment.

5.5.2.2. Hypotheses 2b and 2c

Contrary to the initial hypothesis and in line with the results from Hypothesis 1, ADT did not predict higher fear of negative appearance and physical performance evaluation nor higher body image concerns. Since the ADT and ADT-naïve group did not significantly differ for age (as they did with respect to the control group), the lack of effect of ADT on body image outcomes cannot be attributed to differences in ages between groups. The lack of significant effect of ADT on body image outcomes could be interpreted in a number of ways. For example, the fact the analyses did not include the number of side-effects each patient was experiencing nor their intensity did not allow the analysis to investigate in full detail the magnitude of ADT influence on body image. For this reason, number and intensity of side-effects was added in Study 3 (Chapter 6).

These results could also be due to the fact that a diagnosis of PCa, - regardless of ADT treatment - could negatively affect patients’ body image. This would explain the lack of difference between the ADT and ADT-naïve group when testing Hypothesis 2 b and c. It is important to note that the analyses for Hypothesis 1 did not detect any significant effect when comparing ADT and ADT-naïve and the control group either. However, these analyses were affected by the significant difference in age between the two PCa patients groups and the cancer-free group (which was composed by significantly younger men, who could have been on average more preoccupied with body image due to their age, therefore masking the differences with the two patients groups). To fully investigate the differences in body image issues between PCa patients on ADT, ADT-naïve patients, and cancer-free men it will be necessary to recruit a perfectly homogeneous sample in terms of age.

Lastly, as previously stated, it could be that only some PCa patients on ADT suffer from body image issues as a consequence of ADT side-effects. This interpretation would be consistent with the results of qualitative studies and the mixed results of quantitative research on the topic. Following this interpretation, it would be necessary to deepen the exploration of potentially protective factors preventing the development of negative body image, which could help most PCa patients cope well with hormone therapy side-effects, but still leaving some men struggling with body image issues. For this reason, Study 3 (Chapter 6) investigated the effect of different coping strategies on the development of negative or positive body image in PCa patients undergoing ADT.

5.5.3. Hypotheses 3a and 3b

Exercise frequency was expected to predict positive body image outcomes and less masculine self-esteem issues. Fear of negative evaluation for appearance and physical performance were expected to predict lower exercise frequency in PCa patients undergoing ADT.

5.5.3.1. FNAE and FNPPE both predicted higher body image issues, but exercise frequency did not mediate either of these relationships.

The analyses revealed that both fear of negative appearance evaluation and fear of negative physical performance evaluation significantly predicted worse body image issues in PCa patients undergoing ADT. This result is in line with previous studies finding that being preoccupied with other people's judgement towards one's appearance and physical performance tends to be detrimental for one's body image (Lundgren et al., 2004).

However, contrary to the study's hypothesis, exercise did not mediate either of the relationships. In fact, neither fear of negative appearance evaluation nor fear of negative physical performance evaluation were associated with lower exercise frequency. Despite contradicting the original hypothesis and previous literature in the general population (Brudzynski & Ebben, 2010), this finding positively suggests that PCa patients on ADT might still manage to exercise, irrespective of their level of fear of negative evaluation.

In contrast with previous literature, exercise frequency did not predict lower body image issues (Langelier et al., 2018). This result suggests that while exercise still holds a general positive effect on medical and psychological health in cancer patients (Culos-Reed et al., 2010), there is still no clear evidence that - at a population level – higher frequency of exercise would be beneficial for PCa patients' body image specifically.

While previous literature supports the positive effect of exercise on body image (A. Campbell & Hausenblas, 2009), it is important to note that higher frequency of exercise might not necessarily be the most informative nor beneficial factor to consider. Research found that men suffering from disordered eating and severe body image dissatisfaction reported very high exercise frequency (Strother, Lemberg, Stanford, & Turberville, 2012). Therefore, when investigating the effect of exercise on body image this study should have not only included exercise frequency, but also controlled for which motivations participants had to exercise, whether they were appearance or health related. In this regard, a study by Homan and Tylka (2013) found that in women aged 18-51 years exercise frequency was related to higher positive body image whilst high levels of appearance-based exercise motivation (the extent to which exercise is pursued to influence weight or shape) weakened this association (Homan & Tylka, 2014). On the contrary, health-related motivations to exercise have been associated with higher levels of body appreciation and positive body image among both men and women (Tylka & Homan, 2015). Although no equivalent study has yet been conducted among older men, research by Fatt et al (2019) found that high appearance-based exercise motivation and low health-based exercise were associated with low body satisfaction among 118 Australian men aged between 18 and 27 (Fatt, Fardouly, & Rapee, 2019). The fact that the study did not control for exercise motivations represents a limitation and could explain the non-significant effect of exercise frequency on body image outcomes. It is also important to note that assessing exercise frequency with self-report measures has limitations, since some participants might not be accurate when recalling and estimating their exercise habits (Verplanken & Melkevik, 2008). An inaccurate estimation of exercise frequency could also explain the lack of mediation between fear of negative appearance and physical performance evaluation and masculine self-esteem by exercise frequency.

5.5.3.2. FNAE and FNPPE both predicted lower masculine self-esteem. Exercise frequency significantly predicted better masculine self-esteem, but did not mediate the relationships between FNAE and FNPPE with masculine self-esteem.

Both fear of negative appearance evaluation and fear of negative physical performance evaluation significantly predicted more severe masculine self-esteem issues (i.e., higher MSES scores). This finding represents a novel contribution to the literature, as it is the first to test the association between these variables.

Again, exercise frequency did not mediate the relationship between fear of negative appearance and physical performance evaluation and masculine self-esteem, contradicting the study's hypothesis. As previously stated, this null result could suggest that fear of negative evaluation does not necessarily represent an exercise barrier for men diagnosed with PCa undergoing ADT.

In line with the study's hypothesis and with previous literature (Cormie, Galvão, et al., 2015; Cormie, Turner, Kaczmarek, Drake, & Chambers, 2015; Gentili et al., 2019; Langelier et al., 2018), exercise significantly predicted better masculine self-esteem (i.e., lower levels of masculine self-esteem issues). This result suggests that engaging in exercise might help PCa patients following ADT to restore masculine self-esteem.

5.5.3.3. FNAE and FNPPE did not predict functionality appreciation and exercise frequency did not mediate these relationships.

Similarly, exercise frequency did not mediate the relationship between fear of negative appearance and physical performance evaluation and functionality appreciation. Again, this result suggests fear of judgment regarding one's appearance and/or physical capacities may not necessarily represent an exercise barrier, but also may not prevent PCa patients on ADT from appreciating their body functionality. This result is in line with positive body image theory, postulating that positive and negative body image should not be considered extremes of the same continuum, but rather as two separate psychological factors that can co-exist in the same individual at the same time (Tylka & Wood-Barcalow, 2015). Contrary to the study's hypothesis, exercise did not predict functionality appreciation in any of the models. In line with previous results, the study suggests that there is still no clear evidence that - at a population level – exercise could have a positive impact on body image related outcomes for PCa patients on ADT. As previously stated, the fact that motivations to exercise were not included in the model and the challenges to assess exercise frequency through self-report might have masked the effect of exercise frequency on body image-related outcomes (Homan & Tylka, 2014; Tylka & Homan, 2015).

5.6. Strengths and limitations

This is the first study implementing a measure of fear of negative physical performance evaluation, contributing to the construction of a new questionnaire, the FNPPE scale. However, the implementation of a not completely validated measure is a limitation of the current study. Nevertheless, internal consistency of the scale was excellent in all the samples and future research should therefore carry on the validation of the FNPPE scale. In particular, this scale represents a relevant contribution not only to body image research, but also to sport and exercise psychology research, given the lack of a validated measure assessing the worry for being judged by others for one's physical performance.

Similarly, the implementation of a non-validated measure to investigate hegemonic masculine ideals represents another limitation. The HMIS was designed and implemented because of the current lack of a validated questionnaire specifically measuring hegemonic masculinity ideals. The questionnaire presented an acceptable internal consistency ($\alpha = .648$), but further research is needed to test the psychometric validity of the scale. This scale represents a contribution not only to PCa psycho-oncology research, but also to gender and sociological studies.

The presence of a cancer-free group is a strength of the study. This is the first body image study comparing PCa patients on ADT not only to ADT-naïve patients, but also to cancer-free men. While the age inclusion criteria was aimed at minimizing the age difference between the control group and the two PCa patients groups (as discussed in detail in section 5.2.6.), the fact that the control group's age was still significantly lower than the ADT and ADT-naïve groups' age represents a limitation. On this note, the fact that this study does not provide information on the experience of older PCa patients is also a limitation. Future research should therefore find better strategies to recruit older cancer-free men when applying a similar study design. For example, including cancer-free men in the PPI process might have helped improve recruitment strategies to reach a slightly older sample. Moreover, adopting a stratified sampling method would have allowed to match the groups in numbers and mean age.

As for Study 1, participants were not asked to disclose their cancer stage. As previously mentioned, the clinical advisors supported this choice for two main reasons: patients might not necessarily know their cancer stage, and posing said question might be triggering for some. This would have increased the risk of disrupting their experience of the online survey. However, the lack of information on cancer stage still represents a limitation as it was not possible to analyse the results on the basis of cancer progression.

Having adopted a cross-sectional design means that the present study does not provide information regarding the potential development and fluctuation over time of body image and masculine self-esteem issues in PCa patients. While the present study included time since diagnosis as a covariate to the regression analyses (obtaining non-significant results, Table 5.13), future research in the field should still implement longitudinal designs from the point of diagnosis onwards.

The demographics questions presented some limitations. The majority of participants reported to be from the UK and the USA (Table 5.4.), however the study did not register which specific regions participants were responding from. This represents a limitation as it does not allow an analysis of different experiences and levels of support in different areas of the same country. Another minor limitation is due to the fact that participants were not given the choice to indicate whether they lived both with their partner and their children. This option was then made available for Study 3. Similarly, the study did not explore the influence of living alone and/or being in a relationship on the outcome measures. Future studies on the impact of ADT on PCa patients' body image should include said factors as covariates since living alone is often found to be associated with poorer outcomes in cancer survivorship studies (e.g., Elovainio, Arffman, Manderbacka, Pukkala, & Hakulinen, 2021). Moreover, when investigating the effect of ADT on body image, the demographics questionnaire should have also assessed the number and intensity of side-effects experienced by participants (in order to add them as a covariate to the regression analyses). In Study 3 (Chapter 6) both number of side-effects, their specific intensity, and bother were included in the survey and in the analyses.

Lastly, the majority of men who took part in the study were white, heterosexual, and highly educated. As previously stated, despite reaching a slightly more diverse sample than the group of participants interviewed for Study 1, this study still presented a rather homogeneous sample, with the majority of participants belonging to groups with a moderate level of privilege. These results are therefore only representative of a specific group of individuals which represents a study limitation (which is fully discussed in Chapter 7, section 7.4. of this thesis). Online support groups dedicated to ethnic and LGBTQ+ minorities existed on social media but as with Study 1, most of them did not grant the author access as a white cisgender researcher. As mentioned in Chapter 4, the stricter rules for acceptance might be explained by the higher discrimination and online bullying that minority groups tend to be exposed to when interacting with white cisgender people (Hu et al., 2019; G. Mason & Czapski, 2017).

5.7. Conclusion and future directions.

Overall, Study 2 obtained mixed results. Contrary to what was initially hypothesised, there were no significant differences in body image related outcomes between PCa patients undergoing ADT, ADT-naïve patients, and cancer-free men. While this result could be due to the difference in age between the groups (Table 5.4), the mismatch between qualitative and quantitative results could indicate that while some PCa patients on ADT seem to struggle with body image issues (Study 1 in Chapter 4), many of them seem to cope reasonably well (results from Study 2). For this reason, Study 3 (Chapter 6) will focus on the influence that different coping strategies have on body image and masculine self-esteem related issues in PCa patients currently undergoing ADT.

Study 2 also found that both ADT and hegemonic masculine ideals significantly predicted more masculine self-esteem related issues. To the best of the author's knowledge, this is the first study investigating the influence of hegemonic masculinity ideals when assessing the impact of ADT on masculine self-esteem. This result suggest that alternative conceptualisations of masculinity (e.g. caring masculinities) might be protective of patients' masculine self-esteem while undergoing ADT, and future research should further explore this topic.

As hypothesized, fear of negative appearance and physical performance evaluation were both associated with higher body image and masculine self-esteem issues. However, fear of negative appearance and physical performance evaluation did not predict levels of functionality appreciation. This result is in line with positive body image theory postulating that positive and negative body image are not extremes of the same continuum but separate psychological constructs, meaning that an individual could experience both at the same time (Tylka & Wood-Barcalow, 2015b).

Contrary to the initial hypothesis, exercise frequency did not mediate either of those relationships. As previously stated, future research should take into account not only frequency but also different motivations to engage in exercise as well as type and intensity of exercise.

To conclude, the findings from Study 2 only partially overlap with the conclusions drawn from Study 1. In order to develop the field further, Study 3 (Chapter 6) attempted to shed more light on such mismatch, analysing the potential influence that different coping strategies might have on body image and masculine self-esteem when dealing with ADT side-effects. In doing so, Study 3 adopted a mixed methods approach with the aim of better explaining potentially contradicting results by combining qualitative and quantitative data.

Chapter 6

Study 3: A mixed methods exploratory study of the influence of coping strategies on body image and masculine self-esteem in prostate cancer patients undergoing ADT.

This chapter presents Study 3, which adopted a mixed methods approach to investigate how engaging in different coping strategies might influence body image and masculine self-esteem outcomes in PCa patients undergoing ADT. The chapter provides an overview of the coping model by Lazarus and Folkman (Lazarus & Folkman, 1984) which frames the conceptualization of coping strategies in this thesis. The chapter also discusses Somerfield's approach to applied psycho-oncology coping research (Somerfield, 1997), with a focus on the micro-level approach to studying coping in cancer which was adopted in this study.

6.1. Introduction

The present study design was based on the combined analyses of the results from Study 1 and Study 2. As mentioned previously, the qualitative results of Study 1 suggested that ADT side-effects were associated with both masculine self-esteem issues and body image issues (Chapter 4). However, the results of the quantitative analyses in Study 2 suggested that while ADT was associated with masculine self-esteem issues, undergoing hormone treatment did not predict body image issues (Chapter 5). The results from these two studies seemed contradictory and this final study aimed to shed light on this mismatch. As stated in Chapter 3, a mismatch between qualitative and quantitative results should not be dismissed as the signal that one of the studies "did not work out". In fact, within a mixed methods research project it is good practice to consider contradictory results as an informative suggestion that other factors need to be considered (or deepened) in order to thoroughly explore the research questions (Heath, 2020; Hesse-Biber, Rodriguez, & Frost, 2015; Morse, 2016).

The fact that participants in the qualitative study expressed body image issues related to ADT-induced bodily changes and that this finding was not confirmed in the quantitative study reflects a similar pattern in the previous literature. As discussed in Chapters 2 and 5, the majority of qualitative studies in the field found an association between ADT and body image issues (Ervik & Asplund, 2012; Gentili et al., 2019; Kelly, 2009; Navon & Morag, 2003) while quantitative studies often did not confirm this an association (Harrington & Badger, 2009; Taylor-Ford et al., 2013). Such mismatch could be interpreted in one of two main ways:

1) The quantitative studies incorporate questionnaires that are not effectively detecting and measuring PCa patients' body image issues as a result of ADT-side effects. While this remains a logical interpretation of the contradictory findings, it is unlikely to be the case when implementing body image questionnaires that have been validated and used widely among PCa patients (such as the Body Image Scale by Hopwood et al, that was implemented in Study 2) (Hopwood et al., 2001).

2) Some individual characteristics not explicitly investigated in the first two studies might play a role in determining the fluctuations of the outcomes – in this instance body image issues. In this particular case, the qualitative study advertisement material (Appendix A3) might have encouraged the self-selection of participants who experienced body image issues. The quantitative study advertisement did not explicitly refer to body image (Appendix B4) and did not confirm such findings at a population level. However, the fact that body image issues were not detectable at a population level should not invalidate the individual experiences captured by the qualitative investigation. Therefore, further investigation should be directed at understanding which individual factors (that had not been taken into consideration so far) might make some PCa patients undergoing ADT more vulnerable to developing body image issues than others. Study 3, explored this second interpretation. Understanding which risk and protective factors might influence the onset and intensity of body image and masculine self-

esteem issues is vital to inform supportive interventions and advice for those PCa patients who do struggle with their body image.

While Study 2 controlled for both appearance investment and hegemonic masculinity ideals, the different coping strategies that each individual might employ to deal with ADT side effects were not taken in consideration. Dealing with ADT side effects by applying different coping strategies might result in different levels of body image concerns related to the physical changes induced by hormone treatment and, in turn, to different levels of QoL (Harrington & Badger, 2009). A better understanding of which coping strategies seem to be associated with positive body image outcomes while undergoing ADT could inform the design of future body image interventions for PCa patients.

6.1.1. Coping strategies: Lazarus and Folkman's stress and coping theory

Coping mechanisms are a complex psychological phenomenon which numerous theoretical models have attempted to explain. A complete overview of the theories on coping mechanisms is beyond the scope of this PhD thesis. However, this section will summarize one of the most widely used and influential theories on coping and stress, the Stress and Coping Theory by Lazarus and Folkman (1984) (Biggs et al., 2017; Lazarus & Folkman, 1984), which guided the choice of this study's design and measures. While this model was first published in the 1980s, Lazarus and Folkman's theory is still widely used and cited today, including in psycho oncology research (e.g., (Kang, Kim, Kim, & Kim, 2020).

According to Lazarus and Folkman (1984) *coping mechanisms* are personal and dynamic cognitive-behavioural efforts aimed at managing specific external and/or internal demands that are appraised as stressful and/or exceeding one's resources (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986). According to Lazarus and Folkman's theory, coping strategies have three key characteristics:

1) Coping strategies are *process-oriented*, meaning that an individual's choice of coping strategies depends on the specific stressful encounter and its evolution over time. For this reason, Lazarus and Folkman's theory focuses on state rather than trait coping.

2) Coping strategies are *context-dependent*, meaning that an individuals' choice of coping strategies will be influenced by the person's appraisal of the situation and by the resources that can be accessed.

3) Therefore, different coping strategies *<u>cannot</u> be classified as inherently good or bad*. Coping strategies are a person's efforts to manage situational demands. The success of the chosen coping strategies will depend on the specific context in which they are put in place. According to this theory, coping strategies should not classified as "good" or "bad" a-priori and regardless of whether these efforts will resolve to be successful or not.

Lazarus and Folkman's Stress and Coping Theory (1984) conceptualizes coping strategies as a response to the way an individual will cognitively appraise an event. In particular, *primary appraisal* is performed in response to an internal or external event and aims to consider such event as either positive, neutral, or stressful. For example, a man receiving a PCa diagnosis might appraise the event as stressful. Stressful events can in turn be appraised as challenging or threatening (Figure 6.1.). Threat appraisal refers to an event that can cause harm or damage, while challenge appraisal implies that an event also has the potential for rewards and growth when sufficient coping resources are available (Biggs et al., 2017). A man who has just received a PCa diagnosis might appraise the event as not able to bring rewards but rather as causing harm, appraising it as a threat. On the other hand, a PCa patient facing the beginning of ADT might appraise the situation as a challenge and focus on the therapeutic effect of hormone treatment as reward for the side-effects. When an event is appraised as stressful, Lazarus and Folkman's theory refers to the process of *secondary appraisal.* Secondary appraisal can be defined as the assessment of one's available resources, situational variables, and previous similar experiences which will eventually lead to the choice of the coping strategies that the individual will enact to manage the event (Dewe & Cooper, 2007) (Figure 6.1). Once the coping strategies are chosen and enacted, the individual will then engage in a series of re-assessments of the evolving situation, adjusting their coping mechanisms throughout the process (Biggs et al., 2017) (Figure 6.1).

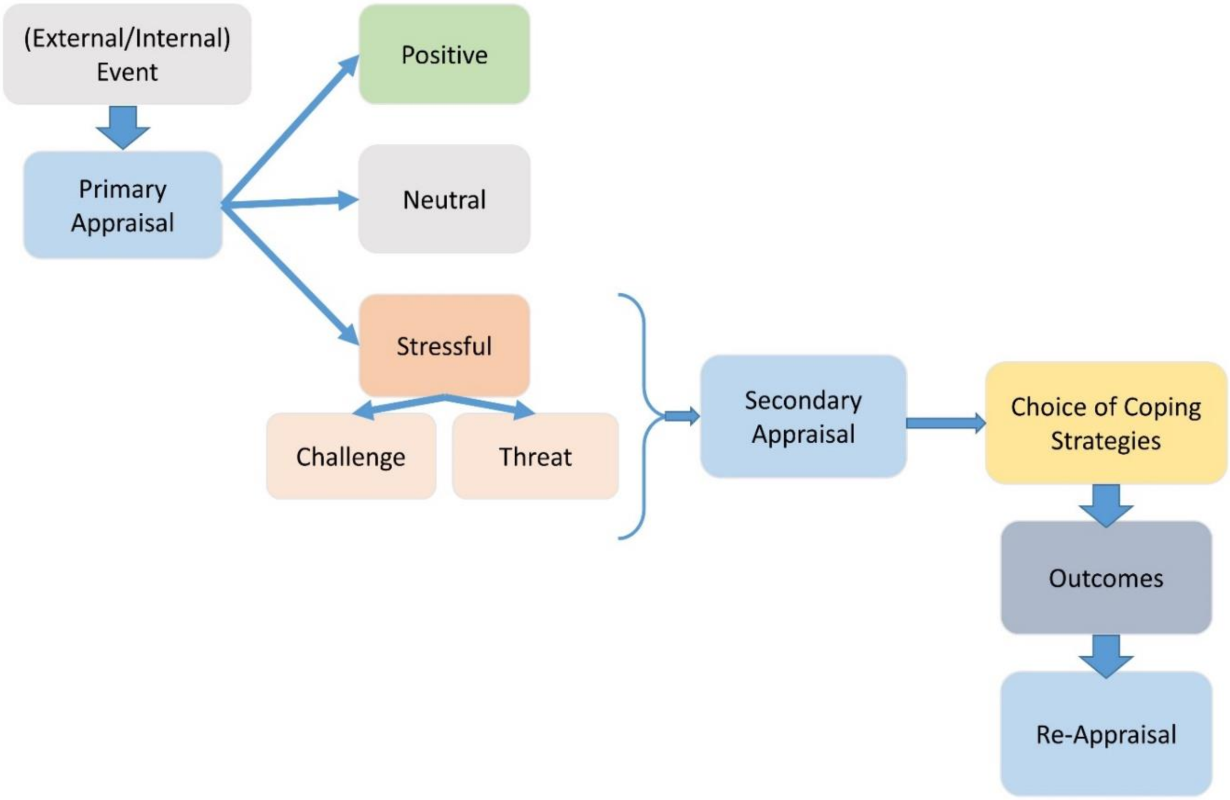


Figure 6.1. Lazarus and Folkman's Stress and Coping Theory (Biggs, Brough, & Drummond, 2017)

While Lazarus and Folkman’s theory of coping was kept as a reference point for the design of the study and the choice of a coping strategies measure (section 6.2.3.3. in this chapter), the present study focused on the exploration of coping strategies and did not test the entire Lazarus and Folkman Stress and Coping Theory on PCa patients undergoing ADT. For the justification of why the study focused on coping strategies only, see the section 6.1.2. within this chapter.

Several critiques have been made of Lazarus and Folkman's Stress and Coping Theory. While a complete overview of the decennial debates on this theory is beyond the scope of this PhD thesis, it is important to note some of the main criticism that have been moved to this model of coping processes. The conceptualization of primary and secondary appraisal has been criticized by some for implying that coping strategies are necessarily conscious, and not considering the role of unconscious (i.e., cognitive events happening of individuals are not aware but that still influence actions, cognitions, and emotions) reactions to stress (Somerfield & McCrae, 2000). While this critique is extremely important for a complete definition and research of coping strategies, it is important to note that since the present study relied on self-report measures (see section 6.2.3. of this chapter), the exploration of coping strategies had to be limited to conscious processes due to the study methodological characteristics. Therefore, while recognizing that individuals might engage in certain coping strategies without being aware of doing so, it is important to specify that this study focused its investigation on the coping strategies that participants were consciously engaging with.

Another critique of Lazarus and Folkman's theory highlights the lack of consideration of simultaneous existence of positive and negative emotions throughout stressful events (Biggs et al., 2017). This critique led to a modification of the theory by Folkman in 1997, to include how stressful events perceived as uncontrollable might lead individuals to focus on their values and life priorities (Folkman, 1997, 2008). While it is important to note this limitation, as previously stated Study 3 did not aim to quantitatively test the model of stress and coping by Lazarus and Folkman but only to adopt its definition of coping strategies.

6.1.1.2. Coping strategy taxonomies (and why they were not considered for this study).

An extensive amount of literature has focused on employing factor analyses to test potential taxonomy models in order to classify coping strategies into specific categories. For example, Lazarus and Folkman proposed to group coping strategies as either problem-focused and emotion-focused (Biggs et al., 2017). While problem-focused coping mechanisms are defined as strategies aimed at changing at least some aspect of the actual problematic situation (e.g., exercising to compensate on loss of muscles caused by ADT), emotion-focused strategies are considered aimed at regulating the emotional response one might have to the said situation (e.g., focusing on appreciating ADT effectiveness in slowing down cancer growth in order to better deal with the side-effects) (Biggs et al., 2017). However, this taxonomy has been found to be fundamentally limited as it is not conceptually clear, it is not mutually exclusive (i.e., a coping strategy could potentially belong to both categories, for example the strategy of planning is both problem oriented and serves the purpose of calming anxiety), and not exhaustive (meaning that the taxonomy does not capture other important characteristics that can pertain to the coping strategies in the category) (Skinner, Edge, Altman, & Sherwood, 2003).

This study used the Brief COPE (Carver, 1997), a measure that was derived from Lazarus and Folkman’s theory. This questionnaire is comprised of 14 sub-scales, each referring to a specific coping strategy (Carver, 1997). Several studies have performed factor analyses on the Brief COPE subscales, with the scope of grouping the various coping strategies subscales into broader categories. However, such factor analyses have obtained mixed results and researchers have not reached agreement on which taxonomy to apply to the Brief COPE inventory subscales.

In particular, when looking at the implementation of the Brief COPE in psycho-oncology research, several studies attempted to define a taxonomy among the questionnaire subscales, obtaining mixed results. The various taxonomies vary both for the number of identified categories, ranging from two (Tang, Chan, Ng, & Yip, 2016) to four (e.g.,(Baumstarck et al., 2017), as well for the type of categories identified by each study (Baumstarck et al., 2017; Bose, Bjorling, Elfstrom, Persson, & Saboonchi, 2015; Kapsou, Panayiotou, Kokkinos, & Demetriou, 2010; Tang et al., 2016).

For this reason, Study 3 did not implement any taxonomy and focused on testing the association of each specific coping strategy (measured by the Brief COPE subscales) with body image and masculine self-esteem related outcomes.

6.1.2. Coping strategies and their application to psycho-oncology research: Somerfield's model.

Coping-focused research has been considered particularly useful in health psychology as it offers a potential scientific foundation for interventions (Costa, Somerfield, & McCrae, 1996). When looking at some of the most popular coping theories, including Lazarus and Folkman's stress and coping theory, it is clear that these are intricate systems trying to capture complex and dynamic processes. The inherent complexity of such models can represent a methodological challenge such as testing *saturated models* (in which there are as many estimated parameters as data points) presenting a perfect fit but no statistical use (since it is not possible to estimate variance) (Gana & Broc, 2019). While it is necessary to find methodological strategies that would allow the researcher to test statistically meaningful – and therefore simpler – models, it is also necessary to not trivialize the complex human experience of adaptation while testing a quantitative model of coping (Somerfield, 1997).

In order to navigate this choice, this study implemented a mixed-methods design (discussed in section 6.2.1. in this chapter) and followed Somerfield's micro-level investigation strategy for applied coping research in psycho-oncology (Somerfield, 1997) which suggests targeting a narrower stressor in order to allow a more conceptually sophisticated analyses of individual adaptation to that specific threat. When looking at the study of coping with cancer, Somerfield individualizes three main levels of investigation:

1) Macro-level, referring to studies treating cancer as a unitary stressor, with no consideration for its various components (i.e., sub-stressors) (e.g., investigating the general impact of PCa on patients' mental health). Somerfield suggests that macro-level investigations tend to be poor in meaning. Since cancer is a complicated and chronic stressor, considering it as a single event (rather than as a series of stressful events, differing in duration, intensity, and appraisal) might result in confusing interpretation of the data. Each individual response to the question "How did you cope with cancer?" might refer to a specific subset of challenges related to living with cancer, making the comparison between and/or grouping of responses meaningless. For example in the case of PCa, some patients might refer to the shock of diagnosis, while other might refer to dealing with side-effects of one of the treatments they received.

2) Meso-level investigations refer to those studies that focus on a sub-stressor of cancer, for example diagnosis, or treatment. Somerfield argues that these areas of investigation are still very broad. For example, when considering the sub-stressor of cancer diagnosis it is evident how this specific aspect of cancer includes in itself a large variety of experiences: dealing with one's emotional response, navigating treatment choice, organizing practical arrangements, etc. Therefore, meso-level analyses might end up presenting the very same issues as macro-level analyses.

3) Micro-level studies of coping with cancer are defined by Somerfield as those protocols encouraging a very defined referent for coping assessment, meaning that participants are asked to answer questions about coping with a very specific stressor in mind. For example when investigating survivorship, a micro-level investigation could focus either on residual physical problems, treatment-induced sterility, or fear of reoccurrence. In this regard, focusing on how patients cope with bodily changes induced by treatment and their impact on body image related outcomes can be considered a micro-level investigation. Even within a micro-level investigation, stressors can vary for their severity, changeability, and chronicity. For these reasons, all these information still need to be recorded and considered in micro-level studies on coping. The investigation of a well-defined stressor allows the researcher to understand what participants are referring to when answering coping items (while asking a broad question like "How do you deal with cancer?" would leave the researcher guessing what aspect of cancer participants were thinking of while responding). Therefore, a micro-level investigation allows an inclusive and informative analysis of the coping strategies put in place to deal with a specific stressor (Figure 6.2).

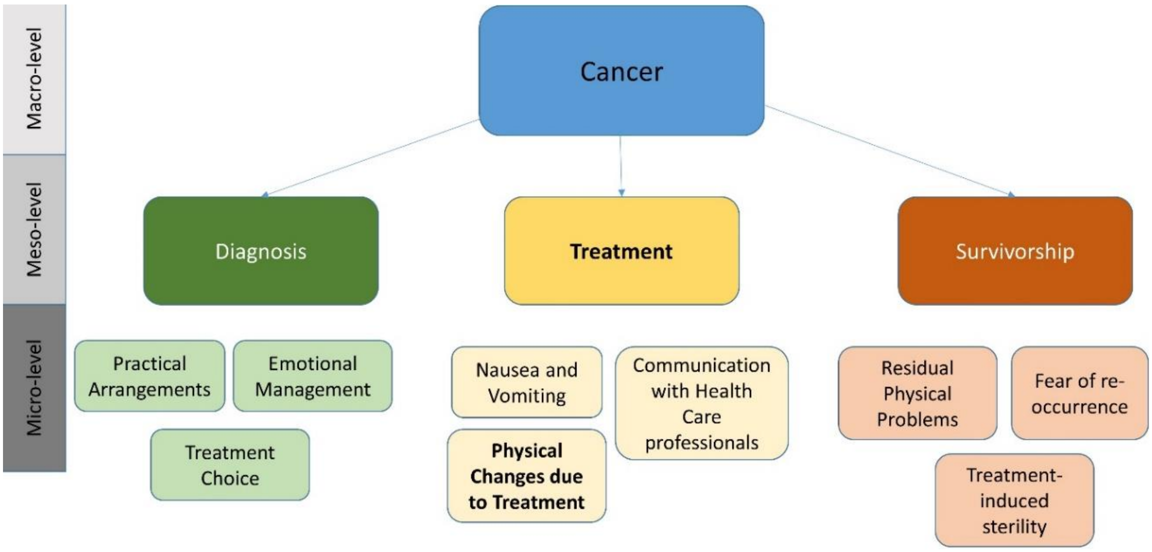


Figure 6.2.. Multi-level conceptualization of cancer-related stress according to Somerfield (the sub-stressors of Diagnosis, Treatment, and Survivorships are non-exhaustive examples).

The present study followed Somerfield's micro-level investigation strategy for applied coping research in psycho-oncology and explored which coping strategies respondents put in place to deal with ADT-induced bodily changes specifically, assessing both the frequency and bother of each side-effect.

It is important to acknowledge that Somerfield's model has been the subject of debate among researchers in the field of stress and coping. Many academics claimed that a micro-approach to applied coping research could translate into research results that are highly context-dependent and therefore not generalizable and therefore not clinically useful (Coyne, 1997). Researchers also pointed out how this approach would affect the interpretation of coping scale scores, impeding a consistent interpretation of relative differences in coping scale scores across individuals and studies (Coyne, 1997; Coyne & Gottlieb, 1996). However, since ADT is received by 50% of PCa patients at least once during their treatment and they will likely live with treatment side-effects (Chen et al., 2014), it is important to note that the application Somerfield's approach to the study of coping strategies will still produce results that are valid for a large proportion of men living with PCa. Moreover, the implementation of a mixed-methods approach allowed an in-depth analysis of individual conceptualizations of the various coping strategies employed to deal with ADT side-effects.

6.1.3. Association between coping strategies and health outcomes in PCa patients: a literature overview.

Over the years, health psychology has consistently focused on the topic of coping as a potential empirical avenue of investigating the basis of intervention designs. A study by McSorley et al. (2013) analysed the frequency of use of different coping strategies by 149 PCa patients undergoing both radiotherapy and ADT over one year. Participants completed the

Brief COPE at four time points and the study found that patients frequently used the strategies of acceptance, positive reframing, emotional support, planning and "just getting on with it". Only a minority of men engaged in strategies such as using alcohol, behavioural disengagement, and self-blame (McSorley et al., 2014). Similarly, a recent review by Spendelow (2018) examined 18 qualitative studies on coping strategies adopted by PCa patients to deal with their illness and found that the most common strategies put in place by patients were "avoidance, minimisation, and withdrawal", "directing cognition and attention", "reframing masculinity and seeking support", "retain pre-illness identity and lifestyle", and "symptom/side-effect management" (Spendelow, Joubert, Lee, & Fairhurst, 2018). Despite being very informative, the results of McSorely et al (2013) and Spendelow et al (2018) do not suggest whether some of these coping strategies might have helped patients deal with ADT side-effects nor identified the specific aspect of PCa that respondents were referring to while answering questions on their preferred coping mechanisms (Somerfield, 1997).

While to the best of the author's knowledge there is currently no published paper investigating the association of different coping strategies and body image related outcomes in PCa patients experiencing ADT side-effects, psycho-oncology literature on PCa has investigated the association between different sets of coping strategies and a variety of health-related outcomes. Both cross-sectional and longitudinal studies have found that the adoption of coping strategies such as seeking social support, active coping, planning, positive reframing, as well as acceptance, venting, humour, and religion could significantly influence PCa patients' psychological and physical health (Lafaye et al., 2014; Pascoe & Edvardsson, 2016; Roesch et al., 2005; Zhou et al., 2010).

No study has investigated the association between coping strategies and body image and masculine self-esteem related outcomes in PCa patients undergoing ADT. Despite the absence of published literature on this topic, the results presented above suggest that coping strategies can influence health related outcomes in patients diagnosed with PCa undergoing ADT, potentially including body image and masculine self-esteem related outcomes as well.

Lazarus and Folkman's theory postulates that no coping strategy is inherently good or bad, but that their desirability is context-dependent and most importantly stressor-dependent (Folkman et al., 1986). Given the lack of information regarding coping strategies applied by PCa patients to deal with ADT side-effects in relation to their body image and masculine self-esteem specifically (i.e., the stressor), it is not possible to formulate a-priori hypotheses on which strategies will be associated with positive and negative outcomes. For this reason, this study adopted an exploratory approach.

6.1.4. Study aims

Study 3 aimed to explore which coping strategies tend to be adopted more frequently by PCa patients when dealing with ADT side-effects and what personal meaning participants would assign to said strategies. The study also explored the association between different coping strategies and positive/negative body image and masculine self-esteem outcomes, with no a-priori assumptions formulated on such associations. Exploring which coping strategies seem associated with positive body image and masculine self-esteem outcomes among PCa patients dealing with ADT, would contribute to the production of context-informed knowledge useful for intervention design and clinical advice for those PCa patients suffering from body image and masculine self-esteem issues as a result of ADT.

6.2. Methods

6.2.1. Design

Study 3 applied a concurrent mixed methods exploratory approach (Creswell, 2003; Driscoll et al., 2007), which aimed at integrating the partially contradicting evidence of the first two studies and generate new knowledge that could help explain such mismatch (Figure 6.3).

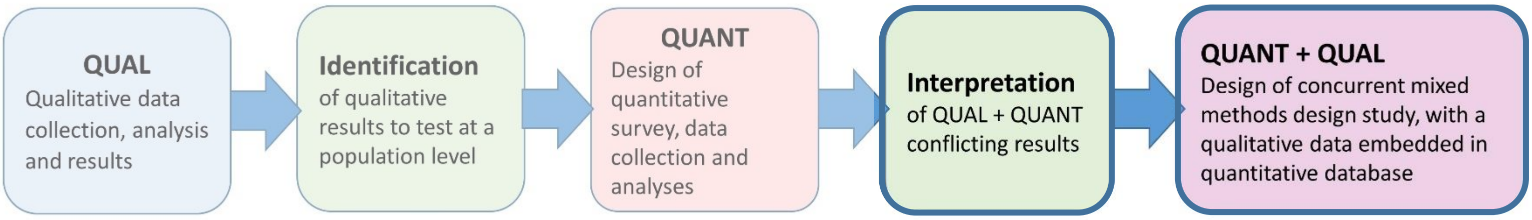


Figure 6.3. Overview of PhD sequential exploratory mixed-methods design. The interpretation and integration of qualitative and quantitative results from study 1 and 2 was at the base of Study 3 design.

The primary quantitative database was collected at the same time as the secondary qualitative database (Figure 6.4). The quantitative database consisted of data collected from validated questionnaires, while the qualitative dataset was formed by answers to open-ended questions (see section 6.2.3 for a complete overview of the adopted data collection techniques). The qualitative database was embedded in the quantitative one, with the aim of clarifying quantitative data and seeking information around coping strategies at a more individual level, therefore implementing qualitative data to describe aspects that could not be quantified (Creswell, 2003) (Figure 6.4). Integrating both quantitative and qualitative data in one study has several advantages when exploring complex research questions. While statistical analyses can provide information on response patterns, qualitative data can help provide personal meanings and deepen the understanding of survey responses (Driscoll et al., 2007).

