

**Men's Experiences and Management  
Strategies Following Treatment for  
Prostate Cancer**

THESIS

PRESENTED FOR THE DEGREE OF

DOCTOR OF PHILOSOPHY

BY

Richard John Green

ROYAL HOLLOWAY AND BEDFORD NEW COLLEGE

UNIVERSITY OF LONDON

2017

## **Declaration of Authorship**

I Richard Green hereby declare that this thesis and the work presented in it is entirely my own. Where I have consulted the work of others, this is always clearly stated.

Signed: .....

Date: .....

## **Abstract**

Prostate cancer is the most commonly diagnosed cancer in men in the UK. Survival rates are high yet side effects from treatments are common and can persist for many years after treatment. Sociological scholarship has posited that cancer has chronic dimensions and recent work has sought to conceptualise prostate cancer as a chronic illness. This research examines men's chronic illness experiences following treatment for prostate cancer and how men seek to manage these experiences.

Qualitative interviews with 29 men who have been treated for prostate cancer were undertaken. These men, aged 53-83 years, were recruited from two prostate cancer support groups (PCSGs) in South-East England. Men's prostate cancer experiences, from pre-diagnosis onwards, were explored within the broader context of men's health, employment, and family lives.

This research identified chronic illness dimensions in men's accounts. Men experienced uncertainties about the fear of cancer recurring, the fear of having made the 'right' choice in opting for treatment, and how to manage ongoing cancer treatment side effects. Men commonly experienced urinary incontinence (UI) and erectile dysfunction (ED) following treatment, both conditions that posed challenges to their masculine identities.

In response, men employed vigilance strategies to manage their uncertainties. They acquired specialist prostate cancer expertise, facilitated by PCSG attendance, to manage uncertainties and maintain masculinity. Strategies to manage UI required planning and constant body attention to engage in public, thereby demonstrating masculinity to others, but were a strain on men's lives, requiring concessions to their activities. Men also sought to normalise prostate cancer by minimising its impact on their lives and by comparing themselves with others. These normalising strategies emphasised men's moral statuses, through values of stoicism and responsibility, to preserve masculinities threatened by illness. These findings contribute to sociological literature on masculinities and how they are maintained following onset of illness.

# Contents

<b>Declaration of Authorship .....</b>	<b>2</b>
<b>Abstract.....</b>	<b>3</b>
<b>Contents .....</b>	<b>4</b>
<b>List of Figures .....</b>	<b>8</b>
<b>List of Tables.....</b>	<b>8</b>
<b>List of Abbreviations .....</b>	<b>9</b>
<b>Acknowledgements.....</b>	<b>10</b>
<b>Chapter One: Introduction.....</b>	<b>12</b>
<b>1.1 Prostate Cancer – Medical Overview .....</b>	<b>12</b>
1.1.1 Pathogenesis, Known Risk Factors, and Incidence .....	13
1.1.2 Diagnosis .....	16
1.1.3 Screening and Surveillance Options.....	20
1.1.4 Treatment Options .....	23
1.1.5 Quality of Life Following Treatment.....	26
1.1.6 After Care and Support Groups .....	28
<b>1.2 Focus of the Study .....</b>	<b>30</b>
<b>1.3 Aims and Methodology .....</b>	<b>30</b>
<b>1.4 Structure of the Thesis.....</b>	<b>33</b>
<b>Chapter Two: The Experience and Management of Chronic Illness .....</b>	<b>35</b>
<b>2.1 Introduction.....</b>	<b>35</b>
<b>2.2 Biographical Disruption.....</b>	<b>37</b>
<b>2.3 Risk, Uncertainty, and Vigilance .....</b>	<b>38</b>
<b>2.4 Patient Expertise .....</b>	<b>41</b>
<b>2.5 Stigma.....</b>	<b>46</b>
<b>2.6 Managing Chronic Illness .....</b>	<b>48</b>
<b>2.7 Morality, Healthicization, and Moral Repertoires .....</b>	<b>51</b>
<b>2.8 Conclusion.....</b>	<b>55</b>
<b>Chapter Three: Masculinities and Prostate Cancer.....</b>	<b>58</b>
<b>3.1 Introduction.....</b>	<b>58</b>
<b>3.2 Connell’s Theory of Masculinities.....</b>	<b>59</b>
<b>3.3 Criticisms of Connell.....</b>	<b>62</b>
<b>3.4 Masculinities, the Body, and Embodiment.....</b>	<b>65</b>
<b>3.5 Masculinities and Ageing .....</b>	<b>72</b>
<b>3.6 Health, Illness, and Embodied Masculinities.....</b>	<b>74</b>
<b>3.7 Prostate Cancer, Masculinities, and Gender Relations .....</b>	<b>81</b>
3.7.1 Power Relations.....	81
3.7.2 Production Relations.....	84

3.7.3	Cathexis Relations.....	85
3.7.4	Symbolic Relations .....	87
<b>3.8</b>	<b>Conclusion.....</b>	<b>90</b>
<b>Chapter Four: Methodology.....</b>		<b>93</b>
<b>4.1</b>	<b>Introduction.....</b>	<b>93</b>
<b>4.2</b>	<b>Research Design .....</b>	<b>93</b>
4.2.1	Qualitative Interviewing.....	95
<b>4.3</b>	<b>Ethics .....</b>	<b>96</b>
<b>4.4</b>	<b>Sampling.....</b>	<b>99</b>
4.4.1	Recruitment from Support Groups.....	101
4.4.2	Sample Characteristics .....	103
<b>4.5</b>	<b>Data Collection.....</b>	<b>107</b>
4.5.1	Conducting Interviews .....	107
4.5.2	Masculinity within Interviews.....	110
<b>4.6</b>	<b>Analysis.....</b>	<b>116</b>
<b>4.7</b>	<b>Conclusion.....</b>	<b>119</b>
<b>Chapter Five: Managing Uncertainties following Treatment for Prostate Cancer.....</b>		<b>120</b>
<b>5.1</b>	<b>Introduction.....</b>	<b>120</b>
<b>5.2</b>	<b>Surveillance, Uncertainty, and Opting for Treatment.....</b>	<b>123</b>
<b>5.3</b>	<b>Common Uncertainties following Treatment for Prostate Cancer.....</b>	<b>129</b>
5.3.1	Fear of Cancer Recurrence: Interpreting PSA Test Results .....	129
5.3.2	Fear of Cancer Recurrence: Interpreting Bodily Sensations.....	131
5.3.3	Treatment Side Effects.....	134
5.3.4	Making the 'Right' Choice .....	136
<b>5.4</b>	<b>Management Strategies for Post-Treatment Uncertainties ....</b>	<b>139</b>
5.4.1	Reinterpreting Biomedical Knowledge .....	139
5.4.2	Planning for Future Uncertain Events .....	144
5.4.3	Support Groups as Vigilance Networks.....	147
<b>5.5</b>	<b>Conclusion.....</b>	<b>149</b>
<b>Chapter Six: Acquiring and Using Patient Expertise.....</b>		<b>154</b>
<b>6.1</b>	<b>Introduction.....</b>	<b>154</b>
<b>6.2</b>	<b>Specialist Prostate Cancer Expertise .....</b>	<b>156</b>
6.2.1	Contributory Expertise.....	157
6.2.2	Interactional Expertise and Special Interactional Expertise.....	161
<b>6.3</b>	<b>Factors Facilitating the Acquisition of Specialist Expertise for Prostate Cancer .....</b>	<b>166</b>
6.3.1	Referred Expertise.....	167
6.3.2	Having a Technical Interest.....	171

6.4	<b>Communal Licensing and Sharing Prostate Cancer Expertise</b> .....	174
6.5	<b>Conclusion</b> .....	181
<b>Chapter Seven: The Experience and Management of Urinary Incontinence and Erectile Dysfunction</b> .....		
	<b>7.1 Introduction</b> .....	185
	<b>7.2 Experiences of Urinary Incontinence</b> .....	188
	<b>7.3 Management Strategies for Urinary Incontinence</b> .....	190
	7.3.1 Self-Monitoring as a Balancing Act.....	190
	7.3.2 Negotiating Public Spaces .....	196
	<b>7.4 Experiences of Erectile Dysfunction</b> .....	199
	<b>7.5 Attempted Management Strategies for Erectile Dysfunction</b> .....	201
	<b>7.6 Embodied Masculinity as a Facilitator and Barrier to Managing Treatment Side Effects</b> .....	203
	<b>7.7 Conclusion</b> .....	209
<b>Chapter Eight: Normalising the Impact of Prostate Cancer</b> .....		
	<b>8.1 Introduction</b> .....	212
	<b>8.2 Social Actors</b> .....	214
	8.2.1 Other Men Attending a Support Group.....	214
	8.2.2 Other Men Outside of Support Groups.....	216
	8.2.3 Wives.....	219
	8.2.4 Children of Divorced or Widowed Men.....	223
	<b>8.3 Common Discourses for Minimising the Impact of Treatment Side Effects</b> .....	226
	8.3.1 The Ageing Discourse.....	227
	8.3.2 The Chance Discourse.....	230
	8.3.3 The Choosing Life Discourse.....	233
	<b>8.4 Conclusion</b> .....	238
<b>Chapter Nine: Discussion and Conclusion</b> .....		
	<b>9.1 Introduction</b> .....	242
	<b>9.2 Key Findings</b> .....	242
	9.2.1 Uncertainties and Uncertainty Management.....	243
	9.2.2 Patient Expertise .....	245
	9.2.3 The Experience and Management of Treatment Side Effects ...	248
	9.2.4 Normalising Prostate Cancer.....	251
	<b>9.3 Contribution to Sociological Knowledge</b> .....	255
	9.3.1 Theorising Vigilance .....	256
	9.3.2 Determining Expert Status .....	257
	9.3.3 Preserving Moral Status.....	261
	9.3.4 Moral Positioning to Preserve Masculinity.....	263

9.3.5	Maintaining Masculinity .....	268
9.4	<b>Strengths and Limitations of the Research .....</b>	<b>272</b>
9.5	<b>Recommendations for Future Research .....</b>	<b>275</b>
9.6	<b>Concluding Remarks .....</b>	<b>279</b>
	<b>Bibliography .....</b>	<b>282</b>
	<b>Appendices .....</b>	<b>313</b>
	<b>Appendix 1: Participant Information Sheet .....</b>	<b>313</b>
	<b>Appendix 2: Consent Form.....</b>	<b>316</b>
	<b>Appendix 3: Topic Guide for Interviews .....</b>	<b>318</b>
	<b>Appendix 4: Email Advert Sent to Support Group 1 Mailing List.....</b>	<b>323</b>
	<b>Appendix 5: Email Advert Sent to Support Group 2 Mailing List.....</b>	<b>324</b>
	<b>Appendix 6: Observations from Attending a Meeting at Support Group 2 .....</b>	<b>326</b>
	<b>Appendix 7: List of Developed Codes .....</b>	<b>328</b>

## List of Figures

	Page	
Figure 1.1	Average Number of New Cases of Prostate Cancer Per Year by Age and Age-Specific Incidence Rates in the UK, 2012-2014	14
Figure 1.2	Proposed Treatment Algorithm for Early-Stage Prostate Cancer	19
Figure 3.1	Watson's Model of 'Being in Shape': An Embodied Concept of Masculinity	70
Figure 3.2	Robertson's Model of the Relationship between Health and Hegemonic Masculinity	75
Figure 9.1	Annotations to Robertson's Model of the Relationship between Health and Hegemonic Masculinity Showing the Moral Positioning of Men Treated for Prostate Cancer	264

## List of Tables

	Page	
Table 1.1	National Institute for Health and Care Excellence (NICE) Guidance for Assessing Localised Prostate Cancer Risk	18
Table 1.2	36-Month Functional Outcomes Following Treatment for Prostate Cancer by Treatment Choice (%)	27
Table 2.1	Collins' (2014) Conceptual Framework of Different Forms of Expertise	43
Table 4.1	Sample Characteristics: Demographic and Treatment Information	104



## List of Abbreviations

BT	Brachytherapy
ChT	Chemotherapy
CT	Clinical Trial
DRE	Digital Rectal Examination
ED	Erectile Dysfunction
GP	General Practitioner
HT	Hormone Therapy
LPD	Life Preserving Drugs
PCSG	Prostate Cancer Support Group
PSA	Prostate-Specific Antigen
RARP	Robot-Assisted Radical Prostatectomy
RBT	Reflexive Body Technique
RP	Radical Prostatectomy
RT	Radiotherapy
RTwHT	Radiotherapy with Hormone Therapy
UI	Urinary Incontinence
WaW	Watch and Wait

## Acknowledgements

Working on this thesis has been a valuable and rewarding experience. There are many important people without who I could not have written this thesis and I will attempt to thank as many of them as I can with too few words to do so.

First, I thank my family. To my loving and generous parents who embody the most important values by which I strive to live my life, and to my sisters who bring so much joy and happiness to my life, I am forever grateful. To my boyfriend Duncan my love and thanks for all your support through the highs and lows of this journey are boundless and can never be expressed enough. I hope I can repay your kindness in the years to come.

Secondly, I thank my teachers. To my supervisors Jon, Rob, and Sara I am immeasurably grateful. Your wisdom, guidance, and patience have been above and beyond and I am particularly appreciative of your efforts to show me the charms but also responsibilities of academic life. Special thanks also go to Richard Smith and Sarah Moore for inspiring my love of sociology from undergraduate level and beyond, you are both teachers and characters of the highest calibre. Honourable mentions also to Geoff Cooper, Roger Tarling, Hilary Thomas, and Sarah Earthy for developing my knowledge and interests during postgraduate study. I am also grateful to all staff at the sociology departments at Royal Holloway and Surrey who have been friendly, supportive, and encouraging throughout my studies.

Thirdly, I thank my old and new friends and colleagues. To my dear friend Hannah, I am grateful for your sensible counsel and for all the fun times we share. To Martina, Chris, and John, thanks for sharing your good humour and cynicism, but also for being caring friends. From Royal Holloway, honourable mentions go to Michelle, Priya, Kate, and Anita, and from the University of Surrey: Nadia, Caitlin, Bryony, Eva, and Miriam – you have all been supportive and caring friends and colleagues and it has been wonderful to share this time of my life with you. To other wise, witty, and wonderful students who have inspired me in different ways: Jo, Linnea, Connie, Serena,

Jude, Katherine, Tara, Richard, Pete, David, Fiona, Kylie and many more: you have shaped my world view and I am proud to have known you.

Special recognition and thanks go to the Economic and Social Research Council (ESRC) for funding this research and to the decision-making panel who decided that this research was worthy of funding. I would also like to offer my sincerest thanks to all the men who gave up their time and energy to participate in this research.

Lastly, this thesis is dedicated to three important people who embody the spirit of this work. To my late grandfather, Norman, whose own experiences of prostate cancer inspired and propelled forward this research, and to my sister Jennifer and late grandmother Joyce, whose positive outlooks in the face of illness are a source of inspiration and hope to me.

## **Chapter One: Introduction**

This research was inspired by the experiences of my grandfather who was diagnosed with and treated for prostate cancer in the early 2000s. He maintained an interest in prostate cancer research and was vocal in raising prostate cancer awareness among others until his death in 2009 resulting from a heart attack. However, the impact of the treatment on his life was rarely, if ever, discussed, at least not in my presence. This thesis explores men's experiences following treatment for prostate cancer and how men manage their experiences of prostate cancer-related illness.

As the most common cancer in men in the UK (Cancer Research UK 2017a), prostate cancer has been the subject of much clinical research. With ever increasing research and policy interest there has come a range of clinical guidance for the diagnosis, treatment, and management of prostate cancer. To better understand men's experiences of prostate cancer it is important to first examine the different clinical pathways for prostate cancer: that is the different ways in which the illness can manifest and the different clinical interventions available to address these. To do this, it is necessary to provide some background to the clinical literature on prostate cancer. This will provide context for describing the focus of this study. From this the aims of this research and the methodology employed are described and lastly an outline of the structure of the thesis is presented.

### **1.1 Prostate Cancer – Medical Overview**

'The prostate is a small gland found only in men', is part of the male reproductive system, and is located just below the bladder and surrounds the urethra (Kirby and Kirby 1999: 11). The function of the prostate to 'add its secretions to semen' is minimal and not vital to the operation of the body, yet for such a small gland 'the prostate looms large as a source of disease, especially in men beyond middle age' (Kirby and Kirby 1999: 11). The following sub-sections describe the different possible clinical pathways for

prostate cancer management that a patient might follow. Exploring these helps to understand the kinds of experiences and concerns men might face prior to, during, and after diagnosis and treatment for prostate cancer.

### *1.1.1 Pathogenesis, Known Risk Factors, and Incidence*

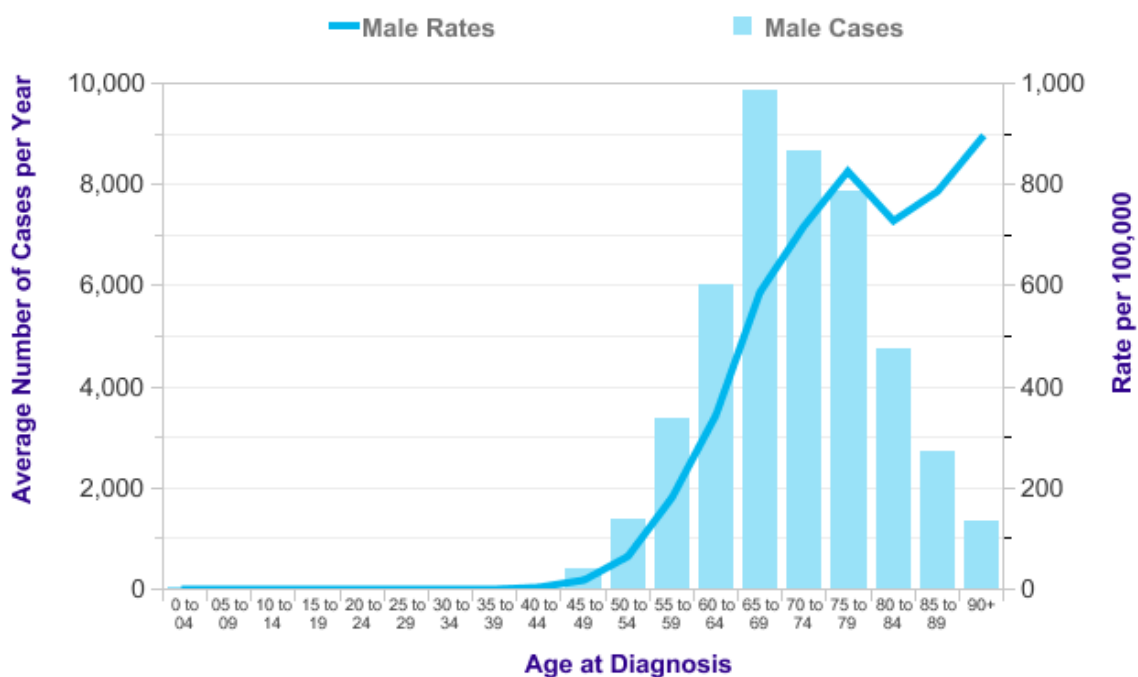
Prostate cancer is medically classified as an *adenocarcinoma* which is a glandular form of cancer (Nelson et al. 2003). Nelson et al. (2003) describe the pathogenesis, or process of development, of prostate cancer. Prostate cancer comes about when normal prostate gland cells mutate. These first mutations occur predominantly in the peripheral zone of the prostate, initially forming lesions known as *proliferative inflammatory atrophy* that develop into clumps of cells called *prostatic intraepithelial neoplasia*. Over time these cancerous cells reproduce and spread further into the prostate forming a tumorous *localized prostate cancer*. Eventually a tumour can grow large enough to invade other organs, or spread through the lymphatic system and bloodstream, and this is known as *metastatic prostate cancer*. The most advanced form of prostate cancer is an *androgen-independent cancer*. The growth of prostate cancer is driven by androgenic male hormone production. When prostate cancer becomes androgen-independent it has become firmly rooted in other organs in the body so that the cancer is no longer dependent on its original site of conception. While the pathogenesis of prostate cancer has been identified within medical research, the exact aetiology or cause of the disease has not. However, a variety of risk factors for developing prostate cancer have been identified, namely: family history (Steinberg et al. 1990; Lesko et al. 1996; Johns and Houlston 2003), age (Grönberg 2003), geography (Bray et al. 2010; Center et al. 2012), and race (Grönberg 2003).

Family history has been identified as a highly significant risk factor for prostate cancer, where having a first degree relative with prostate cancer means you are between just under two (Steinberg 1990) and two and a half times (Johns and Houlston 2003) more likely to develop prostate cancer than someone who does not have a first degree relative. Furthermore, having two

first degree relatives increases the likelihood by between three and a half to five times (Steinberg 1990; Lesko et al. 1996; Johns and Houlston 2003).

Age is one of the most significant known risk factors for prostate cancer. Less than 0.1% of patients diagnosed with prostate cancer worldwide are under 50 years old, whereas approximately 85% of patients are diagnosed after the age of 65 (Grönberg 2003: 859). Autopsies often reveal older men to have died *with* prostate cancer, demonstrating that small, localised cancers can remain undetected in the prostate for years (Leitzmann and Rohrmann 2012). In the UK, between 2012-2014, on average each year 54% of cases were diagnosed in men aged over 70 years (Cancer Research UK 2017a). As Figure 1.1 shows, the number of new cases peaks in the 65-69 years age bracket and remain high before rapidly dropping off after the 75-79 years bracket, although incidence rates continue to rise despite a small dip past the age of 75.

**Figure 1.1 Average Number of New Cases of Prostate Cancer Per Year by Age and Age-Specific Incidence Rates in the UK, 2012-2014**



(Source: Cancer Research UK 2017a)

There are also variations in prostate cancer incidence by geographic location and ethnic group. Incidence in Europe is found to be higher in northern and central regions compared with southern and eastern ones (Bray et al. 2010). Some evidence has also suggested that migration can cause changes in incidence rates for populations, as in the case of Japanese migrants moving to Hawaii, from a low incidence to a higher incidence region, where incidence rates for this migrant population were found to be midway between the Japanese rate and the native Hawaiian rate (Akazaki and Stemmermann 1973).

In the United States incidence rates are 1.6 times higher among African-Americans compared with Caucasians (Grönberg 2003). It is unclear to what extent these differences are a result of 'genetic susceptibility, exposure to unknown external risk factors, or reasons such as cancer registration and differences in health care' (Grönberg 2003: 859). In the UK, between 2002-2006, it was estimated that incidence rates by ethnic group per 100,000 men were: between 96-100 for White men, 29-61 for Asian men, and between 121-248 for Black men. However, the larger ranges for the estimates for ethnic minority groups is a result of the lack of reliable data available for these minority groups with far smaller populations in the UK (National Cancer Intelligence Network 2009). Some environmental factors such as diet, exercise, alcohol and smoking have been identified as possible risk factors, however there is not currently sufficient evidence to conclusively form an opinion on these factors (Grönberg 2003).

The latest publicly available statistics from 2014 indicate that prostate cancer is the most common cancer in men and second most common cause of cancer death in men in the UK (Cancer Research UK 2017a, 2017b). In the same year, 46,690 new cases were diagnosed and there were 11,287 prostate cancer deaths reported in the UK (Cancer Research UK 2017a, 2017b). Damber and Aus (2008: 1711) found that prostate cancer is the most common cancer among men in Europe, with 'about 190,000 new cases every year' and the cause of '80,000 deaths a year' in Europe. Survival rates for prostate cancer in England and Wales, however, are good. Data from 2010-2011 found that

83.8% of men diagnosed survived the disease for ten years or more and survival rates have improved by more than a quarter in the last 45 years (Cancer Research UK 2017c).

### *1.1.2 Diagnosis*

Possible symptoms for prostate cancer include: 'poor urine stream, hesitancy, terminal dribbling, retention, and uraemia' (Chapple and Ziebland 2002: 821). However, these symptoms may present with a benign enlargement of the prostate that commonly occurs as a natural part of ageing (Carter 2004) without cancer being present. Or prostate cancer can occur while presenting no symptoms at all.

There are a range of diagnostic techniques available to clinicians to inform whether a prostate cancer diagnosis can be made. Before any biomedical testing is undertaken, a clinician may choose to undertake a physical examination of the prostate. A digital rectal examination (DRE) is an internal rectal examination by a clinician using their finger to physically feel for lumps, swelling, or abnormalities of the prostate.

Either as a result of a DRE or just for the sake of monitoring a man's health, a clinician may perform a prostate-specific antigen (PSA) blood test. The PSA is a 'glycoprotein produced almost exclusively by the ... prostate gland' (Barry 2001: 1373). A rise in PSA levels in the blood can be an indicator of the onset of prostate cancer. The test is very accurate in its measurement of PSA but the relationship between PSA level and the presence of prostate cancer is not clear cut. There are estimated 'normal' PSA levels for different age groups for men but these are only rough indicators and a PSA level may be high for one man but low for another (Prostate Cancer UK 2017a). However, the rate of change in PSA level over time can be a useful indicator for detecting the presence of cancer and the speed of its growth (ibid). There are also a number of circumstances where PSA level rises are not caused by prostate cancer, such as 'a biopsy of the prostate, ... acute urinary retention, and acute prostatitis' (Barry 2001: 1373), which are known as false positives.



Enlargement of the prostate from the common condition benign prostatic hyperplasia (BPH) can also cause an elevation in PSA level but does not contribute to the risk of prostate cancer.

If a DRE and/or PSA test(s) are a cause for concern for a clinician, they may refer a man for a biopsy. Contemporary biopsy techniques have low morbidity rates, deliver a much less ambiguous diagnosis, and provide more information about the grade of the tumour and the extent of tumour growth (Nelson et al. 2003). A typical needle biopsy will take between 10-14 tissue samples, the results of which are used to construct a Gleason score.

The Gleason score is calculated from the findings of a prostate cancer biopsy. Cancer patterns are graded from 1-5, with 1 being the most differentiated (where prostate cells are distinct from each other) and 5 being least differentiated (where tumorous cells have formed together in clumped masses). The Gleason score is calculated by taking the 'intermediate between the most predominant pattern of cancer and that of the second most predominant pattern' (Nelson et al. 2003: 957), put simply the grades for the most common and second most common cancer patterns are added together. A Gleason score can hypothetically range between 2-10 (although in practice for biopsies the range is between 6-10, as specified in the fine print below Table 1.1), so if the most common cancer pattern was graded a 4 and the second most common a 3 then the result would be 4+3 and 7 in total. Nelson et al. (2003) describe how the difference between a Gleason score of 6 and 7 is the most important in defining prognosis. In fact, the difference between the type of score 7, either a 4+3 score or a 3+4, can be crucial in deciding between treatment or non-treatment. Clinicians use this score in combination with a range of other factors when deciding on a diagnosis and then in choosing how to progress, either with a course of treatment or some form of health surveillance.

Clinicians will use a range of factors to grade a patient's disease risk and recommend treatment or non-treatment on that basis. Guidance for doing this is set out by the National Institute for Health and Care Excellence (NICE) and

Table 1.1 shows a nomogram, a graphical measure used to illustrate risk grading, for assessing risk for localised prostate cancer.

**Table 1.1 National Institute for Health and Care Excellence (NICE) Guidance for Assessing Localised Prostate Cancer Risk**

<b>Risk stratification for men with localised prostate cancer</b>					
	Prostate specific antigen (ng/ml)		Gleason score*		Clinical Stage**
Low risk	<10	and	≤6	and	T1-T2a
Intermediate risk	10-20	or	7	or	T2b-T2c
High risk	>20	or	8-10	or	T3-T4

\*The sum of the predominant histological pattern of cancer (graded 1 to 5) and the next most common pattern. For biopsies (as opposed to radical prostatectomy specimens) it is not possible to allocate a pattern of <3 because of the small quantity of tissue obtained. Therefore the lowest possible Gleason score on a biopsy is 6 (3+3).

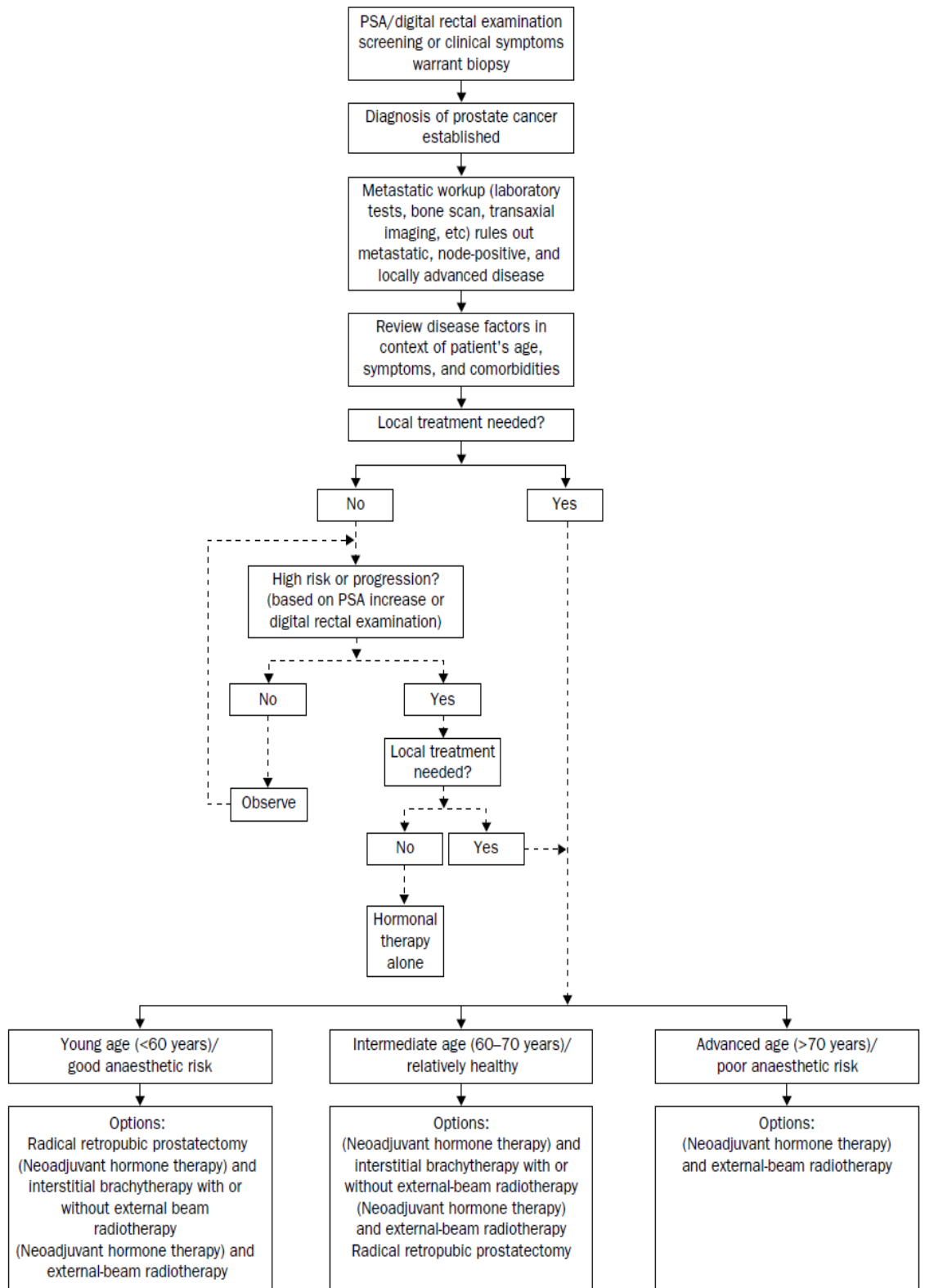
\*\*The anatomical extent of the cancer, informed by the gross resection specimen (in men having a prostatectomy) or by biopsy and rectal findings, sometimes augmented by magnetic resonance imaging. T1-T2a describe low volume disease confined to <50% of one prostatic lobe. T3 and T4 cancers extend beyond the prostate.

(Graham et al. 2008: 611)

Using collected biomedical knowledge, clinicians may then combine a patient's risk status with other factors including but not limited to a patient's age, health, and family history when deciding what course of treatment or non-treatment to take. A template for the sorts of considerations clinicians might make and the options available to them is outlined in the treatment algorithm shown in Figure 1.2.

If the cancer is suspected to have breached the wall of the prostate it may be deemed locally advanced and further diagnostic tests may be required. Imaging techniques such as transrectal ultrasound, magnetic resonance imaging (MRI) scans and X-ray computed tomography (CT) scans can assess if and how far cancer may have spread beyond the prostate (Prostate Cancer UK 2017b). Further still, a bone scan, serum alkaline phosphatase test, and chest radiography can each be undertaken to assess whether the cancer has metastasised and spread more widely within the body.

**Figure 1.2 Proposed Treatment Algorithm for Early-Stage Prostate Cancer**



(Source: Jani and Hellman 2003: 1050)

In the UK, multi-disciplinary teams (MDTs) are integral to the management of prostate cancer patients' care, just as they are becoming increasingly so for cancer patients worldwide (Lamb et al. 2011). MDTs have been defined as a:

Group of people of different healthcare disciplines ... [who] contribute independently to the diagnostic and treatment decisions about the patient (Department of Health 2004: 18).

This has led to group decisions being informed by the knowledge of different specialists and also partly informed by the patient's interests and desires.

This reflects an increasing trend towards more individually targeted approaches to treatment. Advances in technologies and research are quickly moving forward and Faulkner (2012) argues that while we are not yet in an era where predictive genetic testing for prostate cancer has entered the UK marketplace, such a move is anticipated. There is an increasing move towards individualisation in prostate cancer management, with risk assessment, prevention, diagnosis, and treatment being increasingly tailored towards individual patients (Gelmann 2008: 962). These changes are very important for understanding men's experiences of prostate cancer. The great quantity of risk information that men are exposed to undoubtedly plays a role in shaping men's decisions as to how to manage their cancer, the options for which are explored in Sub-Sections 1.1.3 and 1.1.4.

### *1.1.3 Screening and Surveillance Options*

The prostate-specific antigen (PSA) test was introduced across the UK in the late 1980s, but despite much pressure from prostate cancer support group (PCSG) activists and within the national media, the UK government has continuously resisted the introduction of a national screening programme for prostate cancer (Faulkner 2012). A National Health Service (NHS) review entitled *Effectiveness Matters* recommended that routine testing for prostate cancer should be discouraged and called for further evidence on the

effectiveness of PSA testing and prostate cancer screening before these recommendations could change (NHS Centre for Reviews and Dissemination 1997). In subsequent years since this report, with the absence of any reliable new evidence in support of prostate cancer screening, Faulkner (2012) observes that UK policy has adopted a concessional approach where any man above the age of 50 who wants a PSA test should have access to one. This ‘informed choice’ approach has been widely advocated within medical literature and persists in current UK policy.

Faulkner (2012) asserts that this ‘informed choice’ policy was later cemented in a letter from the Chief Medical Officer to medical colleagues in 2009, which describes the findings that had recently been published from two large randomized controlled studies, both casting further doubts on the effectiveness of routine prostate cancer screening (Chief Medical Officer 2009). The balance of the harms and benefits of screening were found to be inconclusive but the number of men who might be unnecessarily treated because of false positives and other factors, as well as the unpleasant side effects of treatment that reduce quality of life, weigh against the argument for introducing routine screening (Sox 2012; Heijnsdijk et al. 2012).

Despite these findings, the Chief Medical Officer’s (2009) letter still advocated for men’s right to have access to the PSA test if they wanted it. The results from more recent controlled studies have not provided enough evidence to change this policy, therefore this same position has been maintained in current national health policy (Public Health England 2016). Faulkner (2012: 229) has identified this ‘informed choice’ approach as part of a larger movement across UK health policy of driving ‘individual responsabilisation’, designed to encourage people to take responsibility for their own health, characterised by Beck (1992) in his seminal work *Risk Society*. Indeed, one route into diagnosis involves taking responsibility for one’s own health by men referring themselves to their General Practitioner (GP) to receive a PSA test.