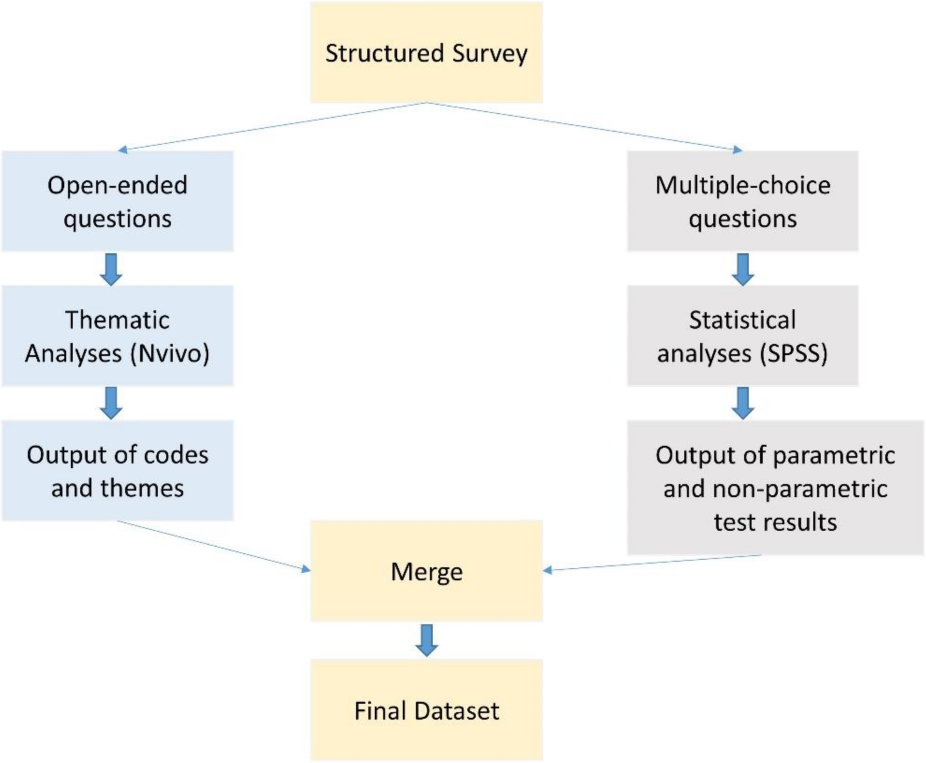


Figure 6.4. Concurrent mixed methods design (Driscoll et al 2007)

A group of 97 PCa patients who were undergoing ADT at the time of data collection participated in the study. All participants were first asked to name the side-effects they were experiencing and to what extent they were affected by them. This first section of the survey was not only aimed at collecting data on side-effects, but also to prime participants to focus on the specific ADT-related symptoms that were affecting them (Figure 6.5). This allowed the investigation on coping strategies to be uniquely focused on ADT side-effects, therefore applying Somerfield's micro-level investigation (Figure 6.2). The second section of the survey quantitatively and qualitatively assessed participants' preferred coping strategies (with respect to the side-effects that they had mentioned in the first section of the survey) (Figure 6.5). The third section of the survey included the quantitative measurement of body image and masculine self-esteem outcomes (Figure 6.5).

6.2.2. Ethical approval

This study obtained ethical approval from the Research Ethics Committee of the Faculty of Health and Applied Sciences at The University of the West of England, Bristol (UWE REC REF No: HAS.18.10.049 Amended, Appendix C1.1.).

This study also obtained NHS ethics approval to recruit through the Bristol Royal Infirmary (BRI) Hospital (Bristol, UK) (IRAS project ID: 276095, Protocol number: HAS-HSS-16-06, REC reference: 20/YH/0065, Appendix C1.2.). However, due to the Covid-19 pandemic, recruitment through the hospital was not carried out. Details on the rationale for obtaining both UWE and NHS ethical approval can be found in section 6.2.4 of this chapter.

6.2.3. Survey

The survey took place online via Qualtrics. A paper version of the questionnaire was also available for distribution through BRI recruitment, which however did not take place due to the Covid-19 pandemic (see above). Paper copies of the survey were available to any participant who requested completing the survey in this way rather than online.

6.2.3.1. Patients and Public Involvement

Two men diagnosed with PCa who had actively participated in Study 2 Patients and Public Involvement (PPI) were invited to review and provide feedback on the study purpose as well as on recruitment methods and study materials (e.g., information sheet, consent form, questionnaires, and online platform). PPI feedback verified that the study materials and design were appropriate, acceptable, and engaging for the intended population. Both men accepted this invitation and provided feedback (Appendix C2). Minor changes were applied to the survey wording and visual format, following their suggestions. Although this input was very useful, it is important to note that given the low number of participants involved in PPI for this study, it is not possible to consider such suggestions representative of all PCa patients' opinions on the survey. The complete survey can be found in Appendix C3.

6.2.3.2. Side-effects

Informed by the limitations of Study 2 (Chapter 5), Study 3 survey measured the type, number, and intensity of side-effects experienced by the respondents. Participants were asked to select the side-effects they were experiencing from a comprehensive list (Appendix C3), with the opportunity of adding any other symptoms they might be experiencing which were not included in the options. They were then presented with a Visual Analogue Scale (VAS) (Crichton, 2001) for each side-effect they had selected, to rate the extent to which they had been bothered by it (Appendix C3 for full survey). A VAS is an instrument that measures a lived experience (e.g., bother, pain, emotions) along a continuum of values. A VAS scale is usually a horizontal line, anchored by at least two word descriptors at each end. The respondent can slide across the bar and mark the point that best represents their perception. In this study, participants had to choose a point between "It does not bother me at all" and "It bothers me a lot". Based on the point along the continuum chose by the respondent, Qualtrics would then automatically allocate a score between 1 and 10, with higher scores indicating that the individual was more troubled by the side-effect.

The questions on side-effects were purposefully placed at the beginning of the survey, before the coping strategies section. The order of these two sections was not randomized. This sequence allowed participants to focus on ADT side-effects rather than on other aspects of living with PCa and maintain their answers to the section on coping strategies focused on ADT by referring to the side-effects they had just listed (Figure 6.5).

6.2.3.3. Measure of coping strategies

Brief COPE (Carver, 1997). This is a 28-item inventory assessing 14 different coping dimensions: (1) active coping; (2) planning; (3) using instrumental support; (4) using emotional support; (5) venting; (6) behavioural disengagement; (7) self-distraction; (8) self-blame; (9) positive reframing; (10) humour; (11) denial; (12) acceptance; (13) religion; and (14) substance use. This scale was chosen as it has been widely used with prostate and breast cancer populations (Green et al. 2011). Each of the 14 subscales is comprised of 2 items; total scores on each scale range from 2 (minimum) to 8 (maximum). Higher scores indicate increased utilization of that specific coping strategy. Total scores on each of the scales are calculated by summing the appropriate items. No items are reverse scored. Since there is no overall score, only total scores for each of the sub-scales, Cronbach's alpha for each subscale and correlations between items of the same subscale are provided in Table 6.1. It was not possible to compare the low internal consistency scores that were found in the Venting and Substance Use subscales with other studies administering the Brief COPE to PCa patients, as these studies performed data reduction by collating the various subscale scores in macro-categories (e.g., Christie, Meyerowitz, Giedzinska-Simons, Gross, & Agus, 2009; Kinsinger, Penedo, Antoni, Dahn, Lechner, & Schneiderman, 2006; Guan, Santacroce, Chen, & Song, 2020).

In order to make sure that participants remained focused on ADT side-effects (rather than other aspects of living with PCa) when answering coping items, the Brief COPE was introduced with a sentence referring to the previous section of the survey: “Thinking of the changes to your body that you just described as bothering you the most, please indicate how often you have used each of the following strategies to feel better and carry on with your daily life” (Appendix C3 for full survey).

Table 6.1. Brief COPE subscales Cronbach's alphas

Brief COPE Subscale	Cronbach's alphas	Pearson's correlation
Active coping (items 2 and 7)	.767	.626**
Planning (items 14 and 25)	.805	.664**
Using instrumental support (items 10 and 23)	.745	.667**
Using emotional support (items 5 and 15)	.595	.461**
Venting (items 9 and 12)	Not acceptable reliability	.031
Behavioural disengagement (items 6 and 16)	.666	.626**
Self-distraction (items 1 and 19)	.289	.302**
Self-blame (items 13 and 26)	.596	.598**
Positive reframing (items 12 and 17)	.519	.293**
Humour (items 18 and 28)	.836	.695**
Denial (items 3 and 8)	.755	.606**
Acceptance (items 20 and 24)	.695	.561**
Religion (items 22 and 27)	.811	.710**
Substance use (items 4 and 11)	.234	.195

Note. The table reports the results of Pearson's correlations between the items of each subscale.

*$p<.05$ (2-tailed)

**$p<.01$ (2-tailed)

Qualitative questions. In line with the mixed methods design with a qualitative dataset embedded within the quantitative one, the Brief COPE was followed by open-ended questions to clarify the meaning of the quantitative results. Specifically:

- Thinking of the changes to your body provoked by ADT that bother you the most, are there specific *activities* that help you feel better about your body? Please list them in the box below.
- Please explain why or how the *activities* you just have mentioned above help you feel better about your body.
- Thinking of the changes to your body provoked by ADT that bother you the most, are there specific *thoughts* that help you feel better about your body? Please list them in the box below.
- Please explain why or how the *thoughts* you have mentioned above help you feel better about your body.

6.2.3.4. Body image measures

Body Image Scale (BIS) (Hopwood et al., 2001). As for Study 2, Study 3 implemented the BIS scale to measure body image issues in PCa patients (e.g., "Since cancer treatment/diagnosis, how much have you felt dissatisfied with your appearance?"). All the details on this scale can be found in section 5.2.3.2 of Chapter 5. The internal consistency of the BIS in Study 3 sample was excellent ($\alpha = .937$).

Body Appreciation Scale-2 (BAS-2) (Tylka & Wood-Barcalow, 2015a). The BAS-2 is a 10-item scale measuring body appreciation (one of the main facets of positive body image) and positive attitudes towards one's own body (e.g., "I respect my body", "Despite its flaws, I accept my body for what it is"). Respondents are asked to rate each item on a 5-point Likert scale (1= *never*; 5= *always*). The global score consists of the mean score of all the item scores, with higher scores reflecting greater levels of body appreciation. In this study, the scale showed excellent internal consistency ($\alpha = .946$).

Functionality Appreciation Scale (FAS) (Alleva et al., 2017). As in Study 2, the FAS scale was administered to measure how much respondents feel appreciation for what their body can do (e.g., "I am grateful for what my body helps me to do"). All the details on the scale can be found in section 5.2.3.3 in Chapter 5. The internal consistency for Study 3 sample was excellent (α = .914).

Appearance Orientation Subscale of the Multidimensional Body-Self Relations Questionnaire (Cash, 2015). The AO was administered to measure appearance investment, as in Study 2. All the details on this measure can be found in section 5.2.3.4 in Chapter 5. The AO subscale internal consistency in Study 3 sample was below the threshold of acceptability (α = .559). This might be due to the fact the AO subscale was not validated for use among PCa patients. However, this interpretation is still in contrast with the good internal consistency detected for AO among PCa patients in Study 2 (section 5.2.3.4.). Further investigations is necessary to better understand the acceptability and reliability of the AO subscale among this population. Due to the low internal reliability, the AO subscale was not included in the exploratory analyses of this study.

6.2.3.5. Masculine self-esteem

Masculine Self-Esteem Scale (*MSES) (Clark et al., 2003).* As Study 2, Study 3 implemented the MSES to measure masculine self-esteem issues. All the information on this questionnaire can be found in section 5.2.3.6 in Chapter 5. MSES higher sores indicate more masculine self-esteem issues. The MSES presented excellent internal consistency in Study 3 sample (α = .948).

6.2.4. Recruitment and survey distribution

The initial study plan implied a combination of online recruitment and recruitment through the Bristol Haematology and Oncology Centre in order to maximise data collection. Combining online recruitment with time-location recruitment would provide access to the survey to a wide range of participants online while ensuring to target a location where potential participants might be identified, such as the Haematology and Oncology Centre. For this reason, both University and NHS ethics approvals were obtained (Appendix C1). The plan to include an NHS site in the Study 3 recruitment strategy was also directed at reaching a more diverse sample than in the previous two studies.

A power analyses performed with G*power suggested that a sample size of 135 individuals would have been adequate to detect medium and small effect sizes ($1\text{-}\beta = .80$, $\alpha = .05$). However due to the coronavirus pandemic, the survey could not be distributed through the Haematology and Oncology Centre, since the delivery of research projects was suspended and the majority of the staff reassigned to Covid-specific wards. This resulted in a sample of 97 participants (out of the ideal sample size of 135) reached through online recruitment alone, which resulted in only slightly underpowered analyses. Once the Covid-19 pandemic began, the online data collection was suspended, meaning that a sample of 135 was not reached by missing 37 participants. This decision was motivated by the fact that during the pandemic PCa patients would have been considered a population highly vulnerable to the virus and living during a pandemic were potentially likely to have influenced participants' responses on coping with ADT side-effects, given the more imminent Covid-19 threat.

Online recruitment allowed individuals in geographically different locations to access the survey. However, Study 3 was also not successful in recruiting individuals from ethnic minorities (Table 6.2). As per Study 2, Study 3 was advertised via a sponsored Facebook post which included the description of the study and the Qualtrics link to access the survey (see Appendix C4 for the study advertisement). The post was shared on:

- several groups dedicated to prostate cancer peer support and men's health;
- CAR Facebook page;
- UWE Facebook page;
- The Facebook page dedicated to the study.

As for Study 2, Study 3 advertisement was published through the pages of local and national Cancer Charities (e.g., Tackle Prostate Cancer, Penny Brohn, Prospect Bristol, Prostate Cancer Research Centre, The Blue Ribbon Foundation, Cancer Research UK), following the same approach strategy as for Study 2 (section 5.2.4, Chapter 5).

Participants were invited to take part in a 20-30 minutes survey about wellbeing and coping with hormonal therapy. Men interested in participating were asked to follow a Qualtrics link (Qualtrics, 2018) to an online survey. Firstly, participants were asked to read and approve an informed consent form. They were then asked to fill out some preliminary screening questions. The inclusion criteria for the study were being between 35 and 80 years old, having a diagnosis of PCa, currently undergoing ADT, and not suffering from dementia or psychosis. Participants were asked to mention whether they suffered from any other condition that affected their daily life (Have you been diagnosed with any another condition that affects your day to day life?), but were not excluded from the survey on this basis (Appendix C3). Participants not meeting the inclusion criteria of the study were directed to a separate page, thanking them for their interest in the study and explaining that they did not meet its eligibility criteria. After filling out the screening questions, eligible participants were automatically directed to the beginning of the survey.

6.2.5. Procedure

As for Study 2, Study 3 took place entirely online. Firstly, participants were asked to create a personalized code in order to let the researcher identify their anonymous response in case they decided to withdraw from the study within two weeks after completion.

After filling out a brief demographic questionnaire, participants were asked to select from a list the ADT side-effects they had experienced (or add any that were not included). They could then assess the extent to which they were bothered by each of the side-effects they had selected using VAS scales. This first step of the survey had two main aims: 1) to collect information on the nature, frequency and intensity of ADT side-effects (correcting for the limitation highlighted in Study 2); 2) to prime participants to focus specifically on ADT side-effects rather than other aspects of living with a PCa diagnosis. The assessment of side-effects was followed by the Brief COPE questionnaire, the instructions for which were modified to refer specifically to the side-effects that the respondent had just signalled as being most bothersome in the previous survey section. This was a necessary step as the standard Brief COPE instructions refer to any potentially challenging situation one might encounter. Since Study 3 aimed to investigate the specific relationship between ADT side-effects, coping strategies, and body image related outcomes, the order of the questionnaires and the modification of the instructions encouraged respondents to remain focused on ADT-related side-effects when answering items on coping. This was done in order to follow Somerfield's micro-level investigation approach for applied coping research in psycho-oncology (Somerfield, 1997).

The Brief COPE was then followed by open-ended questions, detailed above (see section 6.2.3.3). It is likely that the participants' answers to these open questions might have been primed by the items of the Brief COPE. However, after considering the possible consequences of this order-effect, the questionnaires were kept in this sequence for two main reasons: 1) answering the Brief COPE items first encouraged participants to think of the coping strategies they apply more often, helping them to answer the open ended questions - which would have otherwise been intimidating if presented at the beginning of the survey section. 2) The mixed methods design applied in this study implied that the qualitative data set would be embedded in the quantitative one, with the aim of better explaining quantitative findings. The open-ended questions were therefore intended to expand on participants' responses to the Brief COPE.

The open-ended coping questions were followed by the outcome measures section. At this point in the survey the BIS, BAS, FAS, AO, and MSES questionnaires were randomized in order to control for order effect (Figure 6.5).

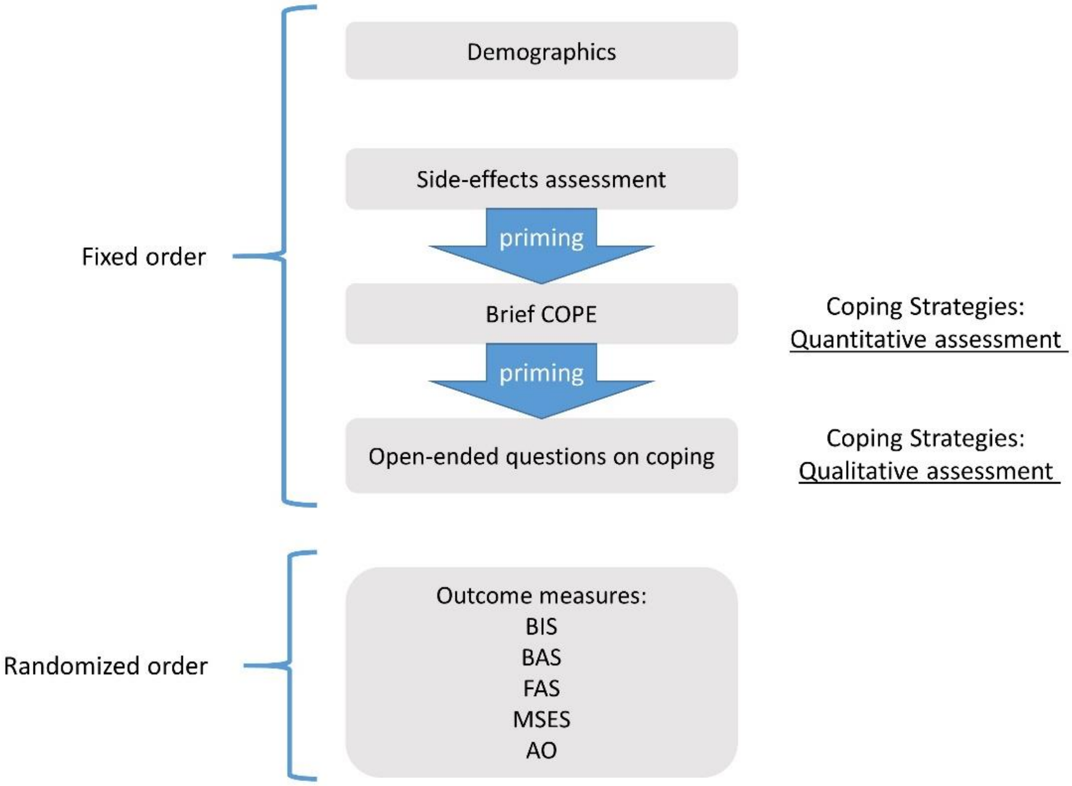


Figure 6.5. Overview of survey structure

At the end of the survey, participants were provided with a list of services they could contact in case they were worried about their physical and/or mental health (Appendix C3). The survey took an average of 26.7 minutes to complete (SD = 17.7 minutes).

As with Study 2, participants were offered the chance to enter a lottery for £70 online shopping vouchers. To do so, they had to leave their email address in a separate online sheet, in order to maintain their survey response anonymous.

6.2.6. Participants

Most participants were British (60.82%) and American (28.86%). Study 3 participants were overwhelmingly white with the exception of two participants who identified as Asian and Hispanic (Table 6.2). The majority of participants were heterosexual (87.63%), followed by a minority identifying as homosexual (6.18%) and bisexual (5.15%). Most participants were in a supportive romantic relationship (80.41%) and lived with their partner (71.13%). Participants' areas of residence equally varied between urban, suburban, and rural. The sample was overall highly educated, with the majority of participants having at least a college (20.61%), bachelor (19.58%), or master degree (18.55%) (Table 6.2). Once again, Study 3 presents a very homogeneous sample, with the majority of participants belonging to traditionally privileged groups. This limitation is discussed in section 6.6 in this chapter and further in Chapter 7.

Table 6.2. Demographics of the sample of Study 3

Age in years *M(SD)*	64.85 (6.84)
Age range in years	46 - 78
Nationality % (n)	
American	28.86 (28)
British	60.82 (59)
Canadian	6.18 (6)
European	1.03 (1)
Irish	2.06 (2)
Venezuelan	1.03 (1)
Ethnicity % (n)	
Asian/Asian British/ Asian European/Asian American	1.03 (1)
Latino/Hispanic	1.03 (1)
White/White British/ White European/ White American	96.90 (97)
Rather not say	1.03 (1)
Sexual Orientation % (n)	
Asexual	1.03 (1)
Bisexual	5.15 (5)
Heterosexual	87.63 (85)
Homosexual	6.18 (6)
Supportive romantic relationship % (n)	
Yes	80.41 (78)
No	18.56 (18)
Rather not say	1.03 (1)
Living Situation % (n)	
Alone	18.55 (18)
with Children	1.03 (1)
with Partner	71.13 (69)
with Partner and Children	6.18 (6)
Rather not say	3.00 (3)
Living Area % (n)	
Rural	27.83 (26)
Urban	31.95 (31)
Suburban	40.20 (39)
Education % (n)	
Vocational/ Technical school	16.49 (16)
High school equivalent	12.37 (12)
Grammar school	4.12 (4)
College	20.61 (20)

Bachelor’s degree	19.58 (19)
Master’s degree	18.55 (18)
Doctoral degree	5.15 (5)
Other	3.09 (3)

Note. M = mean; SD = standard deviation.

On average, participants had received their PCa diagnosis around 3.83 years (SD = 4.06) prior to the completion of the survey and had been on ADT for an average of 2.72 years (SD = 2.86). The majority of participants had received at least another treatment in addition to ADT, the most common being radiotherapy, followed by chemotherapy, and radical prostatectomy. Most participants were not diagnosed with any other medical condition. However, the most frequent comorbid diagnosis was Type 2 Diabetes and High Blood Pressure (Table 6.3).

Table 6.3. Treatment and diagnosis details (Study 3 sample)

Time since diagnosis in months *M(SD)*	45.98 (48.8)
in years *M(SD)*	3.83 (4.06)
ADT duration in months *M(SD)*	32.72 (34.4)
in years *M(SD)*	2.72(2.86)
Number of additional treatments (other than ADT) % (n)	
No additional treatment	14.43 (14)
Only 1	49.48 (48)
2	26.80 (26)
3	8.24 (8)
Prefer not to say	1 (1)
Treatments (other than ADT) % (n)	
Active surveillance	8.24 (8)
Brachytherapy	10.30 (10)
Chemotherapy	27.83 (27)
External beam radiotherapy	55.67 (54)
Radical prostatectomy	23.71 (23)
Radium-223	2.06 (2)
Other diagnosis (other than PCa) % (n)	
No	64.9 (63)
Yes	35.1 (34)

Type of diagnosis (*N*)	
Abdominal Aortic Aneurysm	2
Ankylosing spondylitis	1
Anxiety	1
CREST syndrome	1
Disc Disease	2
Heart Disease	4
Hiatus hernia	1
High Blood Pressure	6
Human Immunodeficiency Virus	1
Irritable Bowel Syndrome	2
Osteoporosis	1
Partial Paralysis	1
Polycythaemia Vera	1
Pleuroparenchymal Fibroelastosis Lung Condition	1
Post Traumatic Stress Disorder	1
Raised Cholesterol	1
Rheumatoid Arthritis	1
Sleep Apnea	1
Type 2 Diabetes	7

Note. M = mean; SD = standard deviation; ADT = Androgen Deprivation Therapy.

6.3. Data analyses

6.3.1. Exploration of data on side-effects (quantitative analyses)

The following statistical plan was agreed prior to data collection:

- Descriptive statistics were performed to calculate the frequency and relative bother of each side-effect.
- Correlation analyses were run between each side-effect’s bother score (VAS) and the outcome variables (BIS, BAS, FAS, MSES scores).
- Correlation analyses were run between the total number of side-effects experienced by participants and the outcome variables.

6.3.2. Exploration of data on coping strategies (quantitative and qualitative)

6.3.2.1. Quantitative analyses

- Descriptive analyses were run on Brief COPE subscales scores to create a list of coping strategies from the most frequently to the least frequently used by participants. However, it is important to note the self-report nature of the Brief COPE. Participants are asked to rate on a 5-point Likert scale how frequently they engaged in a series of behaviours in order to cope with ADT side-effects. Therefore, the Brief COPE scores represent only a self-reported frequency of engagement with different coping strategies. As with all self-report measures, the Brief COPE's accuracy depends on the respondent's ability and willingness to openly report their own behaviour.
- Following the advice of a statistician, statistically-different tiers for Brief COPE subscales were created. To do so, paired-sample t-tests were performed between adjacently ranked subscales. A significant t-test result indicated that the coping strategy with a higher mean score was significantly more used by respondents compared to the coping strategy with a lower mean score. Therefore, the two coping strategies would belong to different tiers. A non-significant t-test result would indicate that participants would engage in those two coping strategies in comparable amounts and they would therefore belong to the same tier.

6.3.2.2. Qualitative analyses

Participants' answers to the open-ended questions represented the qualitative dataset in this mixed-methods study. The text was analysed with the help of NVivo and, as for Study 1, thematic analysis and the constant comparative method were applied. Thematic analysis was chosen as it has been found an appropriate method to apply in mixed-methods studies, as well as to investigate individual experiences in relatively understudied fields (Braun & Clarke, 2006, 2013; Clarke & Braun, 2013). As in Study 1, Study 3 data analysis followed the six phases of thematic analysis. A complete overview of the application of thematic analysis can be found in Chapter 4, section 4.3 and Table 4.2. The initial familiarisation with the data was followed by the development of preliminary codes and then themes (see Appendix C5 for the themes map). Collecting qualitative data online through open-ended questions allowed respondents to not be influenced by their impression of the researcher as may have happened during the interviews of Study 1. While this anonymity might have helped some participants to disclose their feelings, it also resulted in lower levels of engagement with the questions for many respondents. The response rate for the open ended questions was respectively:

- 80% for the first question ("Thinking of the changes to your body provoked by ADT that bother you the most, are there specific activities that help you feel better about your body? Please list them in the box below"), with 78 out of 97 participants responding;
- 77% for the second question ("Please explain why or how the activities you just have mentioned above help you feel better about your body"), with 75 out of 97 participants answering;
- 50% for the third question ("Thinking of the changes to your body provoked by ADT that bother you the most, are there specific thoughts that help you feel better about your body? Please list them in the box below."), with 49 out of 97 participants responding;
- 43% for the fourth open ended question ("Please explain why or how the thoughts you have mentioned above help you feel better about your body.") with 42 out of 97 participants submitting an answer.

As a result of the different levels of engagement with the open ended questions, the qualitative data also presents different levels of depth.

In order to ensure that the qualitative data could better explain the quantitative dataset, the two datasets were integrated following the triangulation method (Östlund et al., 2011). A complete overview of different techniques to integrate quantitative and qualitative data can be found in Chapter 3, section 3.3 and Table 3.1. By applying the triangulation method, the 14 Brief COPE subscales informed the qualitative analyses serving as meta-themes under which the rest of the analyses were organized. The analysis of qualitative data were aimed at finding convergences (the findings from each dataset agree), complementarities (the two datasets offer complementary information on the same issue), dissonances (the findings from the two datasets seem to contradict each other), and silences (a theme or a finding might arise only in one dataset and not the other) (O'Cathain et al., 2010). It is important to note that choosing the Brief COPE subscales as a-priori meta-themes does assimilate this analysis technique to the "Following a Thread" protocol as well (for complete definition see Chapter 3, section 3.3 and Table 3.1.) (Moran-Ellis et al., 2006; O'Cathain et al., 2010). However, since in Study 3 this integration highlighted both discrepancies and silences, the process is still more similar to the triangulation protocol.

It is important to note that researchers have long been debating the epistemological foundations of the triangulation technique (Sandelowski, 1995). Some claim that integrating qualitative and quantitative data via triangulation serves a realist epistemology and that this technique assumes a hierarchy where a methodology is judged more accurate than the other since triangulation aims to find confirmation between datasets (Sandelowski, 1995; Tobin & Begley, 2004). For this reason, some claim that triangulation is not compatible with qualitative approaches, which focus on the importance of analysing experiences from different perspectives to reach a meaningful understanding of the findings (Tobin & Begley, 2004).

While it is important to acknowledge this critique and avoid epistemological incompatibilities, it should be noted that the triangulation technique applied in this study did not only aim to find convergences and complementarities between datasets, but also detected dissonances and silences (O'Cathain et al., 2010). In particular, analysing and interpreting dissonances and silences between quantitative and qualitative findings were considered particularly informative triangulation process to better understand the research question and study findings (O'Cathain et al., 2010) and in line with the pragmatist epistemological approach (for a full discussion on pragmatism, see Chapter 3, section 3.2).

As always, qualitative data collection and analyses needs to be accompanied by the process of reflexivity. While collecting data online meant that my characteristics did not influence the collection of the data, my expectations and values still shaped the data analyses process. A thorough discussion of the social and personal factors that might have influenced data analyses can be found in Chapter 7.

6.3.3. Exploring the association between coping strategies and outcome measures (quantitative)

Correlation analyses were run between the Brief COPE subscale scores and the outcome variables (BIS, BAS, FAS, MSES). These analyses explored the main research questions of the study: can we detect an association between certain coping strategies and positive body image outcomes? Can we detect an association between other coping strategies and negative body image outcomes? After consulting a statistician, the decision was made to run correlation analyses rather than regression analyses. This was motivated by a series of reasons. Given the exploratory nature of the study, testing a causal link between coping strategies and outcome variables would have implied an a-posteriori hypotheses formulation. Moreover, inferring causality from a regression analyses in a cross-sectional design would have been problematic in any case. Since it is only possible to talk about association, a correlation analyses was considered appropriate. Lastly, given the reduced sample (caused by the anticipated interruption of the recruitment due to Covid-19 lock down –see section 6.2.4, above), conducting a regression analyses with the Brief COPE subscales would have suffered from a series of issues. If conducting one regression analyses with all the 14 brief COPE subscales as predictors, the sample size would not have been sufficient for a well powered analysis. Moreover, given the high number of predictors, the regression result would have been likely affected by multicollinearity and conducting 14 x 4 linear regression analyses (analysing the predictive power of each Brief COPE subscale with each outcome measure) would have resulted in multiple-testing errors.

6.4. Results

6.4.1. Exploration of data on side-effects (quantitative analyses)

The descriptive statistics on side-effect frequencies and relative bother revealed that hot flushes were the most frequently experienced side-effect, followed by erectile dysfunction. However, respondents classified incontinence as the most bothersome side-effect, followed by fatigue, cognitive effects, and weight gain (Table 6.5).

Table 6.5. Frequency of ADT side-effects and relative bother.

Treatment Side effect	**Frequency %**	**Bother *M(SD)***
Hot flushes	79.38	5.87 (2.62)
Erectile dysfunction and sexual issues	73.19	6.21 (3.12)
Fatigue	63.91	6.50 (2.70)
Weight gain	60.82	6.34 (2.54)
Mood swings	47.42	5.71 (2.71)
Breast enlargement	38.14	5.29 (3.12)
Hair loss	37.11	2.72 (2.72)

Cognitive effects	20.61	6.50 (2.28)
Other effects	20.61	3.28 (3.28)
Incontinence	19.58	8.05 (1.68)

Note. M = mean; SD = standard deviation; ADT = Androgen Deprivation Therapy. The *Bother* score ranged from 0 to 10, with higher scores indicating that respondents felt more negatively affected by the side-effect.

The correlation analyses between the extent to which the side-effects bothered participants and the outcome variables revealed that hot flushes, fatigue, and mood swings were strongly associated with all the outcome measures, correlating positively with BIS and MSES scores and negatively with BAS and FAS scores (Table 6.6, line 1, 3, and 5). As expected, erectile dysfunction and sexual issues significantly and negatively correlated with BIS and MSES scores (Table 6.6, line 2). Weight gain was significantly and positively correlated with BIS and MSES scores (Table 6.6, line 4). Breast enlargement did not correlate with any of the outcome variables (Table 6.6, line 6). Loss of body hair was significantly associated with MSES scores, while cognitive effects were negatively associated with BAS and FAS scores (Table 6.6, line 7 and 8). Incontinence significantly and positively correlated with BIS scores and negatively correlated with FAS scores (Table 6.6, line 9).

Table 6.6 Correlation between side-effects bother and outcomes variables.

Side-effect bother	***N.***	**BIS**	**BAS**	**FAS**	**MSES**
Hot flushes	77	.312**	-.331**	-.301**	.334**
E.D. and sexual issues	66	.357**	-.157	-.223	.453**
Fatigue	62	.375**	-.493**	-.457**	.369**
Weight gain	59	.327*	-.237	-.153	.299*
Mood swings	46	0.442**	-.468**	-.357*	.516**
Breast enlargement	36	.321	-.209	-.120	.336
Hair loss	29	.471*	-.293	-.300	.414*
Cognitive effects	20	.269	-.613**	-.492*	.280
Incontinence	19	.515*	-.181	-.498*	.357

Note. The table reports the results of Pearson's correlations between the bother score of each side-effects and the outcomes variables. Each correlation has been run selecting the data of those participants who indicated to experience the respective side-effect. BIS = Body Image Scale for Cancer Patients; BAS = Body Appreciation Scale; FAS = Functionality Appreciation Scale; MSES = Masculine Self-Esteem Scale; E.D. = erectile dysfunction.

*p<.05 (2-tailed)

**p<.01 (2-tailed)

The correlation analyses between the total number of side-effects experienced by each patient and the outcome measures showed a significant association. The total number of side-effects was positively correlated to BIS and MSES scores and negatively associated with BAS and FAS scores (Table 6.7).

Table 6.7. Correlation between number of side-effects and psychological outcomes.

	BIS	**BAS**	**FAS**	**MSES**
Total number of side-effects	.514**	-.290**	-.380**	.459**

Note. The table reports the results of Pearson's correlations between the total number of side-effects and each outcome variable. BIS = Body Image Scale for Cancer Patients; BAS = Body Appreciation Scale; FAS = Functionality Appreciation Scale; MSES = Masculine Self-Esteem Scale.

**p<.01 (2-tailed)

6.4.2. Quantitative analyses on coping strategies data.

The descriptive statistics analyses run on the Brief COPE subscales revealed that Acceptance was the coping strategy that participants reported to use the most often. All the Brief COPE subscales are listed in order in Table 6.8, together with the respective tier and a quote from the qualitative analyses (which will be discussed in section 6.4.3). The paired-sample t-tests revealed that participants reported using acceptance significantly more often than all the other coping mechanisms – acceptance was therefore part of tier 1 (Table 6.9, line 1). Active coping was in tier 2, since it resulted to be significantly less used than acceptance but also significantly more used than planning (Table 6.9, line 2). Tier 3 was the wider category, and included planning, positive reframing, humour, seeking emotional support, self-distraction, seeking instrumental help, and venting. In fact, the paired-sample t-tests did not show any significant difference between these subscales scores (Table 6.9, line 3-9), suggesting that participants reported to engage in these coping strategies a comparable amount. Lastly, tier 4 included religion, self-blame, behavioural disengagement, substance use, and denial, which were used significantly less frequently than venting, and a comparable amount to one another (Table 6.9, line 10-14).

Table 6.8. Mean scores from Brief COPE questionnaire and relative qualitative quotes.

Tier (from paired sample t-test)	**Coping strategies**	***M(SD)***	**Quotes**
1	Acceptance	6.99 (1.25)	"Whilst I wish I didn't have these side-effects, I'm happy to accept and tolerate them as part of this new phase of my life. As without the treatment and its side-effects, I'd be dead or dying." *(Matt, 56)*
2	Active Coping	6.19 (1.49)	"Keeping fit and active helps a positive attitude, keeps me busy and helps control weight. All of which add to a better life experience" *(John, 55)*
3	Planning	5.72 (1.86)	"Try to have a plan to keep busy and have structure to day." *(Alex, 66)*
3	Positive Reframing	5.66 (1.44)	"I always look for the positives in the situation I find myself" *(Pete, 60)*
3	Humour	5.63 (1.82)	"Humour is the best medicine" *(Paul, 72)*
3	Emotional Support	5.46 (1.57)	"I have been married for 50 years to a loving wife who provides all the emotional support I need." *(Alan, 73)*
3	Self-Distraction	5.44 (1.73)	"I ride my Harley as often as possible though. This is my escape from reality, I think escaping is important!" *(Nick, 58)*
3	Instrumental Help	5.34 (1.70)	"My main concerns have been about the cognitive aspects, especially the inability to concentrate, loss of memory and poor judgement. My wife saying I CAN do these things, even if it is with some help from her." *(David, 72)*

3	Venting	4.00 (1.69)	“I’m so upset about the whole thing that I get very down and even considered suicide. Talking with people who are willing to listen and not try to offer me solutions to make me feel better. I need people to acknowledge I’m terminal and sometime I’m going to pop off.” *(Vincent, 63)*
4	Religion	3.77 (2.01)	“I don’t know why I got cancer but I know that God is walking me through this valley to greener pastures. He has surrounded me with His love & the love of church family. Whatever the outcome I am eternally grateful that my Father has me in the palm of His hand” *(Sam, 53)*
4	Self-Blame	3.38 (1.68)	“I feel bad about myself not being able to "perform" anymore (…) I just feel constantly burned out” *(Harry, 68)*
4	Disengagement	3.16 (1.61)	“Nothing helps.” *(Adam, 72)*
4	Substance Use	3.08 (1.33)	“Alcohol and cannabis distract my mind” *(George, 48)*
4	Denial	2.84 (1.44)	*N/A*

Note. M = mean; SD = standard deviation

Table 6.9. Results from the paired sample t-tests. The tiers were built on the basis of these results.

Comparison between coping mechanisms	**95% CI UP**	**95% CI LOW**	**t (df = 95)**	***p***	**Tiers**
Acceptance - Active Coping	.43898	1.14435	4.456	**.000**	1
Active Coping - Planning	.19875	.75958	3.392	**.001**	2
Planning – Positive reframing	-.30238	.40655	.292	.771	3
Positive reframing - Humour	-.39827	.46077	.144	.885	3
Humour – Emotional Support	-.29238	.64654	.749	.456	3
Emotional Support - Self-Distraction	-.38545	.42711	.102	.919	3
Self-Distraction - Instrumental Help	-.34829	.53579	.421	.675	3
Instrumental Help - Venting	.86442	1.82308	5.565	**.000**	3
Venting - Religion	-.23332	.69166	.984	.328	4
Religion – Self-Blame	-.08162	.85245	1.638	.105	4
Self-Blame - Disengagement	-.18457	.62207	1.077	.284	4
Disengagement - Substance Use	-.30409	.47076	.427	.670	4
Substance Use – Denial	-.11655	.59572	1.336	.185	4

Note. CI UP = Confidence Interval Upper Case; CI LOW = Confidence Interval Lower Case

6.4.3. Qualitative analyses expanding Brief COPE scale data.

The following section is organized following the Brief COPE structure. At the beginning of each section, readers can find the items composing each subscale as a point of reference for the triangulation of the qualitative data.

6.4.3.1. Acceptance

Items from the Acceptance subscale in the Brief COPE questionnaire:
20. I’ve been accepting the reality of the fact that it has happened.
24. I’ve been learning to live with it.

Tier 1 , *M(SD)* = 6.99 (1.25)

Acceptance was the most frequently reported coping strategy when analysing the quantitative scores of the Brief COPE (section 6.4.2 in this chapter). This result was confirmed by participants’ replies to the open ended questions. In fact, thematic analyses and the integration with quantitative results (following the triangulation and “following a thread” protocols (Moran-Ellis et al., 2006)) showed several points of convergence and complementarity.

When considering complementary results, many participants expressed their decision to recognize their new reality and the limitations that might come with it:

> *“Accepting what is and what isn't”* (Tom, 65)

The open-ended responses also allowed participants to expand the macro theme of acceptance, integrating complementary sub-themes.

6.4.3.1.1. Side-effects are the price to pay for life

In accordance with the results from Study 1 (Chapter 4), ADT side-effects were often considered unpleasant but also a necessary collateral damage in the context of survival.

> *"Whilst I wish I didn't have these side-effects, I'm happy to accept and tolerate them as part of this new phase of my life. As without the treatment and its side-effects, I'd be dead or dying."* (Marc, 56)

In particular, some participants referred to suffering greatly from the sexual issues provoked by ADT, but that they felt they had to choose between being able to have sex and staying alive.

> *"I just have to accept that I can never enjoy sex again and that part of my life is over. But, at the same time there is much else to be happy about. i.e. staying alive."* (Phil, 60)

> *"I resigned to no sex but I'm alive. If I was dead I wouldn't get sex anyways"* (Michael, 72)

Despite missing sex, some respondents found different ways to enjoy intimacy with their partner, which was considered an important factor for the health of the relationship and quality of life.

> (Answering to the question: Thinking of the changes to your body provoked by ADT that bother you the most, are there specific *activities* that help you feel better about your body?) *"... oral sex and being naked with my wife, These activities make me feel better about everything, not just about my body*" (Paul, 64)

6.4.3.1.2. Forced acceptance: "Just get on with it"

Some respondents referred to accepting their new health situation simply because there would be no other choice. This way of conceptualizing acceptance left no space for the expression of feelings of loss and for self-compassion, and echoed the hegemonic masculinity ideals that emerged in Study 1 and that were tested in Study 2.

> *"I just get on with it, have no choice, hits you both mentally and physically, not good"* (Richard, 70)
>
> *"I have two choices either get on with it or be very unhappy. So getting on with it is the only option if you want to make the best life you can for you and those around you"* (Rob, 55)

While overall acceptance seemed to be both a frequent and constructive strategy to deal with ADT side-effects, integrating the qualitative data helped highlight this slightly negative interpretation of the concept of acceptance.

6.4.3.2. Active Coping

Items from the Active Coping subscale in the Brief COPE questionnaire:

2. I've been concentrating my efforts on doing something about the situation I'm in.
7. I've been taking action to try to make the situation better.

Tier 2, *M(SD)* = 6.19 (1.49)

The statistical analyses results suggested that active coping was the second most frequent coping strategy participants reported. Thematic analysis and integration with the quantitative data revealed both convergence and complementarity. In particular, some participants referred to trying to keep a proactive approach towards their prostate journey and their treatment:

> *"I am taking an active role and educating myself on battle strategies targeting a cure for my cancer."* (David, 64)

6.4.3.2.1. Exercise

Respondents often referred to engaging in exercise as a strategy to better deal with ADT-induced bodily changes. This topic has been coded a complementary subtheme within Active Coping. In particular, respondents referred to exercise as a helpful strategy to improve their mood:

> *"I find that getting outside for exercise improve both my mental and physical well being."* (Jamie, 65)

Similarly as in Study 1 findings, exercise was also considered an effective strategy to experience a sense of achievement and control (in Study 1, Chapter 4, paragraph 4.2.2.) in spite of the uncertainty provoked by PCa diagnosis.

> *"It makes me feel in charge and in warrior mode to exercise regularly"* (David, 64)

Interestingly, participants referred to exercise as a helpful strategy to cope with ADT even if not prompted by the questionnaire as they were in Study 1 and Study 2. This finding suggests that exercise is considered helpful by at least some PCa patients.

6.4.3.2.2. Keeping previous habits to maintain identity

Another sub-theme that that was developed in complementarity with the Active Coping macro-theme is the concept of keeping habits to maintain identity. Some respondents referred to the importance of keeping their day to day life as similar as possible to their pre-PCa life in order to maintain a sense of stability and identity.

> *"I have tried to keep doing everything that I once did. Do not let any of this stop me from living day to day. Activities do help me feel better about myself.*

> *“Refusing to let the hormone therapy affect my life in a detrimental way.”* (Bernard, 66)

6.4.3.3. Planning

Items from the Planning subscale in the Brief COPE questionnaire
14. I’ve been trying to come up with a strategy about what to do.
25. I’ve been thinking hard about what steps to take

Tier 3, *M(SD*) = 5.72 (1.86)

Despite the fact that participants reported applying the planning coping strategy fairly often with respect to the other coping strategies listed in the Brief COPE questionnaire, they did not refer to planning frequently when answering the open-ended questions. A few quotes did converge with the quantitative data but there were no cases of complementarity nor dissonance.

> *“Try to have a plan to keep busy and have structure to day.”* (Bernard, 66)

6.4.3.4. Positive reframing

Items from the Positive Reframing subscale in the Brief COPE questionnaire:
12. I’ve been trying to see it in a different light, to make it seem more positive.
17. I’ve been looking for something good in what is happening.

Tier 3, *M(SD*) = 5.66 (1.44)

Participants referred to the process of positively reframing the challenges posed by cancer treatment and diagnosis very often in the open ended responses, especially when replying to the question “Thinking of the changes to your body provoked by ADT that bother you the most, are there specific thoughts that help you feel better about your body?”. The thematic analyses and integration process resulted in both convergent and complementary responses.

> *"Looking back, my diagnosis was a life changing event. I thought deeply about my lifestyle and priorities and made changes. I feel that I am a better person and can give more to the world. While I've suffered some physical deterioration since starting ADT that doesn't (determine) really who I am."* (Max, 72)

6.4.3.4.1. Side-effects are temporary

Some participants referred to focussing on the fact that the side-effects were temporary and that one day ADT would be over and their body would go back to 'normal'. This theme was coded as sub-theme complementary to the Positive Reframing strategy.

> *"The thought that the symptoms will go away or ease after the treatment is stopped (helps)"* (Drew, 76)

Focusing on the temporary aspects of the side-effects helped participants perceive the situation as less negative.

6.4.3.4.2. "Could be worse!"

Another sub-theme that was coded as a complementary element of Positive Reframing referred to participants' considerations of what could make the situation even worse than it already was. In doing so, come participants referred to making a positive comparison between themselves and other PCa patients.

> *"My body is still in reasonable shape, I seem to be coping better than some others."* (Sam, 57)

The theme of social comparison was present in Study 1 results as well (Chapter 4, section 4.4.2.2.), specifically concerning exercising in shared spaces and experiencing the concern of performing worse than other men.

Similar to the results of Study 1 (Chapter 4, section 4.4.3.1.), patients referred to age as a protective factor when dealing with ADT side-effects. In particular, when considering ADT-provoked sexual issues, some men focused on the fact that they had already formed a family and were therefore less affected by the consequences of hormone treatment.

> *"I recognize, and am okay with the knowledge, that a loss of libido is to be expected at the age of 73."* (Alex, 73)
>
> *"At least I already have kids"* (Carl, 55)

6.4.3.5. Humour

Items from the Humour subscale in the Brief COPE questionnaire:
18. I've been making jokes about it.
28. I've been making fun of the situation.

Tier 3, *M(SD)* = 5.63 (1.82)

Participants did refer to humour in their open-ended questions in a convergent fashion as to the items of the Brief COPE questionnaire.

> *"Humour is the best medicine"* (Joe, 72)

However, this theme was not widely developed in the qualitative dataset and therefore it was not possible to construct any complementary theme.

6.4.3.6. Seeking emotional support

Items from the Seeking Emotional Support subscale in the Brief COPE questionnaire:
4. I’ve been getting emotional support from others.
15. I’ve been getting comfort and understanding from someone

Tier 3, *M(SD*) = 5.46 (1.57)

Participants did refer to emotional support in their open ended responses, mostly referring to the support received from their romantic partner. In line with Study 1 findings, participants did not refer to emotionally opening up to friends and people other than their partner.

> *“I have been married for 50 years to a loving wife who provides all the emotional support I need.”* (Alex, 73)

6.4.3.6.1 Giving emotional support (rather than seeking emotional support)

For the Emotional Support theme, *dissonant* sub-theme was developed. For one participant in particular, offering support to others (rather than seeking support) seemed to be a positive coping strategy to deal with PCa and ADT.

> *“Offering emotional support to others in same situation seems to help me mentally & emotionally”* (Tony, 60)

6.4.3.7. Self-distraction

Items from the Self-distraction subscale in the Brief COPE questionnaire:
1. I’ve been turning to work or other activities to take my mind off things.
19. I’ve been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.

Tier 3, *M(SD*) = 5.44 (1.73)

Participants did refer to distracting activities as being helpful to take their minds off cancer treatment and diagnosis. Escaping reality seemed to provide necessary breaks from daily health related worry and stress:

> *"I ride my Harley as often as possible though. This is my escape from reality. I think escaping is important!"* (Peter, 58)
>
> *"Playing guitar help me to cope with the stress but not so much changes to my body"* (Carl, 55)

This theme was not further developed in participants' responses and therefore it was not possible to construct any further complementary nor dissonant sub-themes.

6.4.3.8. Seeking instrumental support

Items from the Seeking Instrumental Support subscale in the Brief COPE questionnaire:
10. I've been getting help and advice from other people.
23. I've been trying to get advice or help from other people about what to do.

Tier 3, *M(SD*) = 5.34 (1.70)

Some participants expressed their willingness to seek instrumental support from others in order to maintain functionality. In particular, romantic partners were mentioned as the main source of instrumental support (as well as for emotional support):

> *"My main concerns have been about the cognitive aspects, especially the inability to concentrate, loss of memory and poor judgement. My wife saying I CAN do these things, even if it is with some help from her"* (Simon, 72)

6.4.3.8.1. Seeking instrumental strategies

A complementary theme that was detected and built from the qualitative data, concerned seeking instrumental strategies to manage ADT side-effects. For example, a participant referred to putting in place a few practical solutions to deal with their hot flushes:

> *"Bought a small fan.... also get cold, bought a cardigan style sweater"* (John, 69)

6.4.3.9. Venting

Items from the Venting subscale in the Brief COPE questionnaire:
9. I've been saying things to let my unpleasant feelings escape.
21. I've been expressing my negative feelings.

Tier 3, *M(SD*) = 4.00 (1.69)

The coping strategy of venting was the last one from Tier 3 and seemed to be positively associated with body image and masculine self-esteem issues (BIS and MSES scores) and negatively associated with functionality appreciation (FAS scores) (Table 10). Participants did not seem to refer to venting as a strategy very often when replying to the open-ended questions. In particular, venting was mentioned as a strategy that was needed to deal with the inevitability of death:

> *"Talking with people who are willing to listen and not try to offer me solutions to make me feel better. I need people to acknowledge I'm terminal and sometime I'm going to pop off"* (Richard, 63)

The theme was not developed any further as the analysis did not identify any complementary or dissonant sub-theme.

6.4.3.10. Religion

Items from the Religion subscale in the Brief COPE questionnaire:
22. I’ve been trying to find comfort in my religion or spiritual beliefs.
27. I’ve been praying or meditating.

Tier 4, *M(SD)* = 3.77 (2.01)

Only one participant referred to their faith as a way to find comfort during their cancer journey. However, a few participants referred to practices such as yoga and meditation as strategies to improve their mental and physical health. Given that the Brief COPE items referred to Religion mention both spiritual practices and meditations, these two elements were both coded as convergent sub-themes. This subscale score was not significantly associated with any of the outcome variables.

> *“I don’t know why I got cancer but I know that God is walking me through this valley to greener pastures. He has surrounded me with His love & the love of church family. Whatever the outcome I am eternally grateful that my Father has me in the palm of His hand”* (Adam, 53)
>
> *“I do yoga and meditation to calm my mind and body”* (Louis, 67)

6.4.3.11. Self-blame

Items from the Self-Blame subscale in the Brief COPE questionnaire:
13. I’ve been criticizing myself.
26. I’ve been blaming myself for things that happened.

Tier 4, *M(SD)* = 3.38 (1.68)

Participants did not report to engage in self-blame frequently in either the quantitative nor qualitative datasets. The self-blame theme was only sparsely expressed in the qualitative dataset and no complementary nor dissonant sub-themes were constructed.

> *"I feel bad about myself not being able to "perform" anymore (...) I just feel constantly burned out"* (Daniel, 68)

6.4.3.12. Behavioural disengagement

Items from the Behavioural Disengagement subscale in the Brief COPE questionnaire:
6. I've been giving up trying to deal with it.
16. I've been giving up the attempt to cope.

Tier 4, *M(SD)* = 3.16 (1.61)

Despite the fact that the behavioural disengagement quantitative scores were in the last tier and were relatively low, several participants referred to disengagement during the open ended questions.

> *"Nothing helps"* (George, 72)

6.4.3.12.1 Depressive symptoms

A complementary sub-theme focusing on depressive symptoms was developed. Some participants referred to struggling with depression and suicidal ideation as a consequence of PCa. These mental health issues often resulted in behavioural disengagement.

> *"Sometimes, I wake up in the middle of the night and have a deluge of negative thoughts, and I cry myself to sleep in spite of being on anti-depressants."* (Daniel, 68)

> *"I'm so upset about the whole thing that I get very down and even considered suicide."* (Richard, 63)

6.4.3.13. Substance use

Items from the Substance use subscale in the Brief COPE questionnaire:
4. I've been using alcohol or other drugs to make myself feel better.
11. I've been using alcohol or other drugs to help me get through it.

Tier 4, *M(SD)* = 3.08 (1.33)

Substance use presented low scores in the quantitative data set. In line with the quantitative results, the theme was a scarcely present in the qualitative data either, with just two patients referring to alcohol and cannabis use as strategies to deal with cancer and its treatment.

> *"Alcohol and cannabis distract my mind"* (Victor, 48)

However, it is important to note that writing about using substances as a coping mechanism might have seemed undesirable and socially unacceptable for some participants and might therefore have been under-reported.

6.4.3.14. Denial

Items from the Denial use subscale in the Brief COPE questionnaire:

3. I've been saying to myself, this isn't real.
8. I've been refusing to believe that it has happened.

Tier 4, *M(SD)* = 2.84 (1.44)

Denial presented the lowest score among the Brief COPE subscales. Following the nomenclature of the Triangulation Method (Moran-Ellis et al., 2006), Denial resulted in a *silence* in the qualitative dataset, meaning that respondents did not refer to this topic in any of their responses to the open ended questions.

6.4.3.15. Further themes

The thematic analyses identified some themes that were present in the qualitative data, despite not corresponding with any of the quantitative factors within the Brief COPE subscales.

6.4.3.15.1 Worry for the future

Some participants expressed their concern for what the future might entail and for the possibility that PCa symptoms and ADT side-effects might worsen with time.

> *"My principal prostate cancer concern is about long-term ADT - I have had regular injections since 2014 and understand these will continue for life. It is the possible long-term side-effects of ADT including cardiovascular, osteroporisis and dementia that are an increasing worry…"* (Neil, 72)

6.4.3.15.2. Body image talk

Another theme that was built from the qualitative data related to body image talk. In the open-ended questions respondents were asked to express which strategies they would put in place to deal with the bodily changes induced by ADT. While most of the responses focused on the coping strategies, some participants also expressed their thoughts on their body image.

6.4.3.15.2.1. Positive body image and self-care

Some participants expressed their engagement with self-care and positive body image attitudes and behaviours. For example, some expressed how they tried to focus their thoughts on functionality appreciation, expressing gratefulness for the capacity that their body has to heal:

> “*My body as well as my thoughts are working towards a positive outcome (healing)”* (Ollie, 76)

Others expressed how they took care of their appearance as an act of self-love and care while going through cancer:

> *“By dressing well I look better and hence feel better about my appearance.”* (Ed, 62)

Similarly, some men explained how their acceptance for the situation was fundamentally rooted in self-compassion, allowing themselves to feel a different range of emotions with no blame:

> *“I never blame myself and accept slight limitations. Most days I get through with no problems at all. I think to myself in the morning, do I feel alright, if I do today is alright. Will deal with things if this changes.”* (Bernard, 66)

In line with these results, some participants also mentioned the importance of allowing themselves to rest:

> *“I rest and time the events to allow recovery.”* (Rob, 55)

Prioritizing rest and recovery is considered an element of positive body image, according to its definition (Tylka & Wood-Barcalow, 2015b).

6.4.3.15.2.2. Negative body image

Other patients expressed their difficulties in findings strategies to deal with ADT side-effects. In line with the findings from Study 1, some patients expressed suffering from body image issues and not being able to find anything that would make them feel better about their body:

> *"No (there aren't any activities that make me feel better). There aren't any - I just don't feel good about my body."* (Ivan, 71)

Again in line with Study 1, for some participants this translated into avoiding mirrors in order to not feel bad about their appearance.

> *"If I don't see myself in a mirror I forget how bad I look"* (Kevin, 59)

6.4.3.15.2.3. Absence of negative body image: it's a women's issue

In line with the findings from Study 1, some participants referred to not suffering from body image issues, given their low investment in appearance:

> *"Body image has not been a major factor in my treatment in prostate cancer, or in my family's view of me during hormone therapy."* (Simon, 72)

Also in line with Study 1, other participants expressed their belief that negative body image is a stereotypically female problem, and that for this reason they could not be bothered by something similar:

> *"Not really bothered about my body to the extent that, perhaps, women might be about theirs.Haven't a clue. I don't think this way. Isn't this a female rather than a male concern for someone of my age. The researcher is giving her sex away, me thinks."* (Joseph, 72)

6.4.4. Exploring the association between coping strategies and outcome measures (quantitative)

A correlation analyses was run between the Brief COPE subscale scores and BIS, BAS, FAS, and MSES scores, exploring whether some coping strategies might be associated with body image and masculine self-esteem issues and others with body appreciation and functionality appreciation. Results showed that acceptance was not only the most frequently applied coping strategy, but was also significantly associated with lower BIS scores and higher BAS and FAS scores (Table 6.10, line 1). Similarly, active coping, planning, and positive reframing were positively associated with BAS and FAS scores (Table 6.10, line 2, 3, and 6). On the other hand, self-distraction was significantly associated with higher MSES scores (Table 6.10, line 5). Seeking instrumental support was negatively associated with BIS and positively associated with both BAS and FAS scores (Table 6.10, line 8). Venting was positively associated with BIS and MSES scores and negatively associated with FAS scores (Table 6.10, line 10). Lastly, self-blame, behavioural disengagement, substance use, and denial were positively associated with BIS and MSES scores and negatively associated with BAS and FAS scores (Table 6.10, line 11, 12, 13, 14).

Table 6.10. Correlation between coping strategies (Brief-COPE subscales) and outcome measures

	BIS	BAS	FAS	MSES
Acceptance	**-.226***	**.294****	**.327****	-.204
Active Coping	-.114	**.369****	**.257***	-.159
Planning	-.039	**.355****	**.271****	-.078
Humour	-.025	.103	.018	-.028
Self-Distraction	.207	.022	-.029	**.209***
Positive Reframing	-.163	**.336****	**.252***	-.199
Emotional Support	-.097	.186	.196	-.123
Instrumental Support	**-.224***	**.267***	**.354****	-.203
Religion	.032	.093	.008	.001
Venting	**.448****	-.149	**-.288****	**.400****
Self-Blame	**.475****	**-.252***	**-.330****	**.446****
Behavioural Disengagement	**.438****	**-.498****	**-.418****	**.388****
Substance Use	**.439****	**-.221***	**-.215***	**.402****
Denial	**.304****	**-.365****	**-.381****	**.391****

Note. The table reports the results of Pearson's correlations between each BriefCOPE subscale and the outcome variables. BIS = Body Image Scale for Cancer Patients; BAS = Body Appreciation Scale; FAS = Functionality Appreciation Scale; MSES = Masculine Self-Esteem Scale.

**p*<.05 (2-tailed)

***p*<.01 (2-tailed)

6.5. Discussion

The present study employed a mixed methods approach to explore the association of different coping strategies with body image and masculine self-esteem related outcomes in 97 PCa patients undergoing ADT. To do so, Lazarus and Folkman's (1984) definition of coping was employed, which in turn meant that a-priori hypotheses on the associations between coping strategies and outcomes was formulated (Lazarus & Folkman, 1984). The study also applied Somerfield's micro-level investigation strategy for applied coping research in psycho-oncology (Somerfield, 1997). This meant that participants were asked to answer coping-related questions by referring to the very specific stressor of dealing with the bodily changes provoked by ADT side-effects. By following the cross-sectional mixed methods exploratory design with concurrent data collection (Creswell, 2003), the primary quantitative dataset was collected at the same time as the secondary qualitative dataset. The two datasets were integrated adopting the "triangulation" and "following a thread" protocols (O'Cathain et al., 2010), with the qualitative dataset contributing to expanding and clarifying the meaning that participants gave to the Brief COPE items on coping.

6.5.1. ADT side-effects

An exploration of ADT side-effect frequency and intensity revealed that the most commonly experienced side-effects were hot flushes, followed by erectile dysfunction. However, respondents classified incontinence as the most bothersome side effect, followed by fatigue and cognitive effects, rather than any other side-effect impacting their appearance. Similar to the findings of Study 2, this result suggests that PCa patients might not be strongly invested in appearance and could therefore be more preoccupied about functional aspects of their body (Chapter 5, section 5.5). This interpretation of the data is supported by the qualitative findings suggesting that several participants were more focused on the functionality of their body (rather than its appearance) (section 6.4.3.15.2.1 in this chapter). In this regard, several studies in the general population suggest that individuals identifying as males tend to experience less appearance-related pressures compared to women and that this might be associated with lower appearance investment (Cash et al., 2004; Daniel & Bridges, 2013; Fredrickson & Roberts, 1997; Szymanski et al., 2011). As stated in Chapter 5 (section 5.5), low appearance investment could act as a protective factor against body image issues for some PCa patients, even when faced with bodily changes such as the ones induced by ADT.

Despite the fact that appearance-changing side-effects were not rated as the most bothersome by PCa patients, some were still associated with body image and masculine self-esteem issues. For example, participants experiencing weight gain and those experiencing loss of bodily hair showed heightened BIS and MSES scores, indicating significantly higher levels of body image and masculine self-esteem issues. Surprisingly though, breast enlargement was not significantly associated with negative body image nor masculine self-esteem issues. This result was in contrast with the findings from Study 1 which identified breast enlargement as one of the most distressing side-effects experienced by PCa patients undergoing ADT and as one of the factors conveying feelings of body feminization and low masculine self-esteem (Chapter 4, section 4.4.1.). This result is also in contrast with published studies that identified breast enlargement as one of the most bothersome side-effects since it was considered to be feminizing and embarrassing (Ervik & Asplund, 2012; Navon & Morag, 2003).

On the other hand, ADT side-effects were associated with overall negative outcomes. For example, incontinence was associated with both high levels of body image issues and low levels of functionality appreciation. Fatigue, hot flushes, and mood swings were associated with high levels of negative body image, low levels of positive body image, and high levels of masculine self-esteem issues. Similarly, erectile dysfunction and sexual issues were associated with negative body image and masculine self-esteem issues. These results suggest that ADT side-effects affecting bodily functions might also contribute to negative outcomes both in terms of body image and masculine self-esteem. This result is in line with previous literature suggesting that erectile dysfunction and sexual issues were often associated with masculine self-esteem in PCa patients undergoing ADT (Hamilton et al., 2015; Keogh et al., 2013; L. M. Walker et al., 2013). Moreover, side-effects like fatigue, hot flushes, and incontinence all impact bodily function and potentially lower body and functionality appreciation. This interpretation is in line with the results of several studies that found an association between chronic illnesses causing pain and fatigue and negative body image outcomes (Markey, Dunaev, & August, 2020; Melis et al., 2015; Öyekçin, Gülpek, Sahin, & Mete, 2012; Senkowski & Heinz, 2016).

6.5.2. Coping strategies

The exploration of coping strategies in this study was guided by Somerfield's micro-level investigation strategy (Somerfield, 1997), suggesting that applied research on coping with cancer should focus on a narrow stressor in order to conduct a conceptually sophisticated analysis of individual adaptation to that specific threat (section 6.1.2 in this chapter). While asking a broad question like "How do you deal with cancer?" would leave the researcher guessing what aspect of cancer participants were thinking of while responding, defining a specific stressor allows to understand what participants referred to when answering coping items and therefore collecting comparable answers (Figure 6.2). For this reason, this study explored which coping strategies respondents put in place to deal with ADT-induced bodily changes specifically, assessing both the frequency and bother of each side-effect. Since the design of Study 3 was based on the interpretation of the partially conflicting findings from Study 1 and Study 2, it was important to maintain the investigation of coping strategies focused on ADT side-effects and therefore in line with the previous two studies (Figure 6.3). By applying the Somerfield's micro-level investigation strategy the investigation of coping strategies focused on ADT side-effects and Study 3 produced insights on Study 1 and Study 2 mixed results.

The analyses revealed that PCa patients on ADT reported engaging with acceptance most often. Brief COPE acceptance sub-scale scores were significantly higher than all the other sub-scales scores. This result is in line with some published studies investigating coping strategies in PCa patients undergoing ADT. For example, McSorley et al (2013) also found that acceptance was the most frequently applied coping strategy by 149 men undergoing radiotherapy and ADT for localized PCa mostly for a year post treatment (McSorley et al., 2014). It is important to note that since McSoreley's study did not apply Somerfield's approach, it is not possible to infer what specific aspects of radiotherapy participants' were dealing with through acceptance. Despite this limitation, this evidence suggests that acceptance is a coping strategy that PCa patients tend to engage with to deal with a variety of stressors related to cancer treatment. Moreover, acceptance was positively associated with both body appreciation and functionality appreciation (BAS and FAS scores) and negatively associated with negative body image (BIS scores), but showed no association with masculine self-esteem. The fact that most of the participants in the sample engaged in a coping strategy associated with positive body image outcomes suggests that most of PCa patients on ADT might be dealing with body image concerns quite effectively. This interpretation is in line with the results of a study by Pascoe and Edvardsson (2016), which found that the capacity to find benefit after cancer diagnosis was significantly predicted by the ability of engaging in acceptance for 209 men diagnosed with PCa and undergoing ADT (Pascoe & Edvardsson, 2016). The authors conclude that understanding which coping strategies might be more predictive of benefit finding would assist clinicians to target men who are less likely to adapt to their diagnosis and treatment and support them to find effective coping strategies to apply throughout their cancer journey (Pascoe & Edvardsson, 2016). However, it is important to note that the correlational design of this study does not allow to make any conclusion on potential causation relationships. Future research should confirm this preliminary interpretation by testing for a causal association between acceptance and body image related outcomes, running a regression analyses in a longitudinal study design.

Qualitative data collection and analyses revealed more information on the conceptualization of acceptance. In particular, some participants expressed how acceptance of their situation was their only choice, and for that reason they had to “just get on with it”. This interpretation of acceptance is characterised by stoicism and leaves less room for compassion and grief. This finding is in line with qualitative data collected by McSorley et al (2013), which found that PCa patients on ADT spoke about accepting the situation they were in since they had no choice but to “get on with things” (McSorley et al., 2014). Stoicism has been reported as a coping strategy that men diagnosed with PCa often tend to put in place in order to deal with their cancer journey (Chambers, Zajdlewicz, Youlden, Holland, & Dunn, 2014; Gannon, Guerro-Blanco, Patel, & Abel, 2010; McAteer & Gillanders, 2019). While acceptance was found to be associated with positive health-related outcomes (Pascoe & Edvardsson, 2016), stoicism seems to correlate with negative health outcomes such as reduced health-seeking behaviour among PCa patients (Chambers, Chung, et al., 2017; Chambers, Ng, et al., 2017; Gerdes & Levant, 2018). Future mixed methods research should therefore ensure a separate measurement of both acceptance and stoicism in order to clearly assess their specific associations with health-related outcomes.

The second most frequent coping strategy employed by participants was active coping. Once again, it was positive to see that this frequently used coping mechanism was associated with positive body image outcomes, in particular high body appreciation and high functionality appreciation (BAS and FAS scores). This is in line with the findings of a meta-analytic review by Roesch et al (2005) investigating the relationships between coping strategies and adjustment indices in PCa patients, which found that active coping was associated with both positive physical and psychological health outcomes (Roesch et al., 2005).

The qualitative analyses helped to expand the conceptualization of active coping. In particular, participants often referred to taking an active role towards their health by engaging regularly in exercise. In line with the findings from Study 1, participants referred to how exercise helped to compensate side-effects (weight in particular), but also to increase fitness and strength, socialize, improve their mood, and (like in Study 1) to experience a sense of achievement and control. The fact that exercise was mentioned by participants in Study 3 is notable. In Study 1, the topic of exercise was explicitly mentioned both in the topic guide and in the advertisement materials (Chapter 4, paragraph 2.3 and Appendix A3), meaning that participants interested in exercise might have self-selected to participate, potentially masking the actual relevance of exercise as a coping mechanism. However, in Study 3 it was spontaneously mentioned by the respondents, suggesting that exercise does represent a common and relevant coping avenue for men undergoing ADT. However, these results are in contrast with the results of Study 2, which found exercise frequency not significantly relate to any body image outcome. As explained in Chapter 5, these incongruent results might be due to the fact that Study 2 only considered exercise frequency and not motivations to engage in it. Exercise is recommended to PCa patients as an effective strategy both to increase survival and reduce cancer re-occurrence (Thorsen et al., 2008). In line with previous literature (Kelly, 2009; Langelier et al., 2018), exercise can help PCa patients improve their mood and energy levels, and increase body appreciation and functionality appreciation. These results, combined with the results from Study 1, suggests that exercise could be an effective and acceptable strategy for PCa patients undergoing ADT to focus on the functionality that their body still has despite their cancer diagnosis. Focusing on what their body can still do might also help PCa patients to increase their body confidence and facilitate acceptance of their altered appearance (Alleva et al., 2014). The fact that both acceptance and active coping resulted to be the most frequently employed coping strategies by PCa patients on ADT is also in line with the results of a recent qualitative study by Langelier et al (2021), based on 15 semi-structured interviews with PCa patients (Mean age 64.9 year). The analyses found that participants often referred to attempt to cope with PCa by trying to re-establish control over their lives, by rationalizing, as well as by tapping in competition within the exercise context, a series of strategies that are similar to the conceptualization of active coping in the Brief COPE. Moreover, participants referred to acceptance as an important strategy to deal with PCa treatment side effects (Langelier, Jackson, Bridel, Grant, & Culos-Reed, 2021).

The coping strategies in tier 3 showed mixed associations with body image and masculine self-esteem outcomes. Both planning and positive reframing were positively associated with body and functionality appreciation (BAS and FAS scores). Similarly, instrumental support was positively associated with BAS and FAS scores and negatively associated with body image concerns (BIS scores). Distraction and venting were both associated with high masculine self-esteem issues, with venting also positively correlating with body image issues and negatively correlating with functionality appreciation. This result is in line with previous literature findings that PCa patients engaging in avoidance coping tend to experience more negative psychological and physical health outcomes (Burns & Mahalik, 2008; Ettridge et al., 2018; Green, Wells, & Laakso, 2011; McAteer & Gillanders, 2019; Roesch et al., 2005). Similarly, venting has been found to be a common coping strategy among long term cancer survivors (rather than among newly diagnosed patients) and has been associated with poor psychological outcomes (Deimling et al., 2006; Dunkel-Schetter, Feinstein, Taylor, & Falke, 1999).

Lastly, coping strategies of self-blame, behavioural disengagement, substance use, and denial were all significantly associated with high body image and masculine self-esteem issues

(BIS and MSES scores) and low body appreciation and functionality appreciation (BAS and FAS scores). It is positive to note that all of these coping strategies belonged to tier 4, the least frequently used by respondents. This is in line with the results of a study by Green et al (2011) which found that denial, behavioural disengagement and self-blame were among the most rarely mentioned coping strategies in a sample of 105 men with PCa (Green et al., 2011). The association of these coping strategies with poor body image and masculine self-esteem outcomes is supported by existing literature. For example, Else-Quest et al (2009) found that self-blame predicted poor psychological adjustment in 46 PCa patients (Else-Quest, LoConte, Schiller, & Hyde, 2009).

Overall, the exploratory analyses on the association between coping strategies and body image and masculine self-esteem revealed a trend where the most frequently used coping strategies were associated with lower body image issues, higher positive body image, and lower masculine self-esteem issues. On the other hand, the least frequently used coping strategies were associated with high body image and masculine self-esteem issues and low body appreciation and functionality appreciation. Given the cross-sectional design and the correlational analyses, it is not possible to infer causality. However, these findings suggest that PCa patients on ADT might be engaging with coping strategies that are mostly effective when dealing with treatment side-effects. If this hypothesis was confirmed by a longitudinal study performing a regression analyses, it would be possible to at least partially interpret why body image issues seem to affect a reduced group of PCa patients undergoing ADT.

6.6. Strengths and limitations

To the best of the author’s knowledge, this is the first study investigating the association of different coping strategies with body image outcomes and masculine self-esteem in PCa patients undergoing ADT. The implementation of a mixed methods design allowed an enriched explanation of the quantitative findings and contributed to the interpretation of the incongruences between the results of Study 1 and Study 2. However, the cross-sectional nature of the design and the correlational analyses represents a limitation as they do not allow to draw any conclusions on causality, namely whether different coping strategies can be protective against the development of body image and masculine self-esteem issues in PCa patients undergoing ADT. The results of this study represent preliminary knowledge that future research should further test by implementing longitudinal designs and regression analyses.

The correlation analyses between the extent to which participants found side-effects bothersome and outcome measures had different sample sizes. Since different numbers of participants experienced each ADT side-effect (see Table 6.6), it was only possible to run the correlations considering those participants who reported experiencing the specific side-effect in the first place. For this reason, it is not possible to accurately compare the strength of the different correlation analyses, as they present different powers. Moreover, when integrating qualitative and quantitative data only the triangulation and "following a thread" protocols were applied (O'Cathain et al., 2010). However, performing a mixed-methods matrix analysis focusing on each subject would have allowed further exploration of whether participants' responses to their open-ended questions corresponded to their quantitative scores on the Brief COPE and their body image and masculine self-esteem scores. This further analysis was not performed due to the time limits of the PhD and the relatively big sample. Future studies should implement the mixed-methods matrix analysis focusing on each subject, especially if analysing rich qualitative data (collected through interviews for example).

As for the previous two studies, participants were not asked about their cancer stage. As previously mentioned, our clinical advisors highlighted how a question on cancer stage could be triggering for many patients and if included could have worsened their experience of the online survey. The advisors also highlighted how cancer stage is not necessarily known by

PCa patients. For these two reasons, cancer stage was not included among the demographics questions. Nevertheless, the lack of information on participants' cancer stage represents a limitation, as it did not allow to analyse potential data patterns linked to cancer progression.

Lastly, as with Studies 1 and 2 the majority of men who took part in this study were white, heterosexual, and highly educated. Despite reaching a slightly more diverse sample than the group of participants interviewed for Study 1, Study 3 still presented a rather homogeneous sample, with the majority of participants belonging to traditionally privileged groups (e.g., white, highly educated, living with a partner, already accessing support, etc.). This represents a limitation since these results are only representative of a limited group of individuals, which will be the focus of the final reflections on the PhD project in Chapter 7. Despite the large reach of online sampling, support groups dedicated to ethnic and LGBTQIA minorities existed on social media but as for the previous studies, most of them did not grant me access. The initial plan to recruit through a large hospital in Bristol, a major UK city, would have possibly increased the chances of recruiting a diverse sample more representative of men diagnosed with PCa in the UK. Unfortunately, it was not possible to follow this recruitment avenue because of the Covid-19 pandemic. Chapter 7 further discusses the issues of lack of diversity in psych-oncology and PCa research.

6.7. Conclusions and future directions

Study 3 was the final study in this PhD. It was designed with the aim of performing a preliminary exploration of the associations between coping strategies and body image and masculine self-esteem outcomes. Its design was motivated by the mismatch between the qualitative results from Study 1 (suggesting that PCa patients undergoing ADT might be suffering from body image issues as a result of treatment side-effects) and the quantitative results from Study 2 (suggesting that at a population level, there was no difference in terms of body image outcomes between PCa patients undergoing ADT, ADT-naïve patients, and cancer-free men). The mismatch between the two previous studies suggested that some individual variables influencing body image in PCa patients on ADT might have not been considered in Studies 1 and 2. For this reason, Study 3 explored whether certain coping strategies might have been associated with high levels of positive body image, low levels of negative body image, and low levels of masculine self-esteem.

Overall this mixed-methods study revealed that participants reported acceptance and active coping as the two most frequently used coping strategies. In turn, both acceptance and active coping were associated with high levels of positive body image, low levels of negative body image, and low levels of masculine self-esteem issues. The least frequently used coping strategies were venting, self-blame, substance use, and denial. These coping strategies were associated with high levels of negative body image, low levels of positive body image, and high levels of masculine self-esteem. These results suggest that PCa patients undergoing ADT might be frequently engaging with coping strategies that are protective against body image issues. Future studies should further explore this hypothesis with longitudinal designs and regression analyses and examine the effect of potential combinations of different coping strategies on body image related outcomes. Moreover, while venting, self-blame, substance use and denial were reported less frequently by the sample, these result still highlight the importance of supporting PCa patients undergoing ADT who might engage in these coping strategies and ensure they have access to additional support for body image and masculine self-esteem issues.

The findings from Study 3 represent a preliminary contribution to better understanding of how coping strategies employed by PCa patients while undergoing ADT can help them to deal with body image and masculine self-esteem issues. A further exploration of this field would produce the necessary evidence to inform the design of interventions, such as one-to-one support, for those PCa patients who do struggle with their body image and masculine self-esteem.

Chapter 7

Discussion, final reflections, and conclusions.