The 'informed choice' approach can also encourage responsibility via another clinical pathway. Men diagnosed with prostate cancer deemed to have a low or intermediate risk localised cancer (see Table 1.1) may sometimes be recommended to follow a regimen of clinical monitoring of the cancer, rather than direct intervention through primary treatment. There are different forms of observation that men can be subjected to. Such options are weighed against a patient's age, predicted life expectancy, and the presence of comorbidities. Observation in the form of *watchful waiting* may be appropriate for older men with co-morbidities, low risk cancers, and shorter predicted life expectancies, where the aim is to control rather than successfully treat and remove the cancer. This form of observation may involve an annual check-up at a GP surgery, likely with a PSA test (Prostate Cancer UK 2017c).

Younger men may be diverted from treatment interventions for prostate cancer in favour of a method of clinical observation known as *active surveillance*. This is more common with low risk cancers that are still localised and contained within the prostate. Active surveillance involves carefully monitoring the cancer with knowledge of the likelihood that the cancer will require treatment at a later stage. Surveillance is undertaken to prolong the period of time before treatment is required, thereby prolonging a higher quality of life for men that would likely decline with the unpleasant side effects following treatment. The form of observation for this option may involve more frequent and varied, hospital based, testing than watchful waiting (Prostate Cancer UK 2017d; Jani and Hellman 2003).

Whether a man opts for treatment or non-treatment surveillance there is an emphasis on taking responsibility in response to a prostate cancer diagnosis. Taking responsibility has strong moral connotations that may be important to the experience and management of prostate cancer but have previously received little attention in sociological research on prostate cancer.

Furthermore, Faulkner (2012) identifies that the UK 'risk management' policy approach to managing prostate cancer, combined with a growing private market emphasis on developing genetic predictive tests and other

more sensitive risk indicators than the PSA test, has contributed to the diffusion of uncertainty for men experiencing prostate cancer. These experiences and how they might shape decisions for managing prostate cancer remain underexplored and warrant attention within sociological research.

#### *1.1.4 Treatment Options*

If surveillance options are not desired or are deemed inappropriate, then there are a host of different treatments available. A radical prostatectomy (RP) is the most popular treatment option for clinicians, with 'high cure rates with decreased morbidity in appropriately selected patients' (Jani and Hellman 2003: 1046). Radical prostatectomy is an umbrella term that covers a range of surgical techniques which all constitute an invasive medical procedure. These include an open retropubic prostatectomy (ORP), laproscopic prostatectomy (LRP), and robot-assisted LRP (RALP). Of the men who were interviewed for this research, just over 60% had undergone a form of radical prostatectomy. The majority of men having a radical prostatectomy received the RALP procedure with a clinician operating a robotic surgical device, using a console and screen monitor to perform the surgery. Other men who underwent a radical prostatectomy received surgical procedures involving a surgeon personally conducting the operation themselves, predominantly following the LRP technique, as this is a keyhole surgery at multiple sites with smaller incisions than the OPR technique, which tends to leave less scarring and reduce post-operative recovery time.

A radical prostatectomy allows a surgeon to view first-hand whether disease has spread beyond the prostate, which is difficult to assess with diagnostic testing. PSA levels drop sharply and remain very low after a prostatectomy, too. This drop can be useful in detecting cancer recurrence, where a rise in PSA levels following surgery may be indicative of this occurring. A prostatectomy comes with a small operative risk and recovery time can be longer compared with other common treatments (Jani and Hellman 2003: 1047); however, the newer robotic surgery technique has been found to have

benefits over the other forms of surgery in reducing adverse side effects (Tewari et al. 2012; Trinh et al. 2012; Novara et al. 2012).

External-beam radiotherapy is another common treatment for prostate cancer. This involves daily treatments of X-ray radiation to the prostate for varying intervals of time, depending on individual cases. External-beam radiotherapy is a non-invasive treatment so comes with no surgical risk, however radiotherapy cannot be undertaken twice in the same area, due to limits in the amount of radiation bodily tissue can be exposed to, and any subsequent treatment that may be required can be complicated by the initial radiotherapy (Prostate Cancer UK 2017e). The recent ProtecT trial has found that radiotherapy is equally efficacious as a treatment for prostate cancer as a radical prostatectomy (Hamdy 2016; Tyson and Penson 2016). Urinary incontinence (UI) is much less common as a treatment side effect with radiotherapy than with a radical prostatectomy, however there can also be rectal side effects with radiotherapy, which are less common with a prostatectomy (Prostate Cancer UK 2017e; discussed further in Sub-Section 1.1.5).

Another form of radiotherapy is brachytherapy, which is a treatment that involves inserting small radioactive sources directly into the prostate to more precisely target the cancer with radiation. These sources are placed with the guidance of transrectal ultrasound; low dose sources are left permanently whereas high dose sources are placed only temporarily. The advantages are that the dose is applied more directly and locally to the cancerous tissue than can be done using radiotherapy, which leads to lower incidence of rectal complications and erectile dysfunction (Prostate Cancer UK 2017f). This treatment also takes a shorter surgery time compared to a prostatectomy and has a shorter recovery time (ibid). The disadvantages of this treatment are that the prostate can shrink in size as a result and constrict the urethra, resulting in urinary function problems (ibid). There is also a concern about distribution of the dose within the prostate as the radioactive sources can migrate from where they are initially inserted. Also, brachytherapy sometimes results in a well-documented rebound of PSA levels between 1-2 years after treatment



which can cause ambiguity about the possibility of cancer recurrence (Jani and Hellman 2003: 1048).

Hormone therapy is another possible treatment for localized prostate cancer and involves the inhibition of testosterone production to delay the progression of the disease. Hormone therapy can be used to prolong watchful waiting to avoid medical intervention but has also been used in combination with radiotherapy with some evidence of increased survival (Jani and Hellman 2003: 1048). The possible side effects for hormone therapy, however, despite mostly being mild and short-lived are numerous and can include 'hot flushes, loss of libido or erectile function, weight gain, gynaecomastia, liver inflammation, and osteoporosis' (Jani and Hellman 2003: 1048).

Beyond the common primary treatments described above are some rarer, more novel therapies that are less widely available. These include Cryotherapy, using extreme low temperatures, and High Intensity Focussed Ultrasound (HIFU) to destroy cancer cells (Prostate Cancer UK 2017g). There are also further secondary treatments failing successful treatment in the first instance, or for men whose cancers have spread further beyond the prostate.

Chemotherapy drugs kill cancer cells and can be used to shrink tumours and slow their growth. There are also other, more powerful hormone therapy drugs for when cancer has spread beyond the prostate and conventional hormone therapy drugs have stopped working. Two notable examples of these are Abiraterone and Enzalutamide, which stop the production of the hormone testosterone. However, they are expensive drugs and access to them is restricted. They are used as life preserving drugs (LPDs) where cancer can no longer be successfully treated or removed (Prostate Cancer UK 2017h).

Importantly, each of the treatments described in this sub-section has costs that can add to men's uncertainties about whether they should opt for treatment and if so, what treatment they should opt for. Having to make these decisions may add to a sense of responsibility that men feel regarding their prostate cancer, for the consequences of treatment in terms of reduced quality of life can be considerable and these are explored in Sub-Section 1.1.5 below.

### *1.1.5 Quality of Life Following Treatment*

Clinical research has previously given more weight to increased survival as a key indicator of screening efficacy and less to the balance of benefits to harms of undergoing different treatments for prostate cancer (Wilt et al. 2008; Djulbegovic et al. 2010). In a systematic review, Wilt et al. (2008) note that only three out of eighteen randomised controlled trials they examined had addressed the benefits and harms of different primary treatments for localized prostate cancer. Djulbegovic et al. (2010), in a larger systematic review, also identify that few studies on prostate cancer have addressed the possible harms that screening and different treatments have on men.

An emerging body of literature has begun to explore men's quality of life following treatment for prostate cancer. Smith et al. (2009) found that while quality of life varied between different treatments for prostate cancer, each had a persistent impact on men's quality of life. Three years after diagnosis, erectile dysfunction was found to be common among all treatment groups (*ibid*). Urinary dysfunction was much more common for men who had undertaken radical prostatectomies, while rectal incontinence and difficulties were more common for those having radiotherapy treatments (*ibid*).

Chen et al. (2009) identified quality of life outcomes for 409 men who had two different techniques of radical prostatectomy, external-beam radiotherapy, and brachytherapy at 36 months following treatment. For those men who self-reported as having 'normal' baseline function prior to treatment, the percentages of men experiencing 'normal', 'intermediate', and 'poor' symptoms for sexual (erectile) dysfunction, urinary incontinence, bowel problems, and urinary obstruction/irritation were identified. These are all represented in Table 1.2 below.

**Table 1.2 36-Month Functional Outcomes Following Treatment for Prostate Cancer by Treatment Choice (%)**

Treatment Choices	Level of Function	Common Treatment Side Effects			
		Erectile Dysfunction	Urinary Incontinence	Bowel Problems	Urinary Obstruction or Irritation
Nerve Sparing Radical Prostatectomy	Poor	64	2	2	8
	Intermediate	28	41	25	34
	Normal	8	57	73	58
Non-Nerve Sparing Radical Prostatectomy	Poor	63	9	2	8
	Intermediate	31	49	25	34
	Normal	6	42	73	58
External-Beam Radiotherapy	Poor	48	1	14	4
	Intermediate	26	17	52	37
	Normal	26	82	34	59
Brachytherapy	Poor	19	1	10	11
	Intermediate	35	16	52	31
	Normal	46	83	38	58

\*Data was not available to distinguish between nerve sparing and non-nerve sparing techniques when measuring outcomes for bowel problems and urinary obstruction/irritation. Therefore, the same result is provided in both rows, indicative of radical prostatectomies generally.

(Chen et al. 2009: 3920)

Chen et al.'s (2009) findings show that erectile dysfunction is by far the most common side effect experienced by men treated for prostate cancer. However, significant percentages of 'intermediate' levels of function are widely reported for all the side effects that were measured across the different treatment groups that were investigated. Other studies have shown how common treatment side effects are frequently reported as factors that reduce quality of life for those treated for prostate cancer (Sanda et al. 2008; Litwin et al. 1995; Penson et al. 2003).

It is also important to consider the quality of life for men who opt for surveillance rather than treatment. Active surveillance has been found to present an opportunity for men to be able to live a healthier lifestyle and can therefore lead to an improved quality of life for some (Daubenmier et al. 2006), however quality of life may also suffer as some men may feel that they cannot tolerate the anxiety associated with active surveillance (Daubenmier et al. 2006; Dall’Era et al. 2012). Findings from the recent ProtecT trial have reported substantial dropout from men following an active surveillance regimen, who opt instead for treatment, not because of a clinically defined need for treatment but rather because of a desire to not live with the uncertainty of possibly having a malignant cancer growing in their body (Inside Health 2017).

Experiences of anxiety or uncertainty have also been found to impact upon men undergoing watchful waiting (Wallace 2002). Watchful waiting can also be accompanied by the negative side effects of a progressing tumour, particularly erectile dysfunction and continence difficulties (Johansson et al. 2011; Steineck et al. 2002), however the degree to which these might be general effects of ageing, rather than disease specific effects, is unclear.

The outcomes of treatment for prostate cancer can impact significantly on men’s lives yet there has been limited sociological research attention on the period following treatment. Experiences at this stage of the illness trajectory will undoubtedly be shaped by the care and support that men receive and this is considered in Sub-Section 1.1.6.

#### *1.1.6 After Care and Support Groups*

Following treatment there is limited clinical follow up. Men receive subsequent PSA testing at decreasing intervals to assess whether prostate cancer may have returned. This form of testing can commonly continue for periods of up to five years following treatment, or even longer if clinically recommended or requested by the patient (Bell and Kazanjian 2011).

There are a range of treatments or interventions to reduce or remove treatment side effects. For urinary incontinence there are a range of options, including: incontinence pads, pelvic floor exercises (to strengthen muscles that control urination), external urinary sheath catheters (to collect urine in containers tied to the outside of the body), an internal male sling (surgically inserted material supporting the bladder, designed to improve continence), and an artificial urinary sphincter (a device surgically implanted to allow for control of urination) (Prostate Cancer UK 2017i).

The variety of treatments for erectile dysfunction include Phosphodiesterase-5 (PDE-5) inhibitor drugs (such as Viagra, Levitra, and Cialis), vacuum pump systems, and a synthetic hormone called Alprostadil. PDE-5 drugs help to relax muscles in and around the penis so that blood can flow more freely. These are oral drugs that can take up to several hours or longer for an effect to be observed. Vacuum pumps work by drawing blood up into the penis and take a shorter period of time to have an effect. Alprostadil can either be injected or used as a urethral suppository. It has a rapid effect caused by a widening of blood vessels allowing greater blood flow to the penis (Prostate Cancer UK 2017i).

To fill the gaps that may exist for men in managing different needs, be they emotional, psychological, or informational, there exist community organised prostate cancer support groups (PCSGs). These groups provide spaces for patients and survivors of prostate cancer and their families to address these needs.

How men manage some of the ongoing issues they face following treatment has received less attention in sociological research, compared with earlier stages prior to and of diagnosis and treatment. In Section 1.2 the focus of my research is outlined.

## **1.2 Focus of the Study**

There has been a range of clinical, nursing, psychological, and some sociological research on prostate cancer (Chapple and Ziebland 2002; Gray et al. 2000, 2002; Fergus et al. 2002; Broom 2004, 2009; Oliffe 2009a). However, limited research attention has been directed to the period following treatment, compared with periods during or prior to treatment. Bell and Kazanjian (2011) have posited that prostate cancer might be better understood as a chronic illness, because of continuing uncertainties that can persist long after treatment. This research seeks to explore men's experiences following treatment for prostate cancer and to examine how common themes of chronic illness experience play a role in men's lives and how these experiences are managed. In Chapter Two some of these common themes of chronic illness experience are described and discussed.

Prostate cancer has been a popular topic for the study of masculinities in recent decades (Wenger and Oliffe 2013, 2014). However, in recent years, new sociological theories for conceptualising masculinities have emerged (Robertson 2006b; Robertson et al. 2010). For the men in this research, living beyond prostate cancer treatment but still with the impacts of it, there is an important question of how men maintain their masculinity following treatment for prostate cancer. New theoretical tools offer a means of drawing fresh interpretations about experiences of prostate cancer and the extended intervals of time from when men were first treated offers new insights into how masculinities are maintained long after treatment. In Chapter Three the topic of masculinity is explored and these contemporary theoretical frameworks for masculinities are examined.

## **1.3 Aims and Methodology**

This research aims to examine men's experiences following treatment for prostate cancer and how any concerns or difficulties that arise from treatment are managed. The following areas will be explored to address this overarching aim.

There has been a growing public discourse around managing and being responsible for one's own health in recent decades (Petersen and Lupton 1996; Petersen 1997; Gough 2006). Public health and charity campaigns have become more prominent, particularly towards men who have for a long time been less inclined to engage with health services (Noone and Stephens 2008; Courtenay 2000; Robertson 2007). In this chapter, clinical pathways into being tested for and diagnosed with prostate cancer have been identified, some of which are followed as a direct result of taking personal responsibility for one's health. This research aims to examine the broader context that shapes how men come to be diagnosed and treated for prostate cancer.

Uncertainty has been identified as a key component of illness, particularly chronic illness, experience (Bury 1991; Gabe 1996; Royer 2000; Robinson 2004). The medical procedures and clinical pathways that guide and shape the illness experience of prostate cancer are dominated by epidemiological risk, as has been demonstrated in this chapter. This heavily technologically mediated process profoundly shapes men's experiences of uncertainty (Gillespie 2012), yet little is known about men's experiences of uncertainty following treatment for cancer, in relation to ongoing diagnostic procedures and experiences of treatment side effects. This research aims to investigate men's experiences of post-treatment uncertainties and how these are managed.

Prostate cancer support groups (PCSGs) have been identified as important sites where men can acquire information, in contrast to women's support groups for breast cancer where expression of emotions has been identified as the primary motivation for attendance (Breau and Norman 2003; Boberg et al. 2003; Oliffe et al. 2011; Bottorff et al. 2008). Viewed through the lens of chronic illness, PCSGs can be understood as sites where lay or patient expertise can be acquired. This research aims to explore the forms and levels of patient expertise men possess and how such expertise is used, drawing on Collins' (2014) recent schema for expertise to do so, in order to inform current debates on how to define lay or patient expertise (both terms are used synonymously in this research).

The experience of treatment side effects has only received scant and passing attention within qualitative sociological research on prostate cancer (Chapple and Ziebland 2002; Oliffe 2009a; Kelly 2009). This research aims to explore how treatment side effects are experienced and managed in the course of men's everyday lives.

The management of chronic illness involves a range of strategies, including the strategic verbal responses that people give in relation to their illness, which Bury (1991) calls 'style'. This involves drawing on 'cultural repertoires' to account for and present features of illness in different ways to others. This research aims to understand how men account for and normalise the disruption caused by prostate cancer illness.

With limited after care services available following treatment for prostate cancer, prostate cancer support groups (PCSGs) can play an important role in managing the impacts of prostate cancer. Oliffe et al. (2011) have found that PCSGs provided men with the tools to reformulate how they talked about health and illness, learning to speak using appropriate biomedical terminology and comprehend medical test measures to engage with risk discourses. This improved health literacy for prostate cancer facilitated the adoption of new strategies within individual clinical consultations, to either facilitate greater parity and involvement with clinicians or to contest what they were saying, to achieve the best possible care outcome. This research aims to explore how PCSG attendance shapes men's experiences and management strategies following treatment for prostate cancer, to observe more broadly how PCSG attendance can continue to be beneficial for men after treatment. This aim and the other aims described above contribute to addressing a broader aim of seeking to understand how men maintain masculinity following treatment for prostate cancer. In seeking to address this, more nuanced theoretical tools will draw together ideas about masculinity, embodiment, and health and illness (Robertson et al. 2010; Robertson 2006b; Connell 2005; Watson 2000; Charmaz 1994) to generate fresh insights into men's changing relationships with masculinity over time following treatment.



These aims were formed following a review of the literature (see Chapters Two and Three). Research questions were then formulated and a qualitative methodological approach was adopted to address these questions. This involved conducting qualitative open interviewing with 29 men, aged 53-83 years, who had previously been treated for prostate cancer. These men were recruited from two prostate cancer support groups in the South-East of England outside of the Greater London area. The interviews were all audio-recorded and verbatim transcribed. The computer-assisted qualitative data analysis software (CAQDAS) Nvivo 10 was used to facilitate analysis of the data. A constructivist grounded theory approach was taken for this research. Further details are provided in Chapter Four and a full outline of the structure of the thesis is presented in the next section.

#### **1.4 Structure of the Thesis**

This thesis comprises nine chapters. The following two chapters review the sociological literature that pertains to this research. The first of these explores literature on the sociology of chronic illness and associated concepts, including risk and uncertainty, patient expertise, stigma, and morality. The second reviews literature on masculinity and how it relates to the concepts of ageing, embodiment, health, and illness. In Chapter Four the adopted methodological approach is outlined along with justifications for undertaking this approach and reflections on conducting the research.

There are four empirical findings chapters. In Chapter Five, men's experiences of uncertainties following treatment for prostate cancer are explored, to identify the concerns men continue to face, often long after primary treatment. The ways men seek to manage these uncertainties by adopting strategies of vigilance are also explored. In Chapter Six, the different forms and degrees of specialist prostate cancer expertise that men were found to possess are examined. The factors that facilitate the acquisition of expertise and how expertise was used by men are also explored. In Chapter Seven, experiences of common prostate cancer treatment side effects are described

and reported management strategies to address these are examined. In Chapter Eight, men's efforts to normalise their prostate cancer are considered and common themes in the ways that men seek to account for their treatment side effects are identified. The strategies that men employ to maintain their masculinity and the importance of preserving moral status as part of these strategies are then discussed. Lastly, in Chapter Nine, the main findings of the empirical chapters are summarised and the key contributions to sociological knowledge are discussed. Limitations of the research and possibilities for future research are also considered.

# Chapter Two: The Experience and Management of Chronic Illness

## 2.1 Introduction

Parsons' (1951) work, where he formulates illness as a distinct social behaviour, identifies a 'sick role' that people can legitimately occupy in certain circumstances to allow for the continuing functioning of society. Parsons argues that an ill person has a responsibility to seek and follow medical advice and in doing so is granted sick status and is freed from societal obligations for a short period of time. Parsons' theory demonstrates that social spaces are available where illness can be legitimised by society. However, there are a range of other factors that Parsons failed to consider, as outlined below.

Varying behaviours by social class, cultural background, gender, and age (among others) have been identified as stratifying illness experience and management (Gabe et al. 2004). Furthermore, other factors relating to the nature of the illness itself, how frequently the illness recurs, the degree to which the illness affects everyday activities, the period of time for which the illness persists, and perceived ability to cope with symptoms have all been identified as mediating issues in shaping illness management and health-seeking behaviours (Gabe et al. 2004).

Chronicity is one aspect of illness experience that warrants special attention. Chronic illness has been defined as a 'major kind of disruptive experience' (Bury 1982: 169). The emergence of chronic illness as a key feature of modern life has been particularly prominent in the last half century in the UK, because of declining mortality rates and increasing diagnoses of chronic and/or degenerative and debilitating conditions (Bury 1997). Chronic illnesses can bring sets of experiences and management challenges that are distinctly different from acute illnesses. This chapter explores these different characterising features and considers whether prostate cancer can be regarded as a chronic illness, as Bell and Kazanjian (2011) have suggested.

Bury (1982, 1988, 2001) has examined the impact of chronic illness and how the meanings and patterns of everyday encounters are disrupted by it. In Section 2.2, the concept of biographical disruption (Bury 1982, 1988, 2001) and associated concepts are described, to illuminate key overarching frameworks for understanding chronic illness.

Uncertainty is a significant aspect of the lived experience of chronic illness (Charmaz 2000; Royer 2000). The initial response to a diagnosis of chronic illness is generally one of shock and crisis, where previous presumptions a person has about the stability of their life are called into question. Responding to diagnosis raises profound questions as to why the sufferer has been subjected to illness, what can be done about it, and what does the sufferer's future hold for them (Charmaz 2000). In Section 2.3 the topic of uncertainty with regard to illness experience is examined to consider how this may pertain to men's experiences following treatment for prostate cancer. In Section 2.4 the topic of patient expertise, one response to or outcome of chronic illness (Collins 2014), is explored, with the aim of understanding what levels and forms of expertise men treated for prostate cancer possess, how such expertise is acquired, and how it is used.

Maintaining moral character and identity are important concerns for those with chronic illnesses. Gerhardt (1989) associates chronic illness with the 'loss of self'. People often respond either through 'crisis' whereby they directly suffer from the stigma of their illness and form a 'deviant identity', or 'negotiation' whereby they adapt to the emerging aspects of the illness experience by struggling to normalise their experiences while facing illness uncertainty. Stigma (Goffman 1963) can be a significant aspect of chronic illness experience and how this may be pertinent to men's experiences of prostate cancer treatment side effects is explored in Section 2.5. In Section 2.6, broader strategies for managing chronic illness are explored and normalisation (Bury 1991) is recognised as an important strategy among a range of others that may be undertaken by men.

Lastly, in Section 2.7, the concept of morality is explored. The increasing role of morality in the field of health is considered in relation to concepts of 'healthicization' (Conrad 1987; Zola 1972; Armstrong 1995) and risk (Roth 2010) and these ideas inform a discussion of diagnostic testing for prostate cancer. Notions of morality are also identified as being bound up in the way that people talk about health and illness, where illness can be the subject of blame for perceived 'moral failing' (Galvin 2002).

These facets of chronic illness experience and common management strategies are explored with the aim of understanding how these may be pertinent to the concerns and difficulties men face following treatment for prostate cancer.

## **2.2 Biographical Disruption**

The onset of chronic illness can cause biographical disruption (Bury 1982, 1988, 1991, 2001). The notion of biographical disruption and recent amendments to the theory can further inform an understanding of how chronic illness is experienced and managed.

Bury (1982) views chronic illness as a 'disruptive event' to a person's sense of biography, where the usually distant world of pain and mortality is brought suddenly closer to the present. Bury (1982: 169-70) observes this disruption occurring in three ways; the first is disruption of taken for granted assumptions and behaviours, the second is the more profound disruption of explanatory systems of the world and of the self, and the third is the disruption of how resources are mobilised in the living of an individual's everyday life. When biography is disrupted by illness, people search for meaning to make sense of the illness within the context of their own lives. Medicine as a societal institution can offer people the meanings they are searching for in this respect, but often through lack of medical knowledge lay people fill in these meanings by 'drawing on their own biographies' (Bury 1982: 179) to make sense of their illness.

Bury's notion of biographical disruption has subsequently been viewed as not being able to fully account for all aspects of chronic illness experience (Williams, S. 2000), leading to modifications to address these gaps. For people who have already experienced hardship or difficulty in their lives, the onset of chronic illness may instead of disruption be understood as *biographical continuity* (Williams, S. 2000) or *biographical flow* (Faircloth et al. 2004). For those who are marginalised or already have stigmatised identities, the onset of a chronic stigmatising illness associated with their stigma – for instance HIV or AIDS in relation to the stigma of homosexuality or intravenous drug use – may be *biographically reinforcing* (Carricaburu and Pierret 1995). While those who possess greater resources may be able to achieve some degree of *biographical repair* (Charmaz 1991). More recently, Monaghan and Gabe (2015) found that disruption can be *biographically contingent* on a range of factors, including the severity of symptoms but also other lifestyle disruptions to an individual's own biography.

The degree to which the onset of prostate cancer might be considered a biographically disruptive event has received little attention within sociological research (Cayless et al. 2010). To better understand how prostate cancer may be disruptive it is necessary to explore some of the core themes of chronic illness and how these might apply to prostate cancer, starting with uncertainty in the following section.

### **2.3 Risk, Uncertainty, and Vigilance**

Uncertainty is central to the experience of chronic illness, where the worsening or improvement of symptoms can be difficult or impossible to predict over time (Royer 2000; Charmaz 2000). Uncertainty has historically been defined largely in relation to risk. Simply put, 'if you don't know for sure what will happen, but you know the odds, that's risk' whereas 'If you don't know the odds, that's uncertainty' (Knight 1921).

The term risk has been so dominant historically that it has permeated from professional into lay public discourse, so much so that risk and

uncertainty have often blurred together and been used to mean the same thing (Ewald 1991). A risk, according to common lay usage, is considered an event that may be dangerous, regardless of whether the probability of this event occurring can be predicted or not. This blurring has resulted in the term 'risk' being 'used inconsistently in both medical science and lay discourse' (Zinn 2005: 1). This is problematic because meanings of risk may vary substantially between patients and medical practitioners. The dangers of this are identified in the work of Parsons and Atkinson (1992, 1993, 2004), where they found that clinicians and women who had the carrier gene for Duchenne's muscular dystrophy had very different understandings of genetic risk, which had complex ramifications for women's reproductive choices of whether to have children or not.

Perceptions of risks are shaped by wider social circumstances. Perceiving a phenomenon as a risk can be shaped by social and economic constraints and by the degree of habitual regularity of encountering that phenomenon (Bloor 1995a, 1995b). Perceiving a phenomenon as a risk can also be shaped by a person's familial 'sphere of influence' (Schutz 1970), particularly concerning genetic conditions (Cox and McKellin 1999), and also by biographical factors over the life course (Cox and McKellin 1999; Parsons and Atkinson 2004). Risks are not solely objective measures but are perceived and made sense of within social contexts which frame their meanings. This has implications for how they are subjectively experienced.

Risk is also not the sole determinant of experiences of uncertainty (Zinn 2008), despite our living within a culture that is increasingly reliant on risk-based explanations and solutions to all manner of problems, including illness (Beck 1992). A range of other factors: trust, hope, heuristics (learning based practice), and emotions also play an important role in shaping experiences of and responses to uncertainty (Zinn 2008). Zinn (2008) places uncertainty as the experience of primary importance that is mediated by other factors, including risk, and which plays an important role in shaping health behaviours and decision-making in relation to illness. In view of this, an emphasis is placed

in this research on *experiences* of uncertainties and how uncertainties are managed by drawing on different resources, particularly risk information.

Uncertainty within medical sociology can be divided into two forms: clinical and existential (henceforth referred to as 'experiential') (Adamson 1997). Clinical uncertainties are gaps in current medical knowledge and are collective, social problems. Experiential uncertainties are part of illness experience and are individual, private problems. A focus of my research will be to explore the experiential uncertainties that men treated for prostate cancer face following treatment. Experiences of cancer can evoke strong feelings of experiential uncertainty. Brown and de Graaf's (2013) found that people with advanced cancers with poor prognoses alleviated their uncertainties by imagining different possible futures, drawing on risk information and hope to deal with the extreme uncertainties they were facing. Survivors of cancer also face experiential uncertainties. Roberts and Clarke (2009) found women struggled to plan for their futures following successful cancer treatment, where fears of cancer recurrence distorted and limited imagined projections for the future.

For prostate cancer there has been limited research exploring men's experiences of uncertainties. Gillespie (2012) and Biddle et al. (2015) have explored the experiences of men receiving routine prostate-specific antigen (PSA) testing prior to a prostate cancer diagnosis. They found that the biomedical testing designed to provide more certainty in managing the risk of illness actually produced a feeling of 'measured vulnerability' (Gillespie 2012) to cancer that exacerbated uncertainties (Biddle et al. 2015). Bell and Kazanjian (2011) found in their interview study of seven men from a prostate cancer support group (PCSG) that routine PSA tests for up to five years following treatment contributed to ongoing fears of cancer recurrence. This led Bell and Kazanjian to posit the notion that prostate cancer might be better understood as a chronic illness, an idea which has informed the direction of my research.



The focus of my research will be broader than just the experiences of uncertainty that are shaped by biomedical testing for prostate cancer, as in the works of Gillespie (2012) and Biddle et al. (2015), and will include areas of experience beyond diagnostic and clinical encounter concerns. The aim of this research is to explore the concerns and uncertainties that men face *following* treatment for prostate cancer, by addressing the research question: *what uncertainties do men face following treatment for prostate cancer?*

Subsidiary to this question is a concern with understanding how men respond to and manage their uncertainties. Weitz (1989) asserts that uncertainty management is based on two strategies: avoidance or vigilance. Avoidance is a practice whereby people 'protect themselves from unpleasant knowledge' by seeking not to acquire it, whereas vigilance involves people seeking to 'reduce uncertainty by seeking knowledge and acting on that knowledge' (1989: 270). Importantly, Weitz's notion of vigilance does not refer to keeping watch, as the term is often employed in general usage. The following research question is posed as a subsidiary question to that presented in the paragraph above: *how are the uncertainties that men face managed?*

Weitz's (1989) approach offers a way of understanding how men respond to illness uncertainties. Given the focus on men recruited from PCSGs, this research will seek to explore men's vigilance strategies particularly and seek ways to develop Weitz's notion of vigilance beyond its current basic definition. If vigilance (Weitz 1989) is a response to uncertainty by seeking knowledge, then developing expertise about illness constitutes a form of vigilance. Patient expertise is described and examined in the following section.

## **2.4 Patient Expertise**

Medical knowledge has been described as a 'black box' to people outside the medical profession (Whitley 1970). Since the 1980s in the UK, there has been an increasing policy drive towards greater patient involvement in healthcare (Prior 2003; Taylor and Bury 2007) and a greater emphasis on shared decision-making (Elwyn et al. 2000). Increasing access to health information

over the last couple of decades has heightened the expectations placed on patients to be 'expert patients' (Ziebland 2004). This is especially the case for those who experience chronic illness, where expectations for a person to self-manage and attend to their own health are high and where expertise about their condition is likely to develop over time (Charmaz 1995; Collins 2014).

Prior (2003) identifies three themes in lay expertise research. Firstly, patient expertise has been understood as the result of experiential knowledge, where first-hand experience of illness provides patients with a unique understanding of their own situation (Busby et al. 1997; Monaghan 1999; Thorne et al. 2000). Secondly, patient expertise has been conceptualised as being valued equally with scientific expertise (Wynne 1996; Epstein 1996; Arksey 1994, 1998). Lastly, patient expertise has been understood as being produced by interaction within organised social groups (Brown 1987; Rabeharisoa 2003; Brown et al. 2004), where self-help groups have been described in terms of the challenges that they can pose to medical authority (Kelleher 2006; Williams and Popay 2006).

However, in Prior's view, none of these elements are sufficient to generally qualify patients as 'lay experts'. Prior's (2003: 48) own research has shown how patient or carer expertise is limited to the one specific case of the sufferer and may not reflect broader facets of the illness which are not present in every case; while patients may be experts of their own bodies, this knowledge is 'partial and limited'. An expert, in Prior's view, requires substantial 'expertise' but also appropriate and relevant 'license' or qualification to give expert advice. Consequently, Prior argues for a clarification in the use of terms, positing that it is important not to confuse expertise with the manipulation of technical knowledge, while Collins and Evans (2002) also emphasise the dangers of the expanding use of the term 'lay expert'.

Collins (2014) has more recently provided a framework for understanding and better conceptualising the concept of 'expertise' generally, rather than lay or patient expertise specifically. According to Collins, we all

have a variety of everyday, or *ubiquitous* expertises, such as speaking the native language of our country or tying our shoelaces, but *specialist* expertises, such as the practice of science, require specific forms of training to acquire. In his book, Collins refers to ‘expertises’ when describing different forms of expertise that he identifies and the same practice is followed throughout this thesis. Addressing the problematic questions of whether we are all experts now, and if not, how do we decide which experts to listen to, Collins (2014) posits two categories of ‘specialist tacit knowledge’ (specialist expertise) that can help to distinguish a scientific expert, namely ‘contributory expertise’ and ‘interactional expertise’. Table 2.1 outlines the different expertises in Collins’ (2014) framework and *specialist* and *contributory expertise* have both been underlined (for a more detailed table see Collins and Evans 2007: 14).

**Table 2.1 Collins’ (2014) Conceptual Framework of Different Forms of Expertise**

<b>1. Ubiquitous Expertises</b>					
<b>2. Specialist Expertises</b>	Ubiquitous Tacit Knowledge			Specialist Tacit Knowledge	
	Beer-mat knowledge	Popular Understanding	Primary Source Knowledge	<u>Interactional Expertise</u>	<u>Contributory Expertise</u>
<b>3. Meta-Expertises</b>	External (Transmuted Expertises)		Internal (Non-Transmuted Expertises)		
	Ubiquitous Discrimination	Local Discrimination	Technical Connoisseurship	Downward Discrimination	Referred Expertise

(Collins 2014: 62)

The three forms of expertise highlighted in bold will first be briefly described. *Ubiquitous expertises* are forms of knowledge that are common to a culture but require extensive learning and skill to acquire, such as learning to speak your own language or tying shoe laces. *Specialist expertises* are rarer and require varying degrees of conscious study. The three forms of *ubiquitous tacit knowledge* are easier to acquire and are therefore distinguished by a marked-out border from *specialist tacit knowledge*, which is harder to acquire. *Specialist expertise* on a subject can be *ubiquitous tacit knowledge* in that it may be readily accessible through different mediums, as the subject of mass produced media or popular discourse, as in the cases of *beer-mat knowledge* or *popular understanding*, or more rarely through non-expert exploration of *primary source knowledge*.

The third form of expertise, *meta-expertises*, are different ways that a person can discriminate between competing sources of knowledge to form a judgement. *Ubiquitous discrimination* is the everyday practice of being able to discern who is honest and who is not. *Local discrimination* relies on having some inside information about the person or expert presenting the knowledge, this is more reliable than just ubiquitous discrimination. These are *transmuted expertises*, they take judgements of people and turn them into choices. The three *non-transmuted* options are non-transmuted because they do not rely on judgements by other people but instead on ‘substantive technical expertise’ (Collins 2014: 77). *Technical connoisseurship* is an understanding of how things are supposed to work and whether a job has been done properly, an example being work on plumbing. This is a ubiquitous expertise. *Downward discrimination* involves a more senior specialist discriminating against the expertise of a more junior one in the same field. *Referred expertise* is when someone transfers their expertise in one area into another (see Collins and Evans 2007 for further details on all of these forms).