7.1. Results overview

Initially, the broad scope of this PhD was to investigate whether ADT side-effects might elicit body image issues in patients diagnosed with PCa and to study the benefits and barriers of exercise encountered by patients on hormonal therapy. When this PhD began, only a few studies had investigated body image issues in this population, obtaining mixed results (Chapter 2, section 2.3). Overall, most of the studies confirming the risk of developing body image issues when undergoing ADT adopted qualitative methods and highlighted how patients experienced "body feminization" as a result of treatment side-effects (Ervik & Asplund, 2012; Kelly, 2009; Navon & Morag, 2003). For this reason, the area of investigation of this PhD was expanded to the impact of ADT on masculine self-esteem and the role of hegemonic masculine ideals. Literature on exercise indicated that regular physical activity would bring both physical and psychological benefits to patients: studies conducted with the general population, and also with PCa patients, supported the association between exercise and positive body image outcomes (Langelier et al., 2019; McAuley et al., 2000). This suggested that exercise could be an effective coping strategy to deal with ADT side-effects. However, exercise rates were low (Keogh et al., 2014), suggesting the need for further investigation of exercise barriers in PCa, including barriers potentially linked to body image issues.

Overall, this PhD aimed to:

<u>1.1.</u> Better understand the impact of body image issues in PCa patients. Specifically, to investigate how body image issues in this population might relate to their masculine self-esteem, experience of illness and the process of ageing (Study 1, Study 2).

1.2. Explore whether some PCa patients undergoing ADT might be more vulnerable than others to developing negative body image. In particular, which characteristics might lead to either positive or negative body image, such as holding hegemonic masculine ideals and applying different coping strategies (Study 2, Study 3).

2.1. Investigate the impact of masculine self-esteem issues and their relation with body image issues in men undergoing ADT (Study 1, Study 2).

2.2. Better understand which risk factors might contribute to the development of masculine self-esteem issues (Study 2, Study 3).

3.1. Further explore the impact of exercise on body image and masculine self-esteem in PCa patients undergoing ADT. In particular, to explore the meaning attached by patients to exercise behaviour in relation to illness, ageing, body image and masculine self-esteem (Study 1, Study 2).

3.2. Explore the role of body image related exercise barriers such as FNAE in PCa patients undergoing ADT. In particular, whether body image related worries might be present; if so, how they might influence patients' exercise behaviour and whether body image related worries might prevent individuals from exercising (Study 2).

Study 1 adopted a qualitative approach and found that ADT side-effects seemed to impact participants' body image. In line with previous literature, the treatment-induced bodily changes seemed to affect patients because they were conceptualised as feminising and therefore damaging patients' masculine self-esteem (Ervik & Asplund, 2012; Navon & Morag, 2003). Moreover, Study 1 found that engaging in exercise seemed to be an effective strategy to compensate ADT side-effects. Participants reported that exercise gave them a sense of achievement and control over the deterioration of their body due to cancer. Exercise appeared to improve their physical self-efficacy and their body functionality. However, it seemed as if worrying about being judged for one’s appearance and physical performance prevented some men from enjoying exercising, especially in a public setting. This led some participants to exercise alone or drop exercise completely, therefore missing out on its positive psychological and physical effects.

Study 2 adopted a cross-sectional quantitative design and compared a group of PCa patients undergoing ADT (n = 60), with a group of ADT-naïve patients (n = 60), and a group of cancer-free men (n = 60) on body image and masculine self-esteem related variables. Study 2 obtained mixed results. Contrary to what was initially hypothesized, no significant differences were found in body image related outcomes between PCa patients undergoing ADT, ADT-naïve patients, and cancer-free men. The incongruences between qualitative and quantitative results could indicate that while some PCa patients on ADT seem to struggle with body image issues (Study 1 in Chapter 4), when looking at broader numbers many PCa patients seemed to be coping with body image and masculine self-esteem issues reasonably well (results from Study 2). Study 2 also found that both ADT and hegemonic masculine ideals significantly predicted more masculine self-esteem related issues, suggesting that alternative conceptualisations of masculinity (e.g. caring masculinities) might be protective of patients’ masculine self-esteem while undergoing ADT. As hypothesized, fear of negative appearance and physical performance evaluation were both associated with higher body image and masculine self-esteem issues. However, fear of negative appearance and physical performance evaluation did not predict levels of functionality appreciation. This result is in line with positive body image theory postulating that positive and negative body image are not extremes of the same continuum but separate psychological constructs, meaning that an individual could experience both at the same time (Tylka & Wood-Barcalow, 2015b). Contrary to the initial hypothesis, exercise frequency did not mediate either of these relationships. This result could be explained by the fact that only exercise frequency was considered for the analyses and exercise motivations were not included. In fact, a study by Homan and Tylka (2013) found that even if exercise frequency was related to higher positive body image, high levels of appearance-based exercise motivation (the extent exercise is pursued to influence weight or shape) weakened this association (Homan & Tylka, 2014).

At the outset, the PhD plan included the design and pilot of an intervention to improve body image related outcomes and promote exercise among PCa patients undergoing ADT. However, the empirical evidence from Study 1 and 2 was not sufficient to conclude that such an intervention was necessary at this point in time, given the mixed results. For this reason, the divergent findings between Study 1 and Study 2 informed the design of Study 3. The last study explored whether the application of different coping strategies might contribute to different body image and masculine self-esteem outcomes among PCa patients undergoing ADT. The incongruences between Study 1 and Study 2 findings suggested that some individual variables influencing body image in PCa patients on ADT might have not been considered thus far in the PhD. For this reason, Study 3 explored whether different coping strategies might influence body image and masculine self-esteem related outcomes. Overall, the study found that participants reported acceptance and active coping as the two most frequently used coping strategies. Within the active coping theme, participants often referred to exercise as a positive strategy to be proactive towards their health and to experience a sense of achievement and control (in line with findings from Study 1). In turn, both acceptance and active coping were associated with high levels of positive body image, low levels of negative body image, and low levels of masculine self-esteem issues. This result is in line with literature which found both acceptance and active coping associated with positive psychological outcomes in PCa patients (McSorley et al., 2014; Roesch et al., 2005). Conversely, the least frequently used coping strategies were venting, self-blame, substance use, and denial. These coping strategies were associated with high levels of negative body image, low levels of positive body image, and high levels of masculine self-esteem. This is in line with results from previous literature finding that disengagement, self-blame, substance use, and denial were associated with negative psychological outcomes in PCa patients (Else-Quest et al., 2009; Green et al., 2011). These results suggest that PCa patients on ADT might be mostly using coping strategies that are protective against body image issues.

7.2. Reflection on the research methods

This PhD adopted a pragmatic, mixed methods approach, which directed the design of each study on the basis of the most appropriate method for answering each research question (Johnson & Onwuegbuzie, 2004). Mixed methods can offer a wide range of benefits (Doyle, Brady, & Byrne, 2009), such as the corroboration between qualitative and quantitative results which can lead to a comprehensive representation of the phenomenon of study and a better explanation of the findings. However, mixed methods also present several limitations and are at times criticized (Heath, 2020). For example, the application of mixed methods design can lead to the adoption of different ontological, epistemological and methodological assumptions depending on the qualitative/quantitative methods of each study. Ultimately, qualitative, quantitative, or mixed methods approaches present different strengths and limitations, which should be assessed within the context of the area of study (Johnson, Onwuegbuzie, & Turner, 2007).

For example, quantitative research is often considered the gold standard of research as it stems from an ontological and epistemological approach which assumes the existence of a single truth, to be uncovered through the scientific method (Doyle et al., 2009; Johnson & Onwuegbuzie, 2004). However, the exclusive application of a quantitative approach might be limiting for psycho-social research, as it would not allow a full exploration of the subjective meanings created by participants through their perspective on reality and cultural contexts

(Creswell & Creswell, 2017). This PhD adopted a pragmatic approach in order to both explore the subjective meaning attributed by PCa patients to their cancer-journey through qualitative data, as well as test whether those qualitative findings could be considered valid at a population level. The pragmatic approach reduced the restrictions imposed by the strict principles of quantitative research (largely positivist) or qualitative research (largely constructivist) (Yvonne Feilzer, 2010). On the other hand, pragmatist mixed methods designs do not have a defined methodology, which can lead to more inconsistencies and results that could be difficult to compare to other studies (Denscombe, 2008; Johnson & Onwuegbuzie, 2004).

Given the fact that body image issues among PCa patients are a relatively under-studied field, a mixed methods approach was considered appropriate for this PhD. In fact, adopting a different approach for each study allowed a combination of the strengths of each methodology to ensure the best exploration of each research question (Doyle et al., 2009).

A fundamental step of mixed method research is represented by the integration of qualitative and quantitative findings. Of the different approaches that can be employed for this purpose, this PhD implemented the triangulation approach both for the integration of the findings of Study 1 and Study 2, and for the integration of the qualitative and quantitative dataset in Study 3 (Fig 7.1).

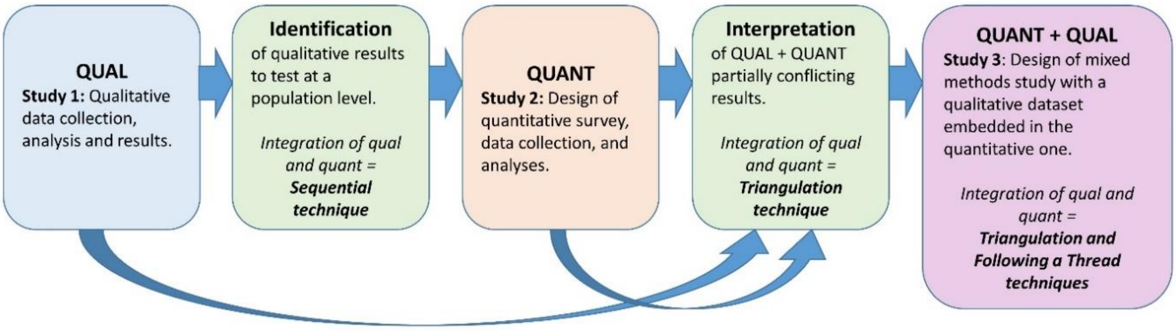


Figure 7.1. Overview of PhD sequential exploratory mixed-methods design

Triangulation requires the comparison of quantitative and qualitative findings once they have both been interpreted separately (Chapter 3, section 3.3, Table 3.1) (O'Cathain et al., 2010). The comparison between the two sets of findings can result in convergence, complementarity, dissonance, and silences (O'Cathain et al., 2010). As extensively discussed in the previous chapters, the triangulation of the findings of Study 1 and Study 2 resulted in a dissonance. While findings do not necessarily have to be identical to be considered convergent (J. Mason, 2006), it is extremely important to explore potential sources of differences between findings whenever dissonance occurs (Farmer, Robinson, Elliott, & Eyles, 2006). Rather than assuming that either one of the qualitative or quantitative techniques must be incorrect, inconsistencies may relate to different aspects of the same outcome measure or signal that further variables should be included for a full exploration of the research question (Slonim-Nevo & Nevo, 2009).

In this instance, the mismatch between Study 1 and Study 2 was in line with some of the inconsistencies observed in the published literature, where body image issues in PCa patients are mostly detected in qualitative studies but less often by quantitative research (DeFrank et al., 2007; Harrington & Badger, 2009; Langelier et al., 2018; Taylor-Ford et al., 2013). Despite the challenges posed by the task of integrating mixed results, a mixed methods approach was fruitful for the exploration of this PhD's research questions. In fact, had the PhD applied the same approach taken with the qualitative study it might have wrongly concluded that most PCa patients on ADT do suffer from body image issues. On the other hand, had the PhD exclusively applied quantitative methods, it might have come to the opposite conclusion: that PCa patients on ADT do not suffer from body image issues. The application of mixed methods allowed access to a more nuanced level of information. Although these findings did not support the design of an intervention at this stage, they allowed to expand the research to the investigation of coping mechanisms, suggesting new avenues for studies and intervention design (section 7.6 in this chapter).

As discussed in Chapter 3, this PhD only implemented cross-sectional studies. This design is time-efficient as it allows the researcher to collect multiple outcomes and apply multiple methodologies at once (Levin, 2006). Despite their efficiency, the large implementation of cross-sectional studies in psychology has sometimes been deemed problematic, since these designs do not allow to soundly infer causality when testing a model (Levin, 2006). This limitation impacted on some elements of these PhD studies. For Study 2 in particular, the regressions and mediation analyses were conducted on data collected at one point in time and would therefore not be deemed as sound as a longitudinal design to infer causation between independent and dependent variables. Similarly, Study 3 could have benefitted from a longitudinal design. Collecting information on the use of different coping strategies over time, alongside longitudinal data on the outcome measures would have allowed coping strategies' ability to predict body image and masculine self-esteem related outcomes over time to be tested.

Despite these limitations, using cross-sectional designs maximised the number of research questions explored within the time-frame of this PhD (October 2017 – October 2020). Plus, since cross-sectional studies are aimed at identifying the prevalence of a phenomenon in a population or testing associations between variables (Mann, 2003), their implementation was ultimately appropriate for the scope of this PhD. Lastly, cross-sectional studies are considered useful to provide a base of evidence for hypotheses generation to test longitudinally (Levin, 2006). As such, the results of this PhD could be further tested and expanded through longitudinal designs (section 7.6 of this chapter).

7.3. Body image and male identities: a reflection on research tradition and my positionality as a researcher.

I started this PhD in 2017 with a five-year background in body image and exercise research. All the studies I had conducted until that point had focused on either girls or young women: I had never worked with older men. My research background at the time was in line with the distribution of body image research, which had historically heavily focused on women and girls (Tiggemann, 2004).

The fact that body image research has been mostly focusing on women and girls can be explained by several factors, such as the presence of societal appearance pressures disproportionally affecting women compared to men (Daniel & Bridges, 2013; Fredrickson & Roberts, 1997; Szymanski, Moffitt, & Carr, 2011) and significantly higher rates of eating disorders and disordered eating occurring among women (e.g., Dahlgren, Wisting, & Rø, 2017). Among said factors, it is also important to consider the strong link that body image research has with the Body Objectification Theory (Fredrickson & Roberts, 1997). This feminist theory posits that women and girls living in Western societies are culturally accustomed to internalize an observer's perspective as their primary assessment of their physical self (Fredrickson & Roberts, 1997; Moradi, 2010). Self-objectification and strong investment in appearance can lead to self-consciousness and body image dissatisfaction (Rodin, Silberstein, & Striegel-Moore, 1984; Tiggemann, 2004; Walker, White, & Srinivasan, 2018). The link with Objectification Theory has influenced body image research and its strong focus on girls and women, which lead to the validations of a large amount of questionnaires on female samples only (Tiggemann, 2004).

However, as extensively discussed in Chapter 2, in recent years research has started to investigate body image issues in male samples as well. This research is finding that although rates are lower compared to female participants (McCabe & Ricciardelli, 2004; Oberg & Tornstam, 1999; Pope Jr et al., 2000), boys and men can also suffer from body image issues as well as disordered eating (Griffiths, Murray, Krug, & McLean, 2018; Kimmel & Mahalik, 2005). However, when expanding body image research to male identities, it is necessary to do so in accordance with the socio-cultural contexts in which body image issues might arise in men (and not do so in a vacuum). Applying body image concepts, measures, and models that were built on the basis of feminist theories to male populations might result in meaningless findings. While men's body image issues are likely to be rooted in stereotypical gender norms (Kimmel & Mahalik, 2005), they will not be as strongly tied to sexual objectification and gender oppression as for female populations (Harned, 2000; Mason, Lewis, & Heron, 2018).

Thus, when conducting body image research with men, researchers should not assume that the same methodologies developed in studies with female participants will be directly or equally applicable to male participants. Researchers should instead strive to adapt the research constructs and methodologies to fit the subjective meanings that men attach to *their* body image (Hargreaves & Tiggemann, 2004). In this regard, some studies have highlighted how body image issues in males tend to focus on muscularity, height, strength, and higher functioning rather than appearance itself (McCreary et al., 2004; McCreary & Saucier, 2009; Smolak & Murnen, 2008). Similarly, a study by Daniel and Bridges (2013) found that while body image dissatisfaction was strongly linked to lower sexual satisfaction for women, for men it was masculine self-esteem (and not body image) that predicted sexual satisfaction (Daniel & Bridges, 2013). This gender difference in terms of body image discontent mirrors a difference in stereotypical gender norms (Hargreaves & Tiggemann, 2004), which tend to glorify male bodies' strength and physical capacities (rather than sexually objectifying them). These findings are in line with Objectification Theory, which posits that while women's sense of physical self tends to focus on perceived physical attractiveness, for men it often hinges on perceived physical effectiveness (Fredrickson & Roberts, 1997).

As highlighted in Chapter 2, similar findings characterise the (sparse) research on body image in older adults, which found how the pressure to adhere to ageist appearance norms is much stronger for women than for men (Jankowski et al., 2016). These findings are in line with Objectification Theory which highlights how older women might still internalize the feminine ideals prescribed by a culture that objectifies the female body (Fredrickson & Roberts, 1997). For some women, growing old may be synonymous with becoming unattractive, unlovable and invisible (Clarke & Griffin, 2008). On the other hand, research findings (including the findings of this PhD), highlight how ageing impacts men's body image with a stronger focus on preoccupation around independence, sexual power and ability to be a provider (Halliwell & Dittmar, 2003).

7.3.1. My positionality as a researcher throughout the PhD: my experience working with girls and the transition to working with older men.

As previously stated, when I began this PhD I had mostly worked with women and girls in studies focusing on body image and exercise. Taking on this project on Prostate Cancer and Body Image required a deep reflection and reconsideration of what body image issues mean to different groups of people. In particular, the qualitative interviews (Study 1) were an opportunity to explore the different perspective that these participants had on body image. I clearly remember one of the most meaningful conversations with one of the participants, which allowed me to open up and deeply re-structure my approach to this area of investigation:

> *"You know actually I never put myself as a young female (laugh)… I never sort of regarded it as a body image issue… you know (…)I don't think of myself as having a body image"* (Jacob, 68 years old)

Although challenging, this process was extremely valuable for my research, as it allowed me to shape the designs of the following quantitative studies accordingly. I am forever thankful to all the men who gave their time to participate in this project, particularly in Study 1. In fact, had I not spoken one-to-one with participants first, I would have risked designing a quantitative body image study on PCa while unaware of my bias on the topic (due to experience working with women and girls). Adapting the conceptualization of body image issues to PCa patients' perspective meant, for example, focusing less on appearance-related societal pressures and more on social comparison with other men in terms of physical performance. Similarly, I shaped my studies in order to focus on masculine self-esteem and hegemonic masculinity ideals rather than self-objectification. Finding quantitative body image measures validated for older men was challenging in itself. While I included as many validated measures as I could (e.g., Body Image Scale for Cancer patients, which was validated for PCa patients (Hopwood et al., 2001)), I noticed that most body image measures are still strongly shaped by the traditionally female-focused body image research. There is still a strong need for body image questionnaires designed, or at least validated, for men and their specific body image issues.

Working with prostate cancer patients gave me the opportunity to learn how to better communicate with people with very different backgrounds and experiences from my own. Especially during the qualitative interviews, navigating how to present my identity as a young Italian woman (living in the UK for 3 months) while interacting and building trust with participants going through the existential crisis posed by prostate cancer, represented a new challenge (for a full discussion on this see Chapter 4, section 4.6.2.). Until that point in my career, I had only worked with participants with whom I could mostly identify, having several experiences in common with them. Working on this PhD was challenging and rewarding and I believe it helped me to grow into a better researcher. Working with prostate cancer patients encouraged me to reflect deeply on the concept of body image and body image research, while also giving me the opportunity to better understand and study how toxic gender norms can negatively affect the physical and psychological health of both women and men (e.g., Study 2, Chapter 5). As discussed in Chapter 2 (section 2.4), hegemonic masculine self-esteem has been associated with negative mood, poorer social well-being, poorer health behaviours, higher health risks, and medical comorbidities (Burns & Mahalik, 2008; Campbell et al., 2012; Cecil et al., 2010; Chambers, Chung, et al., 2017; Chapple & Ziebland, 2002). In Study 2, I also found that hegemonic masculinity was associated with poor masculine self-esteem in both PCa patients undergoing ADT and ADT-naïve patients (Chapter 5).

Lastly and most importantly, I believe that during these three years I had the chance to grow into a better psychologist, as I was given the opportunity to learn that empathy for human experiences can indeed bridge a gender, age, and nationality gap.

7.4. The problem of lack diversity in the studies samples: a reflection on the current state of psycho-oncology research.

As mentioned in Chapters 4, 5, and 6, one of the main limitations of the studies composing this PhD is the lack of diversity in the samples, both in terms of members of the LGBTQIA (Lesbian, Gay, Bisexual, Trans, Queer, Intersex, Asexual) community and in terms of ethnicity and cultural background. All the three studies recruited predominantly White, heterosexual, and highly educated people (Table 7.1).

Table 7.1. Overview of (lack of) diversity in the study samples.

	Study 1	**Study 2**	**Study 3**
% White participants	100%	ADT= 95% ADT-naïve = 98% Control = 93%	97%
% Heterosexual participants	100%	ADT= 91% ADT-naïve = 96% Control = 91%	88%
% participants with at least a college degree	65%	ADT= 81% ADT-naïve = 62% Control = 68%	68%

Note: ADT = Androgen Deprivation Therapy

Diversity in a research sample has been historically conceptualized as a potential source of noise in the data (Nagayama Hall, 2006). However, a large amount of literature shows how a diverse sample not only reflects the moral and ethical commitment of the researcher to fair representation and equity, but also provides a much deeper understanding of the studied phenomenon (Jensen, 2012; Mertens, 2014; Nagayama Hall, 2006).

While I recognize the gravity and the negative implications of such homogeneity in the samples of this PhD studies, it is important to note that unfortunately this limitation is not novel in psychology research. For example, Arnett (2009) analysed articles published from 2003 to 2007 in leading psychology journals, revealing that 96% of the participants were from Western industrialized countries (68% from the United States) and that 99% of first authors were at universities in Western countries (73% from the United States alone) (Arnett, 2009): 96% of psychological samples came from countries with only 12% of the world’s population (Arnett, 2016; Nielsen, Haun, Kärtner, & Legare, 2017). Henrich, Heine, and Norenzayan (2010) once again highlighted the tendency in psychology research to publish and generalize results obtained by samples that are entirely drawn from Western, Educated, Industrialized, Rich, and

Democratic (WEIRD) societies (Henrich, Heine, & Norenzayan, 2010). These attempts are part of decades of critiques of lack of diversity in psychology samples (Bell & Hertz, 1976; Kline, Shamsudheen, & Broesch, 2018; Nagayama Hall, 2006). These critiques did translate into policy changes. For example, in the Revitalization Act of 1993 and its additional amendments from 2001, the NIHR (National Institute for Health Research in the UK) mandated the inclusion of minorities and women in all NIHR-funded research, stating that “it is imperative to determine whether the intervention or therapy being studied affects women or men or members of minority groups and their subpopulations differently” (Chen Jr, Lara, Dang, Paterniti, & Kelly, 2014).

Unfortunately, despite these efforts, such calls to action did not translate into a substantial diversification of samples in psychology research: a recent study by DeJesus, Callanan, Solis, and Gelman (2019) found that across 1,149 articles published in 2015 and 2016 in 11 psychology journals, 73% did not even mention the race and ethnicities of their participants (DeJesus, Callanan, Solis, & Gelman, 2019; Roberts, Bareket-Shavit, Dollins, Goldie, & Mortenson, 2020). Performing psychological research with samples predominantly composed by individuals from WEIRD societies is both politically and scientifically problematic. In fact, assuming that certain findings are generalizable to the wider population when they have been obtained from samples composed by the most privileged percentage of individuals implies the assumptions that no variation across human populations exists or that individuals from WEIRD societies are “standard subjects” (Henrich et al., 2010). Not considering cultural variation will lead to inaccurate conclusions, which represents a major limitation to theoretical progress in psychological sciences (Apicella & Barrett, 2016; Evans & Schamberg, 2009; Mani, Mullainathan, Shafir, & Zhao, 2013; Nielsen & Haun, 2016; Rowley & Camacho, 2015; Votruba-Drzal, Miller, & Coley, 2016).

When interpreting the findings of this PhD, it is important to consider the decades of critiques advocating for lack of diversity in psychology samples and the risks that come with the generalization of findings obtained from homogeneous WEIRD groups. Thus, the results of Studies 1, 2, and 3 can be considered valid mostly for White, heterosexual, highly educated men and not for the general population of PCa patients. Such lack of generalizability would be a limitation for any health psychology study (Gurven & Lieberman, 2020), but it is particularly problematic given that this project focused on prostate cancer, a health condition predominantly affecting Black men. According to Lloyd (2015), the lifetime risk of being diagnosed with PCa is 1 in 4 for Black men (23.5–37.2 %) compared to 1 in 8 for White men (13.2%-15%), and 1 in 13 for Asian men (6.3–10.5 %) (Lloyd et al., 2015). Data on the higher incidence of PCa among Black men (Kheirandish & Chinegwundoh, 2011; Merrill, Potosky, & Feuer, 1996) is paired with findings suggesting that PCa results in higher chances of death among Black patients (Brawley, 2012), with mortality rates being 2 to 3 times greater in Black than in White American men according (Powell, Bock, Ruterbusch, & Sakr, 2010).

Conducting studies on PCa on predominantly White samples is particularly problematic as it results not only in lack generalizability of the findings (Gurven & Lieberman, 2020) but also in complicity with a system that creates health inequalities.

1. Lacking generalizability. When looking at the results of psycho-oncology studies conducted with Black Asian and Minority Ethnic (BAME) groups, it is clear that the studies of this PhD captured a very specific perspective on PCa. For example, a comprehensive review by Rivas et al (2016) summarized BAME patients' and their partners’ experiences of PCa. The authors undertook a systematic meta-synthesis of thirteen existing qualitative studies (based in the UK and USA). Their review highlights several themes that seem to be specific to the African American and British Caribbean communities, the two groups most affected by PCa, which tend to not be detected in psycho-oncology studies focusing on White PCa patients. For

example, the meta-synthesis found that patients put a *strong emphasis on spirituality and religion as* a way to develop resilience and connect to the struggles of their ancestors (Rivas et al., 2016). This theme was completely absent in Study 1 and only marginally cited in Study 3, with only one out of 97 patients referring to religion as a way of coping with cancer. Another finding that emerged from Rivas et al's (2016) review was the conceptualization of PCa as "*one more thing in the lifelong fight against adversity"* (pg. 1150): both patients and their partners identified a significant series of adversities linked to their BAME status. Dealing with cancer was normalized in light of all the other struggles they had to face in their lives as members of an ethnic minority. Referring to their life long struggles as BAME families often had the function to empower each other and remind themselves of all the resilience skills they had learned through their path (Rivas et al., 2016). When looking at other meta-syntheses conducted with White PCa patients as well as at the results of Study 1 and 3 in this PhD, we can see that while normalization is a common coping mechanism, White PCa patients do not refer to life-long struggles related specifically to their race/ethnic group (Bottorff et al., 2008; Rivas et al., 2016). Another theme signalled in Rivas' review is the *lack of economical capital*, highlighting how the economic impact of PCa (e.g., unemployment) tends to affect BAME families more strongly - for example uninsured BAME patients in the USA did not have access to the same health care as middle class White Americans (Major et al., 2012; Rivas et al., 2016). Once again, none of the participants referred to the cost of PCa nor Study 1 nor in Study 3. However, since the topic guides of the studies did not explicitly prompt participants to talk about the economic impact of PCa, it is not possible to draw strong conclusions on this specific aspect.

2. Complicity with a system that creates health inequalities. As previously mentioned, several studies highlighted how Black men face a higher risk of PCa and a higher mortality rate (Ben-Shlomo et al., 2008). Moreover, epidemiological studies suggest that such difference in

incidence and mortality rates among BAME PCa patients is likely to be influenced by environmental factors such as socioeconomic status (Kheirandish & Chinegwundoh, 2011). For example, a review by Klein et al (2015) examined the influence of Social Economic Status (SES) on PCa inequalities (Klein & von dem Knesebeck, 2015) and found that lower SES was associated with:

- lower screening uptake (Ross, Taylor, & Howard, 2011; N. Williams et al., 2011) which might be due to lower awareness of PCa symptoms as well as higher barriers to access the health care system (Lyratzopoulos, Barbiere, Greenberg, Wright, & Neal, 2010);
- more advanced cancer stage at diagnosis (Clegg et al., 2009; Lyratzopoulos et al., 2010) which has been associated with patient, doctor or system delays for diagnosis (Hansen, Olesen, Sørensen, Sokolowski, & Søndergaard, 2008; Macleod, Mitchell, Burgess, Macdonald, & Ramirez, 2009);
- lower survival rates, especially for BAME patients (Bravo, García, & Collazos, 2014; A. I. o. Health & Welfare, 2018; Jansen et al., 2014; Shafique & Morrison, 2013).

The review concluded that about 75% of 46 eligible studies indicated lower PCa survival in lower SES groups and that, most importantly, such inequalities do not seem to have decreased (Coughlin, 2020; Klein & von dem Knesebeck, 2015; Kogevinas & Porta, 1997; Schrijvers & Mackenbach, 1994). When looking at the UK specifically, national survey data show that BAME men with PCa express considerable dissatisfaction with care (Thompson, 2014; NIHR, 2010).

This highlights the need to gain a better understanding of BAME patients' experiences with PCa in order to improve services, enhance available psychological support, and ultimately reduce inequalities, in line with UK government and charity recommendations (NHS England, 2014). Therefore, by focusing on a predominantly White and middle class sample, the studies composing this PhD do not contribute to the reduction of racial health inequalities, namely differences in health status between different population groups that are unfair and avoidable (Kawachi, Subramanian, & Almeida-Filho, 2002).

Looking at the future of psycho-oncology research for prostate cancer, it will be fundamental to commit not only to equality (i.e. the equal allocation of research efforts among population groups), but most importantly to equity (i.e., the allocation of research efforts on the basis of existing disadvantages) (Figure 7.1).

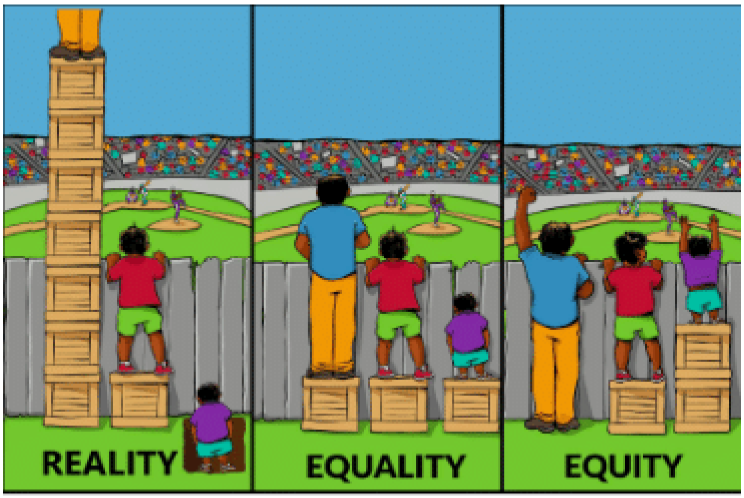


Figure 7.2. A visual representation of the difference between an equal and equital distribution of resource. Source: Dr David J. Leonard website

The discussion around the challenges of including a diverse sample in psychology studies is not new. In fact, very often BAME and low SES samples are defined as "hard to reach" populations. It is important to highlight that "*the least constructive rationale proposed to explain lack of success recruiting non-White participants has been to blame non-White participants for researchers lack of success in engaging them*" (Sugden & Moulson, 2015) (page 9). As Sugden & Moulson wrote, the identification of any group of people as “hard to reach” is in itself problematic, as it shifts our attention away from the fact that this failure may originate in the way scientific research has historically treated these individuals (Sugden & Moulson, 2015). One proposed explanation for the lack of diversity in psychology research samples is that historical abuses of minorities in research settings might have led to high levels of mistrust towards academic staff and lower levels of participation (Sugden & Moulson, 2015; Swanson & Ward, 1995; Winett, Moffatt, & Fuchs, 1975). However, this does not mean that researchers are excluding non-White participants. Luckily, data also shows that establishing a better relation with participants from minority groups is possible (Yancey, Ortega, & Kumanyika, 2006).

In particular, a review by Roberts et al (2020) analysed 26,000 empirical articles published between 1974 and 2018 in top-tier psychology journals with the scope of examining the diversity among participants, principal investigators, and editors and analysing whether people who edit, write, and participate in the research are systematically connected (Roberts et al., 2020). In line with previous research (Nielsen et al., 2017), Roberts et al (2020) found that across the past five decades, psychology publications highlighting race have been rare. Among other analyses, the authors ran regression tests which found that samples composed by mostly WEIRD populations were significantly more common in publications written by White authors (52% of participants) and significantly less common in publications written by authors of Colour (35% of participants). On the other hand, participants of Colour were significantly more common in publications written by authors of Colour (65% of participants) and significantly less common in publications written by White authors (48% of participants) (Roberts et al., 2020). Therefore, scarcity of research participants of Colour may be symptomatic of a scarcity of scholars of Colour (Roberts et al., 2020).

These finding are extremely informative and bring hope for the future of psychology research in general and PCa research in particular. These data shows that diversifying the staff of our research groups will translate in a diversification of our participants: authors of Colour are more invested in communities of Colour, they have a better understanding of the cultural contexts of participants of Colour and will therefore have better access to these communities (Nzinga et al., 2018). This will not only contribute to dismantling the systemic inequality that exists within psychological research (Roberts et al., 2020), but will also translate in a more trustful relationship with participants of Colour and ultimately better science.

When looking at the future of PCa research, a diversification of the research staff's cultural and ethnic background could contribute to the diversification of study participants. Another important strategy to favour a diversification of participants in PCa research consists in ensuring a proper investment of time and resources into forming relationships with gatekeepers of communities of Colour. During the course of this PhD one organizer of a local Afro-Caribbean PCa support group was approached for supporting the data collection of Study 2. While this strategy resulted in the participation of two Black men diagnosed with PCa, future research should account for more time dedicated to forming partnerships with gatekeepers of communities of Colour. Establishing positive relationships with multiple community gatekeepers in combination with online recruitment and recruitment through the NHS (as it was initially planned for Study 3) would be beneficial for future PCa studies' recruitment.

7.4.1. Other factors to consider in the lack of diversity of the studies samples.

Since PCa disproportionally affects Black men, it is essential to focus on the limitation of having collected data from a predominantly White sample and to analyse potential strategies to avoid this issue in future research. However, it is important to consider barriers to accessing research for PCa patients living with other identities and disadvantages as well.

As previously mentioned, all the studies saw a disproportionally higher participation from individuals identifying as heterosexual, and lack of representation from LGBTQIA PCa patients. In particular, the inclusion of LGBTQIA PCa patients, especially in the first qualitative study, would have allowed for a more nuanced and complete exploration of different masculinity ideals as well as different lived experiences with respect to ADT-induced sexual issues (e.g., Jägervall, Brüggemann, & Johnson, 2019). The participation of PCa patients who are also members of the LGBTQIA community in Study 1 might have led to different results, which might have shaped the conceptualization of the following studies differently. As mentioned in the limitations of Chapter 4, a strategy to engage LGBTQIA men could have been distributing recruitment flyers in areas with high proportions of LGBTQIA social networks. Moreover, consulting LGBTQIA organizations during the PPI phase (even if not explicitly dedicated to supporting PCa patients) could have allowed for the implementation of better strategies to engage more LGBTQIA men throughout the recruitment phases of three studies (e.g., snowball sampling starting from gatekeepers in the community) and would have helped checking the acceptability of the study materials.

As previously mentioned, the three studies collected data from a mostly highly educated sample (Table 7.1.). Education is a key predictor of social economic status (SES) (Mattsson, Fors, & Kåreholtet, 2017), therefore we can infer that the studies presented in this thesis likely collected data from a majority of men in a stable economic situation. As mentioned in paragraph 7.4., low SES has been associated with lower PCa screening uptake (Ross, Taylor, & Howard, 2011; Williams et al., 2011), more advanced cancer stage at diagnosis (Clegg et al., 2009; Lyratzopoulos et al., 2015), and overall lower survival rates (Bravo, García, & Collazos, 2014; Health & Welfare, 2018; Jansen et al., 2014; Shafique & Morrison, 2013; Klein & von dem Knesebeck, 2011). Scarce representation of people living with a low SES does not allow this research to capture the lived experience of those PCa patients who would be more likely to struggle throughout their cancer journey and would therefore be in higher need of support. Lack of engagement with PCa patients living in a disadvantaged SES might be due to a number of factors, such as less time availability due to multiple work commitments, potentially less literacy around research scopes, and lack of sufficient monetary incentive to participate in the studies. Recruiting through the NHS might have given access to a broader and more diverse group of PCa patients, which might have potentially included PCa patients from a lower SES. Future studies should aim to further invest and diversify PPI sessions in order to gain more insight on the best way to facilitate research access to economically disadvantaged communities. In this regards, online recruitment and online data collection for Study 2 and 3 aimed at minimizing participation costs and improve research accessibility (Heath, Williamson, Williams, & Harcourt, 2018; Wilkerson et al., 2014). However, it is important to note that online recruitment still represented a barrier to access for individuals who might not be able to afford a reliable and private internet connection and/or might not have good levels of media literacy.

Lastly, as mentioned in Chapter 4, the present studies were conducted in English. Due to limited resources it was not possible to hire translators and validate the measures implemented in the studies in different languages. Lack of language diversification represented a barrier to research access for those individuals belonging to ethnic minorities living in UK but only speaking languages different from English.

7.5. The impact of Covid-19 pandemic

As previously mentioned (Chapter 6, section 6.2.4), Study 3’s initial plan to reach participants through the NHS Bristol Royal Infirmary (BRI) (Bristol, UK) was affected by the Coronavirus pandemic. The BRI had to suspend the delivery of all non-essential research projects and re-direct some of their staff to Covid-19 specific wards.

Apart from the delivery of research materials, Covid-19 had a strong impact on the availability of treatment and face-to-face support for PCa patients. The delivery of PCa treatment had to be re-prioritized, adjusted, and tailored to manage the concurrent risk of Covid-19. The benefits of PCa care had to be weighed against the potential of infection, while also considering a wise consumption of restricted healthcare resources (Obek, Doganca, Argun, & Kural, 2020). In particular, in several countries including the UK, non-urgent in-person clinic visits as well as PSA screenings and DRE, imaging, and biopsies were postponed, conducted via telephone if possible, or suspended (Obek et al., 2020; Stroman, Cathcart, Lamb, Challacombe, & Popert, 2020). The delays in referrals, screenings, and primary care due to Covid-19 resulted in an increase in projected PCa mortality rates in the UK, which will keep affecting patients even after the end of the pandemic (Sud et al., 2020).

PCa patients are considered a group at high-risk for Covid-19 mortality, especially those receiving chemotherapy or other treatments disrupting the functioning of their immune system (Ghiringhelli & Apetoh, 2014). For this reason, during the pandemic men newly diagnosed with metastatic PCa have not been offered chemotherapy but have been offered newer generation ADT options to slow down cancer growth without suppressing their immune system (Prostate Cancer UK and NHS England).

The treatment and screening delays have been accompanied by the restructuring of PCa support services, which had to switch from in person to online meetings (e.g., Prostate Cancer UK online community), in adherence to social distancing measures. The disruption of well-established treatment and support pathways has had a negative impact on cancer patients' mental health (Ciążyńska et al., 2020; Wang et al., 2020) including PCa patients, creating uncertainty and anxiety among men and their families.

As mentioned in Chapter 6, online recruitment for Study 3 was interrupted when the pandemic hit the UK. While research on the psychosocial impact of Covid-19 is needed more than ever to support PCa patients during the pandemic, continuing the data collection of Study 3 throughout the first lock-down would have meant analysing data collected in two very different conditions for the provision of PCa care (pre and during pandemic). Especially considering the prescription of new generation ADT instead of chemotherapy for advanced PCa during Covid, future psycho-oncology studies focusing on ADT should explore the lived experience of PCa patients following this new treatment avenue.

7.6. Areas for further research

The results of these studies contribute to the psycho-oncology literature on PCa patients' experience with ADT and open several new and relevant research avenues:

1) The mismatch between the results of Study 1 and 2 is in line with contradictions existing in published literature. Taking into consideration the publication bias that affects psychology publications (i.e.,scientific journals' tendency to only accept articles with significant results) (Francis, 2012; Kühberger, Fritz, & Scherndl, 2014), it would be extremely valuable to review published and *unpublished* data on body image issues among PCa patients undergoing ADT. The inclusion of unpublished data in the review would allow researchers to better interpret the mixed findings on body image and ADT and understand whether the low publication rate of non-significant results might contribute to skewing the findings towards positive findings (Young & Hopewell, 2011; Ziai, Zhang, Chan, & Persaud, 2017).

2) Study 2 found that both ADT and hegemonic masculine ideals significantly predicted more masculine self-esteem related issues. To the best of my knowledge, this is the first study investigating the influence of hegemonic masculinity ideals when assessing the impact of ADT on masculine self-esteem. Previous qualitative research found that a common coping

mechanism applied by PCa patients undergoing ADT is re-negotiating their conceptualization of masculinity through their cancer journey (Gannon et al., 2010; Rivas et al., 2016). Altogether, these findings highlight the need to further investigate how alternative conceptualizations of masculinity (e.g. caring masculinities) and LGBTQIA views on masculinities might be protective of patients' psychological wellbeing while undergoing ADT.

3) Study 2 led to the development of two scales: the Hegemonic Masculine Ideals Scale and the Fear of Negative Physical Performance Scale. Both these questionnaires presented good internal consistency for the study samples. The further validation of these measures represents another relevant research avenue stemming from this PhD.

4) Study 3 performed a preliminary mixed-methods cross-sectional exploration of the association between different coping strategies, body image and masculine self-esteem outcomes in PCa patients undergoing ADT. Future studies should further explore this field with longitudinal designs and regression analyses.

5) As highlighted in this Chapter (section 7.3), implementing body image measures originally aimed at young female samples in PCa studies can be problematic. Future research should design body image measures dedicated to men diagnosed with PCa. This will allow researchers to expand body image research in PCa with methodologically-sound questionnaires.

6) This PhD only focused on PCa patients' experiences on the impact of ADT and did not explore health professionals' views on men's support needs. Future research should implement both qualitative and quantitative designs to investigate health professionals' attitudes and ideas around providing support for body image and masculine self-esteem concerns to PCa patients undergoing ADT. Pursuing this research avenue would allow to better understand how and in which capacity body image support could be provided to PCa patients.

7) Lastly, the literature is currently lacking reviews analysing the ethnic composition of psycho-oncology studies. While referring to reviews analysing psychology papers in general is still valuable (Roberts et al., 2020), it would be important to conduct a review focusing on PCa studies specifically and examine the diversity of samples, principal investigators, and editors in our field. This kind of investigation would help current researchers to better direct their work towards diversity, equity, and inclusivity.

7.7. Suggestions for clinical practice

While this PhD did not end with the design and pilot of an intervention, it is still possible to draw broad suggestions for health professionals to psychologically support PCa patients undergoing ADT:

1) For support organizations and health care professionals working with PCa patients undergoing ADT, it would be valuable to ask questions around their need of support around body image. In fact, while many patients might be coping with treatment-induced bodily transformation relatively well, a minority of them seems to struggle with negative body image. For example, in order to identify and support those PCa patients undergoing ADT who might be struggling with the treatment-induced bodily changes, support organizations and health care professionals could mention body image issues among the possible challenges that patients could expect to face during their treatment within their informational materials. Similarly, introducing screening for body image issues within the routine care for PCa would support an ethos that considers such worries as valid and acceptable as other aspects of living with PCa and ADT, like fatigue. This would contribute to a normalization of the topic of body image issues and in turn might encourage patients to seek help if they need to.

2) In the context of support groups (both charity-based and NHS-based), it would be important to check patients’ need to discuss themes related to their masculinity. If in line with

PCa patients desires, it would be important to include the exploration of masculinity within support groups agendas. It would be beneficial to facilitate discussions among peers on the changes that masculine identity goes through during the PCa treatment journey as well as conversations on the various ways to be masculine beyond the hegemonic ideal. In particular, those individuals with a hegemonic masculinity ideal and going through ADT might need extra attention and support through the process of re-shaping their concept of masculinity while following hormone treatment.

3) Exercise seems to be an overall effective strategy to cope with ADT side-effects and is already recommended for PCa patients undergoing ADT (Chapter 2, section 2.5.1). However, the findings of these studies highlight that a high exercise frequency might not necessarily be beneficial. Support organizations and trainers offering group or private exercise sessions might want to explore patients' motivations to exercise and work with them to frame exercise as part of a self-care practice. When working on exercise barriers, the findings of this PhD suggest that some patients might be comparing themselves to other men, both for their appearance and physical performance. Working with PCa patients to reduce social comparison during exercise would also be valuable. For example, when designing and delivering exercise interventions for PCa patients it would be valuable to include specific sessions dedicated to identify motivations, objectives, expectations, and factors that might hold men back in the context of the program at regular time points. Moreover, when promoting exercise among PCa patients in various contexts (whether exercise is recommended by health care professionals, or by distributing informational materials, as well as on websites, and in the context of charitable organizations), it would be important to mention the importance of not comparing oneself to others when exercising. Similarly, the promotion of exercise among PCa patients should be accompanied by an encouragement to practice self-acceptance and self-compassion, especially

in public exercise environments (like gyms and pools, where the risk of comparison and self-judgement is higher).

4) Lastly, the findings of this PhD suggest that many PCa patients might be implementing constructive coping mechanisms when dealing with ADT side-effects, such as acceptance and active coping. However, mental health professionals should explore with their PCa patients whether strategies like acceptance are based on self-compassion rather than detachment from feelings of grief and loss. Moreover, while coping strategies such as self-blame, disengagement, substance abuse, and denial seem to be rarely applied by PCa patients on ADT, the findings from Study 3 highlight how clinicians should still pay particular attention to those patients engaging with these maladaptive coping mechanisms as they are associated with negative psychological outcomes, including negative body image and low masculine self-esteem.

7.8. Conclusion

This PhD has demonstrated ability to conceptualise, design and implement a programme of work for the generation of new knowledge around body image, masculine self-esteem, exercise behaviour, and coping strategies experienced by PCa patients undergoing ADT. This work resulted in peer-reviewed publications for professional audiences, as well as lay communications for the target population and the general public

This thesis has provided a critical overview of the current knowledge regarding body image and masculine self-esteem issues for PCa patients undergoing ADT. Using both qualitative and quantitative research methods to conduct original research, new knowledge has been created and interpreted both around the role of exercise and other coping strategies that patients might put in place during their cancer journey. In summary, while this PhD found that ADT can have an impact on PCa patients’ body image and masculine self-esteem, the results of these studies also suggest that many men manage treatment side-effects well and engage in strategies that are effective when coping with the impact of such bodily changes. Various forms of exercise seemed to support some PCa patients to deal with the physical and psychological impact of ADT. However, more research is needed to fully understand the effect that different forms of exercise and different motivations to engage in exercise might have on PCa patients' wellbeing.

Ultimately, this thesis had the ambition to better understand the lived experience of men diagnosed with PCa undergoing ADT and to highlight potentially unmet needs for support throughout their treatment journey. None of this work would have been possible without participants who were willing to give their time and energy to support this project and I am deeply thankful for their irreplaceable contribution.

Glossary
(from the online Medical Dictionary www.medicinenet.com)

Alopecia. Baldness, loss of hair from the head and body. There are many types of alopecia, each with a different cause.

Antigen. A substance that the immune system perceives as being foreign or dangerous. The body combats an antigen with the production of an antibody

Apoptosis. A form of cell death in which a programmed sequence of events leads to the elimination of cells without releasing harmful substances into the surrounding area. Apoptosis plays a crucial role in developing and maintaining the health of the body by eliminating old cells, unnecessary cells, and unhealthy cells.

Cystoscopy. A procedure in which a lighted optical instrument called a cystoscope is inserted through the urethra to look at the bladder.

Cytotoxic drugs. A substance that is toxic to cells, cell-toxic, cell-killing. Any agent or process that kills cells. Chemotherapy and radiotherapy are forms of cytotoxic therapy. They kill cells.

Diagnosis (differential). The process of weighing the probability of one disease versus that of other diseases possibly accounting for a patient's illness.

Enzyme. Proteins that act as a catalysts in mediating and speeding a specific chemical reaction.

High-energy X-ray beams. High-energy radiation with waves shorter than those of visible light. X-ray is used in low doses to make images that help to diagnose diseases and in high doses to treat cancer.

Hyperplasia. An increase in the number of normal cells in a tissue or an organ. Hyperplasia can represent a precancerous condition but can also be benign.

Immunosuppression. Suppression of the immune system and its ability to fight infection. Immunosuppression may result from certain diseases, such as AIDS or lymphoma, or from certain drugs, such as some of those used to treat cancer. Immunosuppression may also be deliberately induced with drugs, as in preparation for bone marrow or other organ transplantation, to prevent the rejection of a transplant. Also known as immune-depression.

Mitosis. The ordinary division of a body cell (a somatic cell) to form two daughter cells, each with the same chromosome complement as the parent cell.

Multi-parametric MRI (Magnetic resonance imaging). A procedure that uses magnetism, radio waves, and a computer to create pictures of areas inside the body. Abbreviated MRI.

Osteoporosis. Thinning of the bones, with reduction in bone mass, due to depletion of calcium and bone protein. Osteoporosis predisposes a person to fractures, which are often slow to heal and heal poorly.

Perineum. The area between the anus and the scrotum in the male and between the anus and the vulva (the labial opening to the vagina) in the female.

PET (Positron emission tomography) scan. Unlike CT or MRI, which look at anatomy or body form, PET studies metabolic activity or body function. As a result, PET can detect tumors in lymph nodes, for example, even before they enlarge and are detectable with MRI or CT. In PET imaging, the patient receives a small intravenous injection of a radio-active medication (a form of sugar).

Prognosis. The forecast of the probable outcome or course of a disease; the patient's chance of 'recovery.

Secondary sexual characteristics. Any physical characteristic developing at puberty, which distinguishes between the sexes but is not directly involved in reproduction.

Sepsis. The presence of bacteria, other infectious organisms, or toxins created by infectious organisms in the bloodstream with spread throughout the body. Sepsis can be a serious situation, a life-threatening condition that requires urgent and comprehensive care.

Testis. The male sex gland, located behind the penis in a pouch of skin called the scrotum. The testes produce and store sperm and are also the body's main source of male hormones, such as testosterone. These hormones control the development of the reproductive organs and other male characteristics, such as body and facial hair, low voice, and wide shoulders.

Ultrasonography. A test in which high-frequency sound waves (ultrasound) are bounced off tissues and the echoes are converted into a picture (sonogram).

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Chapter 1

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Appendix A: Study 1

A1) Ethical Approval

Faculty of Health & Applied Sciences
Glenside Campus
[redacted]

[redacted]

UWE REC REF No: HAS.18.01.080

9th February 2018

Caterina Gentili
[redacted]

Dear Caterina

Application title: Appearance changes and body image issues: what is their impact on exercise engagement after prostate cancer diagnosis?

I am writing to confirm that the Faculty Research Ethics Committee are satisfied that you have addressed all the conditions relating to our previous letter sent on 1st of February and the study has been given ethical approval to proceed.

Please note that any information sheets and consent forms should have the UWE logo. Further guidance is available on the web: https://intranet.uwe.ac.uk/tasks-guides/Guide/writing-and-creating-documents-in-the-uwe-bristol-brand

The following standard conditions also apply to all research given ethical approval by a UWE Research Ethics Committee:

1. You must notify the relevant UWE Research Ethics Committee in advance if you wish to make significant amendments to the original application: these include any changes to the study protocol which have an ethical dimension. Please note that any changes approved by an external research ethics committee must also be communicated to the relevant UWE committee. http://www1.uwe.ac.uk/research/researchethics/applyingforapproval.aspx

2. You must notify the University Research Ethics Committee if you terminate your research before completion;

3. You must notify the University Research Ethics Committee if there are any serious events or developments in the research that have an ethical dimension.

Please note: The UREC is required to monitor and audit the ethical conduct of research involving human participants, data and tissue conducted by academic staff, students and researchers. Your project may be selected for audit from the research projects submitted to and approved by the UREC and its committees.

Please remember to populate the HAS Research Governance Record with your ethics outcome via the following link: https://teams.uwe.ac.uk/sites/HASgovernance.

We wish you well with your research.

Yours sincerely

[redacted]

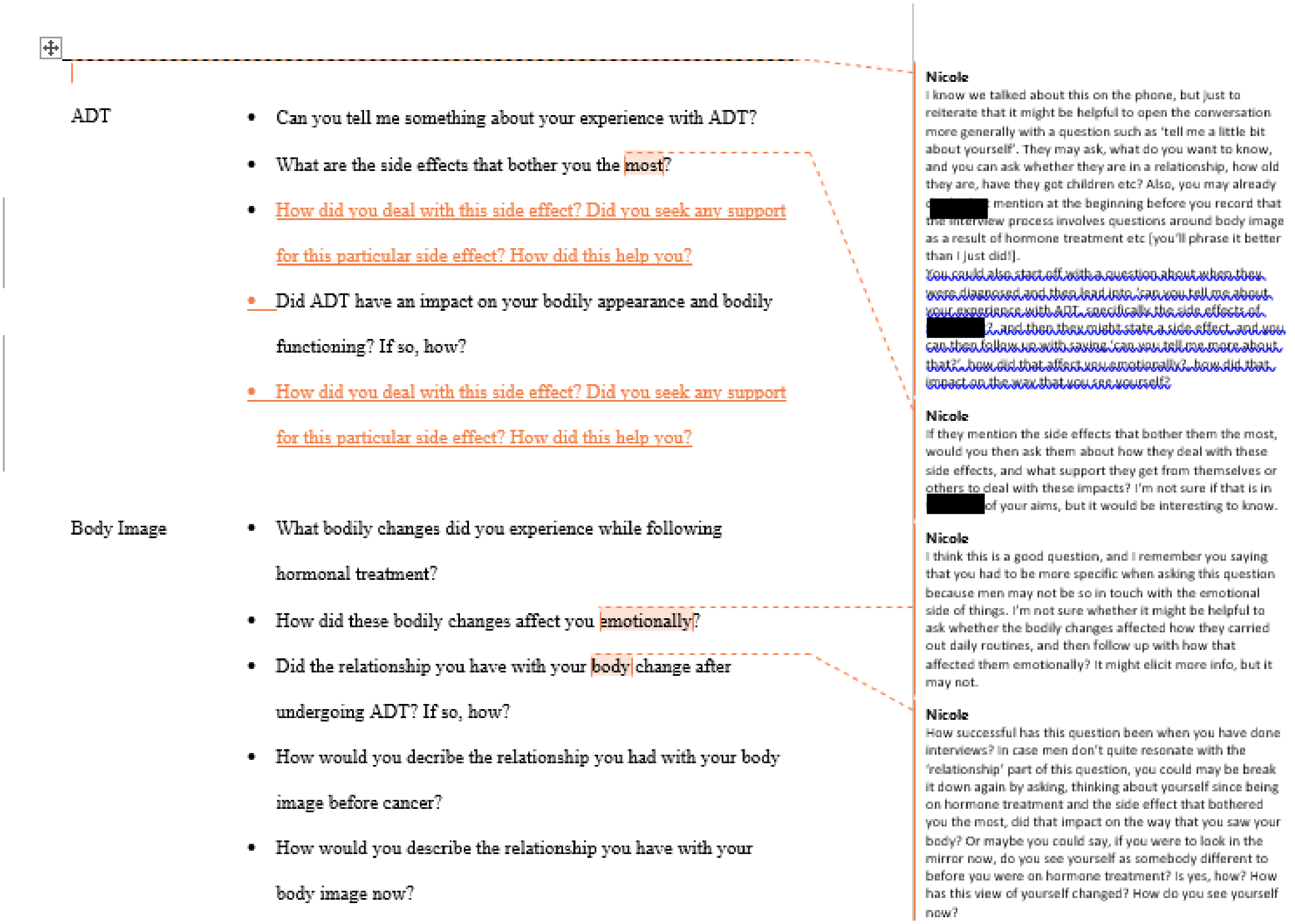
Chair

Faculty Research Ethics Committee

[redacted]

[redacted]

A2) Example of work in progress on the topic guide with feedback comments



ADT	• Can you tell me something about your experience with ADT? • What are the side effects that bother you the most? • How did you deal with this side effect? Did you seek any support for this particular side effect? How did this help you? • Did ADT have an impact on your bodily appearance and bodily functioning? If so, how? • How did you deal with this side effect? Did you seek any support for this particular side effect? How did this help you?
Body Image	• What bodily changes did you experience while following hormonal treatment? • How did these bodily changes affect you emotionally? • Did the relationship you have with your body change after undergoing ADT? If so, how? • How would you decribe the relationship you had with your body image before cancer? • How would you describe the relationship you have with your body image now?

Nicole
I know we talked about this on the phone, but just to reiterate that it might be helpful to open the conversation more generally with a question such as 'tell me a little bit about yourself'. They may ask, what do you want to know, and you can ask whether they are in a relationship, how old they are, have they got children etc? Also, you may already [redacted] mention at the beginning before you record that the interview process involves questions around body image as a result of hormone treatment etc [you'll phrase it better than I just did!].
You could also start off with a question about when they were diagnosed and then lead into 'can you tell me about your experience with ADT, specifically the side effects of [redacted]?, and then they might state a side effect, and you can then follow up with saying 'can you tell me more about that?', how did that affect you emotionally?, how did that impact on the way that you see yourself?

Nicole
If they mention the side effects that bother them the most, would you then ask them about how they deal with these side effects, and what support they get from themselves or others to deal with these impacts? I'm not sure if that is in [redacted] of your aims, but it would be interesting to know.

Nicole
I think this is a good question, and I remember you saying that you had to be more specific when asking this question because men may not be so in touch with the emotional side of things. I'm not sure whether it might be helpful to ask whether the bodily changes affected how they carried out daily routines, and then follow up with how that affected them emotionally? It might elicit more info, but it may not.

Nicole
How successful has this question been when you have done interviews? In case men don't quite resonate with the 'relationship' part of this question, you could may be break it down again by asking, thinking about yourself since being on hormone treatment and the side effect that bothered you the most, did that impact on the way that you saw your body? Or maybe you could say, if you were to look in the mirror now, do you see yourself as somebody different to before you were on hormone treatment? Is yes, how? How has this view of yourself changed? How do you see yourself now?

A3) Study recruitment documents

A3.1) Study 1 Social media post

I'm a researcher from the Centre for Appearance Research (UWE, Bristol UK). I'm posting here since I'm looking for men with a diagnosis of prostate cancer who are following hormonal treatment (ADT) who would like to take part in a study about body image, exercise, and physical activity. Patients who decide to participate will be interviewed (either face to face of over the telephone) for about 30-45 minutes around themes like:

- your experience of hormonal treatment (ADT);
- how you feel about your body and appearance after treatment;
- your views on exercise and physical activity.

As a thank you, you will have the possibility to win a £70 Online Shopping Voucher.

If you are interested or if you would like to have any further information, please contact Caterina Gentili at

[redacted]

Thank you all so much for your help!

A3.2) Study 1 Flyer

My body after prostate cancer

Would you like to share your experience and help research?

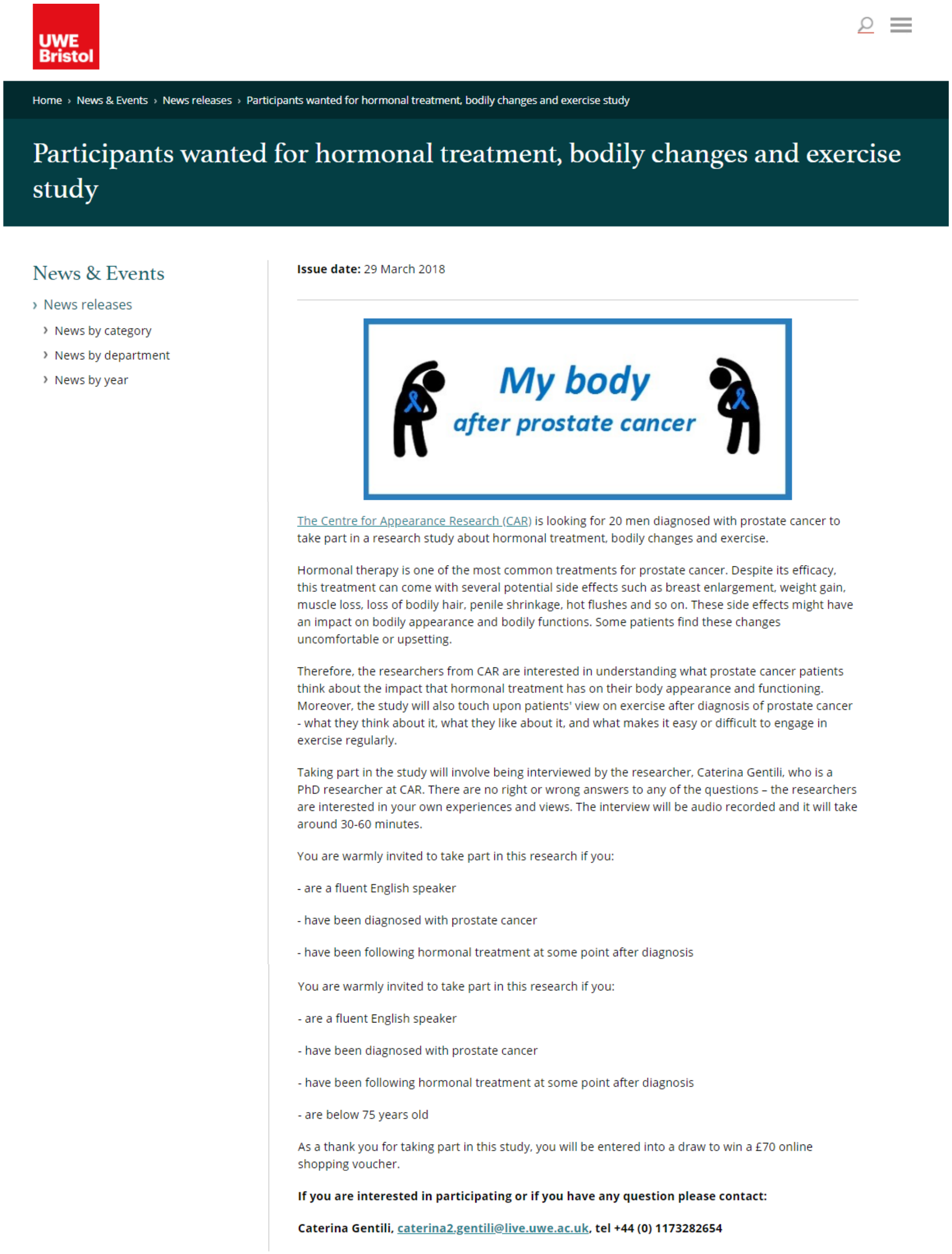
The Centre for Appearance Research (UWE Bristol) is looking for men with a diagnosis of **prostate cancer** who are following **hormonal treatment (ADT)** who would like to take part in a study about **body image, exercise, and physical activity.**

You will be interviewed by a qualified PhD S, and asked questions about:

- your experience of hormonal treatment (ADT);
- how you feel about your body and appearance;
- your views on exercise and physical activity.

As a thank you, you will have the possibility to **win a £70 Online Shopping Voucher.**

A.3.3) UWE press release



UWE Bristol

Home › News & Events › News releases › Participants wanted for hormonal treatment, bodily changes and exercise study

Participants wanted for hormonal treatment, bodily changes and exercise study

News & Events

- News releases
  - News by category
  - News by department
  - News by year

Issue date: 29 March 2018

My body

after prostate cancer

The Centre for Appearance Research (CAR) is looking for 20 men diagnosed with prostate cancer to take part in a research study about hormonal treatment, bodily changes and exercise.

Hormonal therapy is one of the most common treatments for prostate cancer. Despite its efficacy, this treatment can come with several potential side effects such as breast enlargement, weight gain, muscle loss, loss of bodily hair, penile shrinkage, hot flushes and so on. These side effects might have an impact on bodily appearance and bodily functions. Some patients find these changes uncomfortable or upsetting.

Therefore, the researchers from CAR are interested in understanding what prostate cancer patients think about the impact that hormonal treatment has on their body appearance and functioning. Moreover, the study will also touch upon patients' view on exercise after diagnosis of prostate cancer - what they think about it, what they like about it, and what makes it easy or difficult to engage in exercise regularly.

Taking part in the study will involve being interviewed by the researcher, Caterina Gentili, who is a PhD researcher at CAR. There are no right or wrong answers to any of the questions – the researchers are interested in your own experiences and views. The interview will be audio recorded and it will take around 30-60 minutes.

You are warmly invited to take part in this research if you:

- are a fluent English speaker

- have been diagnosed with prostate cancer

- have been following hormonal treatment at some point after diagnosis

You are warmly invited to take part in this research if you:

- are a fluent English speaker

- have been diagnosed with prostate cancer

- have been following hormonal treatment at some point after diagnosis

- are below 75 years old

As a thank you for taking part in this study, you will be entered into a draw to win a £70 online shopping voucher.

If you are interested in participating or if you have any question please contact:

Caterina Gentili, caterina2.gentili@live.uwe.ac.uk, tel +44 (0) 1173282654

A3.4) Study 1 Information Sheet

Information Sheet

We would like to invite you to participate in a study entitled

My body after prostate cancer

Please read this information sheet which explains what the study involves. Please take your time to decide whether or not you would like to take part, and contact the researcher if you have any questions about it – her contact details are at the end of this sheet.

This study is for men who have been given a diagnosis of prostate cancer and who are following hormonal treatment (androgen deprivation therapy, or ADT). We are looking for participants who are willing to share their experience of hormonal treatment, its impact on their body functioning and appearance, and their views on exercise and physical activity. The study is part of a PhD which is funded with the support of the Above and Beyond charity.

Our aim

Hormonal therapy is one of the most common treatments for prostate cancer. Despite its efficacy, this treatment can come with several potential side effects such as breast enlargement, weight gain, muscle loss, loss of bodily hair, penile shrinkage, hot flushes and so on. These side effects might have an impact on bodily appearance and bodily functions. Some patients find these changes uncomfortable or upsetting. Our aim is to understand what prostate cancer patients think about the impact that hormonal treatment has on their body functioning and appearance.

We would also like to collect information about patients' view on exercise and physical activity after diagnosis of prostate cancer - what they think about it, what they like about it, and what makes it easy or difficult to engage in exercise regularly.

The study

Taking part will involve being interviewed by the researcher, Caterina Gentili, who is a PhD student at the **Centre for Appearance Research**, based at the **University of the West of England, Bristol (UWE)**.

If you choose to take part, you will be asked questions about:

- your experience of hormonal treatment (ADT);
- what you think about your body functioning and body appearance now compared to how you felt about it before your diagnosis;
- your views on exercise.

There are no right or wrong answers to any of the questions – we are just interested in your own experiences and views. You can choose how and when the interview takes place – it can be over the telephone or face-to-face at a place of our choice (for example your own home, or at the university). We would like your permission to audio record the interview, and we anticipate it will take around 30-60 minutes.

Who can join?

You are warmly invited to take part in this research if you:

- are a fluent English speaker;
- are younger than 75 years old;
- have been diagnosed with prostate cancer;
- have been following hormonal treatment (ADT) at some point after diagnosis;
- do not have a major physical injury that stops you exercising or taking part in physical activity.

We are looking to recruit 20 men to take part in this study.

To thank you

As a thank you for taking part in this study, you will be entered into a draw to win a £70 online shopping voucher. If you will have to travel to come to the interview, your travelling costs will be reimbursed.

Are there any risks? And what if I want to stop?

We do not believe that taking part in this study poses any risks. However, we are aware that the topics covered in the interview can be sensitive and emotive issues for some men. You are free to stop your participation, with no need to provide a reason. In particular, you have the right to withdraw from the study at any time before the interview and within two weeks after the interview, without having to give a reason. You have the right to choose not to participate in this study. Rest assured that choosing not to take part will not influence your medical treatment in any way.

Privacy

Your identity and your data will be completely anonymous and confidential, including your name, your contact information, and the answers you give. Only the researchers involved in the study will have access to the data, which will be stored securely at all times.

However, if you do disclose any information that raises concern, for example anything that suggests you or somebody else are in danger, the researcher has a duty to share this information with appropriate services and health-care professionals. If this should be the case, the researcher will discuss this with you.

Ethical approval

This study has been approved by a Research Ethics Committee at the University of the West of England, Bristol (UWE).

If you want to participate

If you want to participate or if you have any questions, please e-mail or phone the researcher, Caterina Gentili. **Email:** [redacted] **Phone** [redacted]

Support Services

This is a list of organisations that you can contact if this study raises any issues for you, or if you would like any support or information about how to deal with prostate cancer and body image concerns. Alternatively, you can contact your GP for advice.

- **Prostate Cancer UK**
  https://prostatecanceruk.org/
  0800 074 8383

- **NHS choices**
  https://www.nhs.uk/conditions/prostate-cancer/

- **Southmead Hospital Charity**
  https://www.southmeadhospitalcharity.org.uk/
  hello@southmeadhospitalcharity.org.uk

  0117 414 0170

- **Tackle Prostate Cancer**
  http://www.tackleprostate.org/
  0800 035 5302

- **Men's Health Forum**
  24/7 stress support for men by text, chat and email.
  www.menshealthforum.org.uk

- **Samaritans**
  Confidential support for people experiencing feelings of distress or despair.
  116 123 (free 24-hour helpline)

www.samaritans.org.uk

A3.5) Study 1 Consent form

Consent Form

for participation in the research study:

“My body after prostate cancer”

- ☐ I have been informed of the study.
- ☐ I have read the information sheet.
- ☐ I have had the opportunity to ask questions about the study and any questions I had, have been answered.
- ☐ I have been able to think about my participation in the study, which is completely voluntary.
- ☐ I understand I have the right to withdraw my consent at any time before the interview and within two weeks after the interview, without having to give a reason.
- ☐ I gave my consent to audio-record the interview.
- ☐ I understand that the information I give will be treated as confidential.
- ☐ I understand that I will not be named or identified in any report or presentation that comes from this study.
- ☐ I agree to participate in the study.
- ☐ I am willing to be contacted again in the future with information about other studies.

Name:

Date of birth:

Signature: Date:

Name of person taking consent:

Position:

Signature: Date:

A4) Topic guide for Study 1 interviews

General opening question

- Can you tell me something about yourself? (are you in a relationship, how old are you, have you got children?)

ADT

- Can you tell me something about your journey with prostate cancer and hormone therapy in particular?
- After mentioning some side effects (breast enlargement, weight gain, muscle loss, penile shrinkage, libido, hot flushes, fatigue, loss of bodily hair). Did you experience some of these?
- If so, how did these side effects bother you/which one bothered you the most?
- Can you tell me more about that? How did that affect you emotionally? How did that impact on the way that you see yourself?

Body image

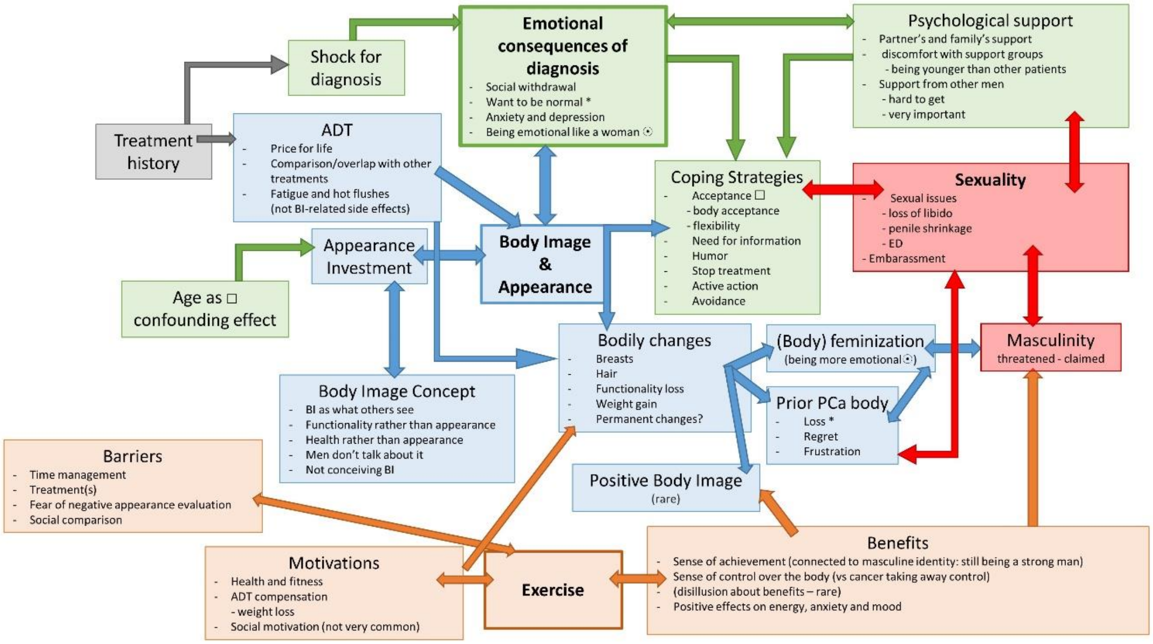
- What bodily changes did you experience while undergoing hormonal treatment?
- How did your body change after prostate cancer and hormonal therapy?
- How did these bodily changes affect you (e.g., in your daily routine, in the way you think about yourself as a man, emotionally)?
- Thinking about yourself since being on hormone treatment (and the side effect that bothered you the most), did that have an impact on the way that you see your body?
- If you were to look in the mirror now, do you see yourself as somebody different from before you were on hormone treatment?
- Is yes, how has this view of yourself changed?
- How do you see yourself now?
- How did you see yourself before?
- Do you ever feel worried about being negatively evaluated for your appearance?

- If so, is this feeling somehow related to ADT side effects or not?
- If so, did this worry ever stopped you from doing something?
- If so, is there a specific aspect of your body that makes you feel worried about other people's judgment?
- Can you identify some particular situations that prompt these feelings?

Exercise

- Do you engage in exercise? If so, what's your favourite type of exercise?
- What would you say are the benefits of exercise?
- Does exercise have an impact on the way you feel?
- Does exercise have an impact on the way you see your body right now?
- Did prostate cancer change your approach to exercise?
- What are the barriers to engage in exercise for you?
- Did ADT side effects make exercise difficult?

A5) Codes map



A6) Themes map

Body Image issues = Body Feminisation

- Loss of pre-diagnosis body
- Breast enlargement
- Fat increase
- Loss of body functionality
- Sexual issues & loss of masculine self-esteem
  - loss of libido
  - penile shrinkage
  - Erectile Dysfunction
  - Embarrassment
- being emotional like a woman
- Loss of masculine identity & Regret for old body left behind

Exercise

- **Side effects vs barriers**
  - Compensate ADT side effects (e.g., weight gain)
  - Side effects as a barrier (e.g., fatigue + time management)
- **Empowerment vs fear of evaluation**
  - What the body can still do (functionality)
  - Control over health-related anxiety
  - Fear of negative appearance and physical performance evaluation

Coping Strategies (coping with body image issues, anxiety and depression)

- **Body acceptance**
  - ADT as price for life/Nothing you can do
  - Age helps manage expectations
  - Men do not worry about body image:
    - low appearance investment/ high functionality investment,
    - It is a feminine thing to worry about

- **Talking about it: it's certainly important, but is it manly enough?**
  - Discomfort with support groups & peer support: it is difficult to talk with other men
  - It is okay to talk to females (partners or health care professionals)

A7) Summary of the results provided to the participants

UWE Bristol University of the West of England

Study Summary

We would like to thank you for participating in the study entitled

My body after prostate cancer

Dear participant,

I would like to thank you for taking part in the study “My Body After Prostate Cancer”.

Your contribution was fundamental for our research. I hope that these results will help improve the psychological support offered to patients with prostate cancer.

Hereby, I would like to provide a summary of the study aims, procedure and results. I hope you will enjoy reading it and please do not hesitate to get in touch with me if you would like any further information.

Our Aim

Hormonal therapy is one of the most common treatments for prostate cancer, but it comes with several potential side effects, which might have an impact on bodily appearance and functions. Our aim was to understand what prostate cancer patients think about the impact that hormonal treatment has on their body functioning and appearance.

I also collected information about patients’ view on exercise and physical activity after diagnosis of prostate cancer - what they think about it, what they like about it, and what makes it easy or difficult to engage in exercise regularly.

Study Methods

- I interviewed 22 men diagnosed with prostate cancer, who followed Androgen Deprivation Therapy (hormonal therapy) at least once in their life.
- During the interview, men were asked questions around their history with prostate cancer, ADT side effects, effects on their body (e.g., appearance and functional changes), and the impact these changes had on them and their lives. I also asked some questions around exercise: whether men liked to exercise, if so how, if not why. Interviews happened either face to face or over the phone. Each interview lasted between 30 and 45 minutes and was audio recorded with permission of each participant.
- I then typed up the recording of each interview and I analysed the content of the text.

The Results

Here are some of our main findings

- Hormonal therapy side effects can represent a challenge to some prostate cancer patients. In particular, hormonal therapy can change men's body both in its appearance (e.g., breast enlargement, weight gain, etc.) and in its functioning (e.g., muscle loss, fatigue).
- Many participants described how prostate cancer and hormonal therapy changed the relationship they have with their body. In particular, one of the main challenges prostate cancer patients referred to face is the feeling of a feminized body, which sometimes threatened their identity as a man.
- However, all participants managed to cope positively with this challenging situation. In particular, they referred that help and support they received from their partners, families, friends, and local charities was very important to them.
- Participants reported that exercising regularly might represent a challenge. In particular, a tight schedule and fatigue (one of the main hormonal treatment side effects) can make fitting exercise in the day a real challenge. Moreover, some participants described that the unpleasant hormonal treatment side effects can sometimes make it difficult to exercise in public places (such as the gym or the swimming pool), where it is natural to feel more exposed to other people's eyes.
- However overall participants managed to exercise and valued this activity positively. In fact, exercising represented a good strategy to compensate for hormonal treatment side effects. Moreover, exercise helped many patients to feel good about themselves and about their bodies. Managing to exercise even a little bit seemed to give patients a sense of achievement and control over their bodies, despite prostate cancer and hormonal treatment side effects.