Returning to *specialist tacit knowledge*, under which heading are the most important forms of expertise required to be considered an ‘expert’, *contributory expertise* is developed by learning from other experts and can be likened to an apprenticeship. It is heuristic and is acquired through practical

experience. Collins (2014) gives the specific example of chronic illness sufferers, arguing that they are not 'lay experts' but just experts, experts of their own experiences. They learn from medical practitioners, other illness sufferers, and personal experience of symptoms how to best manage their illness.

*Interactional expertise* is necessary to go beyond the narrow confines of contributory expertise. It involves learning the shared technical language of a field of study and being able to use it with fluency. This form of expertise allows scientists from different specialties to communicate their ideas with each other. Collins (2014: 68-9) asserts that while interactional expertise may not appear to be as substantive as contributory expertise, it is particularly important for the everyday conduct of scientific work.

A special sub-category of interactional expertise named 'special interactional expertise' is also important to mention. Collins' (2014: 116) category of special interactional experts is a 'newly discovered one' and constitutes a 'small and very unusual group of specialist experts' who:

Acquire interactional expertise through occupying a strange role in which they immerse themselves in the discourse of a specialist community without fully participating in that community's expertise.

Collins applies this category to people like himself, meaning researchers who study the practices of other research specialties, as well as to science writers and journalists.

Extensive training to acquire both *contributory* and *interactional expertise* is required to become a specialist expert in a particular field of study. Collins (2014) offers a new conceptual framework for examining the degree to which the men interviewed in my research can be considered to possess the different forms of expertise that Collins describes and to examine how such expertises are acquired. In view of this, the following research question is posed: *what forms of specialist expertise do men treated for prostate cancer possess regarding prostate cancer?*

For prostate cancer, there has been little research exploring the acquiring or possession of patient expertise. Oliffe et al. (2011) have found that prostate cancer support groups (PCSGs) facilitate an increase in men's health literacy about prostate cancer. Through attendance at PCSG meetings, men came to understand prostate cancer using numerical test results and other clinical measures associated with the disease. This informed men's discourse about prostate cancer and fostered a health consumerism approach to managing it. Such an approach was empowering for men by allowing them to align with but also at other times contest medical expertise, in order to secure what they considered to be the best treatments available for them. Oliffe et al.'s (2011) work shows that PCSGs facilitate health literacy for men, yet does not explore in depth the forms of expertise men possess or how these expertises are acquired and developed over time, particularly in relation to the role PCSGs may play in this respect. In view of this and the broader discussion on patient expertise throughout this section, the following research questions are also posed: *how do men acquire their expertise?* And, *how do men use their expertise?* One possible use of expertise, as discussed in Section 2.3, is to manage uncertainties following treatment for prostate cancer. In the following section an entirely different concern of chronic illness is examined, namely the experience and management of stigma in relation to illness.

## **2.5 Stigma**

Erving Goffman is the most prominent academic to theorise the notion of stigma. A stigma is an aspect of a person, be it their physical body, their behaviour, or identity, which is socially ascribed as being discrediting (Goffman 1963). Importantly, a stigma is not a fixed and determined object but rather a social process of judgement formed through interactions between people. Physical illness can cause stigma and this section examines the notion of stigma in relation to illness and the ramifications that stigma can have on people's lives.

When first meeting a stranger we all engage in character judgements of that person and form in our minds a 'virtual social identity' which is only an *impression* of the actual qualities they possess: their 'actual social identity'. A stigma is a 'special discrepancy' (Goffman 1963: 3) between a virtual and actual social identity. When there is an immediate and obvious discrepancy between a person's virtual and actual social identity, in such a way as to be stigmatizing, then this person is 'discredited'. When such a discrepancy is not immediately apparent but is still present, then they are 'discreditable'. Stigmatized people can be treated as unwelcome outsiders and be the subject of discrimination and verbal and physical abuse. This can cause distress and over time wear on people's identities and adversely affect their daily lives (Goffman 1963; Scambler and Hopkins 1986).

A further, later distinction in the use of the term stigma is particularly important for understanding experiences of illness: between enacted and felt stigma (Scambler and Hopkins 1986; Scambler 1989). Enacted stigma is the overt discrimination resulting from stigma because of its 'social unacceptability', whereas felt stigma is the feeling of shame or fear of experiencing enacted stigma (Scambler 2009). Scambler and Hopkins (1986) explored experiences of stigma among adults with epilepsy. They found that when diagnosed, many people would hide their diagnosis from others and felt a strong sense of shame associated with their condition, namely felt stigma. Enacted stigma, in the form of epileptic episodes occurring in public, were rarer incidents, as people were predominantly able to effectively control seizures through medication. Instead, felt stigma was far more commonly experienced and disruptive to people's lives, with much time spent worrying about the possibility of seizures and devising strategies to hide their epilepsy from others.

Side effects resulting from prostate cancer treatment have received little attention regarding stigma, despite these potentially stigmatising side effects being well documented in quantitative and qualitative research (Korfage et al. 2006; Mols et al. 2009; Chapple and Ziebland 2002; Oliffe 2009a;

Broom 2004, 2009; Kelly 2009). Side effects are common outcomes of all major primary treatments for prostate cancer (Chen et al. 2009; see Table 1.2).

For urinary and bowel incontinence, two of the most common treatment side effects, there has been little sociological attention as to how these conditions may or may not be stigmatising. Fergus et al. (2002) has identified an 'invisible stigma' for men experiencing erectile dysfunction (ED) resulting from prostate cancer treatment. This refers to the shame men feel about their ED but also the fact that the condition cannot be seen by others and so is kept 'invisible'. Importantly, the onset of ED and other side effects poses important challenges to men's masculinity (see Sub-Section 3.7.4). To better understand men's experiences of treatment side effects it will be important to examine how these conditions may or may not be stigmatising and how these conditions are managed.

Goffman (1963) describes how being in a 'discreditable' state leaves people with the ongoing concern of how much information they want to give to others about their stigma. He suggests there are three main strategies for managing this: 'passing, covering, and withdrawal'. Passing involves managing 'undisclosed discrediting information about self' (Goffman 1963: 42). Covering involves managing being discredited when stigma is evident so that the stigma does not disrupt social encounters (1963: 102). Lastly, withdrawal is the limitation and sometimes cessation of social activities with others. Such strategies help stigmatised people to adjust the perceptions of others towards themselves and also adjust to others' perceptions about themselves. In the following section management strategies for dealing more broadly with chronic illness are explored.

## **2.6 Managing Chronic Illness**

Bury (1991: 452) describes the three strategies 'coping', 'strategy' and 'style' that people employ to manage disruption caused by chronic illness. 'Coping' constitutes the internal cognitive processes whereby individuals come to tolerate and live with the effects of their illness. 'Strategy' takes the form of the



actions people undertake in response to their illnesses to effectively manage them. Finally, 'style' refers to how people draw on 'cultural repertoires' to account for and, importantly, *present* features of their illnesses or treatment regimens to others (1991: 462).

Royer (1995: 32-37) has identified six strategies that people employ when adjusting to chronic illness:

- Avoiding potentially embarrassing situations
- Making efforts to maintain a normal appearance
- Controlling information or covering up
- Engaging in usual activities despite severe physical limitations
- Limiting contact with people who are in similar circumstances
- Pacing energy by giving up certain activities

Royer's identified activities draw together the stigma management strategies described by Goffman (1963) in the previous section and Bury's (1991) chronic illness management strategies described above. The concerns behind these activities are with avoiding shame, appearing as normal to others, making sense of illness, and preserving 'moral character' (Goffman 1963). Presenting oneself as 'normal' and preserving 'moral character' often requires a combination of strategies. In everyday life, some people may be aware of a person's discreditable condition, while others may not. Depending on the nature of the illness, it may be possible to 'pass' as normal in some situations, while at other times stigma may be visible and 'covering' may be required to avoid disrupting social encounters (Goffman 1963). Schneider and Conrad (1980, 1983) found this for people with epilepsy, where conveying illness information varied by situational context and by perceived likelihood of an impending epileptic episode. Therefore, a combination of passing as 'normal' to some people and 'covering' illness around others, varying from encounter to encounter and depending on a range of factors, is likely to be part of most people's strategies for managing stigmatising chronic illness in everyday life.

This can be recognised in Royer's (1995) strategies, as each could be employed in seeking to either pass or cover, although some strategies are more likely to be used for one rather than the other.

A significant component of managing chronic illness involves normalising illness (Bury 1991). Normalising can involve a person changing their own perception of an illness by coming to tolerate and 'cope' with chronic illness, while people also engage in actions and talk, through 'strategy' and 'style', to normalise their illness to others and to themselves (ibid). Seeking to maintain a normal appearance or 'normalise' in the wake of illness has also been identified as an important strategy for coping with illness in Royer's (1995) work (see also Kelly 1991, 1992a, 1992b).

Normalisation has been defined as a behavioural attempt at maintaining a normal life (Weiner 1975). However, how this behaviour has been conceptualised varies considerably. Kelleher (1988) has conceptualised normalisation as a psychological process of either accepting illness as part of a new identity or compartmentalising the illness as separate from one's identity. Knafl and Deatruck (1986) have suggested multiple stages to normalisation that go beyond mental activity and include attempts to minimise the social consequences of illness and behave in ways that seek to demonstrate normalcy to others. Normalising, then, can be understood as a combination of mental activity and physical action to sustain normality as much as possible. Given the importance of normalising in managing chronic illness, the following research question is posed: *how do men normalise the impact of treatment for prostate cancer?*

Sanderson et al. (2011) have identified how normalisation efforts in relation to illness can be condition specific and can vary according to certain factors, such as the visibility of symptoms and the degree of stigma attached to them. Furthermore, normalisation involves managing the moral components of a person's everyday life. The onset of illness can threaten someone's sense of identity, a person's 'moral career' (Goffman 1959a, 1959b, 1963). Moral careers, in contrast to occupational careers, are private and expressive. They

constitute a sense of who a person considers themselves to be and are built up over time, through peer interaction and affirmation of identity and status by a person's peers. In the course of this research the term 'moral status' is used synonymously with the notion of the 'moral career' but reflects men's current moral positions rather than the broader accumulation of moral identity over time. These moral components of identity have been found at times to present barriers to normalisation efforts and by extension how illness is managed (Sanderson et al. 2011; Sanderson et al. 2015). Sanderson et al. (2015) found that Punjabi women living in the UK with rheumatoid arthritis blamed themselves for their illness and their failure to fulfil family duties as a result of arthritis. This self-blaming led these women to withhold information about their illness from others and this was a barrier to normalisation of their experiences. The moral components of illness are explored in Section 2.7.

## **2.7 Morality, Healthicization, and Moral Repertoires**

The term 'moral' is used as a judgement for something as good or bad (Hitlin and Vaisey 2010: 5). The sociology of morality is rooted in the works of the early classical sociological theorists, such as Durkheim and Weber (Hitlin and Vaisey 2010; Abend 2010) and yet between that period and now sociology has largely neglected the study of morality (Hitlin and Vaisey 2010; Campbell 2006; Smith 2003). Morality is embedded in social structures and material relations (Hitlin and Vaisey 2010; Sayer 2011) but can be examined in the 'observable, reportable conduct of social actors' (Turowetz and Maynard 2010: 522).

Morality is a significant component of relations of care between people, where showing and receiving respect and dignity to and from others is important, particularly to those who are vulnerable and dependent on others (Sayer 2011). Possession of dignity is conveyed through the body, in how a person carries and moves their body, where maintaining self-control and composure are important. Having illness that threatens control over the body

can threaten a person's dignity (Sayer 2011: 205), which can be understood as a threat to moral status.

With regard to chronic illness, Galvin (2002) has identified how chronic illness is increasingly being viewed as 'moral failure' in a society where health risks are becoming better understood and increasingly prevalent within lay discourse. To be chronically ill may conflict with prevalent discourses of being a 'good citizen' (Galvin 2002; Petersen and Lupton 1996), of someone who is economically productive, socially active, makes rational choices, and who is responsible and self-reliant.

More broadly, a 'new health morality' has emerged in recent decades, driven by health promotion, which is premised on individual responsibility (Becker 1986). Health promotion is increasingly a driving focus and concern for state public health agencies (Taylor and Bury 2007). Yet the emphasis on health promotion is accompanied by a strong moralising of health (Crossley 2002a, 2002b; Galvin 2002). Advocating for health promotion places responsibility for maintaining good health on the individual. In failing to maintain health, a person is open to being subjected to blame by others. Conrad (1987) goes so far as to assert that this phenomenon warrants its own term: 'healthicization' (see also Zola 1972; Armstrong 1995). Healthicization advances behavioural or social definitions for previously medically defined problems. Medicalization 'turns the moral into the medical', while healthicization turns 'health into the moral' (Conrad 1987: 267).

When health becomes an increasingly moralised area of social life, this has implications for changes in both health policies and health behaviours. Roth (2010: 471) has asserted that risk has become a 'proxy for moral discourse', where the use of risk assessment techniques by governments, which identify people as 'at risk', serves as a justification for bringing people under social control. Furthermore, the calculation of health risks provides a rationale for surveillance over people's health (Clarke et al. 2010; Roth 2010; Hunt 2003). These health risks seep into daily life and in turn orient people

towards self-surveillance to manage illness and risk, in order to maintain good health and, by extension, reputable moral status.

For prostate cancer, the introduction of the prostate-specific antigen (PSA) test into wide-spread use in the UK in the late 1980s has opened a path for healthicization to occur. As discussed in Sub-Section 1.1.3, PSA testing for all men over the age of fifty is available upon request. With increasing public awareness about prostate cancer, from national and international awareness campaigns from organisations such as *Prostate Cancer UK* and the *Movember Foundation*, as well as more easily accessible health information available on the internet (Ziebland 2004), the act of getting tested for prostate cancer in order to maintain one's health can be viewed as increasingly becoming a moralised issue.

There is some evidence to support a case for an increasing healthicization regarding testing for prostate cancer. A report by the charity *Cancer Research UK* (Marmot 2006) on cancer and health inequalities suggested that unlike other cancers, prostate cancer had a slight inverse rate of incidence by social deprivation, against the more common trend among cancers of higher rates of incidence for greater levels of social deprivation. More recent analysis supports this claim for men in England (National Cancer Intelligence Network 2014). A healthicizing trend increasingly turns attaining and retaining good health into a moral necessity and this is particularly important for the middle classes (Crawford 1984; Calnan 1987; Backett 1992). Therefore, it is possible that prostate cancer bucks the broader trend among cancers because more men from higher social classes, who possess greater health literacy and engage more with health promotion, are seeking medical attention, thereby leading to higher rates of diagnosis within these groups. However, the iatrogenic effects of treatment for prostate cancer, which many of the men who are diagnosed will inevitably experience, could pose a threat to men's moral statuses. So, a person's attempting to maintain their moral status by acquiescing to health surveillance may eventually lead to iatrogenic effects that present new threats to their moral status. Therefore, the ways by which men resist or avoid these threats are particularly important to explore.

Morality is so embedded in our lives that we are unable to avoid making moral judgements (Benhabib 1992), as refraining from moral judgement is in itself a moral judgement (Sayer 2011). In making moral judgements about health, the same ideologies imbued within the 'good citizen' (Galvin 2002; Petersen and Lupton 1996), of responsibility and self-reliance, have been found to be important (Crawford 1977). Yet Backett (1992: 263) found that when accounting for their own health attitudes and practices, people will seek to normalise them by locating them within 'appropriate social contexts and spectrums of behaviour'. In accounting for their own health, an individual is seeking to represent the social world in a particular way (Radley and Billig 1996). In talking about illness, people's accounts have been found to be largely framed around concerns with 'blame and legitimation' (Radley and Billig 1996: 224; see also Dingwall 1976; Cornwell 1984; Calnan 1987; Blaxter 1993, 1997; Williams 1993). Because ill people will often seek to represent themselves as 'normal', it is important not to take people's accounts at face value but also to recognise their positions as aiming to guard against criticisms and loss of moral status (Radley and Billig 1996; Anderson and Bury 1988).

As people age, there is an increasing pressure on their remaining healthy, having well and fit bodies, and demonstrating health and fitness to others (Crawford 1994; Radley 1994; Turner 1995; Jolanki 2004). For such older people, it is important to demonstrate living virtuously through self-care and independent living (Williams 1993), which is often framed through descriptions of physical and social activity (Jolanki 2004).

Jolanki (2004, 2005) found that talking about health or 'health talk' is framed around discourses of whether or not an individual is able to do something about their health. These take the form of moral repertoires. Repertoires are comprehensible systems of meaning that can be drawn upon by different people in different contexts to describe and make sense of events (Potter and Wetherell 1987; Lumme-Sandt et al. 2000; Gabe et al. 2016). Jolanki (2005; see also Jolanki et al. 2000) describes two moral repertoires people draw upon when accounting for health: an 'individualistic' repertoire, where health is a result of agency and individual choices, and a 'fate' repertoire

where health is out of a person's control and subject to fate. Historically there has been a much greater reliance on the 'fate' repertoire, but in more recent times there has been a shift towards emphasising 'individualistic' repertoires (Herzlich and Pierret 1987). Davison et al. (1991) have identified how the constraining social structures that lead to adopting the 'fate' repertoire can result in health talk that is phrased around the notion of luck. For the 'individualistic' repertoire, an emphasis on health resulting from individual choices can result in a moralising of health, however to avoid personal criticism or moral judgements from others, this moralising talk is often mitigated and played down within people's health talk (Jolanki 2004). This kind of moralising talk is 'rich with nuances' (Jolanki 2005: 7) and it is therefore important to recognise the positions that interviewer and interviewee are situated in when examining such talk.

Concerns with maintaining moral status or one's 'moral career' (Goffman 1963) were identified in Sections 2.5 and 2.6 as important aspects of chronic illness management strategies. This section has identified the importance of morality for experiences of health and illness and raises a broader question as to how men treated for prostate cancer seek to maintain their moral status when experiencing the chronic dimensions of their illness. Therefore, the following research question is posed: *How do men maintain their moral status following treatment for prostate cancer?* This question and the theme of morality in general pertains to questions about masculinity. The next chapter will explore the topic of masculinity and how the different dimensions of chronic illness explored in this chapter relate to masculinity.

## **2.8 Conclusion**

In this chapter, sociological literature exploring core facets of the lived experience and management of chronic illness have been explored. These have included biographical disruption, uncertainty, patient expertise, stigma, chronic illness management strategies, and morality.

Risk has been identified as an important mediating factor in shaping people's illness experiences, where biomedical testing can contribute to experiences of uncertainty and play an important role in health care decision-making (Clarke et al. 2010; Gillespie 2012). However, a focus instead on the experiential uncertainties (Adamson 1997) that men face *following* prostate cancer treatment may offer new insights into how uncertainties change over the course of prostate cancer illness and how these uncertainties are managed, by drawing on and potentially building on Weitz's (1989) theory of uncertainty management, through either 'vigilance' or 'avoidance'.

Chronic illness sufferers have been found to possess specialist forms of expertise regarding their conditions (Collins 2014), although the question of whether lay people can possess expertise continues to be a matter of contestation (Prior 2003; Collins and Evans 2002; Collins 2014). For men who attend prostate cancer support groups (PCSGs), health literacy has been found to be high (Olliffe et al. 2011). However, little is known about what forms of expertise men can acquire for prostate cancer and the extent of knowledge that can be acquired for these different forms of expertise. Furthermore, there are important questions as to how such expertise that men may possess is acquired and how it is used by men, which will also be explored in this research.

The experiences of prostate cancer treatment side effects warrant particular attention with regard to interpreting post-treatment experiences through the lens of chronic illness. These conditions have received scant and fleeting attention within qualitative sociological research (Chapple and Ziebland; Olliffe 2009a; Kelly 2009). Common side effects such as urinary and bowel incontinence have received little attention regarding how these conditions may or may not be stigmatising. Furthermore, there are questions as to how experiences of treatment side effects are managed and normalised by men, where normalisation has been identified as an important management strategy for chronic illness (Bury 1991; Royer 1995).



Seeking to understand how men manage treatment side effects and normalise the impacts of prostate cancer treatment is in part related to the concept of morality, as morality has been found to shape people's efforts to normalise illness (Sanderson et al. 2011, 2015). Morality is a core component of chronic illness experience, where moral status can be threatened by a failure to 'live virtuously' (Williams 1993) and demonstrate a willingness to return to good health and live independently without care (Pollock 1993; Jolanki 2004). This research will seek to explore how morality shapes men's experiences of prostate cancer and how men employ notions of morality for their own purposes of managing and normalising illness.

This research aims to explore men's experiences and management strategies following treatment for prostate cancer through the lens of chronic illness. In the next chapter, some of the key themes of this chapter will be returned to in relation to the overarching question of this research, pertaining to how men maintain their masculinity following treatment for prostate cancer.

## **Chapter Three: Masculinities and Prostate Cancer**

### **3.1 Introduction**

The focus of this thesis concerns men's experiences and management strategies following treatment for prostate cancer. In the previous chapter a range of facets of chronic illness experience and common strategies for managing these experiences were described in relation to how these may be pertinent to men who have been treated for prostate cancer. To build on these areas further, it is necessary to explore an overarching theme that is important to men's experiences in relation to prostate cancer, namely masculinity and the role that it plays in shaping health and illness experiences and behaviours.

The concept of masculinity has changed historically within the social sciences. Early social research on masculinities was rooted in notions of sexual difference, where biological differences in sex were seen as determining different social functions and roles (Connell 2005). In this way, qualities that men and women commonly hold were often perceived to be inherent or essential traits of a man or a woman. However, more contemporary social research on masculinities has rejected this basis, because it does not explain differences between masculinities and fails to account for power imbalances between men and women. Current consensus is that gender cannot be viewed as something that is predetermined but instead is constructed through social interaction (Connell 2005).

Sociological research on masculinities has focussed on a range of areas (Messner 1995; Klein 1993; Connell 2005; Whitehead 2002; Connell and Messerschmidt 2005), including how men go about their everyday lives, the institutional structures that men are placed in, and the differences between masculinities and the contradictions within and changeable nature of such masculinities (Connell 2005; Connell and Messerschmidt 2005). Connell and others have drawn upon these themes to develop their own conception of masculinities (Carrigan et al. 1985; Connell 2005), which will be explored in the following section.

In Sections 3.2 and 3.3 the dominant model for understanding masculinities as propounded by Connell (2005) is described and subsequent critiques of this theory are examined. Attention is then paid to two key areas: embodiment in Section 3.4 and ageing in Section 3.5, to consider how these areas which are important for my own research have often been neglected within sociological research on masculinities. During men's lives and as they age, having a fit and healthy body are important for sustaining masculinities, which raises questions about the relationship between masculinity and health and how men sustain their masculinities in the face of illness, topics which are explored in Section 3.6.

Exploring masculinity and how it relates to other concepts will then inform Section 3.7, which returns to key themes from the previous chapter on aspects of chronic illness experience and management which are discussed in relation to literature on prostate cancer and masculinities. My research will apply recent innovations in theories of masculinities in relation to health and illness to explore men's experiences following treatment for prostate cancer. These discussions inform the overarching research question of this research *of how do men maintain their masculinity following treatment for prostate cancer?*

### **3.2 Connell's Theory of Masculinities**

Connell's conception of masculinities is premised on the idea that masculinities are part of a larger system of gender relations (Connell 2005: 71). Masculinities are partly a product of history and are rooted in modern ideologies of individuality and personal agency (2005: 68). Most importantly, masculinities are also *relational*, there is no single, fixed concept with rigid categorisations or definitions that can adequately define 'masculinity' but instead the concept is defined in relation to socially determined non-masculine traits, values, or activities, as well as in contrast to femininity (ibid). Indeed, masculinities are distinct from gender in that they constitute differences *between* different men, as well as between men and women (2005: 69).

According to Connell, masculinities can be defined by the following conditions: a man's position within gender relations, the practices through which that man engages with their place in gender relations, and 'the effects of these practices on bodily experience, culture, and personality' (Connell 2005: 71). Social practice is ordered around gender and masculinity is a 'configuration' for how gender is practiced (Connell 2005: 71-72).

Masculine power structures, previously defined as 'patriarchy', have been characterised by Connell through a fourfold model of gender relations: power, production, cathexis (or emotional), and symbolic (Connell 2002, 2005). These can be summarised in turn as: men sustaining power and subordination over women, the gendered division of labour whereby men are the major accumulators of wealth, the emotional practices where men are privileged in the realisation of their desires (2005: 73), and through language and other symbolised discourses (Connell 2002, 2005). These structures of gender relations serve to stratify how gender is configured in practice. How men relate to and are positioned in relation to these structures shapes their masculinities. Masculinities are not fixed and are subject to change. Each of the four structures described above have been subjected to challenges in recent years, for instance the increasing participation of women in the labour market has challenged production relations. Such challenges have caused disruptions in the hegemonic order of gender relations, which have contributed to internal contradictions in masculinities (2005: 73) and crisis tendencies within contemporary masculinities (2005: 83).

Of the various forms of masculinity that Connell identifies, hegemonic masculinity is the dominant form. Hegemonic masculinity is based on Gramsci's (1971) notion of 'hegemony' where the wider population are complicit in the privileging of the values and attributes of the dominant classes. Carrigan et al. (1985) and Connell (1987, 2000, 2002, 2005) developed a notion of 'hegemonic masculinity' to examine the hierarchical order of different types of masculinities. Importantly, these are not fixed definitions for different masculinities with specific criteria for each, but hegemonic masculinity is a *relational* concept. So, hegemonic masculinity can be

understood as the dominant *form* of masculinity within a pattern of gender relations that exists within a culture, which is always prone to contestation and change (Connell 2005: 76). Hegemonic masculinity constitutes the symbolic ideal within a culture of masculinities. This need not necessarily be represented within dominant institutional powers but there will be a close association between these powers and broader cultural ideals, for example in film actors or characters in modern cultures (2005: 77).

In reality, most men are not hegemonic but instead are *complicit* in the hegemonic order. By strategically complying with hegemonic masculine conventions and aligning themselves with associated behaviours without necessarily engaging in them, some men are able to reap the 'patriarchal dividend' of such behaviours (2005: 78). An example would be for a man to remain emotionally withdrawn so that the emotional labour of family relationships is predominantly undertaken by his spouse. The patriarchal dividend can yield men 'honour, prestige, and the right to command' (2005: 79). However, hegemonic masculine ideals can also be restrictive as to the sorts of attitudes or behaviours men can adopt. It is the case that hegemonic masculine values are dynamic and can vary considerably at a local and global level, yet a range of common themes persist within Western cultures, such as having bodily strength, control, and power, being self-reliant, unemotional, material providers, and prepared for violence (Courtenay 2009; Connell 2005; Helgeson 1995; Kimmel 1994).

Some groups of men are subjected to *subordination* by more dominant groups of men in the hegemonic order of masculinities. Heterosexual men dominate over homosexual men who are subordinate within material practices in Western cultures, and are regularly subjected to cultural, legal, and physical violence (Connell 2005: 79). Other groups of men are not only subordinated but are also *marginalised*. While black athletes in the United States may generally be regarded as masculine role models, young black men are heavily restricted by social and economic barriers from achieving this ideal and are therefore a marginalised group (2005: 80).

A core aim of this research is to examine how men maintain their masculinity following treatment for prostate cancer. A key aspect of this will be to examine how men's relationships to the four structures of gender relations, which Connell (2002, 2005) identifies, change in the wake of the disruption that prostate cancer treatment causes. This is explored further in Section 3.7.

### 3.3 Criticisms of Connell

Critics of Connell's theory of masculinities have sought to challenge and change or replace the theory in a number of ways. Connell and Messerschmidt (2005) responded to some of these criticisms in a review of the concept of *hegemonic masculinity* that was originally posited about twenty years earlier. In their paper, they describe that the two main challenges to Connell's theory of masculinities have come from realist and poststructuralist perspectives.

Collinson and Hearn (1994) and Hearn (1996, 2004) have argued against Connell's approach to masculinities, criticising it as being too broad and diffuse so as not to serve as a useful analytical tool (Connell and Messerschmidt 2005). According to Hearn, Connell's theory does not sufficiently emphasise the role of power, where economic and political class differences are undervalued within hegemonic masculinity (Hearn 2004; Donaldson 1993). Hearn proposes instead that the focus should be on the 'hegemony of men' rather than hegemonic masculinity. Instead of focussing on masculinities, Hearn (2004: 59) asserts that:

The hegemony of men seeks to address the double complexity that men are both a *social category formed by the gender system* and *dominant collective and individual agents of social practices* (original emphasis).

Connell and Messerschmidt (2005) do not directly challenge Hearn's thesis in their work, perhaps because it is unclear how his approach differs substantially from their own. Connell (2005: 71-72) treats masculinity as a 'configuration' for how gender is practiced, therefore the means by which men

acquire and maintain power, or are subordinate to it, through hegemonic practices, can be observed and understood following Connell's theoretical approach. A focus on political or economic power in relation to men, as Hearn (1996, 2004) advocates, is entirely possible and compatible following Connell's approach. It is unclear why a focus on the hegemony of men, rather than masculinities, would be of greater analytical value.

Seidler (2006) has made the case for a poststructuralist approach to masculinities. He argues that Connell's work relies on a rationalist modernity model of masculinities and that in doing so Connell reproduces the notion that dominant masculinities can easily be transferred and amended among different cultures, which Seidler refutes. Instead, Seidler emphasises the role of diffuse networks of power at the local level as being the determining force for forming and practicing masculinities. Thus, the focus of masculinities research should instead be on how masculinities are constructed and practiced discursively (Whitehead 2002; Seidler 2006). In response, Connell and Messerschmidt (2005) have resisted assertions that hegemonic masculinity is an essentialising or rigid concept and emphasise that despite limited instances where it may have been applied as such, there has been a wealth of recent research to support the validity and applicability of the term (see Halberstam 1998; Messerschmidt 2004; Gutmann 2006; Warren 1997).

Perhaps one of the most consequential critiques of Connell's theory has come from Wetherell and Edley (1999), who have asserted that the concept of hegemonic masculinity is abstracted from men's experiences and practices of masculinities. In their research, they identify that hegemonic masculinity is an ideal type which can never be achieved and that masculinities can be better understood by exploring the different ways that men are subordinate or resistant to localised hegemonic masculine ideals. In practice, Wetherell and Edley (1999) found when examining men's accounts that men take different imaginary positions, as 'heroic', 'ordinary', or 'rebellious' in relation to the dominant ideologies of hegemonic masculinity. A 'heroic' position closely aligns with these dominant values, an 'ordinary' position questions some values but adheres to others, while the 'rebellious' position subverts standard

expectations of masculinity. Wetherell and Edley (1999) treat hegemonic masculinity as playing an important role for men, whereby they define their social positions in relation to dominant ideologies through their discourse. In this way men are strategically able to traverse the multiple meanings of hegemonic masculinity within different social encounters in the ways that they publicly present themselves. By investigating the social positioning within discursive practice of presenting oneself in relation to hegemonic masculinity, it is possible to observe the workings of institutional power structures and render the 'invisible subject', within Connell's notion of masculinities, visible (Whitehead 2002: 93).

Connell and Messerschmidt (2005) have recognised the validity of Wetherell and Edley's (1999) critiques, as well as other critiques from discursive psychology, by emphasising the fruitfulness of such research in documenting and comprehending experiences of masculinities at the local level. However, Connell and Messerschmidt (2005: 842) maintain that such approaches give greater emphasis to the *symbolic* form of gender relations, whereas the concept of hegemonic masculinity was originally derived from 'non-discursive practices' as well as discursive ones. It is important to consider all of the structures of gender relations to more fully comprehend men's relationships with masculinity, which is central to the focus of my research.

Connell's theory of masculinities is adopted for my research despite the criticisms outlined in this section. Connell's theory is compatible with a micro level and interactional approach to sociology, yet still recognises and accounts for the role of macro structures in shaping masculinities. Connell's approach is also grounded in an analysis of material and symbolic structures, which is compatible with my own research approach discussed in the following chapter. Lastly, Connell's theory of masculinities has become the dominant framework for understanding masculinities in relation to health and illness. Important theorists discussed throughout this chapter have relied on Connell's concept and this has a strong bearing on how my own research will develop. This is the case for Watson's (2000) conceptual framework for understanding



the relationship between masculinities and embodiment, which is discussed in the following section.

### **3.4 Masculinities, the Body, and Embodiment**

An embodied approach to masculinities can provide a fuller understanding of men's lived experiences. The centrality of the body to Connell's work will be discussed in this section. This will inform a discussion of embodiment and how the relationship between masculinities and embodiment has been theorised.

Bodies have long been understood to be the central and dominant sources from which masculinities 'proceed' (Connell 2005: 45). In Connell's (1983) early work on masculinities among young boys at school, the role of the body is clearly central. Within schools and beyond, boys' social experiences are strongly defined by sport and their engagement with it. The taking and occupying of physical space, holding the body still, and skilful use of a powerful body all become important capabilities for a boy constructing their own masculinity. Later, as an adult, the physical emphasis of men's gendered roles turns towards other concerns, namely work, fatherhood, and sexuality.

Connell's (1983: 30) understanding of how masculinities are constructed through the body is best expressed in the following extract:

The embedding of masculinity in the body is very much a social process, full of tensions and contradiction; that even physical masculinity is historical, rather than a biological fact ... constantly in process, constantly being constituted in actions and relations, constantly implicated in historical change.

Here the body plays a central role in the social processes of masculinities being produced and reproduced over time, to such an extent that masculinity appears to be a biological fact rather than a historical one.

Connell's approach here is at odds with traditional essentialist approaches to gender that have drawn on metaphors of the human body as a

'machine' which 'functions' or 'operates' in different ways, varying by sex (Connell 2005: 48). These pervasive metaphors have filtered into wider public discourses and are commonly mobilised to make sense of differences in gendered behaviours. The effect of this dominant historical discourse has been profound to the degree that men are frequently represented by others and also represent themselves as having a predominantly functional relationship with their bodies while avoiding an experiential one (Seidler 2007; Peate 2004; White 2001). Bodily function undoubtedly has an important relationship with masculinity, for if the body fails to function effectively then it may not be possible to enact masculine behaviours (Sparkes and Smith 2002; Smith and Sparkes 2005, 2008; Gerschick and Miller 1995). Yet this emphasis on function belies a more complex relationship men have with their bodies (Robertson 2003, 2006a, 2006b, 2007; Robertson et al. 2010; see Section 3.6).

Connell (2005: 61) has developed the notion of 'body-reflexive practices' to conceptualise how bodies can be both objects *and* subjects of social practice. Social processes and historical forces in part produce bodies and yet bodies are still material and the way that bodies are used in practice 'shape[s] the structures within which bodies are appropriated and defined' (2005: 61). Therefore, the ways in which we use our bodies are reflexively shaped by wider social and historical processes, but in turn these processes are also shaped by the ways we use our bodies. Connell's (2005) approach here offers a way of theorising masculinities as being *embodied*. However, to discuss embodiment further it is necessary to explicate the concept in more detail.

The relationships people have with their bodies, the bodily practices they form, and how bodies interact with the physical and social world are important sociological concerns. Embodiment offers a way of overcoming problematic dualisms in sociological thinking, where the body can be understood as the site where dilemmas such as the relationships between structure and agency and between subject and object can be reconciled and reformulated. Crossley (2006, 2007) has theorised the concept of 'reflexive embodiment' and this bears similarities to Connell's (2005) notion of 'body-

reflexive practices'. These are explicated by discussing two key aspects of both theories: body techniques and reflexivity.