Sharing the results

The results from this study have been shared with fellow researchers and health professionals both locally, nationally, and internationally (for example at the International Congress of Psycho Oncology in Hong Kong!). The study results have been received with great interest and they have inspired fellow researchers in the field too. I am also currently working on a scientific paper which will be submitted to publication to a peer-reviewed journal. This would not have been possible without your help, thank you so much!

Rest assured that information about your identity and your data are completely **anonymous and confidential**, including your name, your contact information, and the answers you give. Only the researchers involved in the study have access to the data, which is stored securely at all times.

To Further Thank You

As a thank you for taking part in this study, you are being entered into a draw to win a £70 online shopping voucher. We will soon let you know if you won!

What Am I Doing Next?

More research! I am about to start a new study to further explore the themes we talked about during the interview in which you took part. However, this time I will do it through questionnaires. Hopefully, this second study will give us even more information that will support the final goal of improving the psychological support available for prostate cancer patients undergoing ADT who might be dealing with body image issues.

If You Want To Get In Touch

If you have any further question about our research, please do not hesitate to get in touch:

Caterina Gentili, PhD candidate
caterina2.gentili@live.uwe.ac.uk
+44 (0)1173282654

Centre for Appearance Research
http://www1.uwe.ac.uk/hls/research/appearanceresearch.aspx
Faculty of Health & Applied Sciences
University of the West of England, Bristol (UWE)

If You Need Help

This is a list of organisations that you can contact if this study raised any issues for you, or if you would like any support or information about how to deal with prostate cancer and body image concerns. Alternatively, you can contact your GP for advice.

- **Prostate Cancer UK**
  https://prostatecanceruk.org/
  0800 074 8383

- **NHS choices**
  https://www.nhs.uk/conditions/prostate-cancer/

- **Southmead Hospital Charity**
  https://www.southmeadhospitalcharity.org.uk/
  hello@southmeadhospitalcharity.org.uk
  0117 414 0170

- **Tackle Prostate Cancer**
  http://www.tackleprostate.org/
  0800 035 5302

- **Men's Health Forum**
  24/7 stress support for men by text, chat and email.
  www.menshealthforum.org.uk

- **Samaritans**
  Confidential support for people experiencing feelings of distress or despair.
  116 123 (free 24-hour helpline)
  www.samaritans.org.uk

Once again, thank you so much!

This research would not be possible without you! Sincerely, Caterina Gentili

Appendix B: Study 2

B1) Ethical Approval

Faculty of Health & Applied Sciences
[redacted]

Tel: [redacted]

UWE REC REF No: HAS.18.10.049 Gentili

21 November 2018

Caterina Gentili
[redacted]

Dear Gentili

Application title: Exercise and body images issues in prostate cancer: comparing prostate cancer (PCa) patients undergoing androgen deprivation therapy (ADT), to ADT-naive PCa patients and age-matching controls

Your ethics application was considered by the Faculty Research Ethics Committee and, based on the information provided, has been given ethical approval to proceed. **However, the Chair has requested that you explain on the information sheet - how men can choose to complete a paper version of the questionnaire.**

You must notify the committee in advance if you wish to make any significant amendments to the original application using the amendment form at http://www1.uwe.ac.uk/research/researchethics/applyingforapproval.aspx

Please note that any information sheets and consent forms should have the UWE logo. Further guidance is available on the web: https://intranet.uwe.ac.uk/tasks-guides/Guide/writing-and-creating-documents-in-the-uwe-bristol-brand

The following standard conditions also apply to all research given ethical approval by a UWE Research Ethics Committee:

1. You must notify the relevant UWE Research Ethics Committee in advance if you wish to make significant amendments to the original application: these include any changes to the study protocol

which have an ethical dimension. Please note that any changes approved by an external research ethics committee must also be communicated to the relevant UWE committee.

2. You must notify the University Research Ethics Committee if you terminate your research before completion;
3. You must notify the University Research Ethics Committee if there are any serious events or developments in the research that have an ethical dimension.

The Faculty and University Research Ethics Committees (FRECs and UREC) are here to advise researchers on the ethical conduct of research projects and to approve projects that meet UWE's ethical standards. Please note that we are unable to give advice in relation to legal issues, including health and safety, privacy or data protection (including GDPR) compliance. Whilst we will use our best endeavours to identify and notify you of any obvious legal issues that arise in an application, the lead researcher remains responsible for ensuring that the project complies with UWE's policies, and with relevant legislation. If you need help with legal issues please contact safety@uwe.ac.uk (for Health and Safety advice), James2.Button@uwe.ac.uk (for data protection, GDPR and privacy advice).

Please note: The UREC is required to monitor and audit the ethical conduct of research involving human participants, data and tissue conducted by academic staff, students and researchers. Your project may be selected for audit from the research projects submitted to and approved by the UREC and its committees.

Please remember to populate the HAS Research Governance Record with your ethics outcome via the following link: https://teams.uwe.ac.uk/sites/HASgovernance.

We wish you well with your research.

Yours sincerely

Dr [redacted]

Chair

Faculty Research Ethics Committee

c.c. *Diana Harcourt*

B2) Invitation Emails for Public and Patients Involvement

Dear (name of participant),

I hope this email finds you well!

Firstly, I would like to thank you one more time for taking part in the interview for the study “My body after prostate cancer”. Your contribution was extremely helpful and our research would not have been possible without you. I also hope you enjoyed reading the summary of the study I sent in the previous email. In this regard, please feel free to get in touch and ask any question that might be relevant to you.

I am currently designing another research aimed at deepening the themes that emerged from the interviews. This second study will make use of questionnaires, which will be mostly delivered online. I am writing you this email because I would like to collect some feedback from men diagnosed with prostate cancer on the pilot version of this second study. Given that your contribution to the previous research was particularly detailed and helpful, I was wondering if you would be interested in sharing your opinion on the pilot of the second study.

Hearing what you think would be extremely helpful to improve the quality of the research design before starting data collection (for example: are the questionnaires relevant to you? Is the study too long/too brief/right length? Do you think my strategies to get in touch with patients are adequate? How would you advertise the study? etc. etc).

If you would be willing to give your contribution, please reply to this email and I will happily provide you with more details.

Thank you in any case for the time and energy you invested in our research so far!

Kindest regards,

Caterina Gentili

PhD candidate
PGR HAS FRDC representative
Faculty of Health and Applied Sciences
[redacted]

My pronouns are: she / her / hers

Dear xx,

I hope this email finds you well!

Firstly, I would like to thank you once again for accepting to give some feedback on the pilot version of my second study.

I am contacting you since the online pilot is finally ready. In this regard, my apologies for the delay with respect to the original schedule.

If you are still interested in sharing your opinion on the pilot, please follow this link to access the survey, which will take about 20 minutes to complete:
https://uwe.eu.qualtrics.com/jfe/form/SV_0JslW06Gn73ZaGV

Hearing what you think about it would be extremely helpful to improve the quality of the research design before starting data collection. Here's some examples of topics you could feedback on:

- are the questionnaires relevant to you?
- Is the study too long/too brief/right length?
- Do you think distributing the research online would be a good recruitment strategy?
- How would you advertise the study?
- Do you think the questions are clear?
- Is the program working smoothly?

Or any other comment that you might have.

In this regard, I would be very happy to schedule a telephone call with you sometimes after Jan 8th to have a chat about the pilot. Are there any dates and times working well for you?

Thank you in any case for the time and energy you invested in our research so far!

I look forward to hear from you and I wish you a very happy Christmas.
Kindest regards,

Caterina Gentili

PhD candidate
PGR HAS FRDC representative
Faculty of Health and Applied Sciences
[redacted]

My pronouns are: she / her / hers

B3) Survey items

A survey on men's health

This online survey investigates various aspects of men’s health.

Please read the information sheet below.

Then click to go to the next page where you will be asked to give your consent to take part.

Afterwards, you will be asked to fill out some questions concerning men’s health.

The study will only take a single session.

Time of completion may vary, but most participants usually take between 20 and 30 minutes.

Information sheet

Who can join?

You are warmly invited to take part in this research if:

- You are a male between 35 and 75 years old;
- You do not have a major physical injury that stops youexercising or taking part in physical activity;
- You have a good understanding of English

To thank you for taking part in this study, you will be entered into a draw for a chance to win a **£70 online shopping voucher.**

Are there any risks? And what if I want to stop?

We do not believe that taking part in this study poses any risks. However, we are aware that the topics covered in the study can be sensitive and emotive issues for some men. You are free to stop your participation, with no need to provide a reason. In particular, you have the right to withdraw from the study at any time before and during the study and within two weeks after completing the survey, without having to give a reason. If you want to withdraw within two weeks after completing the survey, you can contact Caterina Gentili (see contact details below). You have the right to choose not to participate in this study.

Privacy

Your identity and your data will be completely anonymous and confidential, including your name, your contact information, and the answers you give. Only the researchers involved in the study will have access to the data, which will be stored securely at all times.

Ethical approval

This study has been approved by a Research Ethics Committee at the University of the West of England, Bristol (UWE).

If you want to get in touch, please contact:

Caterina Gentili, PhD researcher
caterina2.gentili@live.uwe.ac.uk
+44 (0)1173282654
Centre for Appearance Research
University of the West of England, Bristol

If you decided to participate, please:

- carefully read the completion instructions we will provide;
- read each question carefully answer the questions truthfully;
- keep in mind that there are no right or wrong answers;
- remember that all your data will be kept confidential and your identity will remain anonymous at all times.

Consent Form

Please read carefully all the statements and specify whether you agree (Yes) or disagree (No) with the statement. You will not be included in the study if you do not will to give your informed consent to participate.

I understand taking part will involve completing a survey on one occasion

☐ Yes

☐ No

I have been informed of the study

☐ Yes

☐ No

I have read the information sheet

☐ Yes

☐ No

I have had the opportunity to ask questions about the study and any questions I had, have been answered

☐ Yes

☐ No

I have been able to think about my participation in the study, which is completely voluntary.

☐ Yes

☐ No

I understand I have the right to withdraw my consent at any time before the beginning of the study and within two weeks after completing the survey, without having to give a reason.

- ☐ Yes
- ☐ No

I understand that the information I give will be treated as confidential.

- ☐ Yes
- ☐ No

I understand that I will not be named or identified in any report or presentation that comes from this study.

- ☐ Yes
- ☐ No

I agree to participate to the study

- ☐ Yes
- ☐ No

Before you start, please create your participation code.
To do so you will have to fill out the spaces down below with:
the first three letters of your mother's maiden name (e.g. Smiths = SMI) the last two digits of your year of birth (e.g., 1952 = 52) the first letter of your town of residence (e.g., Cardiff = C)

First three letters of your mother's maiden name ____________
Last two digits of your year of birth ________________
First letter of your town of residence _____________

Preliminary questions

We will now ask you a few questions to make sure that you are eligible to participate in this study. Please read the questions carefully and answer truthfully.

Do you have a physical condition that prevents you taking part in exercise or physical activity, completely?

- ☐ Yes
- ☐ No

Have you ever been diagnosed with a psychotic disorder or dementia?

- ☐ Yes
- ☐ No

Have you ever been diagnosed with cancer?

- ☐ Yes
- ☐ No

If yes, were you diagnosed with prostate cancer?

- ☐ Yes
- ☐ No

What is your age?__________________
What is your nationality? __________________
How did you hear about this survey?

- ☐ Social Media
- ☐ Through a charity
- ☐ Friends and family
- ☐ Other

What is the highest level of education you have completed?

- ☐ Grammar School
- ☐ High School equivalent
- ☐ Vocational/ Technical school
- ☐ Some college
- ☐ Bachelor's degree
- ☐ Master's degree
- ☐ Doctoral's degree Other

How would you classify yourself?

- ☐ Black/African/Carribbean/Black British/African American/Black European
- ☐ White/White British/White European/White American
- ☐ Mixed/Multiple ethnic groups
- ☐ Asian/Asian British/Asian European/Asian American
- ☐ Arab
- ☐ Hispanic
- ☐ Other ___________
- ☐ Rather not say

What is your sexual orientation?

- ☐ Heterosexual
- ☐ Homosexual
- ☐ Bisexual
- ☐ Asexual/Greysexual
- ☐ Other___________
- ☐ Rather not say

Which of the following best describes the area you live in?

- ☐ Urban
- ☐ Suburban
- ☐ Rural

Who do you usually live with?

- ☐ Partner
- ☐ Alone
- ☐ Relatives
- ☐ Friend(s)
- ☐ Children
- ☐ Other _________
- ☐ Rather not say

When were you diagnosed with prostate cancer?______________________

Did you prostate cancer treatment include Androgen Deprivation Therapy (ADT)/hormone therapy at any point?

- ☐ Yes
- ☐ No

If yes, for how long?_____________

Overall, which treatments have you followed?

- ☐ Androgen Deprivation Therapy
- ☐ Surgery (radical prostatectomy)
- ☐ External beam radiotherapy
- ☐ Brachytherapy
- ☐ Chemotherapy
- ☐ Radium-223
- ☐ Active surveillance / watchful waiting
- ☐ Other________________

Study Questionnaire

Thank you for filling out the preliminary questions, the first part of the survey is done!

Now we will ask you to fill out some questions around men's wellbeing and health.

Please:

- always carefully read the completion instructions we will provide for each questionnaire
- read each question carefully;
- answer the questions truthfully;
- keep in mind that there are no right or wrong answers;
- remember that all your data will be kept confidential and your identity will remain anonymous at all times.

Please indicate the degree to which you agree with each of the following statements by selecting the most adequate answer. Remember there are no right or wrong answers.

Since cancer treatment/diagnosis, how much have you felt self conscious?
For control group: In the last year, how much have you felt self conscious?

0	1	2	3
not at all	a little	quite a bit	very much

Since cancer treatment/diagnosis, how much have you felt less physically attractive?
For control group: In the last year, how much have you felt less physically attractive?

0	1	2	3
not at all	a little	quite a bit	very much

Since cancer treatment/diagnosis, how much have you felt dissatisfied with your appearance?
For control group: In the last year, how much have you felt dissatisfied with your appearance?

0	1	2	3
not at all	a little	quite a bit	very much

Since cancer treatment/diagnosis, how much have you felt less masculine?
For control group: In the last year, how much have you felt less masculine?

0	1	2	3
not at all	a little	quite a bit	very much

Since cancer treatment/diagnosis, how much have you found it difficult to see yourself naked?
For control group: In the last year, how much have you found it difficult to see yourself naked?

0	1	2	3
not at all	a little	quite a bit	very much

Since cancer treatment/diagnosis, how much have you felt less sexually attractive?
For control group: In the last year, how much have you felt less sexually attractive?

0	1	2	3
not at all	a little	quite a bit	very much

Since cancer treatment/diagnosis, how much have you like you wanted to avoid people?
For control group: In the last year, how much have you like you wanted to avoid people?

0	1	2	3
not at all	a little	quite a bit	very much

Since cancer treatment/diagnosis, how much have you felt you body was less whole?
For control group: In the last year, how much have you felt you body was less whole?

0	1	2	3
not at all	a little	quite a bit	very much

Since cancer treatment/diagnosis, how much have you felt dissatisfied with your body?
For control group: In the last year, how much have you felt dissatisfied with your body?

0	1	2	3
not at all	a little	quite a bit	very much

Since cancer treatment/diagnosis, how much have you felt dissatisfied with any scar?
For control group: In the last year, how much have you felt dissatisfied with any scar?

0	1	2	3
not at all	a little	quite a bit	very much

Please indicate the degree to which you agree with each of the following statements. Remember there are no right or wrong answers.

My body is sexually appealing.

1	2	3	4	5
definitely	mostly	don’t agree	mostly	
definitely				
disagree	disagree	nor disagree	agree	agree

I like my looks just the way they are.

1	2	3	4	5
definitely	mostly	don’t agree	mostly	
definitely				
disagree	disagree	nor disagree	agree	agree

Most people would consider me good looking.

1	2	3	4	5
definitely	mostly	don’t agree	mostly	
definitely				
disagree	disagree	nor disagree	agree	agree

I like the way I look without my clothes on

1	2	3	4	5
definitely disagree	mostly disagree	don’t agree nor disagree	mostly agree	definitely agree

I like the way my clothes fit me.

1	2	3	4	5
definitely disagree	mostly disagree	don’t agree nor disagree	mostly agree	definitely agree

I dislike my physique.

1	2	3	4	5
definitely disagree	mostly disagree	don’t agree nor disagree	mostly agree	definitely agree

I am physically unattractive.

1	2	3	4	5
definitely disagree	mostly disagree	don’t agree nor disagree	mostly agree	definitely agree

Please indicate the degree to which you agree with each of the following statements. Remember there are no right or wrong answers.

I appreciate my body for what it is capable of doing.

1	2	3	4	5
strongly disagree	disagree	don’t agree nor disagree	agree	strongly agree

I am grateful for the health of my body, even if it isn’t always as healthy as I would like it to be.

1	2	3	4	5
strongly disagree	disagree	don’t agree nor disagree	agree	strongly agree

I appreciate that my body allows me to communicate and interact with others.

1	2	3	4	5
strongly disagree	disagree	don’t agree nor disagree	agree	strongly agree

I acknowledge and appreciate when my body feels good and/or relaxed.

1	2	3	4	5
strongly disagree	disagree	don’t agree nor disagree	agree	strongly agree

I am grateful that my body enables me to engage in activities that I enjoy or find important.

1	2	3	4	5
strongly disagree	disagree	don’t agree nor disagree	agree	strongly agree

I feel that my body does so much for me.

1	2	3	4	5
strongly disagree	disagree	don’t agree nor disagree	agree	strongly agree

I respect my body for the functions that it performs.

1	2	3	4	5
strongly disagree	disagree	don’t agree nor disagree	agree	strongly agree

Please indicate the degree to which you agree with each of the following statements. Remember there are no right or wrong answers.

I am concerned about what other people think of my appearance.

1	2	3	4	5
not at all	slightly	moderately	very	extremely

It bothers me if I know that someone is judging my physical shape.

1	2	3	4	5
not at all	slightly	moderately	very	extremely

I worry that people will find fault with the way I look.

1	2	3	4	5
not at all	slightly	moderately	very	extremely

When I meet new people, I wonder what they think of my appearance.

1	2	3	4	5
not at all	slightly	moderately	very	extremely

I am afraid other people will notice my physical flaws.

1	2	3	4	5
not at all	slightly	moderately	very	extremely

I think that other's people opinion on my appearance are too important to me.

1	2	3	4	5
not at all	slightly	moderately	very	extremely

I am concerned of what other people think of my ability to exercise.

1	2	3	4	5
not at all	slightly	moderately	very	extremely

It bothers me if I know someone is judging my physical performance.

1	2	3	4	5
not at all	slightly	moderately	very	extremely

I worry that other people will find my body not strong and athletic enough.

1	2	3	4	5
not at all	slightly	moderately	very	extremely

In an exercise setting, I wonder if others find me slower or weaker.

1	2	3	4	5
not at all	slightly	moderately	very	extremely

I am afraid other people will notice my physical weaknesses.

1	2	3	4	5
not at all	slightly	moderately	very	extremely

I am reluctant to exercise because of a fear of being judged by people.

1	2	3	4	5
not at all	slightly	moderately	very	extremely

Please indicate the frequency in which you normally engage with the following type of exercise <u>during your typical week</u>:

Strenuous exercise (heart beats rapidly)

(examples: running, jogging, football, vigorous swimming, vigorous long distance bicycling, basketball, skiing, etc)

- ☐ Never
- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7

Moderate exercise (not exhausting)

(examples: fast walking, easy bicycling, easy swimming, gardening, slow dancing, etc.)

- ☐ Never
- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7

Mild exercise (minimal effort)

(examples: yoga, easy walking, golf, bowling, etc.)

- ☐ Never
- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7

Considering a 7-Day period (a week), during your leisure time, how often do you engage in any regular activity long enough to work up a sweat (heart beats rapidly)?

1 - never / rarely 2 - sometimes 3 – often

Please indicate the degree to which you agree with each of the following statements. Remember there are no right or wrong answers.

How often do you happen feel not a proper man?

1	2	3	4	5
never	seldom	sometimes	often	always

How often do you happen to feel lacking in masculinity?

1	2	3	4	5
never	seldom	sometimes	often	always

How often do you happen to feel not the man you should be?

1	2	3	4	5
never	seldom	sometimes	often	always

How often do you happen to feel that others think you are not manly enough?

1	2	3	4	5
never	seldom	sometimes	often	always

How often do you happen to feel weak and small?

1	2	3	4	5
never	seldom	sometimes	often	always

How often do you happen to feel compared unfavorably to other men?

1	2	3	4	5
never	seldom	sometimes	often	always

How often do you happen to feel too emotional?

1	2	3	4	5
never	seldom	sometimes	often	always

How often do you happen to feel it's hard to think coolly and logically as expected from a man?

1	2	3	4	5
never	seldom	sometimes	often	always

Please indicate the degree to which you agree with each of the following statements. Remember there are no right or wrong answers.

I think in society being masculine means being physically strong.

1	2	3	4	5
disagree	somewhat disagree	don’t agree nor disagree	somewhat agree	agree

I think in society being masculine means being sexually active.

1	2	3	4	5
disagree	somewhat disagree	don’t agree nor disagree	somewhat agree	agree

I think in society being masculine means being emotional.

1	2	3	4	5
disagree	somewhat disagree	don’t agree nor disagree	somewhat agree	agree

I think in society being masculine means being vulnerable.

1	2	3	4	5
disagree	somewhat disagree	don’t agree nor disagree	somewhat agree	agree

I think in society being masculine means dealing with problems alone.

1	2	3	4	5
disagree	somewhat disagree	don’t agree nor disagree	somewhat agree	agree

Please indicate the degree to which you agree with each of the following statements. Remember there are no right or wrong answers.

Before going out in public, I always notice how I look.

1	2	3	4	5
definitely disagree	mostly disagree	don’t agree nor disagree	mostly agree	definitely agree

I am careful to buy clothes that will make me look my best.

1	2	3	4	5
definitely disagree	mostly disagree	don’t agree nor disagree	mostly agree	definitely agree

I check my appearance in a mirror whenever I can.

1	2	3	4	5
definitely disagree	mostly disagree	don’t agree nor disagree	mostly agree	definitely agree

Before going out, I usually spend a lot of time getting ready.

1	2	3	4	5
definitely disagree	mostly disagree	don’t agree nor disagree	mostly agree	definitely agree

It is important that I always look good.

1	2	3	4	5
definitely disagree	mostly disagree	don’t agree nor disagree	mostly agree	definitely agree

I use very few grooming products.

1	2	3	4	5
definitely disagree	mostly disagree	don’t agree nor disagree	mostly agree	definitely agree

I am self-conscious if my grooming isn't right.

1	2	3	4	5
definitely disagree	mostly disagree	don’t agree nor disagree	mostly agree	definitely agree

I usually wear whatever is handy without caring how it looks.

1	2	3	4	5
definitely disagree	mostly disagree	don’t agree nor disagree	mostly agree	definitely agree

I don't care what people think about my appearance.

1	2	3	4	5
definitely disagree	mostly disagree	don’t agree nor disagree	mostly agree	definitely agree

I take special care with my hair grooming.

1	2	3	4	5
definitely disagree	mostly disagree	don’t agree nor disagree	mostly agree	definitely agree

I never think about my appearance.

1	2	3	4	5
definitely disagree	mostly disagree	don’t agree nor disagree	mostly agree	definitely agree

I am always trying to improve my physical appearance.

1	2	3	4	5
definitely disagree	mostly disagree	don’t agree nor disagree	mostly agree	definitely agree

Thank you so much for taking part in this study and for completing all the questions!
Your help is indispensable for research.

One last thing before you go...

We are aware that the topics covered in the study can be sensitive and emotive issues for some men. If any of the topics included in the questionnaires raised issues for you, please consult this list of organisations that you can contact if you would like any support or information. Alternatively, you can contact your GP for advice.

Men's Health Forum

24/7 stress support for men by text, chat and email
Website: www.menshealthforum.org.uk

Samaritans

Confidential support for people experiencing feelings of distress or despair.
Phone: 116 123 (free 24-hour helpline)
Website: www.samaritans.org.uk

NHS choices
Website: www.nhs.uk/conditions/prostate-cancer

Prostate Cancer UK

Phone: 0800 074 8383
Website: https:/prostatecanceruk.org/

Tackle Prostate Cancer

Phone: 0800 035 5302
Website: www.tackleprostatecancer.org

Is there anything else you would like to let us know?

B4) Survey advertisement

We are looking to recruit men for a study about prostate cancer, androgen deprivation therapy, and exercise at the Centre for Appearance Research.

We are looking for men between 35 and 75 years old:

- **60 prostate cancer patients who followed hormonal therapy at least once**
- **60 prostate cancer patients who never followed hormonal**

It's an **online survey** which will only take **20-30 minutes** of your time.

As a thank you, you will be entered into a draw to win a **£70 online shopping voucher.**

If you would like to complete the online survey, please follow this link to the online study:

https://uwe.eu.qualtrics.com/jfe/form/SV_0JslW06Gn73ZaGV

The research project.

Caterina Gentili, a PhD candidate from the Centre for Appearance Research, is currently working on a series of studies focusing on prostate cancer, hormonal treatment, body image, and exercise.

Hormonal therapy is one of the most common treatments for prostate cancer. Despite its efficacy, this treatment can come with several potential side effects such as breast enlargement, weight gain, muscle loss, loss of bodily hair, penile shrinkage, hot flushes and so on. These side effects might have an impact on bodily appearance and bodily functions. Some patients find these changes uncomfortable or upsetting.

The aim of the present online survey is to explore physical and psychological health in prostate cancer patients on ADT, but also patients who never followed this treatment and men without prostate. The study takes place entirely online and consists of a 20-30 minutes single session in which participants are simply asked to fill out some questionnaires.

If you want to get in touch.

If you would like to have more information about the study or if you have any question, please contact:

Caterina Gentili, PhD candidate
[redacted]

Centre for Appearance Research
Faculty of Health and Applied Sciences
[redacted]
University of the West of England
[redacted]

B4.1.) Facebook page to advertise the study

Inizia a vendere dalla tua Pagina in pochi passaggi
Ti basteranno pochi minuti per configurare il tuo shop. Inserisci i dettagli della tua azienda, aggiungi i prodotti che vorresti vendere e personalizza la tua vetrina in modo adeguato per il tuo brand.

B5) Validated questionnaires considered but not included to measure worry of negative physical performance evaluation during exercise.

B5.1) Items of the Physical Self Perception Profile (Fox, 1989)

Participants have to indicate which part of the statement they identify the most with and how much (i.e., “Definitely me” “Sometimes me”).

Sport Competence Subscale

1) - Some people feel that they are not good when it comes to playing sport BUT others feel that they are really good at just about every sport.

6) + Some people feel that they are among the best when it comes to athletic ability BUT others feel that they are not among the most able when it comes to athletics

11) - Some people are not quite so confident when it comes to taking part in sports BUT others are among the most confident when it comes to taking part in sports activities

16) + Some people feel that they are always among the best when it comes to joining in sports activities BUT others feel that they are not among the best when it comes to joining in sports activities.

21) – Some people are sometimes a little slower than most when it comes to learning new skills in a sports situation BUT others always seem to be among the quickest when it comes to learning new sports skills.

26) + Given the chance, some people are always among the first to join in sports activities BUT other people sometimes hold back and are not usually among the first to join in sports.

Physical Condition Subscale

2) – Some people are not very confident about their level of physical conditioning and fitness BUT others always feel confident that they maintain excellent conditioning and fitness.

7) + Some people make certain they take part in some form of regular vigorous physical exercise bUT others don’t often manage to keep up regular vigorous physical exercise.

12) – Some people do not usually have a high level of stamina and fitness BUT others always maintain a high level of stamina and fitness.

17) – Some people tend to feel a little uneasy in fitness and exercise settings BUT others feel confident and at ease at all times in fitness and exercise settings.

22) + Some people feel extremely confident about their ability to maintain regular exercise and physical condition BUT others don’t feel quite as confident about their ability to maintain regular exercise and physical condition.

27) + Some people feel that compared to most they always maintain a high level of physical conditioning BUT others feel that compared to most their level of physical conditioning is not usually so high.

Scoring:

Items 1, 2, 8, 10, 11, 12, 13, 15, 17, 19, 21, 23, 25, 29:

First part of the statement: “Definitely me” = 1, “Sometimes me” = 2

Second part of the statement: “Sometimes me” = 3, “Definitely me” = 4

Items 2, 4, 5, 6, 7, 9, 14, 16, 18, 20, 22, 24, 26, 27, 28, 30:

First part of the statement: “Definitely me” = 4, “Sometimes me” = 3

Second part of the statement: “Sometimes me” = 2, “Definitely me” = 1

B5.2.) The Basic Psychological Needs in Exercise Scale

Competence subscale

1) I feel I have been making a huge progress with respect to the end result I pursue.
2) I feel that I execute very effectively the exercises of my training program.
3) I feel that exercise is an activity in which I do very well.
4) I feel that I can manage with the requirements of the training program I am involved.

Relatedness subscale

1) I feel extremely comfortable when with the other exercise participants.
2) I feel that I associate with the other exercise participants in a very friendly way.
3) I feel there are open channels of communication with the other exercise participants.
4) I feel very much at ease with the other exercise participants.

B6) Validated questionnaires considered but not included to measure hegemonic masculinity ideal

Conformity to Masculine Norms Inventory

1) In general, I will do anything to win

2) If I could, I would frequently change sexual partners

3) I hate asking for help

4) I believe that violence is never justified

5) Being thought of as gay is not a bad thing

6) In general, I do not like risky situations

7) Winning is not my first priority

8) I enjoy taking risks

9) I am disgusted by any kind of violence

10) I ask for help when I need it

11) My work is the most important part of my life

12) I would only have sex if I was in a committed relationship

13) I bring up my feelings when talking to others

14) I would be furious if someone thought I was gay

15) I don't mind losing

16) I take risks

17) It would not bother me at all if someone thought I was gay

18) I never share my feelings

19) Sometimes violent action is necessary

20) In general, I control the women in my life

21) I would feel good if I had many sexual partners

22) It is important for me to win

23) I don't like giving all my attention to work

24) It would be awful if people thought I was gay

25) I like to talk about my feelings

26) I never ask for help

27) More often than not, losing does not bother me

28) I frequently put myself in risky situations

29) Women should be subservient to men

30) I am willing to get into a physical fight if necessary

31) I feel good when work is my first priority

32) I tend to keep my feelings to myself

33) Winning is not important to me

34) Violence is almost never justified

35) I am happiest when I'm risking danger

36) It would be enjoyable to date more than one person at a time

37) I would feel uncomfortable if someone thought I was gay

38) I am not ashamed to ask for help

39) Work comes first

40) I tend to share my feelings

41) No matter what the situation I would never act violently

42) Things tend to be better when men are in charge

43) It bothers me when I have to ask for help

44) I love it when men are in charge of women

45) I hate it when people ask me to talk about my feelings

46) I try to avoid being perceived as gay

Scoring:

- 0 (strongly disagree) to 3 (strongly agree).
- Reversed items: 4, 5, 6, 7, 9, 10, 12, 13, 15, 17, 23, 25, 27, 33, 34, 38, 40, 41

Subscale	**Items**
Winning	1 + 7 + 15 + 22 + 27 + 33
Emotional Control	13 + 18 + 25+ 32 + 40+ 45
Risk-Taking	6 + 8 + 16 + 28 + 35
Violence	4 + 9 + 19 + 30 + 34 + 41
Power Over Women	20 + 29 + 42 + 44
Playboy	2 + 12 + 21 + 36
Self-Reliance	3 + 10 + 26 + 38 + 43
Primacy of Work	11 + 23 + 31 + 39
Heterosexual Self-Presentation	5 + 14 + 17 + 24 + 37 + 46

B7) Assumption testing for MANOVA (Hypothesis 1)

1. The variables need to be interval/ratio: ASSUMPTION MET
2. We need 2+ levels of independent variable: ASSUMPTION MET
3. Groups need to be independent: ASSUMPTION MET
4. Sufficient sample size at least 20 per group: ASSUMPTION MET, I have also run the power analysis
5. Multivariate normality: the way it is normally tested is to look at the normality for each of the dependent variables. Looking at Shapiro Wilk test, if p equal or greater than .05 then we can assume normality and multivariate normality. ASSUMPTION NOT MET: None of the variables are normal, a part from AE and AO. This is expected, considering that 66.6% of the sample has a PCa cancer diagnosis, and 33% does not. (see Table 7 in Chapter 5)
6. Normal Distribution: The dependent variables should be normally distributed within groups. ASSUMPTION NOT MET (Table 1,2,3 in Appendix B7). Overall, the F test is remarkably robust to deviations from normality. If group sizes are approximately equal, MANOVA is robust against violations of this assumption. Our groups are equal so the MANOVA will be robust against the violation of this assumption.

Table 1. Normality testing for all dependent variables in the control group

	Shapiro Wilk's	df	*p*
BIS	.963	47	.139
AE	.975	47	.418
FAS	.953	47	.056
FNAE	.871	47	.000
FNPPE	.854	47	.000
MSES	.966	47	.190

Note. The table reports the results of Shapiro Wilk's test, which tests the null-hypothesis that the population is normally distributed. BIS = Body Image Scale; AE = Appearance Evaluation Subscale; FAS = Functionality Appreciation Scale; FNAE = Fear of Negative Appearance Evaluation; FNPPE = Fear of Negative Physical Performance Evaluation; MSES = Masculine Self Esteem Scale; ADT = Androgen Deprivation Therapy.

Table 2. Normality testing for all dependent variables in the ADT-naive group

	Shapiro Wilk's	df	*p*
BIS	.926	60	.001
AE	.976	60	.280
FAS	.935	60	.003
FNAE	.831	60	8.925
FNPPE	.762	60	1.755
MSES	.960	60	0.045

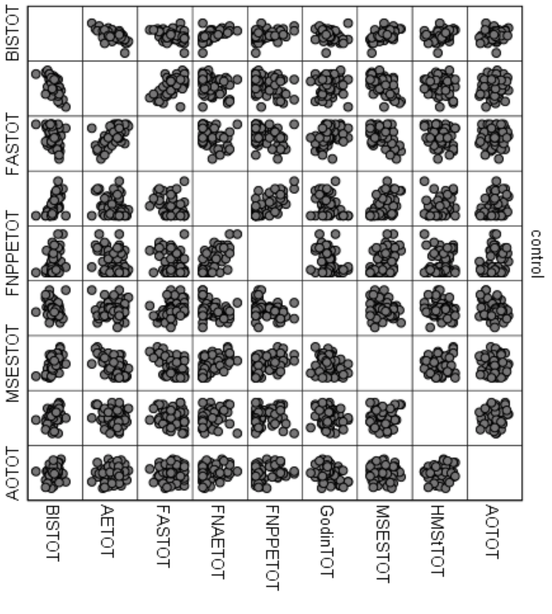
Note. The table reports the results of Shapiro Wilk's test, which tests the null-hypothesis that the population is normally distributed. BIS = Body Image Scale; AE = Appearance Evaluation Subscale; FAS = Functionality Appreciation Scale; FNAE = Fear of Negative Appearance Evaluation; FNPPE = Fear of Negative Physical Performance Evaluation; MSES = Masculine Self Esteem Scale; ADT = Androgen Deprivation Therapy.

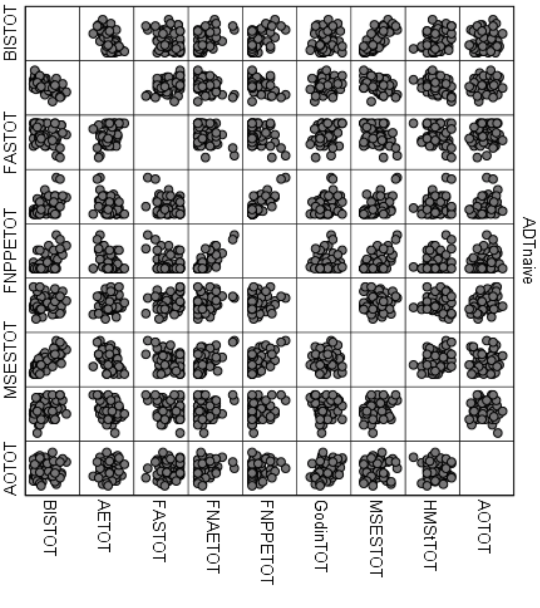
Table 3. Normality testing for all dependent variables in the ADT group

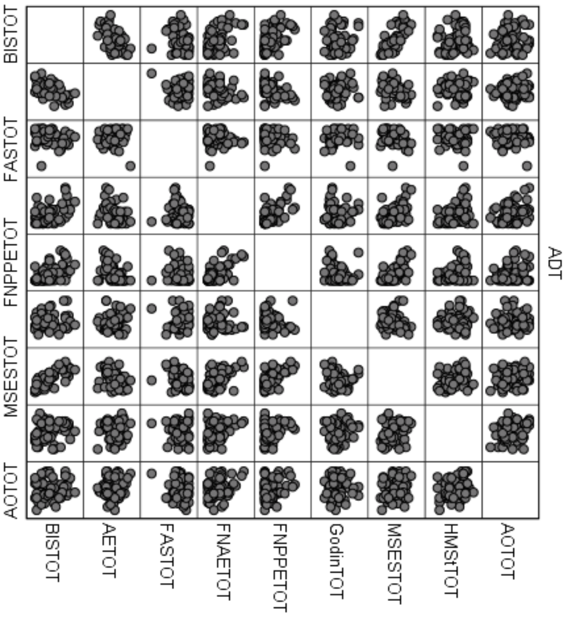
	Shapiro Wilk's	df	*p*
BIS	.928	58	.002
AE	.992	58	.959
FAS	.908	58	.000
FNAE	.888	58	.000
FNPPE	.842	58	.000
MSES	. 968	58	.123

Note. The table reports the results of Shapiro Wilk's test, which tests the null-hypothesis that the population is normally distributed. BIS = Body Image Scale; AE = Appearance Evaluation Subscale; FAS = Functionality Appreciation Scale; FNAE = Fear of Negative Appearance Evaluation; FNPPE = Fear of Negative Physical Performance Evaluation; MSES = Masculine Self Esteem Scale; ADT = Androgen Deprivation Therapy.

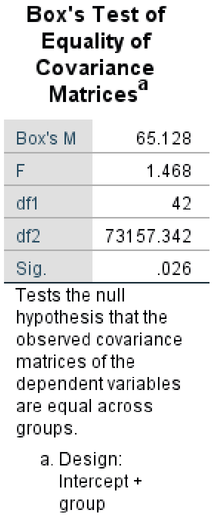
7. Dependent variables should not be affected collinearity. Pearson's value should not be greater than .9 or.8. not lower than .2: <u>ASSUMPTION MET</u> (see Tables 4,5,6 in Chapter 5)
8. There should be a linear relationship between each pair of DV across each level of IV. <u>ASSUMPTION MET</u>







9. Homogeneity of covariance matrixes, tested by checking that the Box Test of Equality of Matrices is non-significant: <u>ASSUMPTION MET</u>



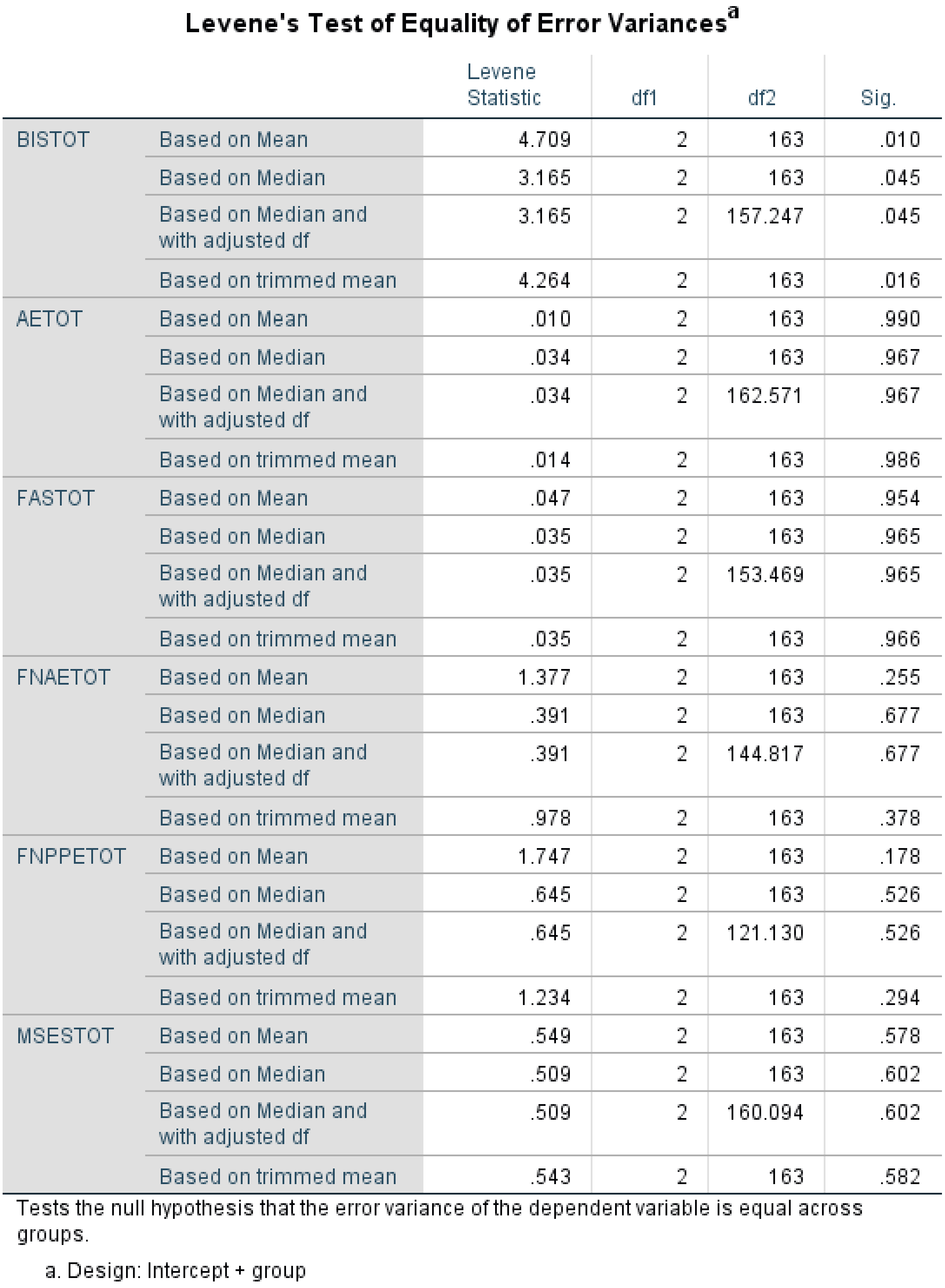
Box's Test of Equality of Covariance Matrices[a]

Box's M	65.128
F	1.468
df1	42
df2	73157.342
Sig.	.026

Tests the null hypothesis that the observed covariance matrices of the dependent variables are equal across groups.

a. Design: Intercept + group

10. Equal error variance, tested with Levine's test: ASSUMPTION MET



Levene's Test of Equality of Error Variances[a]

		Levene Statistic	df1	df2	Sig.
BISTOT	Based on Mean	4.709	2	163	.010
	Based on Median	3.165	2	163	.045
	Based on Median and with adjusted df	3.165	2	157.247	.045
	Based on trimmed mean	4.264	2	163	.016
AETOT	Based on Mean	.010	2	163	.990
	Based on Median	.034	2	163	.967
	Based on Median and with adjusted df	.034	2	162.571	.967
	Based on trimmed mean	.014	2	163	.986
FASTOT	Based on Mean	.047	2	163	.954
	Based on Median	.035	2	163	.965
	Based on Median and with adjusted df	.035	2	153.469	.965
	Based on trimmed mean	.035	2	163	.966
FNAETOT	Based on Mean	1.377	2	163	.255
	Based on Median	.391	2	163	.677
	Based on Median and with adjusted df	.391	2	144.817	.677
	Based on trimmed mean	.978	2	163	.378
FNPPETOT	Based on Mean	1.747	2	163	.178
	Based on Median	.645	2	163	.526
	Based on Median and with adjusted df	.645	2	121.130	.526
	Based on trimmed mean	1.234	2	163	.294
MSESTOT	Based on Mean	.549	2	163	.578
	Based on Median	.509	2	163	.602
	Based on Median and with adjusted df	.509	2	160.094	.602
	Based on trimmed mean	.543	2	163	.582

Tests the null hypothesis that the error variance of the dependent variable is equal across groups.

a. Design: Intercept + group

B8) Assumption testing for regression (Hypothesis 2)

1. Linear relationship between IV and DV and no outliers: ASSUMPTION MET (please see Appendix B7).

2. Multivariate normality: the way it is normally tested is to look at the normality for each of the dependent variables. Looking at Shapiro Wilk test, if p equal or greater than .05 then we can assume normality and multivariate normality. ASSUMPTION NOT MET. Given the sufficient sample size, the data was not transformed in order to avoid bias in the model estimates (Schmidt & Finan, 2018) (see Table 8 in Chapter 5).

3. Sample size: the sample size rule of thumb is that the regression analysis requires at least 20 cases per independent variable in the analysis. ASSUMPTION MET

4. No or little multi-collinearity. ASSUMPTION MET (see Tables 4,5,6 in Chapter 5).

5. No auto-correlation. Tested with the Durbin-Watson's d tests. As a rule of thumb values of 1.5 < d < 2.5 show that there is no auto-correlation in the data. ASSUMPTION MET.

Model Summary[b]

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Durbin-Watson
1	.181[a]	.033	.024	5.77059	1.852

a. Predictors: (Constant), ADT vs ADT naive vs control

b. Dependent Variable: MSESTOT

Model Summary[b]

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Durbin-Watson
1	.033[a]	.001	-.007	4.93179	2.348

a. Predictors: (Constant), ADT vs ADT naive vs control

b. Dependent Variable: FNAETOT

Model Summary[b]

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Durbin-Watson
1	.023[a]	.001	-.008	4.77217	2.136

a. Predictors: (Constant), ADT vs ADT naive vs control

b. Dependent Variable: FNPPETOT

Model Summary[b]

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Durbin-Watson
1	.001[a]	.000	-.009	6.94847	1.965

a. Predictors: (Constant), ADT vs ADT naive vs control

b. Dependent Variable: BISTOT

Model Summary[b]

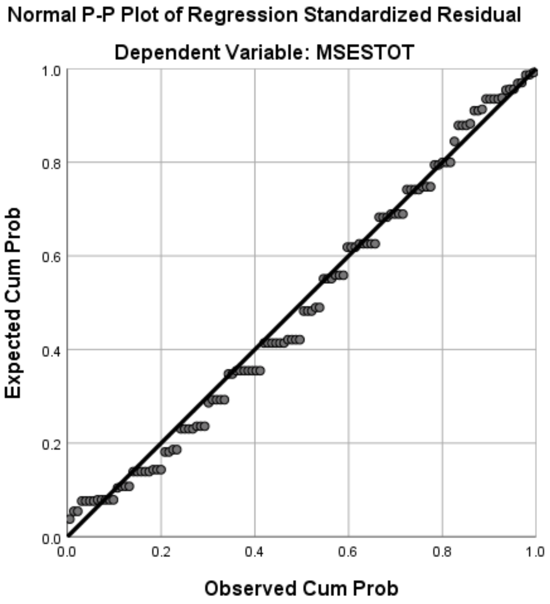
Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Durbin-Watson
1	.124[a]	.015	.007	.70905	2.139

a. Predictors: (Constant), ADT vs ADT naive vs control

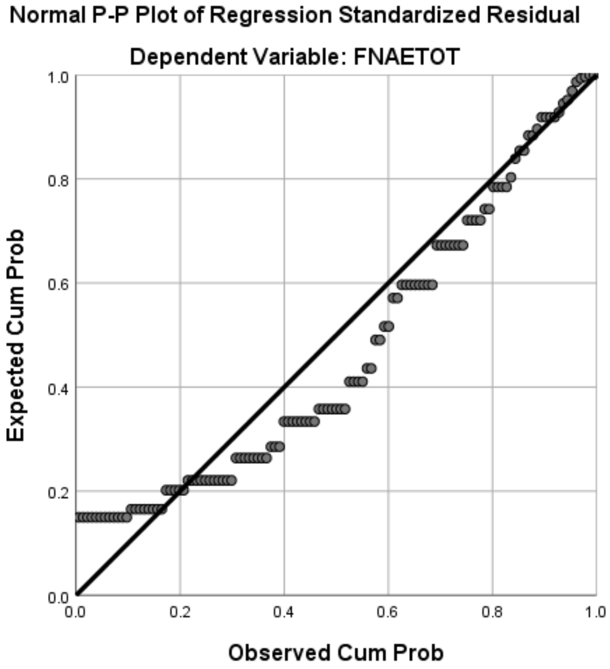
b. Dependent Variable: AETOT

6. Homoscedasticity: the error term is the same across all values of the independent variables). It is usually tested by plotting the predicted values and residuals on a scatterplot. If the residuals are linearly distributed, homoscedasticity is met. ASSUMPTION MET.

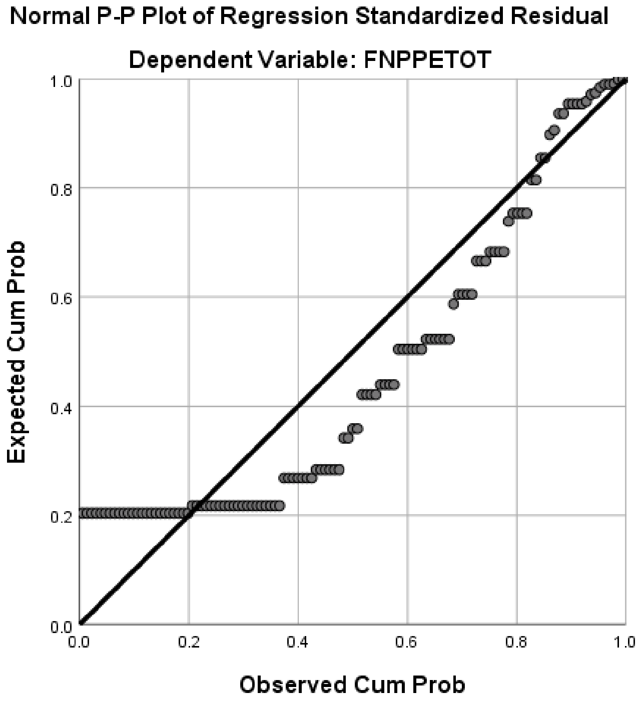
ADT → MSES: ASSUMPTION MET



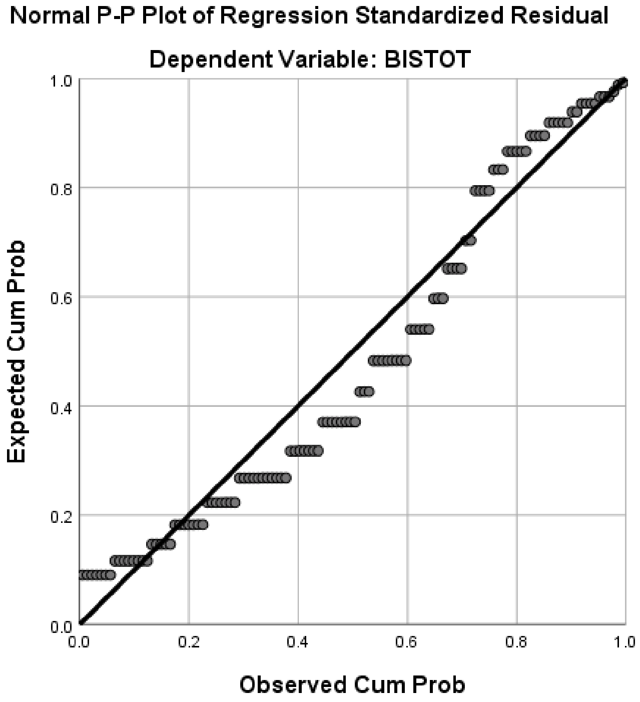
ADT → FNAE ASSUMPTION MET



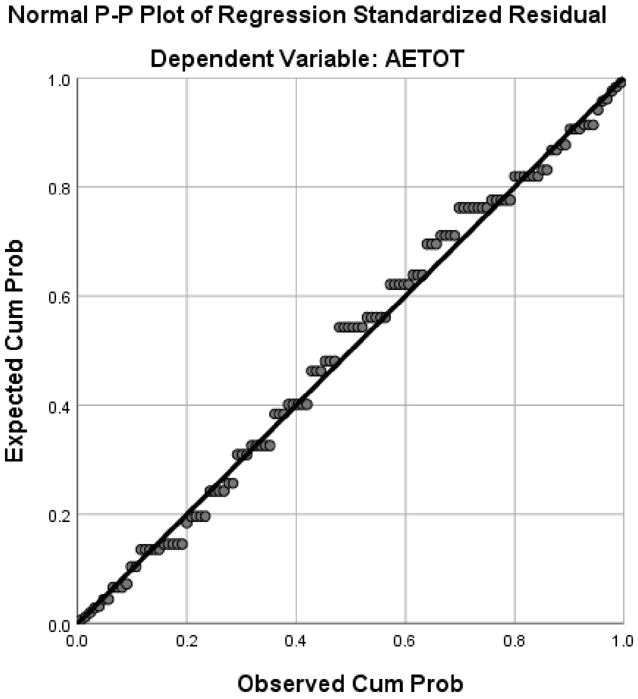
ADT → FNPPE: <u>ASSUMPTION NOT MET</u>



ADT → BIS: <u>ASSUMPTION MET</u>



ADT → AE: ASSUMPTION MET



B9) Assumption testing for regression (Hypothesis 3)

1. Linear relationship between IV and DV and no outliers: ASSUMPTION MET (please see Appendix B7).

2. Given the sufficient sample size, the data was not transformed in order to avoid bias in the model estimates (Schmidt & Finan, 2018). Multivariate normality: the way it is normally tested is to look at the normality for each of the dependent variables. Looking at Shapiro Wilk test, if p equal or greater than .05 then we can assume normality and multivariate normality. ASSUMPTION NOT MET.

Tests of Normality

		Kolmogorov-Smirnov[a]			Shapiro-Wilk		
		Statistic	df	Sig.	Statistic	df	Sig.
ADT	BISTOT	.134	58	.011	.928	58	.002
	AETOT	.063	58	.200*	.992	58	.959
	FNAETOT	.158	58	.001	.888	58	.000
	FNPPETOT	.192	58	.000	.842	58	.000
	GodinTOT	.094	58	.200*	.951	58	.020
	MSESTOT	.090	58	.200*	.968	58	.123
	FASTOT	.112	58	.067	.908	58	.000
	HMStTOT	.133	58	.013	.954	58	.029
	AOTOT	.122	58	.032	.972	58	.190

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

a. Lilliefors Significance Correction

3. Sample size: the sample size rule of thumb is that the regression analysis requires at least 20 cases per independent variable in the analysis. ASSUMPTION MET

4. No or little multi-collinearity. ASSUMPTION MET (see Tables 4,5,6 in Chapter 5).

5. No auto-correlation. Tested with the Durbin-Watson's d tests. While d can assume values between 0 and 4, values around 2 indicate no autocorrelation. As a rule of thumb values of 1.5 < d < 2.5 show that there is no auto-correlation in the data. ASSUMPTION IS MET.

FNAE → MSES : ASSUMPTION NOT MET

Model Summary[a,c]

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Durbin-Watson
1	.525[b]	.275	.262	5.11912	1.338

a. ADT vs ADT naive vs control = ADT

b. Predictors: (Constat), FNAETOT

Dependent Variable: MSESTOT

FNPPE → MSES: ASSUMPTION MET

Model Summary^{a,c}

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Durbin-Watson
1	.678^{b}	.460	.450	4.41979	1.558

a. ADT vs ADT naive vs control = ADT

b. Predictors: (Constant), FNPPETOT

c. Dependent Variable: MSESTOT

FNAE → BIS: ASSUMPTION MET

Model Summary^{a,c}

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Durbin-Watson
1	.497^{b}	.247	.233	5.94788	1.737

a. ADT vs ADT naive vs control = ADT

b. Predictors: (Constant), FNAETOT

c. Dependent Variable: BISTOT

FNAE → AE: ASSUMPTION MET

Model Summary^{a,c}

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Durbin-Watson
1	.294^{b}	.086	.070	.69309	2.054

a. ADT vs ADT naive vs control = ADT

b. Predictors: (Constant), FNAETOT

c. Dependent Variable: AETOT

FNPPE → BIS: ASSUMPTION MET

Model Summary^{a,c}

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Durbin-Watson
1	.552^{b}	.305	.292	5.71396	2.215

a. ADT vs ADT naive vs control = ADT

b. Predictors: (Constant), FNPPETOT

c. Dependent Variable: BISTOT

FNPPE → AE: ASSUMPTION MET

Model Summary[a,c]

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Durbin-Watson
1	.457[b]	.209	.194	.64506	2.362

a. ADT vs ADT naive vs control = ADT

b. Predictors: (Constant), FNPPETOT

c. Dependent Variable: AETOT

FNAE → FAS: ASSUMPTION MET

Model Summary[a,c]

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Durbin-Watson
1	.059[b]	.003	-.014	5.10213	1.484

a. ADT vs ADT naive vs control = ADT

b. Predictors: (Constant), FNAETOT

c. Dependent Variable: FASTOT

FNPPE → FAS: ASSUMPTION MET

Model Summary[a,c]

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Durbin-Watson
1	.140[b]	.019	.002	5.16517	1.538

a. ADT vs ADT naive vs control = ADT

b. Predictors: (Constant), FNPPETOT

c. Dependent Variable: FASTOT

FNPPE → FAS: ASSUMPTION MET

Model Summary^{a,c}

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Durbin-Watson
1	.140^{b}	.019	.002	5.16517	1.538

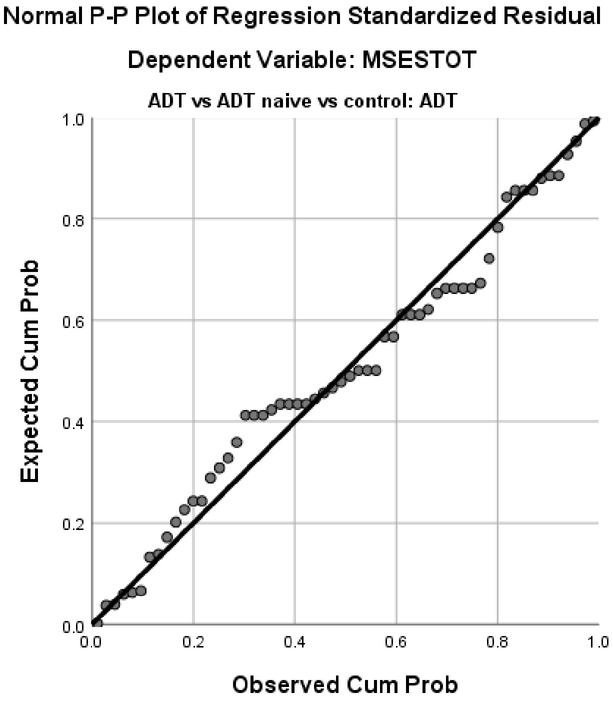
a. ADT vs ADT naive vs control = ADT

b. Predictors: (Constant), FNPPETOT

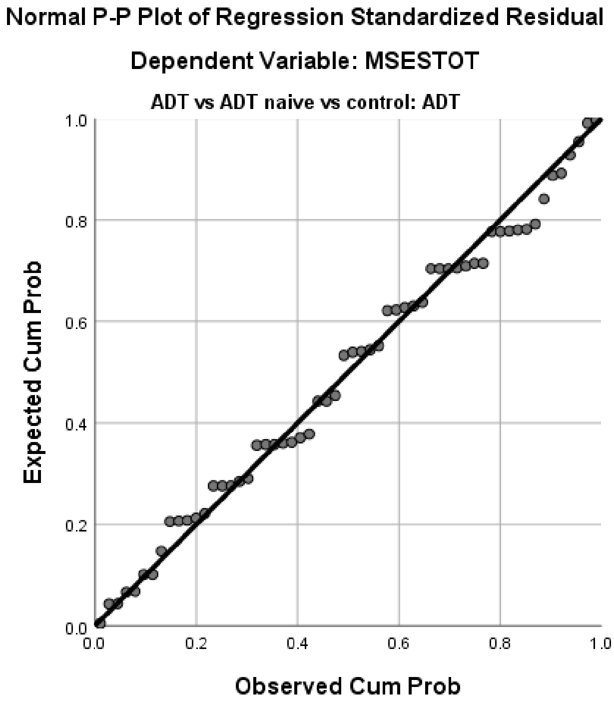
c. Dependent Variable: FASTOT

6. Homoscedasticity: the error term is the same across all values of the independent variables). It is usually tested by plotting the predicted values and residuals on a scatterplot. If the residuals are linearly distributed, homoscedasticity is met. ASSUMPTION MET.

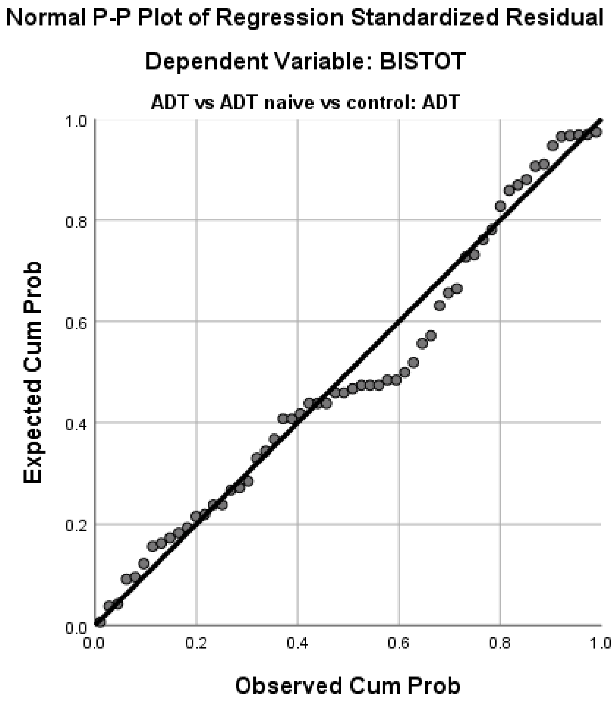
FNAE → MSES: ASSUMPTION MET



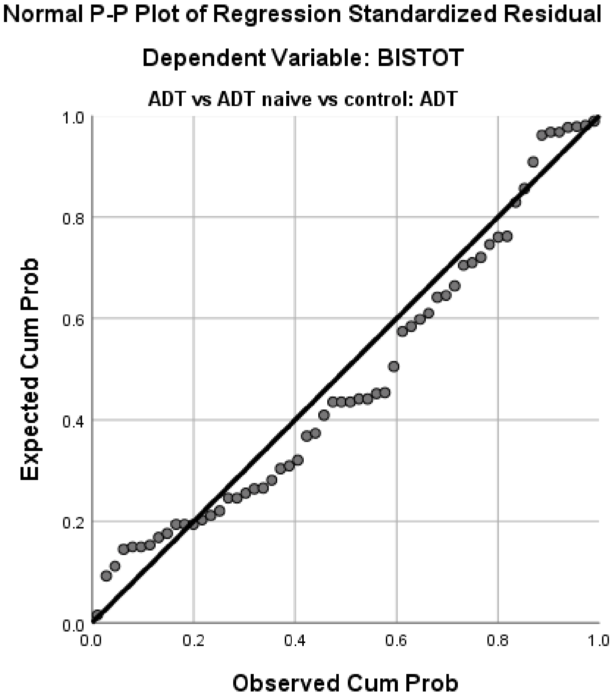
FNPPE → MSES: ASSUMPTION MET



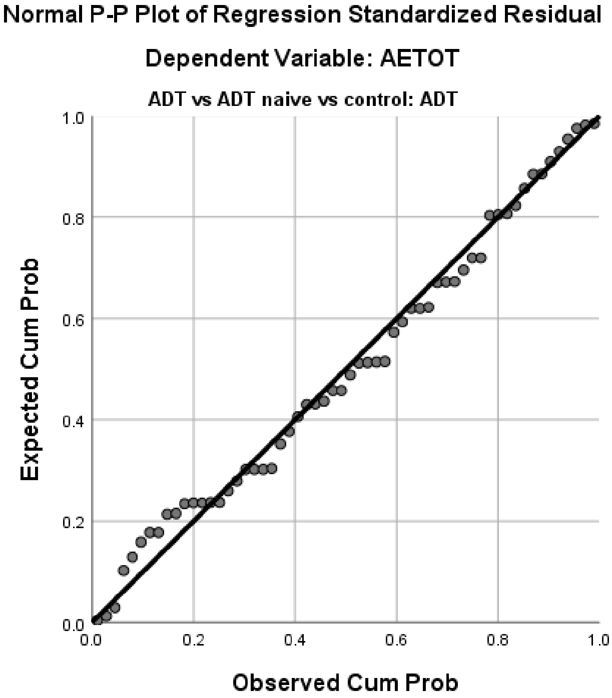
FNAE → BIS: ASSUMPTION MET



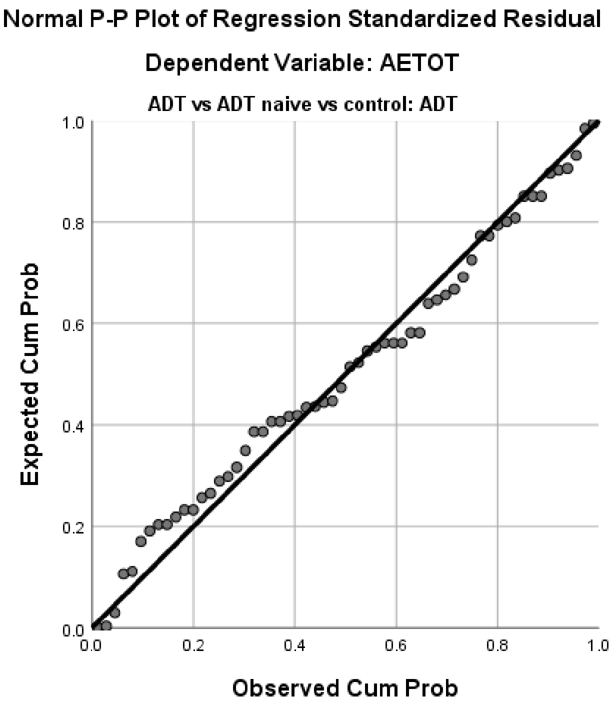
FNPPE → BIS: <u>ASSUMPTION MET</u>



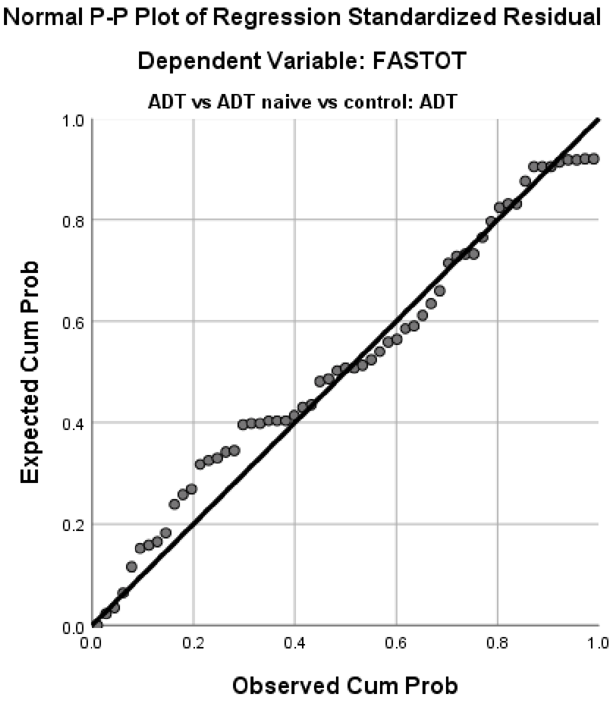
FNAE → AE: <u>ASSUMPTION MET</u>



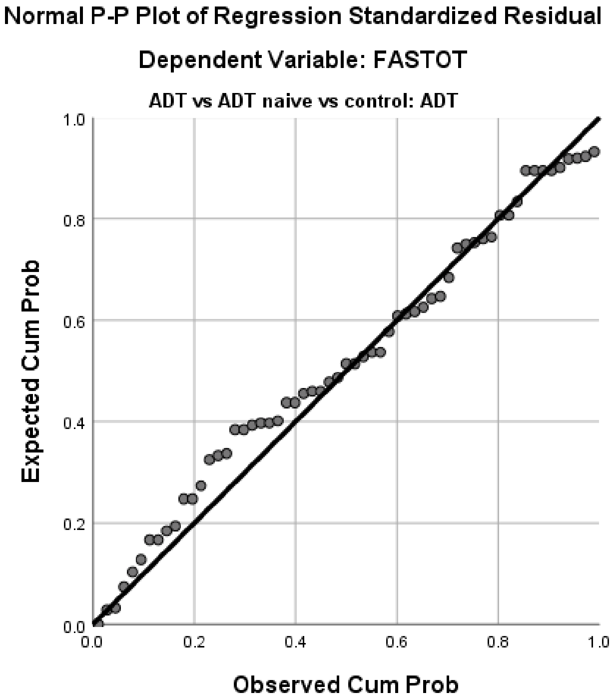
FNPPE → AE: <u>ASSUMPTION MET</u>



FNAE → FAS: <u>ASSUMPTION MET</u>



FNPPE → FAS: ASSUMPTION MET



B10) Summary of the results provided to charities and on social media

Biography

Caterina Gentili is a PhD student from the Centre for Appearance Research at the University of the West of England, Bristol (UK). Her work focuses on the psychological challenges that prostate cancer patients on ADT have to face daily. In particular, her research aims to shed more light on whether ADT side effects (like breast enlargement) might negatively affect patients' relationship with their bodies and self-confidence. Caterina is also interested in investigating whether exercise might help patients to feel better about themselves, improving both their psychological and physical health.

The study

With the help of Tackle Prostate Cancer, Caterina recently conducted a survey on ADT, exercise, and body image. Body image is the subjective evaluation that individuals make of their bodily appearance and functioning.

The survey was filled out by 60 PCa patients on ADT, 60 PCa patients who never followed ADT, and by 60 cancer-free men of the same age. The survey included several questionnaires, measuring body image, masculinity issues, exercise habits, and fear of being negatively judged for one's appearance and physical performance.

The author predicted that patients on ADT will suffer from higher body image concerns, will present higher fear of negative appearance and physical performance evaluation, and will more often face masculinity issues when compared to patients who never followed ADT and cancer-free men. When considering only patients on ADT, the author expected that fear of negative evaluation for appearance and physical performance would lead to stronger masculinity issues and body image. Caterina also predicted that lack of exercise would help maintain this negative circle.

Contrary to what the author expected, patients on ADT did not suffer from more body image concerns and fear of negative appearance and physical performance evaluation when compared to patients who never followed ADT and cancer-free men. This suggests that ADT is not linked to negative body image and that PCa patients tend to be resilient against body image issues. Future research should investigate the coping strategies that PCa patients naturally put in place to deal with the bodily transformations provoked by ADT.

As expected by the author, fear of negative evaluation for appearance and physical performance lead patients on ADT to suffer from stronger masculinity issues and body image. Future research should therefore explore strategies to help PCa patients avoid comparing themselves to others, as this would lead to poorer mental health outcomes. However, contrary to what was expected, lack of exercise did not contribute to maintain this negative circle.

B.10.1) Summary published on Prostate Matters (n.46)

Body image survey by Caterina Gentili

Caterina Gentili is a PhD student from the Centre for Appearance Research at the University of the West of England, Bristol.

Her work focuses on the psychological challenges that prostate cancer patients on ADT have to face daily. In particular, her research aims to shed more light on whether ADT side effects (such as breast enlargement) might negatively affect patients' relationship with their bodies, and their self-confidence.

Caterina is also interested in whether exercise helps patients to feel better about themselves, improving their psychological and physical health.

The study

With the help of Tackle Prostate Cancer, Caterina recently conducted a survey on ADT, exercise and body image. Body image is the subjective evaluation that people make of their bodily appearance and functioning.

The survey was filled out by 60 PCa patients on ADT, 60 PCa patients who never had ADT, and by 60 cancer-free men of the same age.

The survey included several questionnaires, measuring body image, masculinity issues, exercise habits, and fear of being negatively judged for one's appearance and physical performance.

UWE Bristol

Centre for Appearance Research

Would you like to help research improve prostate cancer patients' psychological health?

Caterina's predictions

Comparing the group of men on ADT with the other groups:
Caterina expected that patients on ADT would suffer from more body image concerns and would show greater fear of negative appearance and physical performance evaluation; and that these concerns would cause them to face more masculinity issues when compared to patients who never had ADT and the cancer-free men.

Looking at the group of men on ADT separately:
Caterina expected that men in this group who had a greater fear of negative evaluation for appearance and physical performance would have stronger masculinity issues and body image problems. She also predicted that lack of exercise would reinforce this negative circle.

Many thanks to everyone who contributed to this survey.

Results and further research

Comparing the groups:
What Caterina actually found was that patients on ADT did not suffer from more body image concerns and fear of negative appearance and physical performance evaluation compared to the other groups. So it seems that ADT is not directly linked to negative body image and that PCa patients tend to be resilient against these problems. Caterina feels that future research should investigate the coping strategies that PCa patients naturally put in place to deal with these issues.

The ADT group separately:
But when Caterina looked at this group separately, she found that IF they had high fear of negative appearance and physical performance evaluation, then they were more likely to suffer from masculinity issues and body image concerns. She therefore thinks that future research should explore strategies to help PCa patients avoid comparing themselves to others, as this could lead to poorer mental health outcomes.

However, she found that lack of exercise did not contribute to maintaining this negative circle.

Appendix C: Study 3

C1) Study 3 Ethical Approval

C1.1.) UWE Ethical Approval

Amendment to Existing Research Ethics Approval

Please complete this form if you wish to make an alteration or amendment to a study that has already been scrutinised and approved by the Faculty Research Ethics Committee and forward it electronically to the Officer of FREC (researchethics@uwe.ac.uk)

UWE research ethics reference number:	HAS.18.10.049 Gentili
Title of project:	*Exercise and body images issues in prostate cancer: comparing prostate cancer (PCa) patients undergoing androgen deprivation therapy (ADT), to ADT-naive PCa patients and age-matching controls*
Date of original approval:	*21 November 2018*
Researcher:	*Caterina Gentili, PhD candidate*
Supervisor (if applicable)	*Prof Diana Harcourt*

1. Proposed amendment: Please outline the proposed amendment to the existing approved proposal.

1. Extending the study until July 2020.

2. Stop administering the following questionnaires:
   - Multidimensional Body-Self Relations Questionnaire (Cash, 2015), Appearance Orientation Subscale (AO)
   - Fear of Negative Appearance Evaluation (Lundgren, Anderson, & Thompson, 2004)
   - Godin Leisure-Time Exercise Questionnaire (G-LTEQ) (Shephard, 1997)

3. Start administering the following questionnaires:
   - Brief COPE (Carver 1997): This is a 28-item inventory assessing 14 different coping dimensions: (1) active coping; (2) planning; (3) using instrumental support; (4) using emotional support; (5) venting; (6) behavioural disengagement; (7) self-distraction; (8) self-blame; (9) positive reframing; (10) humour; (11) denial; (12) acceptance; (13) religion; and (14) substance use. This scale was chosen as it has been used with prostate and breast cancer populations (Green et al. 2011). Each of the 14 subscales is comprised of 2

items; total scores on each scale range from 2 (minimum) to 8 (maximum). Higher scores indicate increased utilization of that specific coping strategy. Total scores on each of the scales are calculated by summing the appropriate items for each scale. No items are reverse scored. There is no overall total score, only total scores for each of the scales

- Additional qualitative open questions on coping strategies.
- Body Appreciation Scale-2 (Tylka, 2013): The scale is composed of 10 items to be rated on a 5-point Likert scale (1= never; 5= always). The global score consists of the mean score of all the items scores, with higher scores reflecting greater levels of body appreciation. The questionnaire measures positive attitudes towards one's own body (e.g., "I respect my body", "Despite its flaws, I accept my body for what it is"). The BAS-2 is internally consistent and presents good construct validity (Tylka & Wood-Barcalow, 2015).

(please find the complete overview of the new questionnaires items in a separate attachment)

4. Focusing on recruiting PCa patients on Androgen Deprivation Therapy (ADT) only (stop recruiting PCa patients who do not follow ADT and cancer-free men).
5. In addition to UWE ethical approval, we are planning to apply to NHS ethical approval as well.

2. Reason for amendment. Please state the reason for the proposed amendment.

1. After the analyses performed on the data collected up to June 2019 revealed mixed findings, we concluded that instead of beginning a new intervention study during Caterina Gentili's third PhD year, it would be more methodologically sound to carry on, deepen, and expand the data collection from Study 2 instead.

2. & 3. The analyses carried out up to June 2019 revealed that the variables measured by the questionnaires we are willing to stop using were not centrally relevant to the psychological experience of men living with prostate cancer and undergoing ADT. On the other hand, the preliminary results highlighted the need to collect some information around coping strategies and body appreciation.

4. Since the focus of Caterina Gentili's PhD is on the experience of living with the side effects of ADT, we would like to deepen and expand the findings of Study 2 for this specific subgroup. This will allow us to gather enough information around their psychological experience of diagnosis and treatment, which has been heavily overlooked by research so far. This will also help collect enough background for the design of future interventions.

5. Applying to NHS ethical approval as well will allow us to maximise data collection.

3. Ethical issues. Please outline any ethical issues that arise from the amendment that have not already addressed in the original ethical approval. Please also state how these will be addressed.

All the ethical issues are the same as the ones mentioned in the original ethical approval.

To be completed by supervisor/ Lead researcher:

Signature:	
Date:	*18th November 2019*

To be completed by Research Ethics Chair:

Send out for review:	☐ *Yes* ☐ *No x*
Comments:	*The ethical issues associated with these changes are almost identical to the original application so the amendment can be approved*
Outcome:	☐ *Approve x* ☐ *Approve subject to conditions* ☐ *Refer to Research Ethics Committee*
Date approved:	*20th November 2019*
Signature:	*Dr [redacted] (via e-mail)*

Guidance on notifying UREC/FREC of an amendment.