'Body techniques' is a concept similar to Connell's (2005) 'body-reflexive practices'. Derived from Mauss' (1979) original use of the term as being bodily actions that are historically and culturally produced, Goffman extended the term to understand how body techniques are adapted within different specific social and physical contexts by human agents (Crossley 1995). People's perceptions and assessments of each social encounter contribute to an ordering of each encounter that makes sense of it and follows a pre-established pattern of behaviours that are understood by each member of the social encounter as appropriate to that encounter, located in a specific local social space. Each time these behaviours are enacted they are reproduced and perpetuated. This provides an explanation, on the one hand, for how the micro structures of social interaction play a significant role in shaping and reproducing historically and culturally situated body techniques. While on the other, recognises the possibility of change and of embodied human agency as playing a part in shaping the process. This theorisation addresses the sociological dilemma of the relationship between agency and structure. Our understandings of established patterns of behaviour in different social contexts assists us as we creatively, and sometimes innovatively, negotiate and accommodate our way through physical spaces and social interactions in our everyday lives.

Further to this understanding, Crossley (1995) explores Goffman's (1971) work *Relations in Public*. Within this work, Goffman observes that body techniques that are exercised in public are not just reproducing a practical order but 'equally a moral order' (Crossley 1995a: 140). It is important for people to demonstrate to others that they are of 'sound character' (1995a: 140) and because of this there is a desire to maintain routinized patterns of behaviour within appropriate settings so that people are able to show their soundness of character to others by behaving normally. Consequently 'body techniques, in this respect, are oriented towards a moral order which they both respect and reproduce.' (ibid). Additionally, Goffman (1971) describes

how certain social spaces can be perceived as hazardous or dangerous, which he refers to as 'umwelt'. Understanding how body techniques are shaped by macro social structures is important for seeking to understand the body techniques that men reportedly adopt for managing difficulties following treatment for prostate cancer.

Addressing now the second similarity, concerning *reflexivity*, which Connell (2005) alludes to with 'body-reflexive practices' and Crossley (2006) with '*reflexive* embodiment'. Further above, Connell's (2005) theory has been discussed and the reflexive relationship between people's practices as shaping and being shaped by macro social structures has been outlined. The reflexive aspect of Crossley's (2006) is drawn from the work of George Herbert Mead. Mead's sociology demonstrates that we can be absent from aspects of our own experiences in specific instances. During childhood, we learn that we are seen as an object by others and learn to take on the perspectives of others. We can perceive ourselves as objects, but only historically, the active part of who we are, the 'I', is forever in the present. It is when we reflect upon ourselves, the 'me', that we are constructing ourselves as a historical object. This way of thinking contributes to the dichotomising of the mind from the body. The active 'I' and the passive 'me' are evident in the way that people talk about themselves and their bodies. People engage in work upon their bodies and such work is done to maintain or modify the body in some way, such as brushing your teeth or cutting your hair. The phrase 'I wash myself', that Crossley gives as an example, shows how body work acts back upon the body. In this way 'body work is reflexive work, work on the body by the body' (2006: 105) and such actions can be understood as *reflexive body techniques* (RBTs) (Crossley 2006, 2007).

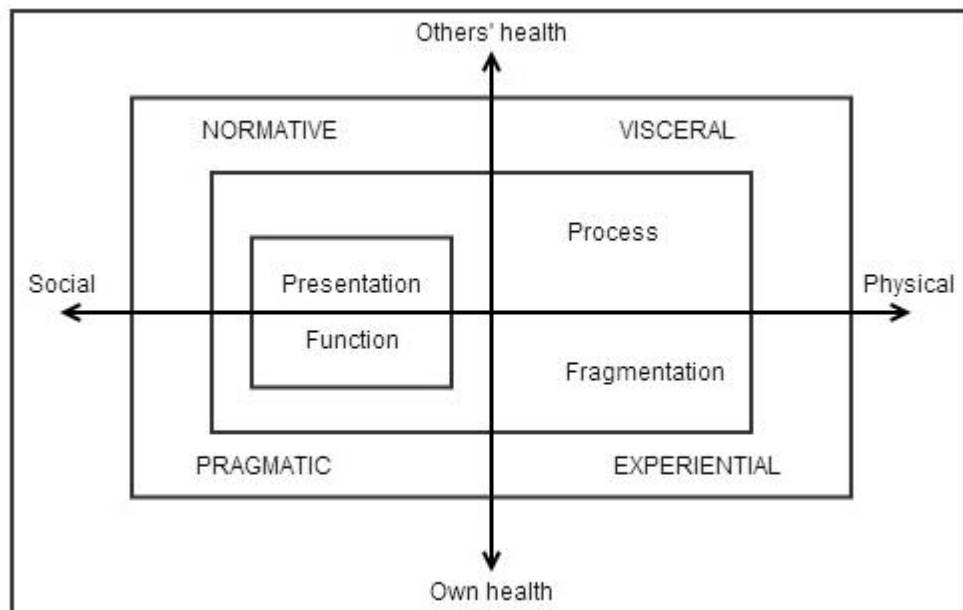
To form new reflexive body techniques (RBTs), close and constant monitoring of the body must first be undertaken (Schrock and Boyd 2006). RBTs have been identified as being disseminated through interactions with others and therefore emerge and take hold throughout a society via social networks. In this way, some RBTs can be more widespread and common, while others can be rarer and more specialised. RBTs are a reflection of the culture

within which they are formed and applied. They can constitute such mundane behaviours that sociologists can fail to treat them as social objects that are worthy of sociological inquiry, yet the patterns and trends of such behaviours can provide rich insights into the values of a society. Crossley's (2006, 2007) notion of reflexive body techniques (RBTs) provides a tool that, while similar to Connell's (2005) notion of 'body-reflexive practices', is more conceptually developed and offers greater explanatory power. Previous research on prostate cancer has explored how masculinities are 'embodied' (Kelly 2009; Chapple and Ziebland 2002), yet such research can inadvertently continue to dichotomise the physical body and cultural practices, perpetuating dualistic thinking, rather than treating these as a unified whole. Such an approach fails to adequately conceptualise the lived embodied experiences of men and the behaviours that they adopt. Crossley's (2006) theoretical approach offers a framework for examining men's reported bodily actions they may have engaged in to manage treatment side effects, in order to answer the research question: *how do men manage treatment side effects for prostate cancer?*

Crossley's (2006, 2007) notion of 'reflexive embodiment' is not directly theorised in relation to masculinity and Connell's (2005) notion of 'body-reflexive practices' offers a broad framework for understanding men's embodied practices. A more focussed theorisation of the relationship between masculinities and embodiment can be found in the work of Watson (2000), who draws on Connell's theory of masculinities. Watson's (2000) empirically informed model of 'being in shape' conceptualises men's embodied relationships with masculinity and health, an important area for my own research. Watson's (2000) model of 'being in shape' is comprised of three components: a 'male body schema', 'managing ambiguities', and 'evaluating social fitness'. Watson's 'male body schema', shown in Figure 3.1, is a unifying theory to comprehend the different levels of embodiment that men occupy, incorporating 'biological, psychological, sociological, and cultural factors' (Geertz 1973: 44, cited in Watson 2000: 115). Just as there are different masculinities (Connell 2005), Watson asserts that masculinities are embodied

in various ways between a person and their environment. Masculinities are embodied at the 'normative', 'pragmatic', 'experiential', and 'visceral' levels.

**Figure 3.1 Watson's Model of 'Being in Shape': An Embodied Concept of Masculinity**



(Source: Watson 2000: 116)

Normative embodiment demonstrates how bodies constitute symbolic modes for transmitting cultural and social values regarding masculinities and health. Normative embodiment is 'presentational' in that judgements about a man's masculinity and health can be formed based on the appearance of their body. Pragmatic embodiment is primarily functional, in that men construct bodies in relation to fulfilling functions for specific gender roles, for example 'brother', 'father', or 'mate'. This form of embodiment concerns the preoccupation for men of 'being healthy and male in the context of having a 'normal everyday body'; it is the 'primary site for interaction between social structure and practice' (Watson 2000: 119). Experiential embodiment is where the boundaries of the social and physical touch. Our experience of the body is 'fragmented and contentious' in the fleeting moments we are conscious

of the predominantly hidden visceral processes, for example in the experience of pain or after heavy exercise (Grosz 1994). Emotions, too, Watson theorises, belong in this area, as direct channels to visceral experience. Lastly, visceral embodiment is constructed by men as the indirect and non-consciously experienced grounding of the body in the world. This cannot be experienced except arising through experiential embodiment or through medical observation or intervention. According to Watson, in this form of embodiment men have constructed the body as largely deterministic of health, in that you have to live with 'the body you're born with' (2000: 120). These are the modes through which men's bodies are experienced and discursively produced and are useful for framing an understanding of how men engage with and experience the world.

The 'managing ambiguities' aspect of Watson's (2000) model, like 'being in shape' as a whole, draws upon the idea that masculinity is a 'going concern' for men (115). Constructing masculinity is a constant process of negotiation that can be problematic, for example a person holding conflicting values about the importance of their health on the one hand but also recognising the importance of not caring about their health in order to be masculine on the other (Robertson 2006a, 2006b). These conflicting values are constantly being addressed and readdressed by men in the course of their everyday lives.

Lastly, 'evaluating social fit-ness' is the recognition of other healthy bodies through identifying how others present themselves, primarily concerning their 'fitness'. For the men in Watson's study, fitness was more important than health, and fitness constituted the capability to perform everyday gendered roles. Watson (2000: 122) summarises this as the 'everyday function = masculine = fitness' equation. To be masculine under Watson's framework, men must be sufficiently fit to fulfil everyday tasks, as opposed to overly fit. It is clear from the equation in Watson's work that the pragmatic mode of embodiment is considered the primary and most important mode for men. Men measure their masculinity by the tasks and functions that they perform and this in turn is a demonstration of their fitness to others.

Watson's (2000) work has been praised for its usefulness in integrating masculinities, health, and embodiment and for examining men's bodies as being both material and representational (Robertson 2006a: 450). Watson's framework highlights the importance of physical capability and action in the construction of embodied masculinities, which raises questions as to how masculinities change as men age and when they experience illness, which are explored in Sections 3.5 and 3.6 respectively.

### **3.5 Masculinities and Ageing**

Manhood is defined through and by age (Hearn 1995) and dominant conceptions of masculinities are biased towards young or middle aged men (Calasanti and King 2005). Youth is prized (Whitehead 2002) and ageing leads to increased distancing from hegemonic masculine ideals (Calasanti and King 2005; Arber et al. 2003). As such, older men have historically been neglected in research on masculinities (Fleming 1999; Calasanti and King 2005) and only in the last decade or so has there been growing research attention in this area.

In later life, men's constructions of masculinities can be beset by a range of difficulties (Evans et al. 2011). As the physical body ages, it becomes harder to continue aligning with hegemonic masculine ideals by keeping the body strong and fit, particularly with the greater likelihood of illness occurring that comes with age. This can lead men to become more distanced from hegemonic masculine values, which some may be able to accommodate while others may instead experience as crisis (Pease 2002). Furthermore, the transitioning from work to retirement can be stressful and pose challenges to masculine identity (Marshall et al. 2001; Soares et al. 2008) and common diseases associated with later life, including prostate cancer (Oliffe 2009a), can add to the attrition to masculine identity that men may experience.

Some research has suggested that as men age the masculine values that they seek to align themselves with will change (Thompson 1994; Robertson 2007), however more recent work has posited that men remain structurally situated within the same dominant ideology as younger men and therefore



they continue to seek to align themselves with hegemonic masculine values as they age (Meadows and Davidson 2006; Solimeo 2008; Davidson and Meadows 2009).

As men become more distant from masculinised spaces they begin to be defined as 'other' (Renold 2004; Meadows and Davidson 2006). Meadows and Davidson (2006: 309), in an extensive qualitative study of older men in the UK, found that rather than embracing alternative, non-hegemonic masculinities, men negotiate and renegotiate their masculinity as they age in order to continue aligning themselves with hegemonic masculine ideals. Even if they could not continue to do this, men were found to be satisfied in at least having attempted to do so, as they could then make credible justifications for their having sought to maintain their masculinities and thereby can resist being treated as 'other'.

Meadows and Davidson (2006) also explored how older men resisted losses of masculine status with regard to power, production, and cathexis relations, in line with Connell's (2005) structures of gender relations (see Section 3.2). To preserve power relations, men engaged in social comparisons with others who were similar to themselves. Previous research on ageing has identified social comparison as an important activity for people to self-evaluate their own competencies (Frisby 2004). To preserve production relations, men emphasised their own physical capability. Previous research has identified how old age has been disassociated in people's talk from chronological age and instead tied to physical capability (Gilleard and Higgs 2000; Minichiello et al. 2000; Fairhurst 2003). Lastly, to preserve cathexis relations, men stressed their physical prowess and emphasised their heterosexuality (Meadows and Davidson 2006).

Older men face challenges to their masculinities as they age and prostate cancer treatment and subsequent concerns add to these challenges. To explore how men maintain their masculinity in the wake of prostate cancer it will be important to examine how they experience and resist changes to the different structures of gender relations (Connell 2005) that are pertinent to

their stages in the life course. Yet to understand this better it is necessary to consider, in addition to the concerns raised in this and the previous section, how health and illnesses shape men's embodied masculinities.

### **3.6 Health, Illness, and Embodied Masculinities**

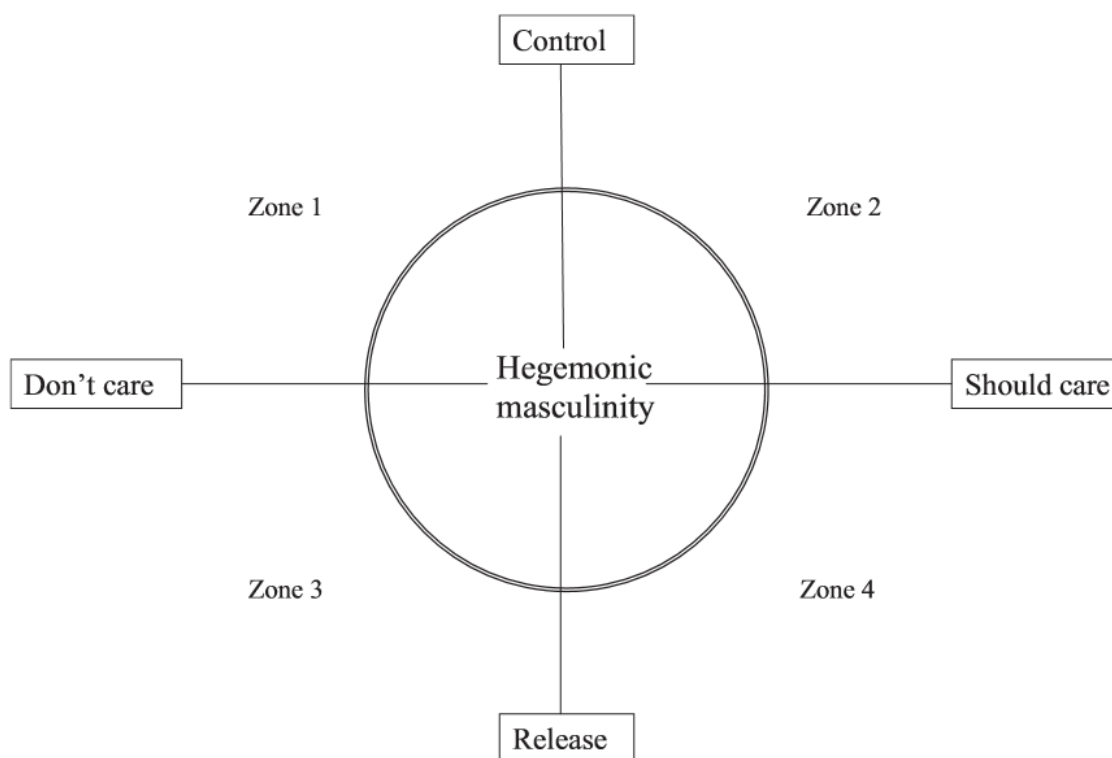
Illness in later life adds to the range of factors described in Sections 3.4 and 3.5 that contribute to a diminishing capability to continue aligning with hegemonic masculine ideals (Arber et al. 2003). Calasanti (2004) found that alignment to hegemonic masculine ideals in young adulthood and midlife can lead to poorer health in later life and old age for men. Poorer health can result from physical harm sustained in competition with other men, neglect of personal health, failure to sustain supportive social networks, and failing to address mental health problems.

It has been posited that 'doing health' is effectively one form of 'doing gender' (Saltonstall 1993). Masculinity has been found to be a key determinant of men's health behaviours. Sabo and Gordon (1995) assert that health is one of the clearest cases where hegemonic masculinity can have a damaging impact, where men are more likely to take risks with their health compared with women (Courtenay 2000). Yet men's health behaviours in relation to risk are more complex than the quantitative data in Courtenay's (2000) study shows. For instance, Mullen (1992) found that men justify taking some risks with their health by avoiding others, attempting to get a 'healthy balance' of 'safe' and 'risky' activity.

Robertson (2006b) took Mullen's 'healthy balance' and developed it into a broader model for understanding men's health behaviours in relation to how men position themselves towards hegemonic masculine values. His model places all men on two continua. The first continuum addresses Mullen's 'healthy balance', in that men will seek to 'control' some health behaviours and 'release' others, taking some risks with their health justified by not taking other risks, or by alleviating the pressures of other risks. This is the 'control-release' axis. The second continuum addresses competing public discourses

that men face: on the one hand ‘that ‘real’ men do not care about health’ and on the other ‘that the pursuit of health is a moral requirement for good citizenship’ (Robertson 2006b: 178). Concerning the latter there is increasing pressure for men to become ‘healthy citizens’ or ‘healthy producers’ (Petersen and Lupton 1996; Crawford 1994, 2000) but also ‘healthy consumers’, where some release from control is itself constructed as healthy (Crawford 2000). This second continuum is referred to as the ‘don’t care–should care’ axis.

**Figure 3.2 Robertson’s Model of the Relationship between Health and Hegemonic Masculinity**



(Source: Robertson 2006b: 186)

Figure 3.2 visually represents Robertson’s model. Men position themselves along each of these axes through their talk to align themselves with hegemonic masculine values. To align oneself too strongly at any of the poles of these axes is to find oneself in an outer zone where a man has either failed to align with dominant masculine forms or is consciously resisting them. Robertson (2006b) finds, however, that men are predominantly involved in

constant (if not conscious) efforts to align themselves towards the central hegemonic masculinity zone.

Robertson's (2006b) model also incorporates the dimension of age into understanding men's health behaviours. At a younger age men are more often involved in risky behaviours and oriented more towards the 'don't care' and 'release' ends of the spectrums. This 'living on the edge' (2006b: 180) is a performance of dominant masculinities. However, as men grow older and form long term relationships and become fathers, their orientation towards hegemonic masculine values shifts (Mullen 1992, 1993). Such men begin to identify more with hegemonic masculine values of materially providing for their family and being able to refrain from excesses, which leads to a shift towards more control in health behaviours and in caring more about their health (Robertson 2007). As specified in the previous section, recent research suggests that men will continue to align with hegemonic masculine ideals as they age (Solimeo 2008; Meadows and Davidson 2006; Robertson et al. 2010), and a general trend of moving from zone 3 to 2 on Robertson's (2006b) model (Figure 3.2) over the life course is predicted, if not yet fully verified, within empirical research (Robertson 2006b; Oliffe et al. 2011).

The importance of marital status in this regard cannot be overlooked. Older married men have consistently reported better health than unmarried older men (Davidson and Arber 2003) and unmarried men have reduced and limited social networks in later life compared to their married counterparts (Scott and Wenger 1995). Indeed, marital status has been linked to Robertson's (2006b) model in the form of the 'legitimated user' position (Noone and Stephens 2008). This is where men will only seek healthcare when they need to and emphasise their limited and necessary use of it (Noone and Stephens 2008). Adopting this position is easier when married, as female family members have been found to legitimise men's illness experiences and their subsequent utilisation of healthcare (Robertson 2003, 2007). This allows men to legitimately care about their health while preserving a masculine front of not caring about it, a dilemma that men are constantly called upon to negotiate (Robertson 2003, 2006a, 2006b, 2007).

Robertson's (2006b) model offers an analytical framework for examining how men balance the dilemmas of competing interests of maintaining good health and masculinity, which draws on Connell's (2005) theory of masculinities. Furthermore, in other works, Robertson has incorporated embodiment, specifically Watson's (2000) notion of embodiment (see Section 3.4), into this conceptual framework. For, despite there being a range of studies on masculinities and the body, and masculinities and health, there has been limited empirical work that draws together the concepts of masculinities, health, and embodiment (Robertson et al. 2010; Robertson 2006a, 2006b, 2007; Watson 2000). Robertson (2006a) has praised the work of Watson (2000) in developing a model to integrate the aforementioned concepts and applies Watson's model when exploring his own empirical data. He finds that Watson's 'male body schema' is particularly useful for examining men's bodies as both material *and* representational (2006a: 450). However, he also finds that Watson overemphasises the significance of pragmatic embodiment and fails to explore sufficiently the interactions between different modes of embodiment.

Building on this, Robertson (2007) has explored the role of emotions and the experiential body for men. He found that far from emotions being minimal or absent from men's relationships with their bodies, they are instead constituted in and through men's bodily actions, and mobilised through pragmatic embodiment. Robertson (2007: 108-9) asserts that: 'men consider instrumentality (action) not merely a form of emotional expression but as constitutive of the emotion itself'. Pragmatic embodiment is not just the mode through which normative embodiment is mobilised, as has been described in Watson's (2000) masculinity equation in Section 3.4, but also mobilises experiential embodiment, too (Robertson 2007; Robertson et al. 2010).

This is evidenced further in a later study of men's experiences of a cardiac rehabilitation programme, where Robertson et al. (2010) showed how experiential embodiment is expressed through pragmatic embodiment. In the process of 'getting back to normal', men were encouraged to engage in a programme of exercise or yoga. Within men's accounts a 'vibrant physicality'

(Monaghan 2001) was expressed in relation to exercise and a 'relaxed physicality' in relation to yoga. Most men opted for exercise, following perceived gendered expectations of appropriate bodily activities for men, despite a recognition that 'relaxed physicality' was important to cardiac recovery. Notions of fitness could still be emphasised by discussing the 'vibrant physicality' of exercising and by describing the effects of exercising on the physiological processes of the visceral body. Such talk was part of attempts to renegotiate embodiment through adopting a 'new outlook' on life, which included a concern with 'relaxed physicality' to manage stress, which is associated with risk of future cardiac events. Robertson et al. (2010) draw from these findings that recovery regimens need to contextually address not only the physical functional needs of individual men but also their emotional needs. Furthermore, they find that addressing men's emotional needs requires a 'pragmatically embodied 'action' component' rather than just 'talking therapies' (2010: 701).

Robertson et al. (2010) also identify that while men are generally regarded as being less body aware compared with women when healthy, in times of illness men generally engage in activities of self-monitoring and acquiring health knowledge in order to maintain control over their bodies (in accordance with hegemonic norms), particularly so as they age (Robertson et al. 2010; Smith et al. 2008). Indeed, Robertson et al. (2010: 706) found that health disruption can cause men to shift towards a 'should care' position on Robertson's (2006b) model (see Figure 3.2). This undoubtedly has important ramifications for men diagnosed with prostate cancer and indeed a shift towards the 'should care' position is anticipated in Oliffe et al.'s (2011) work on men attending PCSGs. However, how men seek to position themselves in relation to the experience of prostate cancer illness and associated treatment side effects warrants further attention.

Viewing men's experiences following treatment for prostate cancer through the lens of chronic illness raises the importance of considering the relationship between masculinities and chronic illness as well. Charmaz (1994) has examined how the onset of chronic illness impacts on men's

masculine identities. Charmaz (1994) identifies four distinct responses from men: first they are awakened to the possibility of death, second they seek to accommodate the uncertainties of their illness, third they seek to control how their illness and any resulting experiences of disability are defined, and fourth they seek to preserve a sense of self, maintaining a coherent sense of who they are amid experiences of loss and change.

The impact of trying to hide illness, particularly for men in seeking to preserve their public identities, can be damaging over long periods (Charmaz 1994, 1995). Charmaz (1995: 268) has asserted that:

Illness can reduce a man's status in masculine hierarchies, shift his power relations with women and raise his self-doubts about masculinities.

The onset of chronic illness can pose a range of 'identity dilemmas' for men (Charmaz 1994). Charmaz (1994) outlines four core dilemmas: the dilemma of either 'risking activity' or being resigned to 'forced passivity', of 'remaining independent' or 'becoming dependent', of 'maintaining dominance' or 'becoming subordinate', and of 'preserving public persona' or 'acknowledging private feelings'. Importantly, whichever ways men choose to direct themselves in relation to these dilemmas there is always a cost to them (Charmaz 1994).

In trying to live normal lives, men will devote considerable time and energy to preserving their sense of self (Charmaz 1991, 1994). They seek to do this in a range of ways, by limiting the advance of illness, minimising its visibility by increasing control over their lives, and seeking to control how the illness is defined. 'Controlling time, pace, space, information, and people' were all strategies employed by men to preserve their sense of self in the wake of chronic illness (Charmaz 1994: 282). In examining prostate cancer as a chronic illness experience, this research will explore how masculinities are maintained in relation to the 'identity dilemmas' and strategies for control that Charmaz identifies.

As discussed in Section 2.7 in the previous chapter, chronic illness is often accompanied by a concern with maintaining one's moral status by adopting the 'right attitude' in relation to health and illness (Galvin 2002; Williams 1993). Robertson's (2006b) model also clearly refers to concerns with moral status, bound up within the 'should care-don't care' horizontal axis. Demonstrating a caring attitude towards health is a way of being a 'good citizen' (Petersen and Lupton 1996), a significant social pressure that older men particularly are subjected to (Robertson 2006b). Within both Robertson's model and Charmaz's (1994) work, moral status can be understood as an important aspect of masculinity. This again raises the importance of addressing the research question posed in Section 2.7 in the previous chapter, concerning *how do men maintain their moral status following treatment for prostate cancer?* In view of the relationship between morality and masculinity, addressing this question will inform the overarching research question of this research of *how do men maintain their masculinity following treatment for prostate cancer?*

In this section, a range of important theories for understanding the relationship between the intersecting topics of masculinities, embodiment, health, and illness have been examined. These works provide a conceptual toolkit for exploring men's experiences and management strategies following treatment for prostate cancer, where Robertson et al. (2010) have recently demonstrated the compatibility of Connell's (2005), Watson's (2000), and Robertson's (2006b) theoretical frameworks for unitary analysis. Exploring further the relationship between masculinities and illness, particularly chronic illness, by drawing on Charmaz's (1994) framework will be an important part of my research. In the following section, literature on prostate cancer and masculinities is explored to further identify where there are gaps in current understandings on this topic.



### 3.7 Prostate Cancer, Masculinities, and Gender Relations

Prostate cancer has come to be recognised as a disease that disrupts stable masculinities (Broom 2004; Oliffe 2006a, 2009a; Chapple and Ziebland 2002). Cameron and Bernardes (1998) were among the first researchers to extensively investigate the relationship between masculinities and men's health and in doing so identified the threat that prostate problems pose to masculinities. Driven by masculine conventions of men not caring about their health, men are often reluctant to seek medical attention when experiencing prostate related symptoms, which can lead to delays in being diagnosed and treated (Chapple and Ziebland 2002; Cameron and Bernardes 1998). Then, when men encounter the medical system, experiences of it are further shaped by men's embodied masculinities (Gray et al. 2000; Broom 2004; Oliffe 2005). These have profound implications for the treatment choices men opt for and their support needs following treatment (Broom 2004).

If masculinities are disrupted by onset of prostate cancer, then an important question arises, namely: *how do men maintain their masculinity following treatment for prostate cancer?* To address this question, it is important to return to Connell's (2000, 2002, 2005) theory of masculinities and to examine the four structures of gender relations: power, production, cathexis, and symbolic, to consider how prostate cancer poses the possibility of change in these different structures for men's lives. These changing structural relations will intersect with some of the research questions posed in the previous chapter, which inform the overarching research question posed here.

#### 3.7.1 Power Relations

Power relations concern the mechanisms by which men maintain authority over and subordinate other men and women in the masculine order. As discussed in the previous section, the means by which men maintain their power over other men and women changes as men age, from a state of conflict and contestation to one largely comprised of co-operation (Robertson 2007).

Prostate cancer challenges men's power relations, in relation to their physical strength, their perceived control over their lives, and their control of physical functions of the body through continence and sexual potency (Broom 2009). Gray et al. (2000) found that *management* of prostate cancer was a core theme in their research, with an important emphasis on regaining control. They found that men and their wives formed strategies in response to their illness, although often in different, gendered ways. Studies of gendered cancer support groups have observed that men are generally more concerned with acquiring informational and instrumental support and women with acquiring emotional support (Gray et al. 1996) for managing cancer. Acquiring information and knowledge, then, may be a means for men of sustaining power relations.

Prostate cancer support groups (PCSGs) have been found to serve a range of beneficial functions for men with prostate cancer, including: mitigating the psychosocial impacts of cancer, empowering patients, facilitating adjustment, helping to cope with life after treatment, and providing information, assistance with decision-making, and peer networking (Manne 2002; Steginga et al. 2001; Coreil and Behal 1999; Cordova et al. 2003; Katz et al. 2002; Oliffe et al. 2011).

In their ethnographic study of PCSGs, Oliffe et al. (2011) observed a range of behavioural patterns. Men employed discourses of logic and rationality in the way they talked. They would refer to their cancer through the numerical and technical language of biomedical test results, would emphasise cause and effect logic using this language, and some would seek to publicly demonstrate personal knowledge and test the knowledge of others. This shared language helped men to make sense of their illness in relation to others, which was viewed by the authors as a way of taking back control after the shock of their diagnosis.

Oliffe et al. (2011) found that PCSG attendance led to an improved health literacy for prostate cancer. A health consumerist approach was also found to be fostered, where activities like 'doctor shopping' (Zeliadt et al.

2006), involving researching the best doctors available for different treatments, and posing questions to doctors during consultations were actively encouraged. This kind of consumerist approach, empowered by greater health literacy, allowed men to align with or contest medical experts and form more balanced doctor-patient power dynamics.

These behaviours have implications for masculinities. Oliffe et al. (2011: 7) found that PCSGs conform with dominant codes of masculinity for older men and 'engage men with rational self-surveillance' with the aim of achieving self-governance. Instead of engaging in risky behaviours to raise masculine status, as younger men are more inclined to do, seeking to control health behaviours by pursuing 'risk reduction and a healthy self were shared values underpinning men's interests' (Oliffe et al. 2011: 8). This leads Oliffe et al. to postulate that men who attend PCSGs reside in zone 2 of Robertson's 'don't care-should care, control-release' model (Figure 3.2). Men emphasise values of 'egalitarianism, self-reliance, and purchasing power' in response to the threats to masculinities posed by prostate cancer illness and treatment (Oliffe et al. 2011: 12).

Oliffe et al.'s (2011) work provides some understanding of how men who attend PCSGs maintain their power relations in the wake of prostate cancer, by using health literacy to empower themselves when interacting with medical practitioners. Yet the focus of their work leaves important questions unanswered. Viewed through the lens of chronic illness, questions can be posed about how PCSGs remain important for power relations over extended periods of time after a man has been treated for prostate cancer, not just in the periods shortly following diagnosis and treatment. The concept of lay or patient expertise (see Section 2.4) is also not addressed in Oliffe et al.'s work. Drawing on the concept of 'expertise' offers a way of exploring how men sustain power relations over longer periods of time after primary treatment. This serves as a reminder of the research questions posed in the previous chapter: *what forms of specialist expertise do men treated for prostate cancer possess regarding prostate cancer? How do men acquire their expertise? And, how do men use their expertise?*

### 3.7.2 *Production Relations*

Production relations pertain to divisions of labour by gender. Due to the nature of the condition, prostate cancer is a disease that predominantly affects men over the age of fifty (see Sub-Section 1.1.1). The highest level of incidence by age group for prostate cancer is in men's mid-sixties (Cancer Research UK 2017a), which is close to the average age of retirement for men in the UK (Office for National Statistics 2013). Prostate cancer can occur before or after retirement or may, in part, contribute to an earlier retirement than was originally planned (Chapple and Ziebland 2002: 829).

Moynihan (1998) found paid work to be a key factor related to masculine identity among men with testicular cancer. Research concerning testicular cancer has found that men experience minimal impact from the disease on their masculinities in the long term (Gordon 1995; Moynihan 1998) and this has been equated with men being able to return to their everyday activities following treatment and continue to engage in masculine behaviours (Gordon 1995). Comparatively younger men in their thirties and forties with testicular cancer, compared with somewhat older men with prostate cancer, found it much easier to maintain their masculinity as they were able to continue fulfilling their gendered roles (Gordon 1995; Moynihan 1986, 1998). For prostate cancer, the capability of men of being able to return to paid employment following treatment has been identified as an important concern for men's masculine identities (Chapple and Ziebland 2002). The disruption of employment resulting from prostate cancer illness has also been identified as impacting significantly on men's identities and can create uncertainty about a previously presumed healthy retirement (Cayless et al. 2010).

Meadows and Davidson's (2006) in their study of older men found that men strongly resented their changing gender roles as they moved from the public sphere of paid employment to the domestic sphere in retirement. To resist this change, men sought to emphasise their continued physical capability in being able to perform gendered functions and roles, thereby demonstrating a continuation of 'pragmatic' masculine embodiment (Watson

2000) in the process. In examining how men maintain masculinity following onset of prostate cancer, it will be important to examine the ways that men respond to changes in their production relations, particularly if prostate cancer onset influences men's transitioning to retirement.

### 3.7.3 *Cathexis Relations*

Cathexis or emotional relations are concerned with the emotional energies and meanings that are attached to people or objects and 'the practices that shape and realise' these (Connell 2005: 74). Such relations are 'organised mainly through the heterosexual couple' (2005: 74). For men with cancer, their spouses or partners have been found to play an important supportive role. Survival from cancer has been found to be longer for married compared to never married men (Krongrad et al. 1996) and partnered men have better mental health and lower symptom distress with cancer than non-partnered men (Gore et al. 2005). For testicular cancer, men redefined masculinities to include emotional expressiveness, empathy, and concern for personal relationships (Gordon 1995). However, differences in average age of diagnosis, likelihood of regular sexual activity, and having paid employment between men with testicular and prostate cancer (briefly discussed in Sub-Section 3.7.2 above) means that the same experiences for testicular cancer cannot be presumed for prostate cancer, too.

Social support has been cited as the main factor that facilitates coping with cancer (Keitel et al. 1990). Having social support is partly dependent on having a wider social network to draw upon and women have been found to generally have larger social networks than men (Babchuck 1978; Longino and Lipman 1982), whereas men more frequently are dependent on their partner for support (Antonucci and Akiyama, 1987; Harrison et al., 1995). For those with prostate cancer, men's spouses or partners have been found to be the primary source of support (Gray et al. 2000, 2002; Fergus et al. 2002).

Gray et al. (2000) observe that couples generally seek to *minimise* the impact of prostate cancer and focus on 'normal' living. Minimisation activities

can be considerable in seeking to hide illness from people outside of family, but men often opened up to their wives (Gray et al. 2000, 2002; Fergus et al. 2002). Men were found to be grateful to their wives for their support but there were often underlying tensions or conflicts in their relationships (Gray et al. 2000, 2002; Fergus et al. 2002). Research on wives' experiences of their husbands' prostate cancer has found that wives often feel constrained by the self-imposed silence of their minimising efforts on behalf of their husbands, as their own ways of coping tended towards expressive communication about their problems (Williams et al. 2014). Wives are conflicted by being deprived of their preferred way of coping and by the difficulty of balancing being supportive to their husband on the one hand and honouring their husbands' desire for self-reliance on the other (ibid). Couples have a great need to return to normal as soon as possible after treatment (Gray et al. 2000; Oliffe 2005; Beck et al. 2009) and just as with minimising, a large part of normalising is undertaken by wives (Williams et al. 2014). A greater understanding of how men seek to normalise their experiences following treatment for prostate cancer is sought in my research by seeking to answer the research question: *how do men normalise the impact of treatment for prostate cancer?*

Fergus et al. (2002) found the onset of erectile dysfunction (ED) following treatment for prostate cancer posed a major challenge for couples' intimate relationships. Participants' accounts made references to the mechanical nature of sex when experiencing ED and to the mechanical devices that can facilitate sex for men with ED but which disrupt the flow of sex (Fergus et al. 2002: 311). For men, sexuality has been defined as 'instinctual reflexive physical performance' that is disrupted by ED (Oliffe 2005: 2253). Therefore, an embodied approach that accounts for the reflexivity of sexual performance is warranted and just such an approach has been discussed in Section 3.4 regarding Crossley's (2006) work. This will inform the approach taken to answering the research question: *how do men manage treatment side effects for prostate cancer?* Erectile dysfunction as a prostate cancer treatment side effect is discussed further in the following sub-section.

### 3.7.4 *Symbolic Relations*

Symbolic relations are the meanings and symbols that express gender attributes. Prostate cancer poses profound symbolic threats to masculinities, some of the most significant of which emerge after treatment for prostate cancer in the meanings attached to treatment side effects (Chapple and Ziebland 2002; Gray et al. 2000; Broom 2009). Such conditions have previously received greater attention within clinical, nursing, and psychological research areas compared with sociological research, as the following literature will show. My research will examine these conditions through the lens of chronic illness to gain further insights.

All treatments for prostate cancer have unwanted side effects (Tannock 2000) and the most common treatments come with considerable risk of erectile, urinary, and/or bowel dysfunction (Stanford et al. 2000). Two of these side effects, erectile dysfunction (ED) and urinary incontinence (UI) are discussed in greater depth below.

Loss of erectile function has been equated with fears of losing both libido and intimacy with partners (Olliffe 2005), as well as a loss of masculine identity (Broom 2004; Chapple and Ziebland 2002). Erectile dysfunction is symbolically loaded, it is both 'de-sexing' and 'disabling' for men and renders men 'impotent' in both senses of the word (Potts 2000: 94). Consequently, a failure to perform sexually can lead to a newly subordinated masculine identity (Flood 2002; Lee and Owens 2002).

Sexual function has been identified as an important factor in treatment or non-treatment decision-making (Gray et al. 2000; Fergus et al. 2002; Kunkel et al. 2000; Arrington 2003). Furthermore, sexuality has been identified as a 'primary supportive care need' (Fergus et al. 2002: 304) for prostate cancer patients, particularly younger men, as ED has been identified as posing 'a threat to who men were' and constituted an 'invisible stigma', the disclosure of which was referred to by men as 'coming out' (2002: 310-11).

Men have sought to respond to this symbolic threat by emphasising that post-treatment ED is a 'rationalized' (Olliffe 2005) 'trade-off' (Gray et al.

2000; Oliffe 2005; Maliski et al. 2008), a necessary cost required for continued survival. Men have also sought to minimise or normalise their ED in other ways, by emphasising circumstantial factors such as age and the comparable unimportance of ED compared with UI (Gray et al. 2002; Korfage et al. 2006). Fergus et al. (2002) found that men's experiences of prostate cancer brought them emotionally closer to their partners. In the wake of cancer, intimacy has been found to be redefined through shared interests and physical touch (Oliffe 2005; Gordon 1995; Fergus et al. 2002; Gray et al. 2002). Potts et al. (2006) have observed a similar trend among couples who often move towards non-intercourse based intimacy as they progress through later life. Performance of masculinities and therefore masculine identity itself is closely tied to demonstrating heterosexuality (Fergus et al. 2002; Potts 2000; Broom 2009).

Another major treatment side effect is urinary incontinence (UI). The symbolic meanings of urinary incontinence have been well documented. To become fully continent as a child marks a symbolic transition to maturity (Hockey and James 1993) and to become incontinent as an adult is not only an indicator of frailty but also of a loss of social capability (Isaksen 2002; Mitteness and Barker 1995), which can be perceived by the sufferer as embarrassing, non-adult behaviour and cause feelings of shame (Eisenhandler 1993). Consequently, hiding incontinence from others (Mitteness and Barker 1995; Manderson 2005) and limiting participation in social activities outside of the home as part of this (Herskovits and Mitteness 1994; Brittain and Shaw 2007) have been identified as important concerns for people with UI.

Jervis (2001) has asserted that UI challenges one of the underlying symbols of Western culture, namely that the mind should have control over the body. Arneil (1999) recognises the mind/body split as essentially a patriarchal one, born from the culture/nature dichotomy, where historically in Western societies men have been equated with culture and the mind while women have been associated with nature and the body. These ideas remain rooted in Western culture and within Western conceptions of hegemonic masculinity having control over the body remains an important masculine trait (Connell 2005). Indeed, Morgan (1993) has asserted that it is more



important for men than it is for women to be able to exert physical control over their body, in terms of the impact this has on identity.

Much of the focus of social research on UI has examined women's experiences of UI (Peake et al. 1999; Peake and Manderson 2003; Eisenhandler 1992) and UI during old age or end of life care (Lawton 1998; Twigg 2000; Jervis 2001; Cassells and Watt 2003; Broom and Cavenagh 2010). Research on men's experiences of UI has identified how the condition can cause shame, embarrassment, distress, a sense of loss of control, difficulties at work, and feelings of isolation from family and loved ones (McCallum et al. 2001; Reeve et al. 2006; Bhojani et al. 2008; Fultz and Herzog 2001). Having UI can also contribute to reduced levels of sexual satisfaction and activity (Gacci et al. 2003), particularly with severe incontinence, and this has been at least partly attributed to the close symbolic relationship of the penis as a site of urination and of sexual pleasure (Paterson 2000; Abouassaly et al. 2006).

The onset of UI results in a struggle for men to be and appear as normal to others (Fultz and Herzog 2001) as UI is a stigmatising condition for men (Paterson 2000). Men employ different techniques to cover their stigma and pass as normal, such as by wearing dark clothing that disguises their incontinence (Elstad et al. 2010). Unfortunately, Boyle et al. (2003) identified a common view among the men in their research that UI is an inevitable outcome of prostate related problems or is a natural consequence of ageing and this is a barrier for men's health-seeking. Consequently, many men suffer from UI without seeking medical assistance (Paterson 2000; Sacco et al. 2006; Petry et al. 2004) Also, men who received prostatectomies have cited being informed about the possibility of UI prior to treatment, yet received inconsistent support from professionals to develop coping strategies to deal with UI afterwards (Burt et al. 2005).

Urinary incontinence, as a treatment side effect for prostate cancer, has understandably received some attention within medical, nursing, and psychology research, as has been illustrated above (see also Kunkel et al. 2000; Sestini and Pakenham 2000; Ficarra et al. 2006; Bhojani et al. 2008; Palmer et

al. 2003; Abouassaly et al. 2006). However, this condition has received little sociological attention, particularly concerning the meanings men attach to this condition and how the condition impacts on masculinity. As noted above, Paterson (2000) has described UI as a stigmatising condition, which leads men to hide incontinence from their public identities. However, Paterson's findings were drawn from just three interviews and further investigation of men's experiences in this regard is warranted. Chapple and Ziebland (2002) have noted the importance of having a 'physically bounded body' (Lawton 1998: 131) and the challenge that UI can pose to this ideal, but have not discussed the condition in any greater depth.

Further empirical evidence is required to understand men's experiences and management strategies of the two common treatment side effects: UI and ED. How men talk about these conditions and their reported strategies for managing them will serve to address the questions of how men manage treatment side effects and normalise the impacts of prostate cancer treatment. This will inform a broader understanding as to how men maintain their masculinity following prostate cancer treatment.

### **3.8 Conclusion**

In this chapter a range of literature on masculinities has been explored. Connell's (2000, 2002, 2005) conceptualisation of masculinities has been outlined and adopted for my research and a series of justifications for doing so have been given, informed by critiques of Connell's work also explored within this chapter. In my research, how men's experiences of prostate cancer change their relationships with the four structures of gender relations: power, production, cathexis, and symbolic (Connell 2002, 2005) will be explored. In addition, important related concepts that have historically been neglected in masculinities research, namely embodiment and ageing, have been explored. Recent empirically-driven theorisations that have sought to both combine and understand the relationships between embodiment and masculinities have been considered (Watson 2000; Robertson 2006a, 2006b), as well as how

these theoretical frameworks have a bearing on health and illness (Robertson 2006b; Robertson et al. 2010). The compatibility of these theoretical approaches to be applied together to understand embodied masculinities in relation to health and illness (Robertson et al. 2010) offers a conceptual toolkit with which to interpret men's experiences and management strategies following treatment for prostate cancer and to address the overarching research question posed: *How do men maintain their masculinity following treatment for prostate cancer?*

Prostate cancer has been the subject of research attention from a range of clinical and social research disciplines, with the study of masculinities being a common theme within such research (Wenger and Oliffe 2013, 2014). However, a range of gaps have been identified in current knowledge about prostate cancer, in both this chapter and the previous chapter, which have informed the research questions that have been posed. The first of these gaps has been described in the paragraph above, where compatible theories for masculinities, embodiment, and health and illness can offer fresh interpretations for understanding men's experiences following treatment for prostate cancer. The second gap identified is the focus of my research to investigating men's experiences at extended periods of time following primary treatment for prostate cancer. This stage along the illness trajectory for prostate cancer has received less attention compared with earlier stages of diagnosis and treatment. This focus on the period *after* treatment shapes the focus of this research towards the third gap in current knowledge, which is to interpret men's experiences and management strategies following treatment for prostate cancer through the lens of chronic illness, as suggested by Bell and Kazanjian (2011) (see Section 2.3). Some of the facets of chronic illness experience have been discussed in relation to masculinity in this chapter, yet others such as experiences of uncertainties and the acquisition of expert knowledge may offer sociological insights that are somewhat separated from the overarching focus on masculinities.

With more elaborate and complex theoretical models for integrating masculinities, embodiment, ageing, health, and illness (Robertson et al. 2010;

Robertson, 2006a, 2006b, 2007; Watson 2000; Charmaz 1994; see also Crossley 2006), and by taking a fresh approach in viewing prostate cancer as a chronic illness, new insights into men's experiences of prostate cancer and how they maintain their masculinity in the wake of the illness may be yielded.

Having reviewed the relevant sociological literature in relation to prostate cancer, it is important to return to the research questions posed in this and the previous chapter, which are recapped below:

- What uncertainties do men face following treatment for prostate cancer?
  - How are the uncertainties that men face managed?
- What forms of specialist expertise do men treated for prostate cancer possess regarding prostate cancer?
  - How do men acquire their expertise?
  - How do men use their expertise?
- How do men manage treatment side effects for prostate cancer?
- How do men normalise the impact of treatment for prostate cancer?
- How do men maintain their moral status following treatment for prostate cancer?
- How do men maintain their masculinity following treatment for prostate cancer?

The earlier questions addressing aspects of chronic illness experience and management, explored in Chapter Two, are posed to inform the overarching question of how men maintain their masculinity following treatment for prostate cancer. In the following chapter the methodology employed to answer these research questions is outlined.

## Chapter Four: Methodology

### 4.1 Introduction

This chapter describes the qualitative methodological approach that was employed to answer the research questions posed at the end of the previous chapter. The chapter is divided into five main sections. The first section outlines the research design, describing the methodological approach and the specific method employed. The second describes the ethical considerations of my research. The third describes the form of sampling that was used, the process of recruitment of participants to my research, as well as presenting some of the characteristics of the final sample that was recruited. The fourth section outlines different aspects of the data collection process and includes some personal reflections on fieldwork experiences. The last section presents the analytical approach that was employed to analyse the data from my research.

### 4.2 Research Design

A research strategy is formulated on the basis of the beliefs a researcher holds about the social world and how it can be studied (Pope and Mays 2008) and the form of reality being examined must be accurately reflected within the methods chosen (Mason 2002). Research strategy and design come together in the recognition of the type of social reality being investigated and finding the most appropriate method to investigate that social reality. The research questions formulated for this research are predominantly concerned with men's *experiences* of illness and therefore the strategy and design must be tailored to examining this form of social reality.

Experiences are complex and multi-faceted (Silverman 2005) and people can create multiple meanings and interpretations for an experience or set of experiences (Gubrium 1997). A qualitative research strategy and design has been devised to investigate men's experiences because such an approach

is best equipped to examine the social reality of experiences. In-depth, open qualitative interviews were the main method employed for this research.

The strength of qualitative research rests on its validity rather than its representativeness (Mitchell 1983: 190). A robust analysis depends upon drawing theoretically informed logical associations between a set of mutual and relevant characteristics, which provides a reasonable explanation for observed phenomena (ibid). Validity is demonstrated through the strength of the theoretical reasoning presented and the analytical strength of such research is largely dependent on the appropriateness of the theoretical framework within which the research is based (ibid).

This research is grounded within a weak social constructionist ontology. This view treats the physical world as a real foundation upon which the symbolic world is shaped and ordered through social interactions and structures. If the social world that we occupy is constructed through social interaction, then it is not enough to take what someone says at face value, as an objective truth. As such, men's talk within interviews is not viewed, in and of itself, as direct representations of their experiences. Rather their talk is taken as an *account* of their experiences, a constructed reflection of their experiences shaped by their current lives, the interview encounter, and as part of a jointly constructed process of sense-making between the interviewer and interviewee (Silverman 2011). Experiences are 'embedded in a social web of interpretation and re-interpretation' (Kitzinger 2004: 128) and Kitzinger (2007) is highly critical of anyone who treats people's speech as a direct representation of their experiences. This approach has profound implications for how qualitative interviewing research should be conducted, how different aspects of the research process should or should not be treated as forms of data, and how the data yielded from such research should be analysed. These issues are discussed in Sections 4.5 and 4.6. In the following sub-section the rationale for undertaking qualitative interviewing for my research is outlined.

#### *4.2.1 Qualitative Interviewing*

The method that has been adopted for this research is in-depth, open qualitative interviewing. Interviews offer insight into the patterns and content of people's experiences and are effective for learning the subjective meanings people give to their experiences (McCracken 1988; Byrne 2004; Denzin and Lincoln 2011).

Qualitative interviewing offers a variety of different forms of data that can be acquired, reflecting the multiplicity of people's experiences and their personhood or identities (Mason 2002; Kvale and Brinkmann 2009; Silverman 2011). Such data can come in the form of people's personally held beliefs or values, their reasons for behaving in certain ways, and their emotions and feelings. In-depth qualitative interviewing affords a greater understanding of participants' lives and assists in situating their experiences of illness within the context of their daily lives.

An open style of interviewing has been employed in this research, as it provides flexibility and adjustability (Mason 2002; Fielding and Thomas 2008; Bryman 2008). This allows for rapid changes in the focus or direction of any individual interview, should interesting new topics arise. The men interviewed received different prostate cancer treatments that had a range of different outcomes and it was therefore important to have a method that was flexible to examine the variety of experiences resulting from these diverse illness and treatment pathways. Crucially, open interviewing also involves active listening, which comprises of letting the research participant speak for themselves and listening for what they are telling the researcher and what issues are important to them (Noaks and Wincup 2004).

Another strength of qualitative interviewing is that it can yield richer data when exploring sensitive topics. Brannen (1988: 553) has argued that researching sensitive subjects cannot simply rely on single questions, as accounts are 'frequently full of ambiguities and contradictions and are shrouded in emotionality'. Interviewing men about their experiences of prostate cancer for this research involved discussing sensitive and emotive

topics. The flexibility accommodated by open interviewing (Mason 2002; Fielding and Thomas 2008; Bryman 2008) allowed for a style of interviewing that could address sensitive topics by returning to them over the course of the interview and approaching them from different angles. This was undertaken to acquire more data on topics that men may be reluctant to discuss, while also seeking to minimise the possibility of emotional upset by being able to quickly move away from topics that men found distressing to talk about.

Qualitative interviewing is not without its challenges. A potential challenge a researcher may face can occur when participants of research are more familiar with technical language and terminology related to the research topic than the researcher is. A researcher's confusion over technical terminology can cause a barrier in communication and limit the generation of new data (Fontana and Frey 2000). To address this, pilot and early interviewing allows for knowledge of technical terms to be developed by the researcher, where the language interviewees use can be looked-up to inform subsequent interviews. Further details of the interviewing approach taken and how the interviews were conducted in my research are discussed in Section 4.6. In the following section the ethical approach taken in my research is outlined.

### **4.3 Ethics**

The research design for this project has been informed and guided by a selection of different ethical practice documents. The Social Research Association's (2003) Ethical Guidelines, the British Sociological Association's (2002) Statement of Ethical Practice and the Economic and Social Research Council's (2015) Framework for Research Ethics were consulted prior to deciding on the research design. In consulting these documents a number of key areas were identified that needed to be addressed before university ethical approval was sought. These areas were producing a risk assessment of the proposed fieldwork, ensuring informed consent was given by participants, protecting anonymity for participants, holding information securely and



maintaining confidentiality, and minimising any risk of physical and psychological harm to the participants and the researcher.

An initial assessment regarding the potential risks and benefits of the research was undertaken and was included on the information sheet provided for respondents (Appendix 1). The information sheet also outlines the purpose of the study, informs readers about their various rights in taking part in the research, outlines participants' rights to withdraw from the study at any time without having to provide a reason, that their anonymity will be protected, and that their information will be held securely in accordance with the Data Protection Act (1998). The information sheet also outlines that interviews were to be audio recorded using a Dictaphone and typed transcribed for purposes of analysis. These points were also made clear verbally before respondents were asked to carefully read the consent form (Appendix 2), ask any questions or seek clarity on any point they were unsure of, and then, if they were happy to do so, to sign the consent form.

The consent form required the participant to tick each item individually to acknowledge that they had read the information sheet and comprehended each of the points on the information sheet that have been described above. Items that required ticking also concerned acknowledging that the participant was given time to ask questions about the research prior to giving their consent to take part. These points were emphasised verbally by the researcher prior to the consent form being signed. These procedures are informed by and in line with recommended research practice (Fontana and Frey 2000; Ryan 2004; Shaw 2008; Silverman 2013). Written questions and a list of key topics to raise in the interviews were included within a topic guide (Appendix 3) that was not given or shown to interviewees but was also not purposefully hidden from their view.

Anonymity was an important concern to address. Pseudonyms have been provided for the names of participants. References within interview accounts to specific locations, people, and other details that were considered by the interviewer to be potentially identifying have also been anonymised.

The PCSGs have been identified as being based in the South East of England outside of the Greater London area to provide some idea of the region where these men and groups were based without providing further information that may threaten anonymity.

In accordance with the ethical proposal submitted to the Centre for Criminology and Sociology at Royal Holloway, and to minimise risk to the researcher, a family member of the researcher was always informed prior to the researcher travelling to undertake an interview. They were provided with details of where the researcher was travelling to and informed by mobile phone when departing following the conclusion of an interview.

The physical and psychological wellbeing of participants and the researcher were central concerns within this research. Raising topics related to men's experiences of diagnosis, treatment and recovery regarding prostate cancer presented the possibility of causing distress to the participant or the researcher and such topics were considered 'sensitive' (Renzetti and Lee 1993). Procedures were designed to reduce this sensitivity and limit any experiences of distress. It was emphasised that if participants wanted to stop the interview at any time they were free to do so without giving a reason. The research design was also devised so that if at any time during an interview the interviewer felt that the interviewee was experiencing considerable physical or psychological distress or discomfort then they would be offered the opportunity to suspend the interview for a short time or until a later date, or to end the interview at that point. Alternatively, if deemed appropriate, the interview would be ended early by the interviewer.

Interviewing men about their experiences of prostate cancer also had the potential to cause physical or psychological distress or discomfort to myself as the researcher. To address this potential concern, I ensured that close friends and family were aware of what my research involved and was therefore able to surround myself with a support network to help manage any potential psychological distress or discomfort. I also had access to the counselling service of my host institution, Royal Holloway, to address any

psychological distress or discomfort that might have arisen while conducting the research. Instances where both myself and some of my participants experienced strong emotions during the discussion of sensitive topics are reflected upon in Sub-Section 4.5.2.

In outlining and meeting with all of the specifications and practices described above, this research received a favourable opinion by the Royal Holloway departmental ethics panel for the Centre for Criminology and Sociology.

#### **4.4 Sampling**

The sample for this research is purposive and strategic (Glaser and Strauss 1967; Bryman 2008) in that it involved selecting specific groups to study on the basis of their relevance to the research questions and the theoretical approach being taken towards the research. The sample for this research fulfils the practical and theoretical needs of the research and therefore the sampling method is appropriate.

The selection criteria for recruitment to participate in this research were that participants had to be men who had been treated for prostate cancer and who lived in the South East of England. These men were to be recruited through voluntarily organised prostate cancer support groups (PCSGs). Choosing to recruit from support groups offered access to men who met with the desired criteria for addressing some of the gaps in current knowledge (see Section 3.8). Men who attend PCSGs have often already received their primary treatment for prostate cancer and my research has sought to explore men's chronic illness experiences *following* treatment for prostate cancer. Furthermore, men attending PCSGs were at varying lengths of time since they had received their primary treatment for prostate cancer. Interviewing men at a range of intervals following their primary treatment offered a way of understanding how men managed the impacts of treatment in the periods following treatment and how men sustain their masculinities over time after they have received treatment.

Not restricting this research by a range of factors, by age or class, by different treatment regimens, or by time interval following treatment, were important choices. This research was inductive and sought to explore some of the common concerns men faced following treatment for prostate cancer. By not seeking to limit the criteria for recruitment, a broader range of experiences could be identified to provide a clearer sense of the common concerns men face.

Age particularly may be an important factor in shaping experiences following prostate cancer treatment. Relatively younger age groups of men treated for prostate cancer, below the age of seventy, may have fewer co-morbidities than those of higher ages. These comparatively younger men may in general terms have a greater expectation in the coming years of having good health, mobility, and quality of life, compared with older men. Many of these men may still be involved in full or part time employment, contributing to some or the majority of the household income. The social positions that men occupy at different stages in the life course, as well as the expectations about their health and future health may vary considerably by age and this must be taken into account when analysing men's accounts.

The range of outcomes that different prostate cancer treatments can bring must also be taken into account. The most widely used primary treatments for prostate cancer all have common treatment side effects, however the numbers of people who experience each side effect and the severity of the side effect can vary considerably across different primary treatments (Chen et al. 2009; see Table 1.2 in Sub-Section 1.1.5). These common side effects include urinary and bowel incontinence and erectile dysfunction. How these conditions are experienced and managed are important concerns that are addressed throughout the findings of the research.

Despite few limiting criteria being adopted when recruiting the sample, interesting commonalities emerged within the sample. The sample predominantly comprised of socially and economically advantaged, highly

educated, married white men. However, these common characteristics served as a basis for comparison within the sample, which has shaped the findings of this research and these findings could not have been achieved by different means. These commonalities were an unintended consequence of recruiting through PCSGs in the South East of England. The generalisability of the research findings is limited by the sample being recruited from this region. In the following sub-section the process of recruiting participants from PCSGs is discussed.

#### *4.4.1 Recruitment from Support Groups*

Voluntarily organised PCSGs were selected as recruitment sites. Support groups can provide spaces that produce a sense of community and which are more free from judgement (Ussher et al. 2006) and are sites where information and experiences are shared (Ussher et al. 2006; Barbuto et al. 2011). Furthermore, cancer support groups can sometimes be emotionally challenging, which can be a welcome contrast for cancer patients from the normalising support offered by family and friends (Ussher et al. 2006). They can also be places where attendees continue to attend after their needs have been met (Coreil et al. 2004). These are all important factors as they encourage men to be more open and talkative about their experiences, which facilitates the acquisition of richer data.

Following ethical approval, recruitment was initially undertaken through a charity that primarily seeks to raise money for prostate cancer research but also hosts a support group and holds two regular pub lunches in different towns about 15 miles from each other. Access to this organisation, referred to as 'Support Group 1', was facilitated by my grandfather's previous association with the group and was secured during an informal meeting with the organiser. Based on men's interview accounts, medical practitioners and other specialists came to give informational talks to PCSG attendees at regular monthly meetings. Unfortunately, during the fieldwork for my research, the leader of this support group had decided to step down from his role but

nobody had agreed to take his place. There was some uncertainty as to whether the support group would continue to operate and no support group meetings were scheduled during this time. This presented a barrier to attending any support group meetings here for recruitment purposes, while also creating a tense atmosphere that some research participants commented on during interviews.

Shortly following access being agreed upon at Support Group 1, access was also secured through a voluntarily run PCSG in another area, which had no explicit charitable goals and was not affiliated with the NHS, although it was sited close to an NHS hospital. Meetings were organised in the same informational talk style as for Support Group 1, but with the difference of having two scheduled social events organised by the group occurring at midway points in the calendar year and one meeting a year where a few of the attendees would give short talks about their own experiences of prostate cancer. Access to this organisation, referred to as 'Support Group 2', was secured via email correspondence and then later confirmed during an interview with the group leader. Access was also likely facilitated by referring to my grandfather's experiences of prostate cancer. Both support groups are based in urban or suburban areas in the South East of England outside of the Greater London area.

There was a small element of reciprocity in the research relationship between myself and my two gatekeepers in that an expectation emerged that I would produce a report of my findings that would be made available to both groups. This report was produced as a collection of webpages to disseminate key findings of the research and to be able to update interested parties about further outcomes of the research. This can be found at the following web address: <https://www.managingprostatecancer.wordpress.com/>.

Initially, potential participants were contacted by email through their support group mailing list. A discussion of the content of the email was undertaken with the organiser of the mailing list for each support group and the content agreed upon before they distributed the email on my behalf. This

email (see Appendices 4 and 5) briefly outlined the focus of my research, provided my contact details, and included more detailed information about my project in the information sheet attached to the email (Appendix 1). Interested respondents were asked within the email to contact me by telephone or email if they had any questions about the project or if they wished to arrange an interview.

In late September of 2014 recruitment to my research had diminished as fewer people were getting in contact. In seeking to encourage further participation in the research I spoke with my gatekeeper at Support Group 2 and was permitted attendance at one of their meetings that month to encourage further participation in the research. A short summary of this experience is presented in Appendix 6. Overall, 29 men were recruited to participate in the research, with approximately a quarter of participants being recruited through Support Group 1 and three quarters through Support Group 2. Recruitment ceased when I felt that 'data saturation' had been reached, where new data no longer generates new theory and analysing differences in the data no longer produces new patterns (Charmaz 2014; Glaser 2001). In the following sub-section, some characteristics of the sample that was recruited for my research are described.

#### *4.4.2 Sample Characteristics*

Table 4.1 shows some key details about the sample recruited for this research. The acronyms for the different treatments found in this table are explained in the *List of Abbreviations* on Page 9.

All participants were men, except for one woman who joined the conversation midway through her husband's interview and subsequently consented to take part in the study and have her account included within the transcript. Her details have not been recorded in this table because of the nature of the data presented here. All of the 29 men in this research were self-reported heterosexuals and all but two were married. One of these non-married men was widowed and the other was divorced. The age range of men

interviewed was broad (between 53 and 83 years) but the majority of the sample were in their late sixties or early seventies at the time of interview, with almost two thirds of the sample falling within this range.

**Table 4.1 Sample Characteristics: Demographic and Treatment Information**

Name	Age (Years)	Primary Treatment	Secondary and Other Treatments	Support Group	Marital Status	Time Since First Treatment (Years)
Jamie	50-54	RARP	None to Date	2	Married	3-5
Shaun	50-54	RARP	None to Date	2	Married	3-5
Geoff	60-64	RP	RTwHT	2	Married	11-15
Mark	60-64	RP	RTwHT	2	Married	0-2
Andy	65-69	RTwHT	RP	2	Married	6-10
Ben	65-69	HT	ChT, then later LPDs	2	Married	6-10
Clive	65-69	RARP	RT	2	Married	6-10
Dan	65-69	RP	None to Date	2	Married	6-10
David	65-69	RARP	None to Date	1	Married	3-5
Joe	65-69	RP	None to Date	2	Married	0-2
Lionel	65-69	RP	None to Date	1	Divorced then Re-married	6-10
Lucas	65-69	RARP	RT	2	Divorced	6-10
Nigel	65-69	RARP	None to Date	2	Married	3-5
Paul	65-69	RTwHT	None to Date	2	Married	0-2
Robert	65-69	RP	None to Date	2	Married	3-5
Terence	65-69	RTwHT	HT, later CT	1	Married	6-10
Alex	70-74	BT	None to Date	1	Married	11-15
Algernon	70-74	WaW	RT	1	Married	3-5
Charles	70-74	RARP	None to Date	2	Married	3-5
Chris	70-74	RP	None to Date	2	Married	6-10
Clarence	70-74	RARP	None to Date	2	Married	0-2
Jonathan	70-74	RARP	RT	2	Married	3-5
Peter	70-74	RP	RT	1	Married	3-5
Edward	75-79	RTwHT	None to Date	2	Married	3-5
Ian	75-79	RTwHT	None to Date	2	Married	0-2
Matthew	75-79	WaW	RP, later RT	2	Married	11-15
Arnold	80-84	RP	None to Date	2	Married	6-10
Duncan	80-84	WaW	HT, later BT	2	Widowed	11-15
William	80-84	RTwHT	None to Date	1	Married	3-5



When speaking to the leader of Support Group 1 about the demographics of his support group, he characterised the men in three distinct groups by age. The youngest, in their fifties or early sixties, were drawn to the support group by the large impact the cancer and its treatment had on their lives. The second group were in their sixties and early seventies and these were the largest group of men. Following treatment, these men were more likely to continue attending the support group for extended periods of time afterwards, compared with the younger men who were often busier and less able to attend. The last group were in their late seventies and above. Some of these men were deemed by medical practitioners to be too old to have treatment and were following surveillance regimens instead, some had previously been treated successfully but continued to come to support group meetings, and a small number had advanced cancers and ongoing treatments to manage these. Although the PCSG leader's characterisation is a rough distinction, the age variance in this research sample to some extent reflects this. The majority of men were in their mid to late sixties or early seventies, like the men in the second group described above, yet there were significant minorities of men in the first and third groups also.

Radical Prostatectomy (RP), either robot assisted or not, was the most common primary treatment with more than 60% of the sample opting for this procedure. Radiotherapy (RT) was the second most common with more than half of the entire sample having some form of radiotherapy as their primary or secondary treatment.

Men were interviewed at a range of intervals following their first treatment, with the majority of the sample having first been treated in the last five years. However, due to many participants having secondary or even tertiary treatments, as well as other tests, treatments, or regimens concerning the management of treatment side effects, these intervals do not always accurately reflect men's ongoing concerns related to their prostate cancer.

Of the twenty-nine men interviewed, twenty were in some form of paid employment at the time of their diagnosis and subsequent treatment. Of these

twenty men, eleven were in full time roles, two in part time roles, and seven were self-employed which afforded some flexibility with regard to working hours, although predominantly working to full time schedules. Almost all of the men were currently or had previously been employed in white collar jobs, in middle or senior management positions, and/or as professionals. The majority of these men had some form of scientific or mathematical education or training. The most common educational backgrounds in this respect were electrical engineering, physics, information technology, and accounting or finance.

This sample of men had a unique and specific set of characteristics that sets them apart from the broader population of men with prostate cancer. The men in this research were all white and the vast majority were British and long term married. They were also well educated and frequently occupied senior positions in white collar employment, often involving technical knowledge and proficiency. Furthermore, all these men previously or at the time of interviewing attended a PCSG. Indeed, some of these characteristics are similar to the samples from previous research on prostate cancer that have recruited from PCSGs (Breau and Norman 2003; Gregoire et al. 1997; Krizek et al. 1999; Steginga et al. 2001; Coreil and Behal 1999). As such, the findings of this research are limited in how far they can be generalised. The experiences of men from ethnic minority and socio-economically disadvantaged groups are not represented within this research. Furthermore, the experiences of men who do not attend support groups, who are by far in the majority (Krizek et al. 1999), are also not represented in this research. However, the commonality between the characteristics of the men in my research and previous research on prostate cancer provides a basis for comparison to test the analytical strength of the research findings. In the following section the process of carrying out the research is outlined and discussed.

## 4.5 Data Collection

Being reflexive in recognising the positions of the researcher and researched is an important part of the research process (Patton 2002; Bryman 2008). As Stanley and Wise (1990) have stressed, a qualitative approach to understanding people's experiences must seek to have experiential as well as analytical validity. To produce experientially valid research, it is necessary to produce a 'description of how research is conducted and knowledge is produced' (1990: 22). Reflecting on the positions that the researcher and participants occupied within the context of the interviews is an important part of achieving this.

### 4.5.1 *Conducting Interviews*

The interviews were solely conducted by myself over an eight-month period. Ethical approval was given in the middle of April 2014 and recruitment and interviewing began shortly after this. The fieldwork concluded in the middle of December when I came to a point where I felt I had reached 'data saturation' (Charmaz 2014; Glaser 2001; see Sub-Section 4.4.1) in relation to the sensitising concepts that I had been exploring and developing in the course of conducting and transcribing interviews.

Pilot interviewing informed how the interviews were conducted in a variety of ways. They provided a way of testing the feasibility and appropriateness of the research design, and identified areas of the interview design requiring amendment. Pilot interviews also informed my approach as an interviewer. Addressing the sensitive topics of men's sexual and urinary function was done timidly and awkwardly in my initial pilot interviews and I quickly learned that such questions needed to be asked matter-of-factly and confidently to encourage substantive responses from men.

I also very quickly discovered that my topic guide (Appendix 3) had been designed too rigidly with set and longwinded questions that were inappropriate for the predominantly conversational style of interaction that

took place. The style of the topic guide was originally structured with specific questions for my comfort as the researcher, with little interviewing experience, to have something scripted to say if at a loss for a question to pose. To make the interviews flow better I instead summarised the key themes at the beginning of the topic guide and soon memorised standard questions relating to these themes or created new questions, prompts, and probes in the moment during interviews to generate data on any given theme. This provided for some consistency and commonality of data between interviews but crucially did not restrict pursuing any tangential lines of questioning that could identify new and important themes. For instance, newly emerging themes of morality and patient expertise in men's accounts could be added into later interviews by having a flexible interviewing format. Furthermore, this more flexible approach can also allow men to raise topics that were important to them, which in turn can inform and shape the focus and direction of research. Written notes were taken when conducting interviews, which informed further questioning and following up on previous points. Themes that were found to be of interest, which were either noted down during the interviews or picked up on when later transcribing the interviews, informed the topics and themes that were raised in subsequent interviews.

Prior to conducting interviews, I had an expectation about the limits of time that participants would have available. The planned length of the interviews, outlined in the information sheet (Appendix 1), was suggested to last between 1-1.5 hours, as men have been found to often be averse to speaking for prolonged periods of time in interviews about health (Oliffe and Mroz 2005) and they may have demanding jobs that take up a lot of their time (Odendahl and Shaw 2002). My research sought to balance a desire for more in-depth interview accounts with expectations about the demands on interviewees' time and diminishing rapport and good will if interviews go on too long. However, while some men engaged in full, flexible, or part time work, others had already retired, and more often than not men did not have substantial restrictions on their time. There were a small number of instances where men were restricted in their time and almost all of these were paid

employment related. Interviews often lasted longer than 1.5 hours, where the shortest interview was just less than 45 minutes and the longest just over three hours long.

It was also specified in the information sheet that interviews were to take place either at the participant's home or at a public venue, whichever was preferable to the participant. Interviewing men in their homes provides material clues as to men's class background, social status, and masculine identity (Manderson et al. 2006) and can also be talking points that facilitate rapport and probing for more elaborated responses (Wenger 2002; Roulston 2010) as I found on several occasions. Interviews were predominantly conducted in interviewees' homes. They took place in clean, tidy public rooms of the house, such as the kitchen, lounge, or dining room. If men's wives were present then they would usually make drinks and bring them through while we, the men, spoke. Wives often took a kind of backstage role where they facilitated the interview with friendliness, providing food and drink, and by generally being unobtrusive and sensitive to a desire for privacy. This research was not designed to include the experiences of men's wives and in only one instance did the wife of one of the participants actively participate within an interview.