Your study was approved based on the information provided at the time of application. If the study design changes significantly, for example a new population is to be recruited, a different method of recruitment is planned, new or different methods of data collection are planned then you need to inform the REC and explain what the ethical implications might be. Significant changes in participant information sheets, consent forms should be notified to the REC for review with an explanation of the need for changes. Any other significant changes to the protocol with ethical implications should be submitted as substantial amendments to the original application. If you are unsure about whether or not notification of an amendment is necessary please consult your departmental ethics lead or Chair of FREC.

C1.2.) NHS Ethical Approval

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Professor Diana Harcourt
Director of the Centre for Appearance Research
University of the West of England
Centre for Appearance Research, Faculty of
[redacted]

Email: hra.approval@nhs.net
HCRW.approvals@wales.nhs.uk

27 February 2020

Dear Professor Harcourt

Study title:	**Investigating coping strategies associated with positive body image outcomes in men diagnosed with Prostate Cancer undergoing Androgen Deprivation Therapy (ADT).**
IRAS project ID:	**276095**
Protocol number:	**HAS-HSS-16-065**
REC reference:	**20/YH/0065**
Sponsor	**University of the West of England, Faculty of Health and Applied Sciences**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the “Information to support study set up” section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **276095**. Please quote this on all correspondence.

Yours sincerely,
[redacted]
Approvals Manager
Email: hra.approval@nhs.net

Copy to: [redacted] Sponsor Contact

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	***Version***	***Date***
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance / Indemnity Arrangements Assessed]	Version 1	25 February 2020
GP/consultant information sheets or letters [Consultant Invitation Letter]	Version 3	25 February 2020
IRAS Application Form [IRAS_Form_10022020]	N/A	10 February 2020
IRAS Application Form XML file [IRAS_Form_10022020]	N/A	10 February 2020
Letter from funder [Letter from Funder]	Version 1	06 March 2017
Other [Student DBS check]	Version 1	10 April 2018
Participant consent form [Consent Form]	Version 2	10 February 2020
Participant information sheet (PIS) [Participants Information Sheet]	Version 3	25 February 2020
Research protocol or project proposal [Research Proposal]	Version 2	10 February 2020
Summary CV for Chief Investigator (CI) [CV Chief Investigator]	Version 1	10 February 2020
Summary CV for student [CV student]	Version 1	10 February 2020
Validated questionnaire [Validated Questionnaire]	Version 2	25 February 2020

Information to support study set up

The below provides all parties with information to support the arranging and confirming of capacity and capability with participating NHS organisations in England and Wales. This is intended to be an accurate reflection of the study at the time of issue of this letter.

Types of participating NHS organisation	**Expectations related to confirmation of capacity and capability**	**Agreement to be used**	**Funding arrangements**	**Oversight expectations**	**HR Good Practice Resource Pack expectations**
There are no NHS research sites in this study, only NHS Participant Identification Centres (PICs).	Organisations will not be required to formally confirm capacity and capability, and research procedures may begin 35 days after provision of the local information pack, provided the ollowing conditions are met: -You have contacted participating NHS organisations (see below for details) -HRA and HCRW Approval has been issued -The NHS organisation has not provided a reason as to why they cannot participate	As the study only involves PICs, sites should make appropriate arrangements with the NHS trusts involved using the model PIC agreement available at https://www.myresearchproject.org.uk/help/hlpsitespecific.aspx#PIC	External study funding has been secured.	The Chief Investigator will be responsible for all study activities performed at PICs.	The sponsor has stated that local staff in participating organisations in England who have a contractual relationship with the organisation will undertake the expected activities. Therefore, no honorary research contracts or letters of access are expected for this study.

	-The NHS organisation has not requested additional time to confirm. You may start the research prior to the above deadline if HRA and HCRW Approval has been issued and the site positively confirms that the research may proceed. You should now provide the local information pack for your study to your participating NHS organisations. A current list of R&D contacts is accessible at the NHS R&D Forum website and these contacts MUST be used for this purpose. The password to access the R&D contact list is Redhouse1.				

Other information to aid study set-up and delivery

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales in study set-up.
The applicant has indicated they do not intend to apply for inclusion on the NIHR CRN Portfolio.

C2) Invitation Emails for Public and Patients Involvement

Dear (name of PPI participant),

I hope this email finds you well!

Firstly, I would like to thank you one more time for the help and feedback you gave to our online survey on prostate cancer, ADT and body image last year. Your suggestions were extremely helpful and they allowed us to improve the quality of our protocol so much! If you are interested, I could also send you a summary of the results study.

I am currently designing my third and last research, which will hopefully shed more light on some of the mixed findings that emerged so far. In particular, we are looking to explore not only body image issues when undergoing ADT, but also (on a more positive note) the coping strategies that men put in place when dealing with this treatment. We thought this would be an extremely valuable information to collect, as it would help us understand whether some strategies might work better than others and, consequently, what kind of support we could offer as psychologists.

As for Study 2, Study 3 will make use of questionnaires, which will be delivered both online and through the NHS. I am writing you this email because, as last year, I would like to collect some feedback from men diagnosed with prostate cancer on the pilot version of our survey. Given how helpful your contribution was for both our previous projects, I was wondering if you would be interested in sharing your opinion on the pilot of this third study as well.

I think your feedback would be of great help to make the design of our study more appropriate before starting data collection (for example: are the questionnaires relevant to you? Is the study too long/too brief/right length? Do you think my strategies to get in touch with patients are adequate? How would you advertise the study? etc. etc).

If you would be willing to give your contribution, please reply to this email and I will happily provide you with more details.

Thank you in any case for the time and energy you invested in our research so far!
Kindest regards,

Caterina Gentili

PhD candidate
PGR HAS FRDC representative
Faculty of Health and Applied Sciences
[redacted]

My pronouns are: she / her / hers

C3) Study 3 Qualtrics Survey

- Block: Information and Consent block (9 Questions)
- Branch: New Branch
  - If
    - If I agree to participate. No Is Selected
  - Block: Non-eligible block (1 Question)
  - EndSurvey:
- Branch: New Branch
  - If
    - If I agree to participate. Yes Is Selected
  - Block: Code and screening questions (6 Questions)
  - Branch: New Branch
    - If
      - If Preliminary screening questions We will now ask you a few questions to make sure that you are eli... No Is Selected
    - Block: Non-eligible block (1 Question)
    - EndSurvey:
  - Branch: New Branch
    - If
      - If Are you currently following hormonal therapy (also known as Androgen Deprivation Therapy or ADT)? No Is Selected
    - Block: Non-eligible block (1 Question)
    - EndSurvey:
  - Branch: New Branch
    - If
      - If Have you ever been diagnosed with a psychotic disorder or dementia? Yes Is Selected
    - Block: Non-eligible block (1 Question)
    - EndSurvey:
  - Branch: New Branch
    - If
      - If Are you between 35 and 80 years old? No Is Selected
    - Block: Non-eligible block (1 Question)
    - EndSurvey:
  - Block: Demographics block (13 Questions)
Block: Side effects measurement (3 Questions)
Block: Coping quantitative (1 Question)
Block: Coping Qualitative (4 Questions)
  - BlockRandomizer: 5 - Evenly Present Elements
    - Block: BIS (1 Question)
    - Block: BAS (1 Question)
    - Block: FAS (1 Question)
    - Block: MSES (1 Question)
    - Block: Appearance Investment (1 Question)
  - Block: End of Survey block (1 Question)
  - EndSurvey:

Information Sheet

This survey investigates your personal experience with hormonal therapy (Androgen Deprivation Therapy, or ADT). Please read the information sheet below Then, click to go to the next page where you will be asked to give your consent to take part. Afterwards, you will be asked to fill out some questions concerning your personal experience and well being while following ADT.
It usually takes 10 to 20 minutes to complete the survey.

Who can join?
You are invited to take part in this survey if you:
- Identify as male
- Are aged between 35 and 80
- Have received a diagnosis of prostate cancer
- Are currently following hormonal treatment
- Are able to complete this survey which is only available in English.

To thank you we will invite to join a prize draw for a chance to win £70 online shopping voucher.

Are there any risks? And what if I want to stop?
We do not believe that completing this survey poses any risks. However, we are aware that the topics it covers can be sensitive and emotive issues for some men. You can withdraw from the study at any time, up to two weeks after completion, without having to give a reason. You have the right to choose not to participate in this study.

Privacy
Your identity and any information you provide will be treated as confidential. Only the researchers involved in the study will have access to the information, which will be stored securely at all times. If you choose to enter the price draw we will ask for your contact details, but these will be kept separate to your data.

Ethical approval
This study has been approved by a Research Ethics Committee at the University of the West of England, Bristol (UK).

If you decide to participate, please:
- read each question carefully;
- answer the questions truthfully;
- keep in mind that there are no right or wrong answers;
- remember that all your data will be kept confidential and your identity will remain anonymous at all times.

If you want to get in touch, please contact:
Caterina Gentili, PhD researcher
caterina2.gentili@live.uwe.ac.uk
+44(0)1173282654
Centre for Appearance Research: https://www1.uwe.ac.uk/hls/research/appearanceresearch.aspx
University of the West of England, Bristol UK

To take part please click the "next" button you will find at the end of the page.
It looks like this:

****It is very important that you always remember to click the "next" button until the very end of the survey, otherwise we will lose all your data****

Consent Form

Please read carefully the statements and specify whether you agree (Yes) or disagree (No) with each of them. You will not be included in the study if you do not will to give your informed consent to participate.

I understand taking part will involve completing a survey on one occasion.

○ Yes (2)

○ No (3)

Q4 I have been provided information about the study.

○ Yes (1)

○ No (2)

Q5 I have read the information sheet.

○ Yes (1)

○ No (2)

Q6 I have had the opportunity to ask questions about the study and any questions I had, have been answered.

○ Yes (1)

○ No (2)

Q7 I have been able to think about my participation in the study, which is completely voluntary.

○ Yes (1)

○ No (2)

Q8 I understand that I have the right to withdraw my consent at any time before the beginning of the study and within two weeks after completing the survey, without having to give any reason.

○ Yes (1)

○ No (2)

Q9 I understand that I will not be named or identified in any report or presentation that comes from this study

○ Yes (1)

○ No (2)

Q10 **I agree to participate.**

○ Yes (1)

○ No (2)

Non-eligible block (only showed if participants did not meet the study inclusion criteria)

Thank you for your interest in our research.
Unfortunately you do not seem to meet the eligibility criteria for this study.
If you have any further question or comment, please get in touch with:
Caterina Gentili
PhD candidate at the Centre for Appearance Research (UWE Bristol)
[redacted]

One last thing before you go...
If there's anything related to your psychological wellbeing that is currently bothering you, please consult this list of organisations that you can contact if you would like any support or information. Alternatively, you can contact your GP for advice.

Men's Health Forum
24/7 stress support for men by text, chat and email
Website: www.menshealthforum.org.uk
NHS choices
Website: www.nhs.uk/conditions/prostate-cancer
Prostate Cancer UK
Phone: 0800 074 8383
Website: https:/prostatecanceruk.org/
Tackle Prostate Cancer
Phone: 0800 035 5302
Website: www.tackleprostatecancer.org
Samaritans
Confidential support for people experiencing feelings of distress or despair.
Phone: 116 123 (free 24-hour helpline)
Website: www.samaritans.org.uk

Study Questionnaire

Before you start, please create your participation code

It is important that you create your participation code because that will help the research team find your response in case you will wish to withdraw from the study within two weeks after completing this survey, while maintaining your complete anonymity.
Here's an example:
- first three letters of your mother's maiden name: e.g., Smiths = SMI
- last two digits of your year of birth: e.g., 1952 = 52
- first letter of your town of residence: e.g., Edinburgh = E

○ First three letters of your mother's maiden name (1) ________________________________

○ Last two digits of your year of birth (2) ________________________________

○ First letter of your town of residence (3) ________________________________

Preliminary screening questions

We will now ask you a few questions to make sure that you are eligible to participate in this study. Please read the questions carefully and answer truthfully.

Have you been diagnosed with prostate cancer?

○ Yes (1)

○ No (2)

Are you currently following hormonal therapy (also known as Androgen Deprivation Therapy or ADT)?

○ Yes (1)

○ No (2)

Have you ever been diagnosed with a psychotic disorder or dementia?

○ Yes (1)

○ No (2)

Are you between 35 and 80 years old?

○ Yes (1)

○ No (2)

Have you been diagnosed with any another condition that affects your day to day life?

○ Yes, I have been diagnosed with (1) ____

○ No (2)

Great you are eligible to participate in the survey! You will now be asked some questions about your personal experience and well-being while following hormonal therapy.

Please: always read the instructions before answering read each question carefully answer the questions truthfully keep in mind that there are no right or wrong answers; remember that all your data will be kept confidential and your identity will remain anonymous at all times.

Demographics

○ What is your age? (1) __

○ What is your nationality? (2) ____

How did you hear about this survey?

☐ through social media (1)

☐ through a charity (2)

☐ via friends and family (3)

☐ from the NHS (4)

What is the highest level of education you have completed?

○ Grammar School (1)

○ High school equivalent (2)

○ Vocational/ Technical school (3)

○ Some college (4)

○ Bachelor's degree (5)

○ Master's degree (6)

○ Doctoral's degree (7)

○ Other (8)

How would you classify yourself?

○ Asian/ Asian British/ Asian European/ Asian American (1)

○ Black/ African/ Caribbean/ Black British/ African American/ Black European (2)

○ Latino/ Hispanic (3)

○ White/ White British/ White European/ White American (4)

○ Multiple ethnic and cultural background (5)

○ Rather not say (6)

○ Any other ethnic background, please describe (7)
____

Q21 Please specify your ethnicity

How would you classify yourself? = White/ White British/ White European/ White American

☐ Northern European (1)

How would you classify yourself? = White/ White British/ White European/ White American

☐ Southern European (2)

How would you classify yourself? = White/ White British/ White European/ White American

☐ Eastern European (3)

How would you classify yourself? = White/ White British/ White European/ White American

☐ American (4)

How would you classify yourself? = White/ White British/ White European/ White American

☐ Australian (5)

How would you classify yourself? = White/ White British/ White European/ White American

☐ Irish (6)

How would you classify yourself? = White/ White British/ White European/ White American

☐ British (7)

How would you classify yourself? = White/ White British/ White European/ White American

☐ Canadian (8)

How would you classify yourself? = White/ White British/ White European/ White American

☐ Gypsy (9)

How would you classify yourself? = White/ White British/ White European/ White American

☐ Any other White background, please describe: (10) ____

How would you classify yourself? = Black/ African/ Caribbean/ Black British/ African American/ Black European

☐ African (11)

How would you classify yourself? = Black/ African/ Caribbean/ Black British/ African American/ Black European

☐ Caribbean (12)

How would you classify yourself? = Black/ African/ Caribbean/ Black British/ African American/ Black European

☐ African American (13)

How would you classify yourself? = Black/ African/ Caribbean/ Black British/ African American/ Black European

☐ Caribbean American (14)

How would you classify yourself? = Black/ African/ Caribbean/ Black British/ African American/ Black European

☐ African British (15)

How would you classify yourself? = Black/ African/ Caribbean/ Black British/ African American/ Black European

☐ Caribbean British (16)

How would you classify yourself? = Black/ African/ Caribbean/ Black British/ African American/ Black European

☐ African European (17)

How would you classify yourself? = Black/ African/ Caribbean/ Black British/ African American/ Black European

☐ Caribbean European (18)

How would you classify yourself? = Black/ African/ Caribbean/ Black British/ African American/ Black European

☐ Other Black/African/Caribbean background, please describe: (19)
____

How would you classify yourself? = Asian/ Asian British/ Asian European/ Asian American

☐ Indian (20)

How would you classify yourself? = Asian/ Asian British/ Asian European/ Asian American

☐ Pakistani (21)

How would you classify yourself? = Asian/ Asian British/ Asian European/ Asian American

☐ Bangladeshi (22)

How would you classify yourself? = Asian/ Asian British/ Asian European/ Asian American

☐ Malaysian (23)

How would you classify yourself? = Asian/ Asian British/ Asian European/ Asian American

☐ Indonesian (24)

How would you classify yourself? = Asian/ Asian British/ Asian European/ Asian American

☐ Chinese (25)

How would you classify yourself? = Asian/ Asian British/ Asian European/ Asian American

☐ Any other Asian background (26)
____

Are you in a committed and supportive romantic relationship?

○ Yes (1)

○ No (2)

○ Rather not say (3)

What is your sexual orientation?

○ Heterosexual (1)

○ Homosexual (2)

○ Bisexual (3)

○ Asexual/Greysexual (4)

○ Other (5)

○ Rather not say (6)

Which of the following best describes the area you live in?

○ Urban (1)

○ Suburban (2)

○ Rural (3)

Who do you usually live with?

☐ Partner (1)

☐ Children (2)

☐ Nobody, I live alone (4)

☐ Relatives other than partner and children (5)

☐ Friends (6)

☐ Other (7)

When were you diagnosed with prostate cancer?

○ month (1) ____

○ year (2) ____

When did you start taking hormonal therapy/Androgen Deprivation Therapy (ADT)?

○ year (1) ____

○ month (2) ____

○ Would you like to add any further information? (3) ____

In addition to hormonal therapy, have you undergone any other treatments for prostate cancer?

☐ None (1)

☐ Surgery (2)

☐ Radiotherapy (3)

☐ Brachytherapy (4)

☐ Chemotherapy (5)

☐ Radium-223 (6)

☐ Active surveillance / watchful waiting (7)

Side Effects Assessment

We'd like to know more about your personal experience with hormonal treatment.
Hormonal therapy is a very common treatment for prostate cancer. However, its side effects can have an impact on the way your body looks and functions. For example it can sometimes cause weight gain, breast enlargement, erectile dysfunction, incontinence, fatigue, hot flushes, etc.
We would like to better understand how patients feel about these side effects. Most importantly, we want to learn more about what patients do in order to carry on in their daily life despite the changes they might be experiencing in the way their bodies look and function.
Which of the following ADT side effects are you experiencing? You can select as many as are relevant to you.

☐ weight gain (1)

☐ breast enlargement (2)

☐ incontinence (3)

☐ fatigue (4)

☐ erectile dysfunction and sexual issues (5)

☐ hot flushes (6)

☐ loss of body hair (7)

☐ cognitive side effects (10)

☐ mood swings (11)

☐ other changes you want to add (8) ____

☐ no side effects at all (9)

To what extent have these changes bothered you?
For each of the changes that you are experiencing, please select a number from 0 to 10 that best describes how much each side effect bothers you.

	does not bother me at all bothers me a lot
	0 1 2 3 4 5 6 7 8 9 10
weight gain ()	
breast enlargement ()	
incontinence ()	
fatigue ()	
erectile dysfunction and sexual issues ()	
hot flushes ()	
loss of body hair ()	
cognitive side effects ()	
mood swings ()	
other changes you added ()	

If there is anything else you would like to add about the side effects you have experienced, please do so in the following box.

____

Brief COPE

We would like to know what you usually do to manage the side effects that bother you the most. Thinking of the changes to your body that you just described as the most bothering for you, please indicate how often you have used each of the following strategies to feel better and carry on with your daily life. Remember there are no right or wrong answers. Your identity will be anonymous at all times.

	1 = never (1)	2 = rarely (2)	3 = sometimes (3)	4= a lot (7)
turning to work or other activities to take my mind off things. (1)	○	○	○	○
concentrating my efforts on doing something about the situation I'm in. (2)	○	○	○	○
saying to myself, this isn't real. (3)	○	○	○	○
using alcohol to make myself feel better. (4)	○	○	○	○
getting emotional support from others. (5)	○	○	○	○
giving up trying to deal with it. (6)	○	○	○	○
taking action to try to make the situation better. (7)	○	○	○	○
refusing to believe that it has happened. (8)	○	○	○	○
saying things to let my unpleasant feelings escape. (9)	○	○	○	○
getting help and advice from other people. (10)	○	○	○	○
using some drugs to help me get through it. (11)	○	○	○	○
trying to see it in a different light, to make it seem more positive. (12)	○	○	○	○
criticizing myself. (13)	○	○	○	○
trying to come up with a strategy about what to do. (14)	○	○	○	○
getting comfort and understanding from someone. (15)	○	○	○	○
giving up the attempt to cope. (16)	○	○	○	○

looking for something good in what is happening. (17)	○	○	○	○
making jokes about it. (18)	○	○	○	○
doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping. (19)	○	○	○	○
accepting the reality of the fact that it has happened. (20)	○	○	○	○
expressing my negative feelings. (21)	○	○	○	○
find comfort in my religion or spiritual beliefs. (22)	○	○	○	○
trying to get advice or help from other people about what to do. (23)	○	○	○	○
learning to live with it. (24)	○	○	○	○
thinking hard about what steps to take. (25)	○	○	○	○
blaming myself for things that happened. (26)	○	○	○	○
praying or meditating. (27)	○	○	○	○
making fun of the situation. (28)	○	○	○	○

Coping Strategies: Qualitative Assessment

Please don’t worry about language style and spelling mistakes. We are simply interested in your own personal perspective on this topic as there are no better experts than patients.

Thinking of the changes to your body provoked by ADT that bother you the most, are there specific **activities** that help you feel better about your body? Please list them in the box below.

____

Display This Question:

If If Please don’t worry about language style and spelling mistakes. We are simply interested in your own personal perspective on this topic as there are no better experts than patients. Thinking of... Text Response Is Not Empty

Q34 Please explain why or how the activities you just have mentioned above help you feel better about your body.

____

Q71 Thinking of the changes to your body provoked by ADT that bother you the most, are there specific thoughts that help you feel better about your body? Please list them in the box below.

____

Display This Question:

If If Thinking of the changes to your body provoked by ADT that bother you the most, are there specific thoughts that help you feel better about your body? Please list them in the box below. Text Response Is Not Empty

Q72 Please explain why or how the thoughts you have mentioned above help you feel better about your body.

____

Body Image Scale for Cancer Patients

Please indicate the degree to which you agree with each of the following statements. Remember there are no right or wrong answers.

Since cancer treatment/diagnosis, how much have you felt...

	0= not at all (1)	1= a little bit (2)	2= quite a bit (3)	3= very much (4)
self conscious (1)	○	○	○	○
less physically attractive (2)	○	○	○	○
dissatisfied with your appearance (3)	○	○	○	○
less masculine (4)	○	○	○	○
that it was difficult to see yourself naked (5)	○	○	○	○
less sexually attractive (6)	○	○	○	○
like avoiding people (7)	○	○	○	○
you body was less whole (8)	○	○	○	○
dissatisfied with your body (9)	○	○	○	○
dissatisfied with any scar (10)	○	○	○	○

Body Appreciation Scale

Please indicate the degree to which you agree with each of the following items. Remember there are no right or wrong answers.

	1 never (1)	2 seldom (2)	3 sometimes (3)	4 often (4)	5 always (5)
I respect my body. (1)	○	○	○	○	○
I feel good about my body. (2)	○	○	○	○	○
I feel that my body has at least some good qualities. (3)	○	○	○	○	○
I take a positive attitude towards my body. (4)	○	○	○	○	○
I am attentive to my body's needs. (5)	○	○	○	○	○
I feel love for my body. (6)	○	○	○	○	○
I appreciate the different and unique characteristics of my body. (7)	○	○	○	○	○
My behavior reveals my positive attitude towards my body; for example, I hold my head high and smile. (8)	○	○	○	○	○
I am comfortable in my body. (9)	○	○	○	○	○
I feel like I am beautiful even if I am different from media images of attractive people. (10)	○	○	○	○	○

Functionality Appreciation Scale

Q45 Please indicate the degree to which you agree with each of the items. Remember there are no right or wrong answers.

	1 strongly disagree (1)	2 disagree (2)	3 neutral (3)	4 agree (4)	5 strongly agree (5)
I appreciate my body for what it is capable of doing. (1)	○	○	○	○	○
I am grateful for the health of my body, even if it isn’t always as healthy as I would like it to be. (2)	○	○	○	○	○
I appreciate that my body allows me to communicate and interact with others. (3)	○	○	○	○	○
I acknowledge and appreciate when my body feels good and/or relaxed. (4)	○	○	○	○	○
I am grateful that my body enables me to engage in activities that I enjoy or find important. (5)	○	○	○	○	○
I feel that my body does so much for me. (6)	○	○	○	○	○
I respect my body for the functions that it performs. (7)	○	○	○	○	○

Masculine Self-Esteem Scale

Please indicate the degree to which you agree with each of the following statements. Remember there are no right or wrong answers.

Since cancer treatment and diagnosis, do you ever feel:

	1 never (1)	2 seldom (2)	3 sometimes (3)	4 often (4)	5 always (5)
not a proper man? (1)	○	○	○	○	○
lacking in masculinity? (2)	○	○	○	○	○
not the man you should be? (3)	○	○	○	○	○
that others think you are not manly enough? (4)	○	○	○	○	○
weak and small? (5)	○	○	○	○	○
compared unfavorably to other men? (6)	○	○	○	○	○
it's hard to think coolly and logically as expected from a man? (7)	○	○	○	○	○

Appearance Orientation Scale (Covariate)

Please indicate the degree to which you agree with each of the following statements. Remember there are no right or wrong answers.

	1= definitely disagree (1)	2= mostly disagree (2)	3= don't agree nor disagree (3)	4= mostly agree (4)	5= definitely agree (5)
Before going out in public, I always notice how I look. (1)	○	○	○	○	○
I am careful to buy clothes that will make me look my best. (2)	○	○	○	○	○
I check my appearance in a mirror whenever I can. (3)	○	○	○	○	○
Before going out, I usually spend a lot of time getting ready. (4)	○	○	○	○	○
It is important that I always look good. (5)	○	○	○	○	○
I use very few grooming products. (6)	○	○	○	○	○
I am self-conscious if my grooming isn't right. (7)	○	○	○	○	○
I usually wear whatever is handy without caring how it looks. (8)	○	○	○	○	○
I don't care what people think about my appearance. (9)	○	○	○	○	○
I take special care with my hair grooming. (10)	○	○	○	○	○
I never think about my appearance. (11)	○	○	○	○	○
I am always trying to improve my physical appearance. (12)	○	○	○	○	○

End of Survey

We want to thank for taking part in this study and for completing all the questions!
Your help is indispensable for our research.
One last thing before you go...
We are aware that the topics covered in the study can be sensitive and emotive issues for some men. If any of the topics included in the questionnaire raised issues for you, please consult this list of organisations that can offer support or information. Alternatively, you can contact your GP for advice.

Men's Health Forum
24/7 stress support for men by text, chat and email
Website: www.menshealthforum.org.uk

NHS choices
Website: www.nhs.uk/conditions/prostate-cancer

Prostate Cancer UK
Phone: 0800 074 8383
Website: https:/prostatecanceruk.org/

Tackle Prostate Cancer
Phone: 0800 035 5302
Website: www.tackleprostatecancer.org

Samaritans
Confidential support for people experiencing feelings of distress or despair.
Phone: 116 123 (free 24-hour helpline)
Website: www.samaritans.org.uk

Please use the box below if there is anything else you would like to let us know.

____

C4) Survey advertisement

C4.1) Facebook post example:

Hello and thank you for accepting me in your group! I hope it's okay to tell you about my study on well-being while following hormonal therapy here. You guys were so helpful with our previous study and with this one so far, that I thought to share again. If not, please let me know and I'll remove the post immediately.

My name is Caterina Gentili, and I'm a PhD researcher from the University of the West of England in Bristol, UK. At UWE, we are conducting a study on well being and coping strategies while following hormonal therapy. We'd like to learn from patients what strategies work best when dealing with the challenges of diagnosis and treatment. We hope that the results will help us improve the currently available services.

The study consists of an online survey, taking only 10-20 minutes, which you can access following this link: http://survey.social/prostatecancer

As a thank you for taking part, you will get the chance to win a £70 online shopping voucher.

If you would like to have any further information, please contact me at:

Email: [redacted]

Phone: +[redacted]

Thank you all so much for your help!

C4.2) Information for recruitment through Charities

Living well during hormonal therapy

You are invited to take part in a survey exploring how those undergoing androgen deprivation therapy cope with the bodily changes proved by the treatment.

Researchers at the Centre for Appearance Research at the University of the West of England in Bristol are conducting this study. Before you decide whether to take part, it is important for you to understand why the study is being done and what it will involve. Please read the following information carefully and if you have any queries or would like more information please contact the lead researcher Caterina Gentili, Centre for Appearance Research, University of the West of England, Bristol via email ([redacted]) or telephone [redacted])
This study is an online study about men's health directed at men diagnosed with prostate cancer undergoing hormonal therapy (androgen deprivation therapy) younger than 75 years old. The study is part of a PhD which is funded with the support of the Above and Beyond charity.

What is the aim of the research?

This survey investigates various aspects of men's health and wellbeing while following hormonal therapy.

Why have I been invited to take part?

Everyone between the age of 35 and 75 years old who received a diagnosis of prostate cancer and is currently undergoing androgen deprivation therapy has been invited to take part.

What will participation involve?

Participation will involve completing a questionnaire about your personal experience with hormonal therapy and how you think and feel about your body, on paper or online. If you'd like to participate online, you will just have to follow this link:
[redacted]

If you'd rather use the paper questionnaire contained in this pack, please return it using the pre-addressed and pre-stamped envelope.

The survey will be entirely in English. We will first ask you to carefully read and fill out an informed consent, which will explain how your data will be treated. Afterwards, you will be asked to fill out some questionnaires concerning your personal experience with hormonal treatment and how you think and feel about your body. The study will only take a single session, which will last about **30 minutes**.

Do I have to take part?

You do not have to take part in this research. It is up to you to decide whether or not you want to be involved, this will not affect your clinical care. If you do decide to take part, you should keep this information sheet and we will also ask you to provide consent to take part before you complete the questionnaire.

Can I withdraw?

You can stop being part of the study at any time, without giving a reason. You can ask to withdraw your data until 2 weeks after completing the questionnaire by contacting Caterina Gentili using the contact details below. After this time, your answers will have been analysed and it will not be possible to remove them from the study. You do not have to give a reason why you wish to withdraw and your recorded answers will be deleted.

What will happen to the information I provide?

We need to use information from you for this research project. This information will be completely anonymous (i.e., it will not include your name or contact details).

Your data will have a code number instead. The data collected will only be accessible to those working on the study. The information on your experience with hormonal therapy and on how you think and feel about your body will ONLY been seen by researchers at the Centre for Appearance Research, and not your health care professionals team. Therefore, this research will not affect your clinical care and any information you provide will be held in the strictest of confidence. Any information that identifies you, will be separated from the information you provide.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

All data from this research project will be deleted permanently five years after the project has ended.

Where can you find out more about how your information is used?

The information you provide will be treated in accordance with the Data Protection Act 2018 at all times You can find out more about how we use your information

- In UWE's privacy notice attached to this information sheet
- By contacting the lead researcher Caterina Gentili, Centre for Appearance Research, University of the West of England, Bristol via email [redacted] or telephone [redacted].

Where will the results of the research be published?

A report will be written containing our research findings and will be available on the University of the West of England's open-access Research Repository. If you will choose to participate, rest assured that your identity will be kept anonymous at all times. In addition, results will be published in an academic journal (or elsewhere) and in Caterina Gentili's PhD thesis. The results will also be presented at conferences.

Ethical approval

This study has been approved by a Research Ethics Committee at the University of the West of England, Bristol (UWE).

What are the potential advantages and disadvantages of taking part?

The present study aims at better understanding the experience of men diagnosed with prostate cancer who are undergoing hormonal therapy. We know that the side effects of hormonal therapy can alter the way one's body looks and function, but there is a lack of research investigating how men cope with these changes on a day to day basis. Participating in this survey will allow you to contribute to a research program that we hope will inform the development of resources to better support those prostate cancer patients who struggle while following hormonal therapy.

We do not believe that taking part in this study poses any risks. However, we are aware that the topics covered in the study can be sensitive and emotive issues for some men. You are free to stop your participation, with no need to provide a reason. In particular, you have the right to withdraw from the study at any time before and during the study and within two weeks after the study completion, without having to give a reason. You have the right to choose not to participate in this study. In this information sheet you will find a list organisations that you can contact if this study raises any issues for you, or if you would like any support or information about how to deal with prostate cancer and body image concerns (please see below).

How do I take part?

If you would like to fill out the questionnaire online, you can follow this link:

[redacted]

Alternatively, you can fill out the paper questionnaire included in this pack and return it in the prepaid and pre-addressed envelope which is also included in this pack. Please post back the questionnaire within 1 week after receiving this pack.

If you have any question, you can contact Caterina Gentili ([redacted]

To thank you

As a thank you for taking part in this study, you will have the chance to enter a draw to win a £70 online shopping voucher.

If you will participate in the online version of the questionnaire, you will be directed to a separate page where you will be able to submit your email address to participate in the raffle. Your email address will be stored separately from the rest of your data.

If you will participate in the paper questionnaire, you will be able to write your email address to take part in the raffle on a separate sheet included in this pack. Your email address will be stored separately from your questionnaire, so that your responses will remain anonymous at all times.

Contacts for further information

If you need further information about this research study, or have any questions, please contact the lead researcher Caterina Gentili at caterina2.gentili@live.uwe.ac.uk, telephone: +44 (0)1173282654

Support Services

This is a list of organisations that you can contact if this study raises any issues for you, or if you would like any support or information about how to deal with prostate cancer and body image concerns. Alternatively, you can contact your GP for advice.

- **Men's Health Forum**

24/7 stress support for men by text, chat and email.
www.menshealthforum.org.uk

- **Prostate Cancer UK**

https://prostatecanceruk.org/
0800 074 8383

- **NHS choices**

https://www.nhs.uk/conditions/prostate-cancer/

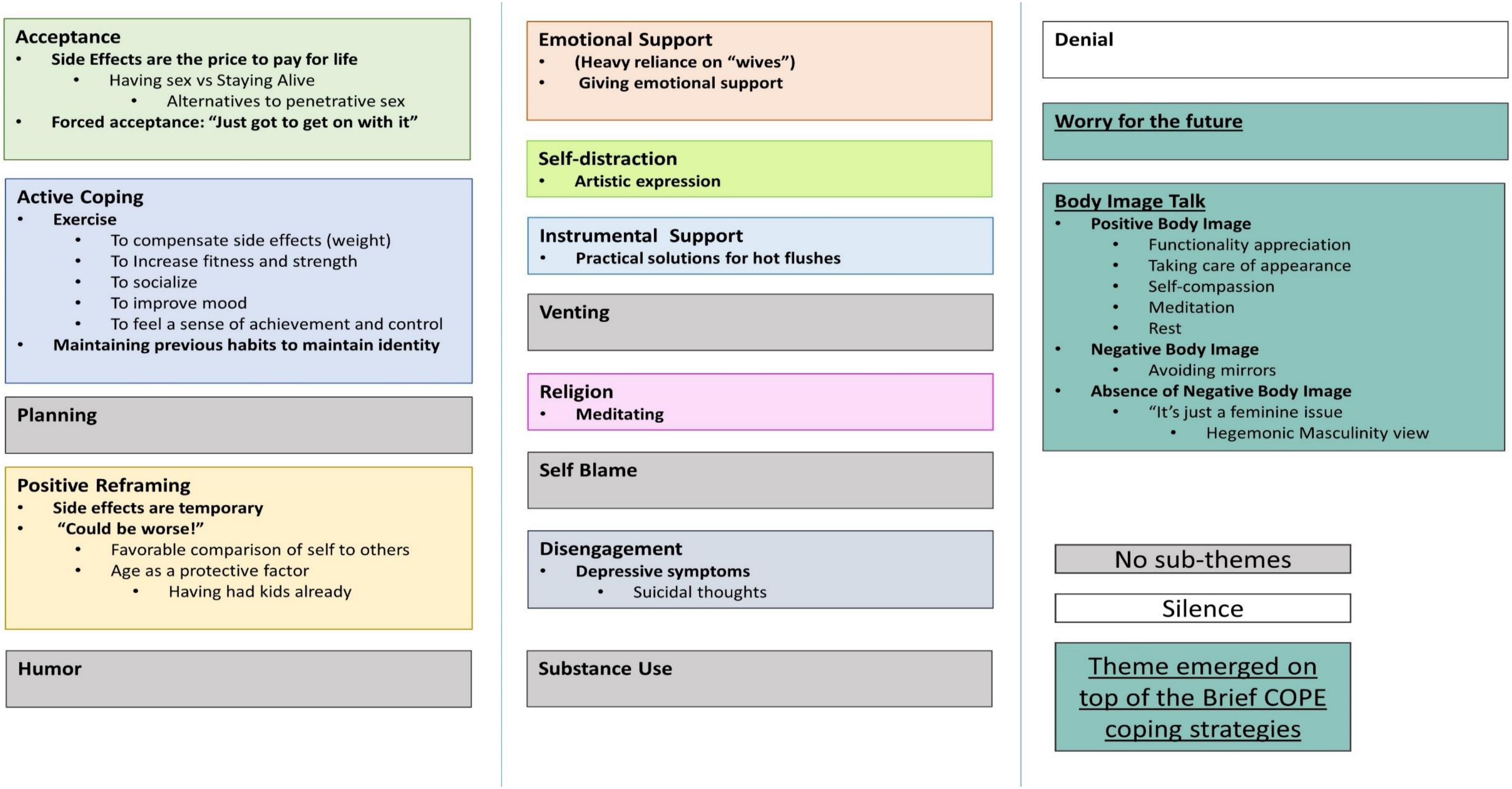
- **Tackle Prostate Cancer**

http://www.tackleprostate.org/
0800 035 5302

- **Samaritans**

Confidential support for people experiencing feelings of distress or despair.
116 123 (free 24-hour helpline)
www.samaritans.org.uk

C5) Themes map



Acceptance
- Side Effects are the price to pay for life
    - Having sex vs Staying Alive
        - Alternatives to penetrative sex
- Forced acceptance: "Just got to get on with it"

Active Coping
- Exercise
    - To compensate side effects (weight)
    - To Increase fitness and strength
    - To socialize
    - To improve mood
    - To feel a sense of achievement and control
- Maintaining previous habits to maintain identity

Planning

Positive Reframing
- Side effects are temporary
- "Could be worse!"
    - Favorable comparison of self to others
    - Age as a protective factor
        - Having had kids already

Humor

Emotional Support
- (Heavy reliance on "wives")
- Giving emotional support

Self-distraction
- Artistic expression

Instrumental Support
- Practical solutions for hot flushes

Venting

Religion
- Meditating

Self Blame

Disengagement
- Depressive symptoms
    - Suicidal thoughts

Substance Use

Denial

Worry for the future

Body Image Talk
- Positive Body Image
    - Functionality appreciation
    - Taking care of appearance
    - Self-compassion
    - Meditation
    - Rest
- Negative Body Image
    - Avoiding mirrors
- Absence of Negative Body Image
    - "It's just a feminine issue
        - Hegemonic Masculinity view

No sub-themes

Silence

Theme emerged on top of the Brief COPE coping strategies