Interviewing men in public places can inhibit discussions of emotional and sensitive subjects (Manderson et al. 2006) and reduce men's feelings of agency (Lee 1997). Despite this, it is important to offer men a choice (Olliffe 2009b), particularly to encourage participation for men in full time employment with limits on their time and availability. Indeed, the four men who were interviewed in public places were all still in paid employment and were taking breaks from their work to take part in the research. Interview locations included two garden centre cafes, one coffee shop, and one work place. The work place was quiet but the garden centre cafes and coffee shop were all loud places that made audio recordings of those interviews difficult to transcribe. The coffee shop interview took place in central London and was very loud, so while most of this interview was determinedly transcribed, small sections of this interview were incomprehensible. Taking place in public

venues, these interviews presented difficulties in raising sensitive topics, however quieter areas, away from other people, were sought where possible and sensitive questions were asked matter-of-factly, so as not to draw attention from nearby people by deliberately lowering my voice. Sensitive topics were discussed in these settings with limited hindrance.

#### 4.5.2 *Masculinity within Interviews*

A potential barrier to generating good qualitative data for this research was getting men to talk about their health. Men have been found to be generally more unwilling to disclose things and to be less expressive than women (Mckee and O'Brien 1983; Oliffe and Mroz 2005). This is a longstanding problem and has been termed the 'cone of silence' that surrounds men when they are asked to talk about their health (Oliffe 2009b). The situations where men talk about their health are predominantly highly structured clinical encounters, so talking to men about their health with an open, qualitative approach is a challenge that the researcher must address (Oliffe 2009b). This challenge can yield greater insights into men's experiences and there is much that can be learned from listening to men talk about concerns that are important to them (Broom et al. 2009).

Men have been found to take account of the interviewer's gender and adjust their responses accordingly (Williams and Heikes 1993; Lee 1997; Pini 2005). Oliffe (2009b) asserts that it is important to recognise that men's talk is *contextual*. Men interviewing men can facilitate the building of rapport (Oliffe 2009b), but can also lead to men performing to the interviewer's expectations and responding to sensitive questions differently depending on the gender of the interviewer (Broom et al. 2009; Schwalbe and Wolkomir 2001). Age, too, is important. Young interviewers have been found to lack a more conversational style and be less willing to share their own experiences within interviews compared with older, more experienced interviewers (Manderson et al. 2006).

Health interviews can pose a challenge to men's masculine identities (Oliffe 2009b; Williams and Heikes 1993; Lee 1997; Schwalbe and Wolkomir 2001, 2002; Oliffe and Mroz 2005). An interview situation constitutes both an opportunity to signify masculinity and a threat towards masculinity (Schwalbe and Wolkomir 2002). Men's talk in interviews can also include 'identity markers' (Oliffe 2009b: 80). These are subtle self-disclosures that can provide further information about how men identify themselves and what things are important to them. These self-disclosures can also be treated as data (Schwalbe and Wolkomir 2002) and inform an understanding of men's experiences, beliefs, and behaviours in relation to health and illness. Interviews are opportunities for men to show themselves to be in control, autonomous, and rational (all masculine ideals), while interviews can threaten masculinity as the interviewer controls the interaction, sets the questions, and puts men's self-portrayals into doubt, not simply affirming men's masculine selves (Schwalbe and Wolkomir 2002: 205).

To address the challenges involved with men interviewing men, a range of strategies were employed, which are discussed throughout this sub-section. To encourage men to talk, Oliffe and Mroz (2005) recommend starting interviews with men by asking open, general questions. I began interviews by asking men to give broad overviews about their lives, inviting responses on topics including their paid employment, their families, and their health in general. I did this to encourage men to take an active role within the interview by letting them tell their own stories in their own ways.

A conversational approach to interviewing was also adopted, as this serves to prevent interviewees from becoming passive within interviews (Oakley 1981). Men were encouraged to ask questions at various points in the interview for a variety of reasons: if they sought clarity, if they wanted my (the researcher's) opinion on a topic, or if they had general or specific questions. A conversational approach serves to break away from the medical consultation model through which men traditionally engage in health talk (Oliffe 2009b).

Other strategies were employed to encourage men to talk. The following conversational devices were employed: prompts – in encouraging men to talk about different topics, probes – to encourage men to talk in greater depth on a topic, and loops – to return back to topics again to acquire more data on a previously discussed topic (Olliffe 2009b). Looping back to previously discussed topics was particularly important for discussing the sensitive topics of urinary incontinence and erectile dysfunction in my research. Men were often reluctant to talk about these topics and getting men to talk about them often depended on looping back to the topic later in the interview, when greater rapport and reciprocity had been achieved.

Another strategy that was useful in facilitating looping back was to repeat things that men had said back to them (Hutchinson et al. 2002; Schwalbe and Wolkomir 2001). During an interview, although men may have previously given little information about a sensitive topic, they might allude to it later when talking about another topic. By quoting what men said back to them, this offered a route into discussing these topics, as men had raised the topic themselves and therefore introducing the topic posed less of a challenge to men's masculinities.

There were many clear incidents where men were not initially willing to talk about sensitive topics. Men also often employed humour (Chapple and Ziebland 2004) when talking about such topics, to downplay the seriousness of their treatment side effects and minimise their impact and I played up to this to encourage openness and talkativeness, but also sought later to question the meanings that were implicit in humorous remarks. Again, this involved looping back and returning to topics later in an interview. In practice, this was not always easy, as mentally juggling the activities of note-taking, thinking of new ideas, remembering to return to previous topics, and listening to the interviewee required prolonged and sustained concentration. However, generally this strategy was effective at getting men to open up about sensitive topics and more rewarding in generating further data on a sensitive topic than might have been acquired by only attempting to talk about a topic once.



One of the most important challenges of interviewing men was finding the balance between seeking to interrogate and unpick aspects of what men were saying by questioning their accounts but doing so without challenging men's masculinity so as to impede the generation of data. Men-to-men interviews are heavily dependent on building good rapport but this can mean that meanings can be passed over and unarticulated, as the rapport is partially dependent on a shared comprehension of the implied meaning and to question that meaning would mean breaking rapport.

I sought to reduce my power as the interviewer in various ways to avoid challenging men's masculinity. I dressed casually for the interviews and sought at all times to present myself as friendly, polite, and courteous so as to facilitate rapport and not promote a sense of competitiveness (Odendahl and Shaw 2002; Oliffe and Mroz 2005). I sought to give participants as much freedom as possible to decide upon the date, time, and location of the interviews. Furthermore, the open and conversational style of interviewing was designed to give the men opportunities to raise their own issues of concern or interest within the interviews, thereby giving men greater autonomy within the interview encounter. By giving men space to talk about their lives at the start of each interview, I sought to offer them power within the interview to tell their own stories in their own ways. In this way, men had the option of taking a leading role in how the interview progressed, under the remit of discussing men's health and illness experiences in relation to prostate cancer.

Interrogating and querying men's accounts was more difficult to balance. Men were adept storytellers and I became increasingly convinced during pilot and early interviews that men had become well-rehearsed in telling their cancer stories, particularly as a result of PCSG attendance. Through constant retelling, men could learn to mediate their accounts to represent themselves and their actions in the best possible way, to best emphasise their own masculinity. Furthermore, men can be keen to exaggerate their masculinity by emphasising masculine values of rationality, autonomy, and control (Schwalbe and Wolkomir 2002) and the knowledge men had acquired about prostate cancer facilitated their accounts in this respect.

During pilot interviews, I was initially more reticent to challenge men's accounts. However, I quickly sought to adapt my interview technique and addressing this dilemma was largely dependent upon making in the moment judgements during interviews to decide which aspects of men's accounts would be questioned and which would not. A very important strategy for querying men's accounts was positioning myself as a 'student' to the interviewee as a 'teacher'. By emphasising my own lack of knowledge and understanding as a student, I could interrogate the implicit meanings of men's health talk while giving some justification as to why the meanings were being questioned without significantly breaking rapport.

Other strategies designed to unpick men's accounts that emphasise rationality, autonomy, and control involved encouraging creative and alternative thinking from participants. A strategy was employed of asking men to imagine how different people, from their family or generally other men, or even their younger selves, might have behaved faced with the same situations that they had faced. Another strategy was to ask men to consider how wider context might have played a role in their decisions. Doing this encourages a way of thinking that decentres men from their masculine portrayals to consider their experiences and motivations in a more critical way.

The student-teacher dynamic that I sought to foster within interviews to a considerable extent relies on the age difference between myself as a researcher in my mid-twenties and participants who ranged from their early fifties to early eighties. Young interviewees have been found to lack a more conversational style and be less willing to share their own experiences within interviews (Manderson et al. 2006) and I have sought to address this by adopting a more conversational and open approach to interviewing that included offering my own stories and reflections within interviews, sometimes in relation to myself or my father or sometimes to my grandfather's prostate cancer experiences.

The age difference between interviewer and interviewees plays an important role in addressing the difficulty of treading the balance between

affirmation and critique of interviewees' masculinities. Likely in reference to my age and inexperience, in relation to interviewees' older age and greater experience, men often sought to challenge my legitimacy as the researcher or my knowledge in the field of prostate cancer. Men often fail to read an information sheet prior to interviewing (Oliffe and Mroz 2005; Odendahl and Shaw 2002) and therefore participants sometimes presumed I was a medical practitioner, likely due to the research topic and medical orientation of PCSSG activities more broadly. Consequently, they may have expected interviews to have followed a more structured format associated with clinical encounters and when this was not the case they may have wanted to assess my knowledge as a researcher. Responses to these challenges were measured and inviting. I sought to prove my knowledge and demonstrate the worth of my research, but also to acknowledge the limits of my knowledge and treat the participant as more of an expert than myself, again drawing on the student-teacher dynamic. Being complicit to men's desires for prestige in this way can yield richer data (Butera 2006).

Furthermore, the strategy of 'mirroring' (Butera 2006; Oliffe 2009b) was also employed when interviewing men, attempting to approximate the styles of language use and patterns of speech that interviewees used. This was undertaken to facilitate rapport building and foster mutual understanding. Given the age difference between interviewer and interviewees, being able to communicate on the same level was an important concern. The levels of expertise that men possessed and the expert language they employed in this research were extensive and the subject of patient expertise is explored in Chapter Six.

Lastly, sensitive topics were discussed in the interviews and men were encouraged to talk about their feelings and emotions, and to varying degrees did so. A few of the men interviewed, when talking about their feelings, became visibly upset or distressed by what they were saying and cried. At these points, phrases such as 'shall we take a break?', 'are you okay?', or 'would you like us to stop?' were used. I was also upset at times by interview discussions and in one interview I became close to tears but avoided crying. For that incident, I

later reflected as to why I had masked my emotions, and concluded it was largely due to me wishing to be seen as a 'professional' researcher who is objectively, emotionally detached from the research subject. This attitude does not reflect the methodological approach of this research, but is arguably bound up in the gendered embodied practices I have been raised with which are difficult to shed in the moment of making snap judgements in a given situation.

On two other occasions I cried after leaving the interviews. For one of these occasions I was exhausted after a long, hot day and difficult interview earlier in the day. On the other occasion, I was upset by the interview I had just undertaken, where the interviewee had a poor cancer prognosis but was upbeat and kept a very active life.

Being prepared for potential physical, psychological, and emotional harm or difficulties in terms of ethical documentation can be quite different from how it is done in practice. Speaking with family, friends, and other qualitative researchers who have researched sensitive topics was useful to me in managing my feelings and reflecting on those feelings and how they shaped research encounters.

#### **4.6 Analysis**

An intimate knowledge of the data is vital for producing good quality analysis (Patton 2002). In the first instance this was achieved by personally conducting the interviews which ensured first-hand experience in co-producing data. Repeated listening to recorded audio files of interviews helped to recapture the interview experience and listening again to recordings assisted in being able to comprehend the meaning, not only from what the men said but also the way that they said things in their inflections, emphases, and pauses. Written notes were also taken during interviews which were also useful for clarifications during transcription and analysis. Computer typed *verbatim* transcription of the audio files was undertaken for the purpose of coding, which also served to further familiarise myself with the data.

The computer-assisted qualitative data analysis software (CAQDAS) tool Nvivo 10 was used to assist in coding the data. CAQDAS tools not only assist coding but also facilitate effective data management (Seale 2005). Participants' accounts and broader themes can be accessed rapidly and displayed clearly, while the software allows for structuring the data around the researcher's preferred framework and provides specialist functions to quantify the data if required.

The data for this research was collected and analysed using a *constructivist* grounded theory approach (Charmaz 2014). Grounded theory was originally designed as a flexible method for developing 'middle range theories from qualitative data' with an emphasis on 'identifying the conditions by which theoretical relationships emerge, change, or are maintained' (Charmaz 2002: 675). Constructivist grounded theory treats data and the findings that result from the data as a process of *construction* from the interview encounter between the interviewer and interviewee. The construction of data is a joint process of meaning making and data are interpreted and re-interpreted over the course of the research.

Furthermore, interpretation and analysis of data is ongoing throughout data collection, as part of a reflexive and reflective analytical process, when following a constructivist approach. Here interviews inform the analysis and the analysis informs and shapes subsequent interviews over the course of conducting fieldwork. For instance, the way that men acquired and used prostate cancer knowledge emerged as an important theme in the research. Further data was generated on this topic and from this the concept of *vigilance* (Weitz 1989) was expanded to encompass the activities men engage in using knowledge they acquire. Furthermore, a new notion of *vigilance networks* was developed, which is outlined in Chapter Five. Developing these concepts involved listening to the concerns men had and how they reported managing them, then engaging further with sociological literature, which informed my questioning in subsequent interviews. I had also originally prepared questions on the topic of recovery but soon found that this topic did not yield much data as the idea did not appear relevant to them. Men's accounts suggested the

importance of *managing* the impacts of treatment and this changed the focus of questions towards different topics, particularly concerning expert knowledge and treatment side effects.

The grounded theory approach employed in this research is not only constructivist but also *qualified*. This departs from Glaser and Strauss' (1967) original conception of grounded theory, which was strictly inductive and relied heavily on building theory from the data. Instead, this research was guided in its design by an initial literature review and questions were generated to address topics of interest identified as a result of this literature review and from pilot interviewing. In this way, a *qualified* grounded theory approach was employed, 'qualified' on the basis of prior knowledge, rather than solely generating new theory on a previously unexplored topic (Charmaz 2014). Given that much previous research on prostate cancer has predominantly been focussed towards health policy related interests, the constructivist and qualified approaches employed drew upon previous research but were also flexible in the focus and direction of my research.

Initially open coding (Corbin and Strauss 2008) was undertaken to identify common themes based on the meanings that participants attached to topics they spoke about. Themes were coded (a full list of codes can be found in Appendix 7) and tested as to whether they were common across all interviews and as to whether emerging patterns were consistent throughout the sample, using the constant comparative method (Glaser and Strauss 1967; Charmaz 2014). Negative cases that contradicted emerging patterns were sought and possible reasons why discrepancies existed were considered. For instance, contrasting accounts were identified for the two divorced or widowed men in how they coped with prostate cancer compared with men who were in long term marriages, demonstrating the importance of marital status in shaping prostate cancer experience and management. In the process of identifying and testing emerging themes, analytical notes were taken as markers to return to, to remind me of my thinking at different stages during the analysis, and to suggest possible links in the data between themes that might contribute to the development of theory. Over the course of the analysis,

codes were subdivided into more specific themes and were sometimes merged when themes overlapped, and the software Nvivo 10 was useful in facilitating this.

The generation of new theory must be founded within the *context* of the research, to avoid unstructured and overgeneralising analysis (Mitchell 1983). This understanding recognises that data are constructed within specific social contexts by people who occupy specific social positions. In this way, the development of theory is itself a constructed interpretation (Bryant 2002; Charmaz 2014). Consequently, bearing in mind how theory is being produced when undertaking the analysis is particularly important. Therefore, it was crucial to record my thinking and my approach in the course of conducting this research, both for the sake of a robust analysis and to be able to demonstrate the rigour of my method (Seale 1999).

#### **4.7 Conclusion**

In this chapter the qualitative methodological approach that has been undertaken for this research has been outlined. This research has been designed to explore men's *experiences*, and how these experiences are managed, following treatment for prostate cancer. A methodological approach that seeks to understand these experiences as being representations in men's talk, which are co-constructed through the interview interaction, has been advanced. This approach serves to answer the research questions that were posed in Chapters Two and Three and which are summarised in Section 3.8. These research questions have been addressed using the data collected from interviews with 29 men who have been treated for prostate cancer. The findings presented in the following four chapters are drawn from a qualified, constructivist grounded theory analysis of the data.

# Chapter Five: Managing Uncertainties following Treatment for Prostate Cancer

## 5.1 Introduction

Prostate cancer is the most common cancer in men in the UK and yet the survival rate is higher compared with other cancers and there are a range of effective primary and secondary treatments available (Cancer Research UK 2017a, 2017c; Prostate Cancer UK 2017g). It is, perhaps, because of this that prostate cancer has more often been treated as an acute condition, with sociological research focussed on issues relating to diagnosis and treatment. The findings presented in the next four chapters, however, will in various ways explore some of the chronic aspects of illness experience following treatment for prostate cancer. The first of these aspects is uncertainty. Uncertainty is a central component of chronic illness, where experience of chronic illness can worsen or improve over time in often unpredictable ways (Royer 2000; Charmaz 2000). Men's experiences of uncertainty following treatment for prostate cancer are explored in this chapter.

To understand men's experiences following treatment for prostate cancer, it is first necessary to understand the broader context of the steps that men follow from initial testing through to treatment. The widespread introduction of the prostate-specific antigen (PSA) test for detecting prostate cancer in the UK in the 1980s has played a significant role in the rise of surveillance medicine for prostate cancer. While there is currently no screening for prostate cancer in the UK, a decision that is based on the best available clinical evidence to date (Chief Medical Officer 2009; Public Health England 2016), there has been historical debate about the introduction of a screening programme, with patient groups comprising a significant and vocal component advocating in favour of one (Faulkner 2012). The current policy allows men to have a PSA test from their GP if they are over fifty years old and request one. Older men also often have PSA checks routinely as part of health check-ups.



This context is important when considering the increasing trend towards 'healthicization' within Western nations (Zola 1972; Conrad 1987; Armstrong 1995), where possessing good health becomes a moral imperative. An increasing moralisation of health, particularly for those in later life, is likely to encourage participation and compliance with surveillance medicine for prostate cancer. This has significant implications for men's experiences and their treatment or non-treatment decisions following a prostate cancer diagnosis. Some of the men in this research were drawn into a trajectory of being diagnosed by engaging with health care services, sometimes seeking to have a PSA test while at other times acquiescing to health surveillance, often without having presented with prostate cancer symptoms. In the absence of symptoms, diagnostic tests come to play a very important role (Gillespie 2012; Bell and Kazanjian 2011; Sulik 2009).

Gillespie (2012) coined the term 'measured vulnerability' to characterise men's interpretations of the PSA test, where men perceived test results as being an indicator of the degree to which they will get the disease rather than what the test actually indicates, namely the level of prostate-specific antigen in their blood. Gillespie (2012) found that PSA testing contributes to a perceived vulnerability to having prostate cancer in men prior to receiving a diagnosis, which results in increased feelings of anxiety and fear. This goes some way in explaining Oliffe's (2006b) findings that men subjected to diagnostic tests within a relatively short space of time strongly favoured opting for active treatments when abnormalities were detected. Furthermore, Bell and Kazanjian (2011) examined men's perceptions of PSA testing following treatment for prostate cancer, finding that men continued to associate PSA levels with the presence or absence of cancer, for often extended periods of time after treatment where PSA testing routinely continued, often for periods of up to five years.

This research builds on the work of Gillespie (2012, 2015) and Bell and Kazanjian (2011) who have investigated men's interpretations of the PSA test. Bell and Kazanjian's (2011) study explored men's experiences following treatment; however, it relied on seven interviews and was focussed towards

biomedical testing. My research examines men's uncertainties in relation to prostate cancer more broadly, including but also beyond clinical testing, in order to more fully understand men's illness uncertainty experiences and management strategies for these.

The other side of the coin with regard to uncertainties is how these experiences are managed. The management of uncertainty fundamentally relies on two basic strategies: avoidance or vigilance (Weitz 1989). Avoidance involves seeking to distance oneself from knowledge that would be unpleasant to learn, self-defining symptoms as unserious, and avoiding clinical encounters (Weitz 1989; Schneider and Conrad 1983). Vigilance is the opposite and involves seeking information and knowledge to understand their illness and find ways to most effectively deal with it and any future problems that might arise (Weitz 1989; Schneider and Conrad 1983; Comaroff and Maguire 1981; see Section 2.3 for broader literature on uncertainty).

Strategies for how men seek to manage the uncertainties of prostate cancer and iatrogenic treatment side effects are explored in this research. Importantly, these strategies were shaped by prostate cancer support group (PCSG) attendance. The informational and instrumental value of support groups have been found to be key motivators for support group attendance for men (Ussher et al. 2006; Barbuto et al. 2011; Gray et al. 1996). In exploring strategies for uncertainty management it is important to examine the role these support groups played and this question also receives further attention in Chapter Six.

In Section 5.2 the broader context of health surveillance is discussed in relation to men's accounts regarding diagnostic testing and available treatment options for prostate cancer. In Section 5.3 the different uncertainties that men faced following treatment for prostate cancer are identified and explored. Lastly, in Section 5.4, three strategies for managing uncertainties following treatment for prostate cancer are identified and discussed.

## 5.2 Surveillance, Uncertainty, and Opting for Treatment

There is currently no screening programme for prostate cancer in the UK, based on the best available evidence (Chief Medical Officer 2009; Public Health England 2016) despite a long running controversy on this issue (Faulkner 2012). However, there are large awareness campaigns orchestrated nationally and internationally encouraging older men to get tested for prostate cancer. Furthermore, an increasing drive of 'healthicization' in Western nations moralises the issues of maintaining good health and engagement with surveillance medicine.

Yet as for men's health more broadly, the ways in which men engage with health care are shaped by gender and masculine configurations. David and Andy's accounts below emphasise that close family members play an important role in legitimating men's engagement with healthcare, as other authors have previously observed (Robertson 2007; Noone and Stephens 2008).

### **David**

*Right, so I had no symptoms at all, one of my neighbours down the road had a prostate problem for some time and was eventually diagnosed with prostate cancer and so went out preaching the word that everybody over-males over a certain age should go and get tested, and my daughter, her in-laws' family had a long history so she suggested I-*

### **Interviewer**

*Of prostate cancer? (referring to the history)*

### **David**

*Of prostate cancer, so I said "ok yeah, next time I go to the doctors I'll just I'll go ask for a test", some months later I had to go, I was called in for I think it was a routine pneumonia injection, so I said to nurse who was doing that, "I've- it's been suggested that I have a PSA test" and she said*

*“well I can do it now if you like?” so she did it, it was 7.5 I think, it came out as 7.5, and then it sort of went on from there*

(69, RARP, Project Manager, IT Industry)

**Andy**

*I went up to a doctor's for a cholesterol test, Jane (Andy's wife) said “why don't you check the prostate?” because there was a lot of talk about it, didn't really know what was what, so I went up, had my cholesterol blood test and I said “could you test me for the prostate?”*

(68, RTwHT, RP, Accountant)

In David and Andy's accounts here it is evident that their diagnoses began, in part, by their being caught up in wider health surveillance practices within the medical system. David sought to have a PSA test while having a seasonal flu jab, while Andy was having a cholesterol test. These men were mindful of their health and were already engaged in health surveillance practices prior to their initial PSA testing and subsequent diagnosis. Geoff was also caught up in health surveillance practices but instead through his paid employment.

**Geoff**

*I was actually entitled to a yearly medical, so I thought oh well, in that case I better make the most out of what the company's giving, and I had a medical, and my PSA was shown slightly [over-raised], I think it was 5.3, so knowing that the normal is sort of zero to four, yeah to four, it was obviously slightly elevated and that then set off the sequence*

(63, RP, RT, HT, Project Manager)

The employment background of all three of these men, and of the whole sample more broadly, presents a possible explanation for their engagement with health practices of monitoring and maintaining their health. These men from professional or senior managerial roles may place a greater emphasis on prioritising health, with health being a particularly important concern for

families within higher socio-economic groups (Crawford 1984; Calnan 1987; Backett 1992).

However, engaging in health surveillance for prostate cancer came with constraints. David and Geoff found that once PSA testing began it was difficult to escape from such surveillance. David describes how 'it sort of went on from there' following his first PSA test, while Geoff sees his 'slightly elevated' first PSA test as having 'then set off the sequence'. Other men's accounts also refer to being caught in a 'sequence' or 'chain' after a PSA test became a cause for concern, leading them into increasing medical surveillance and eventually to treatment. This process could be disempowering and lead men to feel a loss of agency and control. One man likened the experience to being on a train, where he was unable to get off so all he could do was sit and admire the view.

When men had received a diagnosis for prostate cancer then further difficulties arose. Upon diagnosis with prostate cancer there is often the option to undertake a treatment or non-treatment regimen. Indeed, ongoing surveillance either through an 'active surveillance' or 'watchful waiting' regimen can put off treatment and the unpleasant side effects that can accompany treatment for extended periods of time. However, men expressed their reluctance to opt for such non-treatment regimens, as Chris and Matthew describe.

**Chris**

*One of the options he (Chris' consultant) said was that you could watch and wait, you didn't have to do anything, but then he talked about the other options that were available, and I decided to have the operation, it was more psychological than anything else, I thought to myself 'well, the cancer is likely to develop', and he told me that, and was I going to be happy mentally for this to be sitting in my groin and for it to be slowly developing and at some stage I may have to have something done about it?*

(73, RP, Day Trader, Banking)

**Matthew**

*If I criticise anything, I would criticise that they should have said, “well you can wait, but you will have to have treatment”, I thought- and there’s some members in our group who are on watchful waiting, and hopefully they’re not going to get an operation or treatment, but, you know, and I knew one man who wouldn’t have treatment because he had a disabled wife, and I’ve talked to him not that long ago, and he had to go and have radiotherapy, he couldn’t have an op because he couldn’t be put out but radiotherapy he can go daily and have it done, so what I’m saying is it does catch up on you, and I don’t know, you’ll find in your study whether anybody can stay on watchful waiting and get away with it, but I don’t think you can, unless you’re 85 or 90*

(77, WaW, RP, RT, Sales)

For Chris, the reason for opting for treatment was ‘psychological’. He expresses that he would not like the uncertainty of knowing that there was a cancer growing inside him that he was doing nothing about but which he may have to do something about in the future. Matthew’s account is less clear cut. Matthew had been confused about the watch and wait option. He had seen it as a do nothing option, rather than an option that would have involved treatment later. For Matthew, it was the feeling of doing nothing that was problematic for him. This is evident in what Matthew follows on to say, where he tells the story of a man whose situation was limited by his wife’s disability and that this consequently limited that man’s treatment choices. If you’re not being active and prepared in the management of potential illness, then ‘it does catch up on you’. He would rather act and deal with a problem than wait and be caught out by it.

These behaviours have strong parallels to Robertson et al.’s (2010) findings regarding men’s regimen choices of recovery programme following a cardiac event. Men showed a preference for a regimen of exercise over one of yoga, where engaging in a greater degree of physical and bodily activity is more in keeping with the dominant, ‘pragmatic’ mode of male embodiment

(Watson 2000). Furthermore, masculine identity is in part premised on a preference for activity over passivity (Charmaz 1994). Chris and Matthew's accounts above show a preference for *action*, to do something rather than do nothing. Indeed, to do nothing was a concern for men in that they may be charged with blame if they were to do nothing, which is evident where Matthew speculates on whether any man could 'get away with' staying on a watchful waiting regimen, as if this option was some way of cheating an inevitable outcome.

Another concern for men in deciding between treatment and non-treatment comes in the kind of language used in the risk information that men commonly received beyond the PSA test. Geoff and Algernon describe the phrasing that was used by their consultants to describe their Gleason score (see Sub-Section 1.1.2) from their biopsies.

***Geoff***

*I then had a biopsy done and that showed that I had aggressive prostate cancer, Gleason 9, but at that stage it appeared in only three out of the 11 samples that were taken, so it was deemed that it was early stage but an aggressive cancer*

(63, RP, RT, HT, Project Manager)

***Algernon***

*I had a PSA of about 12, 12.4 or something, and I had a Gleason score which seems to be the main determinant, of 8, which signifies aggressive*

(73, RT, Researcher)

Undeniably, the risk assessments made for these grades of cancer are likely to encourage treatment over non-treatment to address the cancer, yet in any case, the use of the term 'aggressive' has connotations of physical threat. The use of this term is a reminder of the metaphors that persist in lay understandings of cancer. Public understandings have changed since Sontag's (1988) seminal study of language use in relation to illness, where associations

were found to be drawn between the character of a disease and the character of a person, yet moral meanings are still attached to descriptive terms. The term 'aggressive' presents cancer as a dangerous malignancy within a 'recalcitrant' and 'unruly' body (Williams and Bendelow 2000). Viewed in this way, the decision to not opt for treatment to remove or destroy the cancer could be viewed as irresponsible and dangerous to a person's health and therefore such language is likely to encourage men to opt for a treatment option to address this threat.

The risk information that men receive is undoubtedly a cause of uncertainty, which serves as a source of 'measured vulnerability' (Gillespie 2012) for men where tangible test results evoke feelings of susceptibility to prostate cancer. These feelings of being physically threatened by and vulnerable to illness must challenge men's feelings of agency and being in control of their own lives. Therefore, it is important to recognise that the desire to remove cancer and be free of worry is a powerful explanatory factor for men preferring treatment over non-treatment, in addition to this preference being associated with a broader gendered way that men 'do health' (Saltonstall 1993) as has been described above and as Joe and Paul's accounts attest to.

**Joe**

*The prostatectomy was the cleanest, because it takes it all away, so I'm glad I did have that actually*

(67, RP, Project Manager, IT Industry)

**Paul**

*If I'd had the choice, and I hadn't had the stroke I would have gone for the radical (prostatectomy) first, I think most men would feel let's get it out, [of my body] you know if it's bad let's get rid of it and the radiotherapy's there as a fall back if there was a problem later, and I'd be surprised if most men didn't go down that path, I can't imagine many opting to go to radiotherapy first unless they had to*

(67, RTwHT, Telecommunications Manager)



As Gillespie (2012) notes, men do not often face prolonged states of uncertainty and therefore are ill-equipped to manage them. Therefore, a preference for treatment in order to escape this state is understandable. Unfortunately, life after treatment is not without its own set of uncertainties, as the following section identifies.

### **5.3 Common Uncertainties following Treatment for Prostate Cancer**

Four common uncertainties were observed in men's accounts of their experiences following treatment for prostate cancer. The first uncertainty is the fear of cancer recurrence that comes from continued PSA testing for monitoring purposes following treatment. The second uncertainty comes from unexplained bodily symptoms that were interpreted as possible signs of cancer recurring. The third uncertainty pertains to iatrogenic side effects following prostate cancer treatment. The fourth uncertainty is whether men had made the 'right' choice in opting to treat their prostate cancer. Each of these uncertainties will be described and examined in turn.

#### *5.3.1 Fear of Cancer Recurrence: Interpreting PSA Test Results*

PSA testing is one of the few and most reliable forms of biomedical knowledge available to men with prostate cancer and therefore plays a crucial role both pre- and especially post-treatment (Bell and Kazanjian 2011). One problematic aspect of the PSA test, however, is that there is no zero value (McLeod 2005), which Mark also characterises below.

#### ***Mark***

*They never give you zero ... I'm due to have another blood test this time next week, and see the oncologist in two weeks' time, and fingers crossed it's still 0.003, if it's not its bad news*

(64, Airline Safety Consultant, RP, RTwHT)

This has led men to experience their prostate cancer survivorship by *degree*, because of PSA biomarkers and an absence of a zero value (Bell and Kazanjian 2011: 192). Small fluctuations in PSA level over time following treatment for prostate cancer can therefore be sources of uncertainty, for, as Bell and Kazanjian found, PSA levels post-treatment were frequently understood by the men in their study as indicators of a recurrence of cancer. This is not only reflected in Mark's account above but also in Joe's account below.

***Interviewer***

*And you mentioned your PSAs following treatment, you sort of said it went 0.00- no, 0.047 to 0.007 to 0.009 and then back to 0.007 then, so that sort of slight, from 0.007 to 0.009, was that perhaps a cause of concern for you, knowing that the PSA is-?*

***Joe***

*It definitely was for me, yes, I was concerned that it might be the start of a rise, that would continue so, so the third reading I had, well the, no, the 47 one*

***Interviewer***

*Yeah the 0.047*

***Joe***

*I did think then that this might be the start of, so I was anxiously waiting the one afterwards, so I thought well if this more than 0.01 then I'm in trouble*

(67, RP, Project Manager, IT Industry)

Variations in PSA levels following treatment, over the extended periods of time when multiple PSA results are accumulated, could be a significant concern for patients and a source of uncertainty, even if those variations were only very slight, as Joe's account demonstrates.

To have a PSA level that was not very close to zero or that was increasing was troubling for Joe. He alleviated his concern by setting boundaries for his PSA, for if his PSA level went over 0.01 again then he would consider that as a sign that the cancer had returned. This behaviour was also evident in Gillespie's (2012) work where he found that men who perceived themselves to be 'at risk' would set thresholds for their PSA levels, which, if they were exceeded, would prompt them to take action. These accounts show a continuing concern with PSA levels following treatment that persisted in some cases for many years following treatment, just as Bell and Kazanjian (2011) observed in their research.

### *5.3.2 Fear of Cancer Recurrence: Interpreting Bodily Sensations*

The fear of cancer recurrence was a commonly cited concern for men in this research. Interpreting bodily sensations following treatment for cancer could therefore be problematic for men, as Peter describes.

***Peter***

*One of the worst things of all with cancer, any cancer, is you don't feel ill. And, (for) lots of people cancer, of all descriptions, is discovered when it's too late, because most cancers can be cured if you catch them early, but- I'm not trying to frighten you*

***Interviewer***

*No you just don't know do you*

***Peter***

*You could well have cancer, luckily I saw blood in my urine, but I didn't know it was cancer to start with, but I thought 'that's not right'*

***Interviewer***

*Hmmm, you thought, something's wrong there*

**Peter**

*There's something wrong there, so I don't know why- I was lucky*

...

**Peter**

*I'm seventy-two, if I can reach eighty I'll be, pretty chuffed to be honest, but, if things go on as they are there's no reason why I shouldn't go over eighty, but there is this thing, and I've spoken to other people who've had cancer as well and got over it, whatever goes wrong with me, straight away I'm 'well is it cancer?', you just, you just can't help feeling 'oh no got, I've got a bad leg, oh god I've got cancer in my leg'-*

**Interviewer**

*Is it the first thing you go to?*

**Peter**

*Yeah, I mean I do try not to do it but I, I just can't help it.*

(72, RP, RTwHT, Engineering Manager)

Not being able to interpret bodily sensations left Peter feeling vulnerable to the possibility of a hidden cancer present in his body that he could not detect. He describes how he was lucky to have noticed blood in his urine as a sign of his cancer when it was first diagnosed and stresses the dangers of late diagnosis, yet he emphasises then and later in the interview the problem of not feeling ill when he was diagnosed with prostate cancer and subsequently trying to discern between bodily sensations as instances of illness or mundane day-to-day sensations. His concern is particularly apparent given that the topic is framed around a discussion of his life expectancy and about death. Chris faces the same concern.

**Interviewer**

*Do you have any sort of, future concerns or worries, sort of around prostate cancer or just in general?*

**Chris**

*I don't think I do*

**Interviewer**

*No*

**Chris**

*No, no, no, we all have our occasional aches and pains and things like that, and you wonder has this got something to do with my prostate cancer?*

*No (laughs)*

**Interviewer**

*No (laughs)*

**Chris**

*It's something completely different, and because I've been working hard in the garden or doing some decoration or something, or this or this, it's not, you can usually pin it down to some, one thing or another, so I don't, no, no issues, either relating to the cancer or not*

(73, RP, Day Trader, Banking)

Chris initially asserts that he doesn't have any concerns for the future but he then raises a concern with whether occasional body sensations are indicative of a return of his prostate cancer. He reaffirms that he knows that these sensations are 'completely different' and are just general aches with no single cause, yet the fact that he raised the issue suggests that it is something Chris worries about.

Horlick-Jones (2011) has identified this same anxiety in his own experiences of being diagnosed with breast cancer. He recognises this anxiety not as an irrational fear, as some previous psychological studies have sought to conceptualise it (see Humphris et al. 2003; Humphris and Ozakinci 2006), but as a loss of what he calls 'everyday health competence', where regular routines for interpreting the body are called into question and second guessed.

However, it is not sufficient to treat these men's experiences as simply a loss of health competence as a result of treatment. Gillespie (2012) found that the lack of symptoms that often accompanied an 'at risk' status exacerbated the feeling of being 'at risk' and increased men's dependence on PSA levels as an indicator of their risk level, as a result of not being able to originally detect the cancer through bodily sensations prior to initial diagnosis. Therefore, fears of not being able to interpret their bodies following treatment for cancer may, for many men, be compounded by their not having interpreted their bodies correctly when they were first diagnosed with prostate cancer, with minor or no symptoms presenting. Loss of health competence for some of the men in this research, then, is not solely a result of cancer treatment but is compounded by the absence of bodily signs of cancer prior to treatment.

For this instance of uncertainty, the strategy of vigilance (Weitz 1989), of seeking to acquire new knowledge to manage uncertainty, is not helpful and is indeed a hindrance. The drive of healthicization encourages men to monitor their bodily sensations in order to maintain their health and engage in vigilance to manage health problems. Consequently, for these men seeking to detect cancer recurrence, the experience of mundane, non-pathological everyday sensations leads to uncertainty and an increased feeling of vulnerability to cancer.

### *5.3.3 Treatment Side Effects*

Men predominantly experienced either minor or no symptoms prior to their prostate cancer diagnosis, yet they often experienced side effects as a result of treatment. Onset of these side effects could bring new uncertainties, regarding how the severity of these side effects may change over time and whether side effects will dissipate or persist indefinitely.

Rectal bleeding is a common treatment side effect. A few of the men interviewed experienced some degree of rectal bleeding as a side effect from their radiotherapy treatment. However, the possibility of this occurring was not always clearly communicated by medical practitioners and its onset could

cause concern and raise uncertainty as to whether this was a new problem or one related to the cancer, as Ian's account illustrates.

**Ian**

*Recently we were away on holiday in June on a cruise and I had a show of blood from the rectum*

**Interviewer**

*Oh right, okay?*

**Ian**

*And I went to see my GP about it, and he arranged for me to go back to the hospital ... but he did say because I'd had radiotherapy he did say that it might just be what they call 'collateral damage', you know, radiotherapy does this, and it might just be, because I just had these two shows of blood, over a period of, one came one day and then about three days later another one, but I've not had it before and I've not had it since, so he seems to think it might be to do with radiotherapy, so I'm hanging on, hoping that's what it is*

(78, RTwHT, Technical Director, Aviation Industry)

Despite clarification of the problem being sought in Ian's case, the event was a stressful one that left him 'hanging on' in a prolonged state of uncertainty until a diagnosis was established.

Urinary incontinence is another common treatment side effect. Men were more often aware that this was a possible outcome of their treatment, however, and therefore uncertainties for this condition tended to be concerned with the severity and lastingness of the side effect. David's continence had improved following his treatment but remained a concern for him, particularly for the future.

**David**

*The thing which I do wonder about sometimes- some stages which is- I wouldn't say I worry about it but is a concern, is long term continence, I'm a-, am I likely to- am I more susceptible to be incontinent, but again there's not much that I can do about it, [from experiences] I know how wonderful the incontinence devices are*

(69, RARP, Project Manager, IT Industry)

Having previously experienced some of the worst effects of urinary incontinence, David was not only uncertain about whether his continence might worsen again in the future but also felt vulnerable to the condition now that he had already experienced it.

Expressing these uncertainties and sometimes feelings of vulnerability too was not always easy for men. David's account above emphasises at the beginning that he doesn't 'worry about' long term continence but that it 'is a concern'. Furthermore, in Chris' account in Sub-Section 5.3.2, when asked if he has any concerns or worries he is reluctant to say anything and it is only after two negative answers and a brief silence that he answers 'no, no, no we all have our occasional aches and pains'. Chris here hesitantly offers this as a worry but couches it in the much broader language of 'we all', so as to emphasise that he is not alone in his concern.

Experiences of common treatment side effects are explored in greater depth in Chapter Seven and uncertainties about treatment side effects are also considered further in the following sub-section on making the 'right' choice.

*5.3.4 Making the 'Right' Choice*

Treatment for prostate cancer rarely came without some sort of cost to men's quality of life. Bell and Kazanjian (2011) observed that, before receiving treatment, men are initially optimistic about removing their cancer and that being an end of their problems, but are more resigned to the incurability of



cancer and inevitability of possible cancer recurrence after treatment. In this research, problems that some men faced following treatment led them to speculate as to whether they had made the 'right choice' in their choice of treatment, as Paul's account below illustrates.

**Paul**

*You've (the interviewer) touched on one of the questions I put to them (various medical practitioners), which was 'if I had gone private when I knew there was something wrong, would you have recommended a different course of treatment to the one I've had through the NHS?' and they've assured me not, and I've asked that question at a number of the support meetings, the group meetings, and- where other consultants have come along, not my own, to talk about prostate cancer but from another treatment path, it might be radical (prostatectomy) or that sort of thing, and they've all come up with very sorts of similar things*

(67, RTwHT, Telecommunications Manager)

Here Paul shows his concern with whether he had made the right choice by comparing his treatment with what his treatment might have been if he had been treated privately. The fact that he had returned to this question repeatedly with different medical practitioners demonstrates the degree of concern he had over this question, despite assurances from practitioners that affirmed his treatment decision.

Dan had opted to have a radical prostatectomy and had very severe incontinence as a result of this treatment. Here he describes his uncertainty about whether he made the right prostate cancer treatment decision, because of the severity of his incontinence he has been left with.

**Dan**

*Now if I had have had a TURP (transurethral resection of the prostate) and they'd just found bits inside then you would have just watched and waited, or they may have then gone on and done some radiotherapy, I*

*suspect. Someone did ask me, am I angry because I made the wrong decision.*

**Interviewer**

*You might regret it, possibly.*

**Dan**

*It's a fault. I wouldn't be incontinent. Um, you know, that's something that isn't going to get better. It's always going to be there when I'm 80, 82, will I be capable of using a sphincter when I'm 82, those are really important things that I suppose worry me more about the future rather than thinking the cancer might come back.*

(66, RP, Consultant Anaesthetist)

Dan's account is more forthright than other men's accounts in going so far as to refer to his treatment choice as the 'wrong decision', even if he is referring to someone else who described it in those terms. By contrast, other men were keen to emphasise that they had made the 'right' choice and defend against any charge that they had not. These instances are examined in Sub-Section 5.4.1. Dan's account, like David's in Sub-Section 5.3.3, also shows a concern with how he will manage his incontinence as he gets older, and that this is more of a worry than the possibility of his cancer returning. How men sought to account for incontinence in relation to their age is explored further in Chapter Eight.

In this section the common uncertainties that men face following treatment for prostate cancer have been identified. In examining these uncertainties some broader insights into men's experiences have been observed. Men often feel that they can no longer rely on their bodies to communicate to them when they are ill. As a result, they come to rely more heavily on biomedical knowledge to manage their fear of cancer recurrence. Men pay close attention to their PSA results, particularly in the period shortly following treatment when PSA tests occur more frequently. Then, with the onset of treatment side effects, men face new uncertainties that have the potential to persist for extended periods of time following treatment and can

leave men feeling vulnerable to their effects worsening in the future. Lastly, with all the uncertainties that treatment for prostate cancer brings, men consequently face the uncertainty of whether they made the 'right' choice in opting for treatment. In Section 5.4 some of the common strategies identified for managing these uncertainties are explored.

## **5.4 Management Strategies for Post-Treatment Uncertainties**

In exploring accounts of how men managed post-treatment uncertainties, three distinct strategies emerged. The strategies are interpreting biomedical knowledge, planning for future uncertain events, and engagement with support groups that served as 'vigilance networks'. Each of these strategies are explored in turn.

### *5.4.1 Reinterpreting Biomedical Knowledge*

Reinterpreting biomedical knowledge is a strategy in response to the uncertainty men faced of whether they made the 'right' treatment choice, identified in Sub-Section 5.3.4. This strategy involved referring back to previous events and biomedical knowledge that men had acquired in the past, which men used to justify that they had made the 'right' treatment choice.

An example of this can be found in the accounts men gave regarding what their surgeons told them about the degree of cancer that was present in their prostate, which was subject to testing following the surgical removal of the prostate, as shown in Geoff's account.

#### ***Geoff***

*The biopsy they did on the prostate when they take it out, they discovered that where they thought they got it early, the prostate was riddled, and had I not done anything at that point in time, by the following year, which is when I would have normally had my medical, it would have broken out*

*and got into other areas, and probably I would have been dead in five years*

(63, RP, RT, HT, Project Manager)

Geoff uses this biomedical knowledge that he had previously acquired to justify to me, the interviewer, that his decision to opt for treatment at the time that he did was the right decision, for the cancer had already spread and would have spread too far if he had waited longer. This demonstrates a concern with being judged about the choice that he made, where if he had made the 'wrong' choice he might be liable to charges of blame. This raises an important issue of men's concerns with maintaining their moral standing or status, which will develop as an important common theme throughout the course of the empirical findings chapters.

Reinterpretation of biomedical knowledge was not always solely used to justify treatment decisions but could also, as was the case with Dan in the previous sub-section, be used to question treatment decisions, as Chris' account also demonstrates.

***Chris***

*I've no reason to doubt the genuine comment, that the comment he (Chris' consultant) made was genuine, because he got the report from the path(ology) lab, he knew what they'd said, and he just said "it was more extensive", that could have been if there was a pin prick (of cancer) it could have been two pin pricks*

***Interviewer***

*Yeah you don't know*

***Chris***

*You don't know*

***Interviewer***

*Yeah to what sort of-*

**Chris**

*But I'm not suggesting he was being dishonest, I was just being cynical  
(both laugh)*

(73, RP, Day Trader, Banking)

Some of the men interviewed who had opted for a prostatectomy shared a similar story to both Chris and Geoff, namely that tests following the surgery showed the removed cancer to be more extensive than the doctor originally suspected. Geoff uses this knowledge to justify his treatment choice, however the onset of erectile dysfunction following Chris' treatment led him to consider whether it would have been better to wait longer before having treatment. Instead of this risk information supporting his decision, Chris questions whether his consultant was bending the truth to make Chris feel better about his decision to opt for treatment.

Further instances of this process of reinterpretation were evident with regard to interpreting events that occurred and knowledge that was acquired prior to treatment. Here, Alex reinterpreted his PSA test scores leading up to his treatment.

**Alex**

*At my age when I (had) the first one (PSA test) done at 57, anything over three would have needed a biopsy pretty quick (referring to PSA level) that's the sort of- of course I was 2.3 at that time, and of course when I got at- over 3, I'd reached 60 and of course the, I think there's a line there which I think is 3.5, now, I would have thought- it's the old story- that the doctor would have said, 'look you're just under the sort of graph, but you're following the graph and that's a concern', but that didn't come out, I'm not blaming the doctor, for that, I'm just saying, in hindsight, what I know now, I say to my friends, "what age are you?" You know, if you're under 60 and you're getting any[where] near 3.*

**Interviewer**

*Yeah, speak to the*

**Alex**

*Yeah, get moving on it and if you're over 60 and you're, you know your past 3, same thing, get some, get some action.*

(71, BT, Construction Manager)

Alex's understanding is different 'in hindsight' with 'what (he) knows now', where he identifies his PSA levels as having risen to dangerous levels for his age prior to treatment.

Following treatment, Paul and Charles further developed their understanding of prostate cancer and developed lay understandings for how cancer affects the nearby urinary system, as they describe here.

**Paul**

*What I thought was just getting older was actually the prostate and me not realising and was thinking 'oh I'm just getting older and things are getting slower (urine flow)', but it wasn't it was the prostate, because it presses on it (the urethra)*

(67, RTwHT, Telecommunications Manager)

**Charles**

*And in fact, I remember now that over the next sort of- over that four months before I had that operation the flow was getting slower and slower, so it was obviously beginning to encroach (referring to the cancer encroaching on his urine flow)*

(71, RARP, Electronics Engineer)

In these instances, the bodily symptoms of prostate cancer that were experienced at the time are reinterpreted with their new understanding of the mechanisms of prostate cancer growth. These bodily signs, now understood in hindsight with an improved medical understanding of how the body functions,

are reinterpreted as signs that their cancers were growing and threatening their levels of continence. These rationalisations using the biomedical knowledge they have acquired are then used to support their justifications of opting for treatment of their prostate cancer.

All of these examples can be understood as an extension of the point raised in Sub-Section 5.3.2, namely that when men are identified as being 'at risk' of cancer but experience no symptoms, their feeling of being 'at risk' is exacerbated and they come to rely more on biomedical knowledge (Gillespie 2012). In Sub-Section 5.3.1 the continuing importance of the PSA test for men in managing their uncertainty about cancer possibly recurring has been shown. Yet, for men who are uncertain about whether they made the 'right' choice in opting for treatment, there are no scientific tests available to objectively assess whether this was the case. Instead, the men in this research have taken to reinterpreting the biomedical knowledge they acquired shortly before they were diagnosed and afterwards. Men reinterpret this knowledge with a different understanding of previously acquired knowledge, given that their own knowledge about prostate cancer has increased thanks to their own experiences of the illness, their own research, and their engagement with their PCSG. These reinterpretations often served the purpose of justifying their treatment decisions to me as the interviewer, which demonstrates a concern about having made the 'wrong' choice and associations of irresponsibility or blame that can accompany this. However, other men were more questioning about what the biomedical knowledge they acquired meant for their case and whether treatment was the right option for them at the time they had it.

These behaviours are similar to those identified by Brown and de Graaf (2013), where they identified that cancer sufferers with uncertain futures would draw upon risk information, among other resources, to imagine different futures to help them manage their uncertainties about their futures. The same is true for the men in this research, who used the biomedical knowledge they had acquired to imagine different scenarios, both affirming and critical of their actions, to make sense of their current situations. Again, this demonstrates the importance for men of both feeling and being able to

show that they have made the 'right' choice in their treatment decision, evident by the degree to which they will re-examine and reconstruct their past actions.

#### *5.4.2 Planning for Future Uncertain Events*

Reinterpreting biomedical knowledge has been identified as a behaviour that reconstructs past events to make sense of the present. The second strategy identified for managing uncertainty is oriented towards the future and concerns men's accounts of the plans they had either conceived or enacted to minimise experiences of uncertainty regarding possible uncertain future events.

Joe described how his choice to have a pelvic sling inserted to improve his continence was in part informed by what possible future treatments he might be required to have.

#### ***Interviewer***

*So is that a consideration that you may have had (to have an artificial urinary sphincter installed), had the pelvic sling not been so successful, or is that something for-?*

#### ***Joe***

*I would have considered that, in fact now I've got the sling, if it deteriorated then they apparently can do the (artificial urinary) sphincter as well, that's one thing I did check, yeah because it doesn't like, as the consultant put it "it doesn't burn any bridges, so you can have the sphincter after this"*

(67, RP, Project Manager, IT Industry)

Part of Joe's choice of treatment involved knowing that he could always go a step further and have a more invasive treatment if his planned treatment failed. Furthermore, it was a comfort for Joe to know that if the sling deteriorated at a later time he would still be able to have the subsequent treatment, which minimised his uncertainty for that specific event occurring.



Lucas' approach is similar to Joe's, although it concerns a decision about a secondary prostate cancer treatment. Having already had a radical prostatectomy only to have a recurrence of the cancer, Lucas was offered a choice of being part of a clinical trial to measure the combined effects of radiotherapy and hormone therapy rather than just radiotherapy. Below, he justifies his decision to opt just for the radiotherapy.

**Lucas**

*I decided having had the journey I'd had so far, I'd made a decision on what I thought was my best primary treatment, having the prostate removed, and the second one was no, if I've got some- there's a sequential approach to this, if I have radiotherapy, and it may well clear it up, I don't need to suffer the effects that hormone treatment could give me as well, unnecessarily, but sequentially, if its, then creeps back in a few years, or five or ten years' time I could still have hormone therapy, so it, to my mind, it seemed to be, it's likely to be, a life extending decision process, so I just took that approach, and if you have radiotherapy now, it's not going to be, very extensive, hormone therapy now, it diminishes its benefit over time I understand, you know, and I'd rather of had that two and a half years to radiotherapy, and then maybe three, five or ten years before it comes back again, if indeed it does, and then have the hormone treatment, and now there is actually another stage after it, the final stage is if you're dealing with suppressing, once the hormones are failing to keep it under control, you've got a couple of drugs that, that deal with kind of end of life health care management, give you, retain the best quality of life for-*

**Interviewer**

*Yeah a longer period*

**Lucas**

*[to stop you dealing with] a lot of problems, so there is a bit more beyond hormone therapy, they're coming into my consciousness (Lucas' view)*

*now, I think they're- they've only been around in the last five, six or seven years or so,*

(66, RARP, Engineer/Risk Analyst)

Lucas takes a 'sequential approach' to his treatment in that he foresees hormone treatment as a possible next step if the radiotherapy failed that he could then fall back on if required. If he elected for hormone therapy combined with his radiotherapy, he worried that the hormone therapy would be less effective the next time around. Furthermore, Lucas demonstrated an awareness of newer life extending drugs that have been developed. All of this shows the extensive degree to which Lucas had considered possible future outcomes and the structured, methodical way with which he approached his planning to avoid undesirable treatment outcomes.

Planning for possible future treatments that might be required may in some cases be shaped by concerns for preserving life or bodily function for longer periods of time, rather than solely for the efficacy of the treatment. In Section 5.2 it has already been demonstrated that a perception of being 'at risk' can encourage patients to opt for aggressive treatments to remove uncertainty (Gillespie 2012). However, the choices that men make following their primary treatment, for their secondary or tertiary treatments, have been found in this sub-section to be more measured, not undertaken with the view to remove uncertainty altogether but with the aim of reducing or delaying uncertainty. This changed attitude is in keeping with a newly perceived inevitability or incurability of cancer that men often describe after they have received primary treatment, which Bell and Kazanjian (2011) observed in their study and which Lucas describes when, referring to his cancer, he says 'before it comes back'. A new perception emerges following primary treatment that prostate cancer cannot be permanently concluded but rather that survivorship must be managed.

Planning is employed as a strategy in looking towards the future and identifying areas that may be problematic in the future. Plans and preparations are made for possible uncertain events occurring in relation to prostate cancer

and associated treatment side effects. This is pre-emptive and importantly does not solely concern the preservation of physical functioning but also the preservation of a person's moral status, which is a theme that will be developed further in Chapter Eight.

This strategy and the previous strategy of reinterpreting biomedical knowledge are both important concerns for men in managing their uncertainty. These strategies can be viewed as being largely facilitated by PCSG attendance and engagement with a PCSG plays a still more important role in the management of uncertainties following treatment, which is examined in the following sub-section.

#### *5.4.3 Support Groups as Vigilance Networks*

Information and support have been identified as key motivators of support group attendance (Ussher et al. 2006; Barbuto et al. 2011), particularly so for men (Gray et al. 1996). Support group attendance can be understood as a means not just of acquiring information and support, which is discussed further in Chapter Six, but also of keeping watch for any problems that may arise and being prepared for those problems if they do. Andy and Paul's accounts describe how they attend their support groups to be prepared for any possible problems that might arise in the future.

#### ***Andy***

*It's nice to keep in touch with people and get an update on the latest technology because you never know when you might need it again*

(68, RTwHT, RP, Accountant)

#### ***Paul***

*If the prostate (cancer) returned and it was in a form that they couldn't deal with it here, would I know where to go? And I'd rather know that*

*now before I'm too traumatised to actually get into that, and go off and get the treatment I need.*

(67, RTwHT, Telecommunications Manager)

Paul describes how preparation before an event occurs is important because if you are diagnosed with a problem without preparation then you may be 'too traumatised' to effectively deal with it.

Mark characterises his support group as a network that is available to him should he need it, a way of contacting a wider pool of people, that are not all immediately known to him, so that he would be able to get relevant, specialised information should he need it.

***Mark***

*It's a way of having support available if I need it and information available if I need it, right, so if something came up and I wanted to get it I could call, or email the chairman, and I'd say look can you do anything with this, or do you know anyone who can do anything with this, and take it from there*

(64, Airline Safety Consultant, RP, RTwHT)

In their ethnographic study of PCSGs in Canada, Oliffe et al. (2011) found that men shared their own personal experiences of cancer with new attendees who had not yet been treated. This information assisted men in helping them to make their treatment choices. This was equally true and commonly reported for the men in this research. Furthermore, the leader of Support Group 2 was a medical consultant, although not a specialist in prostate cancer, and he would regularly be approached by other men seeking advice. However, the variety of different cancer experiences of the men in the group meant that if someone had a question about a particular treatment or concern, then they could be directed to someone else in the group to find out more about that particular issue. In this way, support groups served as a network of experiential and clinical knowledge which allowed men to acquire knowledge, following a strategy of vigilance, as and when they desired or required knowledge. This

could be undertaken to manage different uncertainties: related to a fear of cancer recurring, current or possible future treatment side effects, or a concern with whether they made the 'right' treatment decision. These support groups are identified here as *vigilance networks*, where knowledge can be acquired to assist with managing an uncertainty through a network of contacts who possess a range of specialist knowledge. Understanding PCSGs in this way may go some way to explaining the extended association that many of the men interviewed had with their PCSG, where men would often still attend meetings long after they had been treated. This question is explored further, among questions regarding the acquisition of specialist knowledge and expertise for prostate cancer, in the following chapter.

## **5.5 Conclusion**

This chapter has examined men's experiences of uncertainty following treatment for prostate cancer. The common uncertainties that men face in this regard have been described and the management strategies that they employed to manage these uncertainties have been explored.

Through exploring the broader context of the steps men follow from initial testing through to treatment, a range of factors have been identified that offer some explanation as to why opting for treatment is a popular choice when men are diagnosed with prostate cancer. The men in this research were found to engage with health surveillance practices, likely encouraged by an increasing trend of healthicization that moralises participation in these practices, as one of a range of ways by which older men are able to be 'good citizens' (Petersen and Lupton 1996) when addressing their health. However, when PSA test results became a cause for concern, men expressed a feeling of being trapped and lost a sense of agency and control over what was happening to them. Partly to reclaim this agency, but more broadly with the desire to engage in active, rather than passive, responses (Charmaz 1994; Robertson et al. 2010) to a prostate cancer diagnosis, options to treat were described as being far more preferable than non-treatment surveillance options.

Furthermore, as Gillespie (2012) has described, men are not often accustomed to living with uncertainty for prolonged periods, so the preference for treatment to be free from the worry of possibly having cancer is stronger still. Lastly, the use of the term 'aggressive' to describe a particular grading of cancer recalls the dangers of using metaphors to describe illness, as Sontag (1988) has warned against. The term is heavily value laden, suggesting that the unruly, recalcitrant body (Williams and Bendelow 2000) poses a serious physical threat, which can only add to the other factors described that encourage men to opt for treatment.

Adherence to health surveillance was shaped by men's ages and was often facilitated by men's wives legitimating and encouraging their engagement with health surveillance. Undergoing diagnostic testing exposed men to prolonged periods of uncertainty that men are not commonly exposed to. Then the decision to opt for treatment was shaped by the desire to remove this uncertainty and also to engage in an active treatment regimen, rather than a passive, non-treatment surveillance option. A common theme emerges among these factors in that they are all tied to men's relationships with masculinity. If these factors serve more broadly to encourage men in later life to get tested for prostate cancer and, if diagnosed, to opt for treatment, then this is potentially problematic, as treatment for low risk, slow growing prostate cancers can be unnecessary and lead to a reduced quality of life with persistent treatment side effects.

Four common uncertainties were identified in men's accounts of their experiences following treatment for prostate cancer. The first uncertainty is the fear of cancer recurrence that comes from continued PSA testing for monitoring purposes following treatment. Men monitored their PSA tests following treatment and if their PSA tests became a cause for concern then they set thresholds for their PSA level, which if exceeded would prompt men to seek further information and guidance from medical professionals.

The second uncertainty comes from unexplained bodily symptoms that were interpreted as possible signs of cancer recurring. This fear can be

understood as a loss of 'health competence' (Horlick-Jones 2011) where the initial diagnosis of cancer with few or no symptoms led men to doubt the reliability of their body to inform them when they are ill. Both this uncertainty and the uncertainty that comes with PSA testing both address concerns with the physical threat of cancer returning but the sources of uncertainty, either PSA test results or the body, are different.

The third uncertainty pertains to iatrogenic side effects following prostate cancer treatment. Contrary to hopes that once treated that would be an end to men's worries, as Bell and Kazanjian (2011) found in their sample, my research has found that treatment side effects bring a whole new set of uncertainties. Uncertainties about treatment side effects included concerns with what caused the new symptom, how severe the symptom would be, and how long it would last. Particularly in the case of urinary incontinence, men described feeling vulnerable to urinary incontinence returning and it being a problem that would be harder to manage in old age.

The fourth and last uncertainty is whether men had made the 'right' choice in opting to treat their prostate cancer. The previous three uncertainties were concerned with physical threats, posed by prostate cancer and side effects of treatment for prostate cancer, to the functioning of the physical body. This fourth uncertainty is different in that it was concerned with a moral threat posed by the question of whether men had made the 'right' or 'wrong' treatment choice. That men often felt a need to justify their treatment choice to me as the researcher, but also to engage and play over the question of whether they had made the 'right' choice, demonstrates a concern with how their treatment decisions might impact upon their moral status. This finding introduces moral status as an important concern for men, which is a consistent theme throughout the findings of this research.

Men have been found to experience uncertainties pertaining to the physical *and moral* threats of prostate cancer illness. Three strategies were identified to manage these uncertainties. The first strategy of reinterpreting biomedical knowledge was in response to the moral threat of men not knowing

whether they had made the 'right' treatment decision. Men reinterpreted biomedical knowledge they had received prior to or shortly following treatment to make sense of their current situations, sometimes to justify their treatment decisions but at other times to critique them. This can be understood as a way of imagining different scenarios for uncertain events as a way to alleviate uncertainty, as was identified in Brown and de Graaf's (2013) research. However, instead of imagining different positive or negative *futures*, as Brown and de Graaf observed, the men in this research are reconstructing the past through the lens of the present, in order to try to make sense of the present.

The second strategy for managing post-treatment uncertainties involves planning for possible uncertain future events. Men's accounts of planning possible treatments they required or may yet require at some later point often acknowledged that a longer-term approach would be required to *manage* rather than resolve the concerns of prostate cancer and associated treatment side effects. Both the strategies of *reinterpretation* and *planning* are identified as nuanced strategies that proceed from an overarching strategy of vigilance (Weitz 1989), where men use the knowledge they have acquired for their illness in different ways to manage the uncertainties they face.

Lastly, the third strategy for managing uncertainties involves engaging in prostate cancer support group attendance. Vigilance as a strategy for managing uncertainty involves seeking knowledge to better understand illness and find ways to most effectively deal with it and any future problems that may arise in relation to it (Weitz 1989; Schneider and Conrad 1983; Comaroff and Maguire 1981). Having contact with a PCSG offers access to a range of experiential knowledge from men who have followed different treatment or non-treatment pathways and received varying outcomes from these. Furthermore, with the regular attendance of medical professionals who gave presentations at support group meetings, men also had access to clinical knowledge as well. PCSGs are therefore termed as *vigilance networks* for the important role they play in the acquisition of useful and relevant knowledge for men.



This approach to understanding PCSGs constitutes a departure from the way that Oliffe et al. (2011) have interpreted them. Their study observed the important role that PCSGs play in improving men's health literacy and how men learned to use their knowledge to engage in consumer discourses to at times align with, and other times contest, medical expertise and attempt to 'shop around' (Zeliadt et al. 2006) for the best possible approach to managing their prostate cancer. Certainly, some of Oliffe et al.'s findings are similarly observed in my own research. Men came to communicate using the technical language relating to biomedical testing for prostate cancer and used this knowledge within their clinical encounters with consultants and nurses. However, the consumer discourses that Oliffe et al. observe were less common in my research. This may be a result of many of the men in this research having received their primary treatment some years previously. As has already been noted, a change of attitude can occur in the period following treatment from one of optimism at the possibility of removal of uncertainty to resignation that prostate cancer is an ongoing problem that needs to be managed (Bell and Kazanjian 2011). It is possible that the sample of men in my research, with greater distance in time from their primary treatment, and with ongoing concerns related to their prostate cancer treatment, spoke in very different terms about their experiences. Away from the more empowered consumer discourses of choice that Oliffe et al. observed, towards a focus on uncertainties and uncertainty management that accommodate the ongoing concerns for these men at the later stages following treatment that they occupy.

Another difference between Oliffe et al.'s (2011) findings and my own is the lens through which men's engagement with medical knowledge is framed. Whereas Oliffe et al. explore men's health literacy and how men used health knowledge to engage in consumer discourses, in the following chapter men's knowledge acquisition practices are explored and interpreted through the lens of patient expertise in relation to a broader literature on chronic illness.

## **Chapter Six: Acquiring and Using Patient Expertise**

### **6.1 Introduction**

In the previous chapter, different strategies were identified that men employed to manage uncertainty. These strategies were primarily concerned with using knowledge acquired about prostate cancer, the acquisition and understanding of which was largely facilitated and mediated by prostate cancer support groups (PCSGs). This chapter goes further in exploring men's prostate cancer knowledge and treats this knowledge as patient expertise. In doing so, this chapter will explore the levels of expertise that men possessed, how such expertise was acquired, and how expertise is used and shared with others.

In recent decades in the UK there has been an increasing policy drive towards greater patient involvement in healthcare (Prior 2003; Taylor and Bury 2007; Department of Health 2004) and a greater emphasis on shared decision-making (Elwyn et al. 2000). Increasing access to health information over the last couple of decades has also contributed to expectations placed on patients to be 'expert patients' (Ziebland 2004).

The rise in the use of terms such as 'expert patient' or 'lay expert' in medical sociology in recent decades shows an increasing interest in lay knowledge, moving away from traditional approaches to 'lay beliefs' (Bury 1997; Williams and Popay 2006) and in valuing lay knowledge in greater parity with expert knowledge (Prior 2003). Prior (2003) identifies three themes in lay expertise research. Firstly, patient expertise has been understood as resultant of experiential knowledge, where first-hand experience of illness provides patients with a unique understanding of their own situation (Busby et al. 1997; Monaghan 1999; Thorne et al. 2000). Secondly, patient expertise has been conceptualised as being valued equally with scientific expertise (Wynne 1996; Epstein 1996; Arksey 1994, 1998). Lastly, patient expertise has been understood as an outcome of social groups (Brown 1987; Rabeharisoa 2003; Brown et al. 2004). However, in Prior's view, none of these elements are sufficient to generally qualify patients as 'lay

experts' or the like. Prior's (2003) own research has shown how patient or carer expertise is limited to the one specific case of the sufferer and may not reflect broader facets of the illness which are not present in every case. Patients may become experts of their own bodies, yet this knowledge is 'partial and limited' (Prior 2003: 48). An expert, in Prior's view, requires substantial 'expertise' but also appropriate and relevant 'license' or qualification to give expert advice. Consequently, Prior argues for a clarification in the use of terms, positing that it is important not to confuse expertise with lay experiential knowledge, while Collins and Evans (2002), too, emphasise the dangers of the expanding use of the term 'lay expert'.

Collins' (2014) recent framework, however, is helpful in more clearly conceptualising expertise. Collins identifies a framework of different forms of expertise (See Section 2.4, Table 2.1) that includes two categories of 'specialist tacit knowledge': 'contributory expertise' and 'interactional expertise', which can help to distinguish a scientific expert. All of us have a variety of everyday, or *ubiquitous* expertises, such as speaking the native language of our country or tying our shoelaces, but *specialist* expertises, such as the practice of science, require specific forms of training. It is important to note that Collins (2014) frequently uses the term 'expertises' to refer to different forms of expertise that he has divided into categories. In line with Collins' thinking, the term 'expertises' is used at points throughout this chapter.

Contributory expertise is acquired by learning from other experts and can be likened to an apprenticeship. This form of expertise is developed with practical experience. Collins gives the specific example of chronic illness sufferers, arguing that they are not 'lay experts' but simply experts, experts of their own experiences. They learn from medical practitioners, other illness sufferers, and personal experience of symptoms how best to manage their illness.

Interactional expertise is necessary to go beyond the narrow confines of contributory expertise. It involves learning the shared technical language of a field of study and being able to use it with fluency. This form of expertise

allows scientists from different specialties to communicate their ideas with each other. Collins (2014: 68-9) asserts that while interactional expertise may not appear to be as substantive as contributory expertise, it is incredibly important to the everyday conduct of scientific work.

Extensive training in developing both contributory and interactional expertise is required to become an 'expert' of something, in the popular understanding of the term. This conceptual development by Collins offers a useful framework for exploring the levels of expertise the men in this research possess, as well as the means by which this expertise is acquired and the purposes for which it is used. However, it will also be important to consider the degree of 'license' (Prior 2003) men possess in being able to share expertise with others to gain a full understanding of the expert statuses that men can be considered or not considered to possess.

A further question must also be developed from the previous chapter, where the obligations on men to be 'good citizens' (Robertson 2006b; Petersen and Lupton 1996) led to concerns for men in whether they had made the 'right' choice in opting for treatment and may have shaped their management decisions following a prostate cancer diagnosis. In light of this, it will be important to explore the relationship between expertise and masculinity, drawing on the work of Connell (2005) to examine how men's masculinity shapes the acquisition of expert knowledge and how that knowledge is used.

In Section 6.2 the different forms and degrees of specialist prostate cancer expertise that men possess are identified. In Section 6.3 some of the factors that facilitate the acquisition of these forms of expertise are explored. Then, lastly, in Section 6.4 the means by which men become 'licensed' to share expertise with other men and the purpose this serves for them is examined.

## **6.2 Specialist Prostate Cancer Expertise**

This section explores the degrees to which men were found to possess the two most important forms of specialist knowledge required to be an expert:

contributory and interactional expertise (Collins 2014). Men's possession of a third category of 'special interactional expertise' is also discussed.

### 6.2.1 *Contributory Expertise*

Contributory or 'experience-based' expertise, as Collins (2014: 64) defines it, is a form of 'specialist tacit knowledge' that is acquired by working with other contributory experts which may be likened to an apprenticeship. A specific example which Collins uses is that of chronic disease sufferers, who Collins argues should not be considered 'lay experts' but just experts, with their expertise premised on their experience of illness.

The men interviewed in this study can be considered to have contributory expertise of prostate cancer by the merit of the knowledge they have developed about prostate cancer through their experience of having the illness, treatment for it, and associated conditions, over extended periods of time. Bell and Kazanjian (2011) have posited the idea that prostate cancer might better be understood as a chronic illness, because of the continued use of PSA testing for up to five years, if not longer, following treatment. Furthermore, the extent of management that may be required to manage post-treatment uncertainties, identified in Chapter Five, provides further evidence of the chronic nature of the prostate cancer illness experience.

To illustrate this, William's account describes how he had learnt through experience that he could usually only go up to two hours before needing to urinate, which was a result of his reduced level of continence from his radiotherapy.

#### ***William***

*I can go normally for about two hours, before I have to pee, and I produce a reasonable quantity of urine, but not as much as possibly I ought to, the problem is that I go so frequently, that I'm- I keep off coffee, quite a bit*

**Interviewer**

*Certain things are a trigger?*

**William**

*Coffee does trigger me off, more rapidly than other things, it doesn't matter if I'm within reach of a loo*

(83, RTwHT, Architect/Lighting Design Consultant)

William discovered through experience that coffee is a trigger for his incontinence, 'more rapidly than other things', implying that he has other known triggers. He also implies that the effect of coffee is so rapid that he has not been able to get to the toilet in time in the past, another hard lesson he has learnt through his experiences. William is no longer total master of his own body, he has over time come to know his changed body and become an expert of his urinary function. He understands the time limits which he can reasonably impose on his body and he knows how his body responds to certain external influences, such as coffee. William has developed contributory expertise through his experiences that assists him in monitoring how and when he urinates.

William's account describes how he came to know his own body through his experiences, yet contributory expertise can also involve learning through and with other patients and medical practitioners. Clive also had continence difficulties yet, in an effort to prevent bladder retention, Clive would self-catheterise on a daily basis to maintain his level of continence. This involved inserting a catheter up his urethra and into his bladder to pass urine.

**Clive**

*When I'm doing it, I am careful, but I do put quite a bit of pressure on ... the first ones I used way back were rather flexible, I think about size 12 or something, and as you push them they kink, so the ones I used at first, you had to hold the end, because the others have got the bloody lubricant on ... now I have got new catheters, and the specialist nurse there who*

*was teaching to me and showing me and explaining, gave me an option of which ones you would like, and I chose the one which has a gripper, what you call a gripper on it, and you can actually hold it, you can hold it closer to the tip or closer to your organ, your gland, and which means you've not got too much of this in (referring to a catheter in his hands), and that's where you can apply a bit of pressure*

(76, RP, RT, Electrical Engineer)

This technique involved a craft or skill developed over time and was one which Clive learnt partly through his experience of his own body but also partly through the specialist nurse teaching him the technique. Clive initially struggled with catheters that would kink and that were slippery to hold, but by changing catheter he found a better way to hold and position the catheter – a skill that was developed with practice and through trial and error. This was not a change dictated by a medical practitioner but instead met with Clive's needs on which he was an expert, more so than the medical practitioner who lacks the specific expertise that comes from experiencing the symptom first-hand.

Joe's experience of managing his incontinence demonstrates a further extent by which men could develop their contributory expertise.

**Joe**

*I was quite delighted when I first came home that my urine flow rate seems to have improved a lot, it was around about 10 or 12 mils a second*

**Interviewer**

*Is that something they measured or something you measure?*

**Joe**

*I measure that (laughs)*

**Interviewer**

*Okay*

**Joe**

*Very crude, but it's a stopwatch and a graduated container, which has proved quite useful actually, there is a device which I never got round to buying and I discovered it recently it's called the U-flow meter, and it's like a funnel and they're only about £15 and I was intending to get one, I never did, and um, its shaped with a fixed orifice down at the bottom, obviously, and the idea is that as you pee into that then, depending on your flow rate, it will back up the funnel*

(67, RP, Project Manager, IT Industry)

Measuring urine flow rate was one of the tests that Joe has been subjected to by his doctors and from his doctors he had learnt a basic understanding of what a normal flow rate should be. Joe found a way to mimic this test so that he could collect his own data on his urine flow rate and continue to monitor the quality of his urine flow rate. Joe's account demonstrates how men could be innovative in creating their own data, which they could then interpret themselves to make sense of their situations. Joe's approach here offers a way of addressing the reduction in available data to make sense of uncertainty following treatment, in this case the uncertainty of a urinary problem, which was a dilemma identified in Chapter Five (see Sub-Sections 5.3.2 and 5.4.1).

William, Clive, and Joe's accounts above illustrate how men possessed contributory expertise for their prostate cancers. Men can become experts of their ill bodies through their personal experiences of illness. Furthermore, they can develop contributory expertise by learning from and with medical practitioners to then be able to employ or appropriate medical practices in the management of illness. In Clive and Joe's accounts, these acquired practices were important for the purposes of being able to independently monitor their urinary problems and the importance of *monitoring* for effectively managing treatment side effects is a topic that receives further attention in Chapter Seven.



### 6.2.2 *Interactional Expertise and Special Interactional Expertise*

Anyone who experiences prolonged illness might be capable of developing contributory expertise to some degree, yet interactional expertise is more difficult to acquire. Interactional expertise is 'acquired by engaging in the spoken discourse of an expert community to the point of fluency but without participating in the practical activities' (Collins 2014: 68), the practical activities in this instance being the practice of medicine. A familiarity and engagement with this discourse was evident in men's talk in this research. However, this went beyond a level that may be expected to be acquired in the course of managing prostate cancer and was more developed and broader in remit. Beyond possessing some 'interactional expertise' men were also found to possess 'special interactional expertise' (Collins 2014), the distinction for which will become clear in the course of this sub-section.

Learning to engage in an expert discourse might be achieved in the course of regular appointment meetings with medical practitioners. However, accumulating substantial degrees of interactional expertise in this way for prostate cancer is unlikely. This is because encounters with medical professionals in clinical encounters are unlikely to be very lengthy or to take place on a regular basis over an extended period of time, compared with chronic illnesses that require extensive and regular clinical attention. Instead, a combination of clinical encounters *and* encounters with medical practitioners and other patients and survivors at support group meetings were key to the acquisition of expert spoken discourse for the men in this research.

The commonly high degree of comprehension and utilisation of medical language among the men interviewed was frequently illustrated by the interviewees checking with me, the interviewer, if I understood the technical terms they were using, as the following accounts testify.

**Matthew**

*They said nerve-sparing surgery, I think on this- do you know much about this Da Vinci machine?*

(77, WaW, RP, RT, Sales)

**Mark**

*They wrote me a letter saying basically that they had found a recurrence, but the good news was that it was just one location, in one of the lymph nodes, you understand all those terms, do you?*

...

*Because it is different, basically, you can, you get zapped for about seven- do you understand radiotherapy, the process?*

(64, Airline Safety Consultant, RP, RT)

**Jamie**

*So I had a PSA check done, and it was only, it was 4.2, which is- do you know about PSA?*

(53, RARP, Engineer)

These kinds of instances of testing the interviewer's knowledge were common and can be understood as both a way of testing the legitimacy of the interviewer and also men's demonstrating their masculinity within the interview (discussed in Sub-Section 4.5.2). In fact, the high levels of prostate cancer expertise observed across the sample may be explained by men seeking to reclaim masculinity that was lost following diagnosis and treatment for prostate cancer. An accumulation of expertise could serve to bolster men's 'power relations' (Connell 2005) by being able to explain and rationalise illness with knowledge, in response to a loss of physical strength and sense of stability in their lives that can accompany treatment. This is discussed further in Section 6.4.

Matthew, Mark, and Jamie's accounts above are evidence of men possessing some degree of 'interactional expertise', where these men had acquired knowledge about important prostate cancer terminology in the course of their interactions with others. However, men were also found to possess 'special interactional expertise' (Collins 2014) as well. Men possessed specialist prostate cancer expertise beyond that which may be required for the management of their illness. This is evident in Robert and Charles' accounts below, where they express their understanding and opinions of the longstanding controversy over whether or not it is beneficial to screen for prostate cancer.

**Robert**

*I think there ought to be a lot more screening than there is, I don't think it is- I think you would need some other clue or indication or suspicion of trouble before you go for screening, like getting up too much in the night*

**Interviewer**

*Because of the sort of-?*

**Robert**

*Because there are so many false positives, as I say false positives are a major problem ... it's just not that simple, if its high- I reckon if its high (referring to PSA level) and you've got other suspicions then you need to go for a test*

(67, RP, Information Technology Consultant)

**Charles**

*The people who know about prostate cancer are probably evenly divided between those that say 'everyone should have a PSA test', particularly watching out for a steady rise, and those who say 'random or regular testing', (then directly asking the interviewer) what's the word for regular testing, just in case-*

**Interviewer**

*Screening?*

**Charles**

*Screening, 'regular screening does more harm than good', because it lets too many people into the biopsy procedure, when, when-*

**Interviewer**

*When they may not need it*

**Charles**

*When they may not need it, nobody can be sure, but just on a purely statistical basis they say it does more harm than good, or doesn't do any good, it doesn't improve the mortality rates, having PSA screening*

(71, RARP, Electronics Engineer)

Robert recognises the arguments against a policy for screening for prostate cancer, but argues that a screening policy could be effective if the criteria was restricted to men who presented with symptoms or by other factors that might target men at risk more effectively. Charles also shows a detailed and nuanced understanding of the issues involved within the screening debate. This expert knowledge goes beyond that which is necessary for managing prostate cancer illness, as screening is a broader issue of public health. This raises the question of how men come to possess such knowledge, which would not likely be learned in the course of interaction with medical practitioners within clinical encounters. This level of expertise was acquired through engagement with PCSGs.

The two support groups from which men were recruited both hosted regular monthly meetings with invited speakers, predominantly medical professionals, coming to speak about their specific field of specialist expertise. There were time periods before and after these presentations for men to speak with other attendees, but also potentially with medical practitioners who had come to speak. There were also opportunities to ask questions to speakers

following their talks. This information was gathered through interviews and informal conversations with members of Support Groups 1 and 2 and attendance at one of the meetings of Support Group 2 (see Appendix 6).

Oliffe et al. (2011) identified how men learn ways to contest and align with medical experts through their interactions at support groups. It is within the allocated times in PCSG meetings, where men can ask questions of medical practitioners who give presentations and discuss ideas with other men attending meetings, that interactional expertise is acquired. However, these interactions between medical professionals and lay people serve another important purpose as a means of discerning between non-science and science, and bad science and good science (Brown et al. 2004: 64). Medical professionals gave presentations and attempted to demonstrate good science and through questioning from the attendees dispel non- or bad science. In turn, attendees' questions posed challenges to medical professionals in terms of the robustness of their scientific work. These are the same interactions that occur within communities of scientists, at scientific conferences for instance, that serve to scrutinise scientific knowledge.

The access and contact with medical practitioners through support group meetings, beyond the clinical encounter, enabled men to immerse themselves in the shared technical language of medical research on prostate cancer. Furthermore, interactions within PCSG meetings engaged men in a culture of discerning between science and non-science, and good and bad science (Brown et al. 2004) that serves to review and scrutinise the production of scientific knowledge. By being around experts on a regular basis and immersing themselves in the medical terminologies and practices of medicine, these men were able to develop a richer type of expertise (2014: 68), one which with time would allow men to pass as experts in the field of prostate cancer. However, this is not considered to be interactional expertise to such a degree that we might compare these men's expertise to that of medical professionals, but rather is considered as '*special* interactional expertise' (emphasis own).

Collins' (2014: 116) category of special interactional experts is a 'newly discovered one' and constitutes a 'small and very unusual group of specialist experts' who:

Acquire interactional expertise through occupying a strange role in which they immerse themselves in the discourse of a specialist community without fully participating in that community's expertise.

The men in this research fit this definition because they were able to immerse themselves within the discourse of medical practitioners practicing in the field of prostate cancer through attending support group meetings, yet at the same time did not 'fully participate' in the community's expertise because they were not urologists or other medical practitioners whose everyday working lives concerned the study of prostate cancer.

Collins (2014) applies this category of special interactional expert to people like himself, meaning researchers who study the practices of other research specialties, as well as to science writers and journalists. However, this research has found that lay people within self-help group formations can also acquire special interactional expertise. It is perhaps understandable that Collins makes no mention of this possibility because patients are not commonly immersed for prolonged periods within communities of medical experts who communicate their expertise using complicated language and terms. As posited earlier in this sub-section, this peculiarity may be the product of men's desire to acquire expertise to reclaim lost masculinity. Investigation of the factors that facilitate the acquisition of specialist prostate cancer expertise is undertaken in the following section.

### **6.3 Factors Facilitating the Acquisition of Specialist Expertise for Prostate Cancer**

This section explores factors that have been identified in this research as playing a role in facilitating the acquisition of specialist expertise for prostate cancer. These factors are the possession of 'referred expertise' (Collins 2014)

acquired from men's paid employment and having a technical interest in scientific ideas and processes.

### 6.3.1 *Referred Expertise*

Some instances of expertise, such as speaking our native language or tying a shoelace, are considered ubiquitous expertise by Collins (2014), in that they are possessed by the majority of a population. Other instances of expertise, such as those achieved through the training and conduct of paid employment, can be considered 'specialist' expertise, as they require learning and training to undertake a specialist task. Many of the men interviewed for this study had developed skills in their working lives which they subsequently applied in the pursuit of specialist expert knowledge of prostate cancer.

Mark encountered some trouble when his medical records were misplaced before receiving his first treatment, which caused a delay in his treatment. When it looked like it might happen again for his secondary treatment, Mark phoned up the relevant people to make sure that his records were passed along correctly.

#### ***Mark***

*“we need to get your records from Berkshire, to look at”, and I thought ‘oh, here we go, you know, it's going to take forever’, but, because my name is (says his surname), so I said well- and again really proactive, so I called the planning people at Berkshire because I'd had their number from previously, and I managed to get through to someone and he said “oh we've had a request through and we are- we remember you because you caused no end of confusion last time round, but we know you, we're making sure we've got the right person”, and they said they'd get on it, and they sent this stuff over by an email, that day or the next day*

(64, Airline Safety Consultant, RP, RTwHT)

The use of the term 'proactive' is a common one across men's accounts and is used in this instance and other contexts as a way of expressing a managerial approach to solving problems, as Mark elucidates here.

***Interviewer***

*What was really the driving force behind being quite proactive, in that respect?*

***Mark***

*Well number one- the first one was, I was getting an appointment to, you know, when they were still always dealing with urgent cases, I thought well that's pointless you know, how do I- I want to have it done, so I was phoning people, and once you get in touch with people you're getting them to deal with you etcetera, etcetera, I was very good I mean I used to bring them boxes of chocolates, and, you know not bribing them but,*

***Interviewer***

*No but just to say thank you, yeah*

***Mark***

*Yeah you have to say thank you*

For Mark, being proactive was a way to get things done and to find a way past the bureaucracy in the system that he was encountering. Mark had earlier expressed his frustration at the bureaucracy of the NHS system of arranging appointments, where urgent cases receiving priority meant that he would be seen hours after his appointment was scheduled for. Mark was seeking a simple, straightforward way to 'have it done' and to do this he took to phoning people so that they would have to deal with him. In exchange, he would bring them boxes of chocolates, not as a bribe, he stresses, but as a thank you. This sort of circumvention of standard practice through direct intervention required a specific set of experiences and skills.



**Mark**

*Yeah, and just having the confidence and just taking it, you know, but if you just let the system manage you, you'll get the most common denominator*

Here Mark describes how having confidence to take what you want is important. Mark was motivated to ensure that he did not experience problems in his second treatment and had the administrative skills to track down contact details for hospital staff and to make direct enquiries, outside or behind the backs of clinical frontline staff, to ensure his records were transferred successfully. Mark also had the tact and diplomacy to convey his thanks through gifts of boxes of chocolates. These interpersonal skills and the outlook that Mark has in managing problems are aspects of the specialist expertise Mark has developed from years of experience working within professional office-based employment.

Ben, too, used skills he had developed within the professional expertise of his working life to pursue expertise in the field of prostate cancer. Ben kept a complicated electronic diary over the period of his prostate cancer treatments.

**Ben**

*It's an electronic diary, what I do is tend to take copies of things, when I go abroad or something like that, that is, it (shows interviewer a portion of the diary) ... and there's two columns really, one of what the doctor did, and one of what the hospital did*

(68, HT, ChT, LPD, Cost and Works Accountant)

A clear association can be drawn between the two columns that Ben produced in his diary of his health records and the double-entry system commonly used by accountants, of which Ben is one, that list debit and credit balances in two parallel columns. Ben transferred his working practices from his paid employment to the recording and accumulation of his prostate cancer knowledge. Ben also used the data processing skills he had developed from his

professional work to take the additional step of mapping a graph of his PSA level over time.

***Interviewer***

*Oh wow your PSA is all over the shot, gosh it goes right down really low, and then goes back up*

***Ben***

*Yeah that was Bicalutamide or something like that, that did that, it, what happens is some of these aggravate the generation of testosterone, so the initial thing is it drives it, and then they calm down, so that's, you can see why, it goes on and on (Ben then tracks the start of the treatment, describing events as they occurred, who he saw and for what purpose)*

By recording and measuring his health in this way, Ben was able to take an active role in managing his health and further develop his contributory expertise of prostate cancer, by creating his own data, just as Joe had with his urine flow rate as described in Sub-Section 6.2.1.

Collins (2014: 117) argues that:

Almost everyone who works for a living has a specialist expertise: an expertise associated with the training and experience they gain in doing their specialist job.

All of the men interviewed in this study had their own specialist expertise that they had developed from their paid employment. Importantly, more than two-thirds of the sample were currently or had previously been employed in a managerial role, the majority within mathematical, science, and/or engineering sectors.

These men broadly shared a set of common skills associated with managerial roles, some of which have been exemplified in Mark's description. The managerial roles that these men were engaged in are important because the managerial expertise that they possessed can be understood as being 'referred expertise' (Collins 2014: 77). Referred expertise is a 'substantive

technical expertise' (ibid) from one specialist area that is used in another. 'Management does need kinds of expertise that are referred from other projects' (Collins and Evans 2007: 65), the interactional expertise that managers possess of being able to converse using the technical language of their employment sector is transferrable and referable in facilitating an understanding between different specialist areas. In this research, men have been found to take interactional expertise that they have acquired in their managerial roles and refer this when acquiring new forms of specialist expertise for prostate cancer. Referred expertise facilitates the acquisition of new specialist expertises.

Mark and Ben's accounts in this sub-section also constitute further instances of those described in Sub-Section 6.2.2, where men sought to emphasise their 'power relations' (Connell 2005) by showing they possessed creative and exclusive forms of knowledge which others did not. However, in this sub-section, Mark and Ben's referred expertise, which facilitated the acquisition of specialist prostate cancer expertise, was rooted in men's current or former employment practices, and therefore in their 'production relations' (ibid). With a loss in 'power relations' that may accompany diagnosis and treatment for prostate cancer, skills and experience born from men's 'production relations' are mobilised to reclaim losses to power relations and thereby reclaim masculinity. Further evidence to support this claim is outlined in the following sub-section.

### *6.3.2 Having a Technical Interest*

Having managerial or 'referred' expertise has been identified in this research as an important facilitating factor in developing specialist prostate cancer expertise. Another common theme that emerged in men's accounts is the interest that was often expressed in technical processes and scientific ideas associated with the medical management of prostate cancer and treatment side effects. This technical interest is considered another important facilitator in the development of specialist expertise for prostate cancer, as without it the

desire to develop expertise further than what men are told by their doctor would be weaker. A person must be motivated to develop their expert knowledge in understanding the workings of the body and of the medical technologies involved in medical interventions. This motivation was particularly evident in the accounts of the men who were or had been employed in technically specialised professions within scientific industries such as engineering or electronics. Even for some men who did not end up working in scientific industries, their educational backgrounds were often science and engineering focussed, through apprenticeships or university degrees. More than a fifth of the sample had first degrees in electrical engineering, which is somewhat characteristic for the region where Support Group 2 is based, which has colloquially been referred to as the Silicon Valley of the UK.

To illustrate this, Jamie here tries to describe the sensations of his erectile dysfunction, and that how even though his level of sexual function is fairly good, it is insufficient to have adequate sexual activity. To effectively express this, Jamie uses mechanical metaphors to convey the functioning of the body, likened to the filling of a sink or the pumping of a tyre.

***Jamie***

*You need that extra, bit of- pumping your tyre up, it's those last few pumps that really makes the difference, so it's like a, like a sink, you turn the tap on, you've got the plug in, it fills up, but my plug is sort of only half in, so the bloods pouring in, but it's also pouring back out again, you just need to push the plug in just a little bit more, and then it will fill up, that's, that's, I can feel it, there's there is pressure there, and that's all good, but it just seeping out*

(53, RARP, Engineer)

Discussing the same point a little later, Jamie says: 'how the body generates that kind of pressure is pretty clever really', thereby further showing his interest in the biological functioning of the body.

Lucas, too, has a keen interest in medical processes, describing in a great deal of unsolicited depth how the process of radiotherapy works. His account stresses the accuracy of the treatment and shows a fascination in how the treatment can be so accurate, discussing in detail how the process of radiotherapy works to achieve such effective results.

***Lucas***

*It's extremely accurate, they don't do wide areas of radiotherapy with a lot of scatter damage, again because this is something also with long term repercussions and radiotherapy is, the area will be traumatised, the tissue, it won't heal, or respond to surgery or other repairs ever as well again, and they put three or now its five beams in so that, you know, just if that's the target, (illustrates his point with hand gestures) one two three beams, and they come together and focus there, that's where all the energy's concentrated, that's where the cancer cells are killed, the amount of energy in those beams when they're out here in this other flesh, isn't sufficient to [fully] traumatise other parts of the flesh, the body*

(66, RARP, Engineer/Risk Analyst)

By describing in detail the benefits and efficacy of a treatment that Lucas may require in the future should his cancer return, his interest and confidence in the treatment may be more concerned with assuring himself about his future options (see Sub-Section 5.4.2). However, Lucas undoubtedly also has an interest in the scientific processes involved in radiotherapy, evident in the detail with which he describes them.

Both Lucas' and Jamie's specialist expertise from their paid employment has shaped their orientation towards developing prostate cancer expertise. They are driven to discover and understand the scientific processes related to prostate cancer. Their interest in the subject is shaped by their experience in technical professions within engineering and/or electronics based industries.

These accounts provide some explanation as to why these men's specialist prostate cancer expertises are more considerably developed beyond what might be expected in the acquisition of prostate cancer knowledge simply for the management of the illness. Again, this is further evidence of how the acquisition of specialist prostate cancer expertise is shaped to a significant extent by men's 'production relations' (Connell 2005). This shows that the forms of expertise that men acquire are shaped by their masculinity.

Having identified the specialist expertises for prostate cancer that men possess and considered what factors might facilitate the acquisition of these expertises, the questions remain of what 'license' (Prior 2003) men possess for their expertise and how they use this expertise. These questions are considered in the following section.

#### **6.4 Communal Licensing and Sharing Prostate Cancer Expertise**

Within Sub-Section 6.2.2 the important role that support groups play in facilitating the acquisition and development of interactional and special interactional expertise has already been identified. However, support groups also play an important role in men's acquisition of contributory expertise, as was briefly alluded to in Sub-Section 6.2.1. Support groups served as sites where men could share their contributory expertise with other men. This has previously been described in Sub-Section 5.4.3, where support groups were characterised as *vigilance networks* where experiential and clinical knowledge was readily available from medical professionals, patients, and survivors. The ways in which the men in this research shared knowledge within and beyond PCSGs, and their understandings of what the limits were of what expertise they could share, are explored in this section.

There was a common emphasis among the men interviewed that they were not able to give 'medical advice'. However, men expressed that they were instead able to share their own experiences. This was done to provide a new perspective for other men to help them to better understand the experience of prostate cancer, as Peter's account illustrates.

**Peter**

*I thought, oh that's a good idea, so I thought I want to get involved in that, so as soon as it was all over, I joined the cancer support group to help other [people] and so if somebody comes to us and asks- so I saw a bloke a couple of weeks ago, he was about to make up his mind, of what one he wants, I don't give them medical advice-*

**Interviewer**

*No, you just tell them about your own experiences (repeating what Peter had said earlier)*

**Peter**

*Yes, well the surgeons are great at what they do, but unless you've been through it you don't know what the things are like*

(72, RP, RTwHT, Engineering Manager)

Peter's account demonstrates that continued attendance and association with a PCSG can lead to a change in roles for men, from someone primarily seeking to *acquire* specialist prostate cancer expertise to someone seeking to *share* their contributory expertise with others. In this way men were able to pass on their niche and specialist knowledge as it pertained to them and others around them. This kind of contributory expertise is distinctly different and unique compared with the expertise that doctors can provide because it is based on personal experience of illness, just as Peter's account alludes to.

Prostate cancer support groups play a very important role in legitimising the giving of advice to other men and defining the boundaries of what advice can be offered to and by men attending support groups, as Lucas and Matthew's accounts show.

**Lucas**

*I'm one of the people in the group, that the committee people have approached, and said, would you like to share and discuss your experience with anyone else in the group, I said I'm very happy to, either to listen to*

*them, if they're going through some personal trauma or problems, like counselling sort of, just listening, or to share experiences or give them my limited advice or experience, not advice in a medical sense, you can't deliver medical advice but you can deliver your experience or your belief of your awareness of what processes or things happen, yeah, so yeah I'm very happy to do that, it is worthwhile*

(66, RARP, Engineer/Risk Analyst)

### **Matthew**

*I mean I've got a man, a friend of 53, and he went to- 55, and he went to the doctor and had his MOT it was the earliest PSA and he, and they said his PSA's satisfactory, and I said "well what was it?", and he said "well they didn't tell me", he said "well its satisfactory", but I said "well you want to go back and ask what it is, you've had it done", and eventually he did go back and it was something like 0.17, and he's 55 and he hasn't got any symptoms, and so fortunately he's ok, and I know somebody else who's a similar age, and he's got a PSA of 8, you know, so, mine was 8 when I was 69, I was 68, if he's 55 and he's got 8 he ought to do something about it, or get a second reading or a second opinion, and I'm only an amateur, I'm not supposed to give advice, but I do give advice to men in the group when they tell me their PSA is high, I say go back and get it done again, you know, that's, you know that's what we've got on our thing (support group produced information literature), to say that we can't give medical advice, well we can't, I'm going to give my advice, my experience*

(67, RTwHT, Telecommunications Manager)

Prior (2003) has emphasised that to be a true expert you are required to possess 'license' to be an expert, in the form of publicly recognised and validated qualifications. Being a member of a support group, having become closely associated with a group over an extended period of time, provides a degree of legitimacy from which to offer contributory expertise to others. The limits of that advice are established within support groups and a shared sense



of the limits of what advice can be given is learned within these settings. Lucas' account describes how he was approached by his PCSG committee to take on a role of talking to other men about his experiences and he strictly demarcates between what he can and cannot do in that role. Furthermore, according to Matthew's account, the limits of advice giving are formally established within the literature produced by his support group. Indeed, the constitution for Support Group 2 has as one of its stated aims to seek to provide 'information' and 'awareness' about prostate cancer, but importantly these are loose terms that provide a grey area within which men can take on a limited role as expert.

Licensing of expertise here is a communal process of validation provided by and within prostate cancer support groups. This process involves a curtailing of the limits of that license. The giving of 'medical advice' is restricted but the sharing of experiences for the purposes of providing 'information' or 'awareness' is encouraged.

Having identified the extent and limits of the expertise that men possessed, the question remains of what purpose sharing expertise serves for men. Already throughout this chapter an argument has been made for treating the acquisition of specialist prostate cancer expertise as an attempt to reclaim lost masculinity in the form of 'power relations' (Connell 2005) following diagnosis and treatment for prostate cancer. By drawing on their skills and experience from their paid employment, their 'production relations', men sought to acquire expertise to be able to make sense of and self-define the meanings of their illness experience and therefore reclaim lost 'power relations' (ibid). However, what remains to be discussed is how men claim the authority that their expertise facilitates in order to reclaim their 'power relations', and this is explored now.

As described earlier in this section, with prolonged attendance at a support group, a man's role can change from primarily seeking to receive information and support towards seeking to offer it to others, as Chris' account shows.

**Chris**

*I go along there today, for, I don't feel that I need support, but I feel that I want to give support to others*

(73, RP, Day Trader, Banking)

Chris felt a desire to 'give support to others' and this was a common sentiment among the men who engaged in sharing expertise with others. This was often expressed in terms of reciprocity, of wanting to give something back to the group in gratitude to the help they received, or to inform other men more broadly so that they would not need to suffer as they had suffered. Such accounts have an implicit morality, of doing the right thing and emphasising the importance of responsibility for one's health. These kinds of moral discourses are demonstrated in Clive and Lionel's accounts below of providing advice to men beyond support group settings.

**Clive**

*There's another neighbour ... with a relatively high PSA, so, I mean I've talked with him, I tried, but it's impossible, you can't force people to have a PSA, but you can explain to them*

(76, RP, RT, Electrical Engineer)

**Lionel**

*I mean I introduced a couple of people- (to the support group), I mean I've got a client who says I saved his life, because, I mean he came to see me one day ... I went in to the boardroom, and he wasn't there, and I said "oh, where is he?", and she (Lionel's secretary) said "oh no its fine, he's just popped out to the loo", and I said "oh ok", so we had a meeting, which wasn't an hour, and so I said, "oh right bye Carl (Lionel's client) see you again soon", and he just said "oh can I just use your loo before I go?", and I said "yeah, fine, can you do me a favour, when you've been to the loo can you come back to the boardroom", so he did, and so when he came back in, I said to him, "this is going to seem the most extraordinary question", I*

*said, "but have you ever had your blood test", and he said "no?", and I said "well the reason I asked", I said, "I might be totally out of order", I said, "we've been together three quarters of an hour and you've been to the loo twice", "arghh" he said," its murder", he said "I'm up four times every night", and I said "well can you do me a favour, can you have your blood test"*

(66, RP, Chartered Accountant)

Clive expresses his frustration in trying to talk to his neighbour about prostate cancer but recognises that he can't 'force' him to address the issue but he can impart his expertise by 'explain[ing]' things to him. Clive is advocating for his neighbour to act in a way that he believes will be better for him, he is using his expertise to take a position of moral authority over his neighbour, advocating that he takes responsibility and ownership of his health by addressing the issue of getting his PSA checked.

Lionel's account is a story of how he reportedly 'saved' a client's life through his imparting of advice. His story demonstrates how he picked up on signs that something was wrong for his client, where he was having to go to the toilet frequently. The phrasing is in friendly terms, as between peers, of asking his client to 'do (him) a favour' by getting tested, but his association with his support group, as he comments on in the account, provides him with the moral authority to provide his advice beyond the support group setting.

This moral authority was for Support Group 2 formalised in the activities organised by the group outside of their regular meetings, as Edward's account describes.

### ***Edward***

*We grab men by the throat, if they're of the right age, passing, and tell them to get themselves tested, basically, that's what it's about, yeah, so, you know I think we do quite a lot*

(79, RTwHT, Manager for British Rail)

Edward here describes a community outreach event to raise awareness about prostate cancer at a local town centre. Such events provided another opportunity through a more structured format for men to be able to share their expertise in a legitimate way. The 'license' (Prior 2003) men possess is further legitimised here, as they have been given permission to set up a stand or platform from which to share expertise with strangers in a public venue. Edward's account is strongly suggestive of the power that comes with this role of moral authority, where he describes how they 'grab men by the throats' in a figurative sense, and 'tell' them to have a PSA test.

Through their described acts of sharing their expertise, men demonstrated a 'should care' attitude (Robertson 2006b) and acted with a moral imperative to be 'good citizens' (Robertson 2006b, 2007; Petersen and Lupton 1996) in sharing their prostate cancer expertise with others. In Chapter Five the concerns men had with feeling responsible for how they managed their prostate cancer diagnosis and treatment were explored. Emphasising responsibility as men have done here can be understood as a way of protecting against the threat to moral status that a state of chronic illness can bring (Galvin 2002). By emphasising their moral worth as good citizens, these men may be seeking to resist being blamed by others for their ill health, either resulting from the cancer directly or treatment side effects indirectly.

Further still, the demonstration of expertise by men within their accounts can be understood as a way of maintaining and reclaiming masculinity lost following prostate cancer diagnosis and treatment. When sharing expertise with other men, men were demonstrating themselves to be advocating on behalf of other men and taking a moral position of responsibility in doing so. This position, identified in this research, is termed here as men being *moral advocates*. This term and the themes of responsibility and morality are returned to in Chapters Eight and Nine.

## 6.5 Conclusion

This chapter has sought to discover the forms and levels of specialist prostate cancer expertise men possess, how these expertises were acquired, and how men used them.

The men in this research have been found to possess a range of specialist expertises for prostate cancer. Men possessed contributory, interactional, and special interactional expertise for prostate cancer, which they acquired through personal experience of their illness and in the course of engaging in activities and interactions with medical practitioners in clinical encounters, as well as in PCSG meetings with current and former patients and survivors. In addition to the findings from the previous chapter, the extensive levels of expertise that men were found to possess in this research provides further evidence that prostate cancer may be understood as a chronic illness (Bell and Kazanjian 2011) that requires management for extended periods of time after treatment.

Men had come to learn to use some of the expert discourse of prostate cancer, demonstrating that they possessed some interactional expertise. However, men also possessed knowledge about prostate cancer beyond the remit of knowledge required for the management of illness. Furthermore, men engaged in activities at support group meetings where they were immersed in the expert discourse of prostate cancer and even played a small participatory role in scrutinising scientific knowledge that was presented to them. This 'strange role' (Collins 2014: 116) that these men occupied demonstrates that they possessed special interactional expertise. This finding constitutes a significant break from Collins' characterisation of this form of expertise as the preserve of researchers, science writers, and journalists. One possible explanation for why the men in this research may constitute a new exemplar for special interactional expertise is the strong orientation towards the acquisition of knowledge that men who attend support groups often have (Ussher et al. 2006; Barbuto et al. 2011; Gray et al. 1996; Breau and Norman 2003). Indeed, the men in this research have been identified as being

particularly motivated towards acquiring specialist prostate cancer expertise, as has been demonstrated in this chapter and within Chapter Five.

Acquiring specialist prostate cancer expertise has been facilitated by the specialist expertises men had previously acquired from their current or former paid employment. The large proportion of men who had managerial employment training or skilled technical proficiency in their former or current employment can be understood as having 'referred' expertise (Collins 2014; Collins and Evans 2007). From their employment, men had some interactional expertise which facilitated their interactions with other men and with medical professionals, thereby further enabling their acquisition of specialist prostate cancer expertise. The scientific backgrounds of many of these men's employment or education was an additional facilitating factor which drove their acquisition of knowledge as a personal interest beyond the acquisition of knowledge simply for the purpose of managing illness. These identified factors that facilitate the acquisition of expertise are rooted in men's 'production relations' and this demonstrates how the forms and levels of expertise that men possess are significantly shaped by men's masculinities.

When men had acquired specialist prostate cancer expertises they were often keen to share them with other men. Sharing this expertise was a way of demonstrating masculinity to others, with expertise serving as a form of 'power relations' (Connell 2005) over other men. However, an important question as to how men claim the authority of their expertise over other men warrants attention.

Men's expertise was given a degree of 'license' (Prior 2003) in different ways. Informal limits were imposed both by and within PCSGs on what forms of expertise men were permitted to share. Men emphasised the importance of not giving 'medical advice' but instead the expertise they were permitted to share was limited to contributory expertise of their own experiences of illness. This constitutes a kind of communal licensing of expertise, where a degree of self-regulation within support groups provides some legitimacy to the expert claims of the men within the groups. Community outreach activities arranged

by Support Group 2, providing information and awareness to men beyond support group encounters within public spaces, contributed further to men's legitimacy claims.

The regular attendance of medical professionals at support group meetings and the reviewing and scrutinising of scientific knowledge that occurs between lay men and medical professionals (see Sub-Section 6.2.2) must also offer further legitimacy to men's claims to knowledge. Through this collaborative alignment with medical experts, these men weakened the boundaries between lay and expert knowledge. As 'savvy social actors' (Brown et al. 2004: 64) these men have been fluid in moving between lay and expert status. Just as men took their 'referred expertise' (Collins and Evans 2007; Collins 2014) from their paid employment to facilitate the acquisition of specialist prostate cancer expertise, they also used this expertise by sharing it with others within and beyond support group settings.

Lastly, the authority of men's claims to prostate cancer expertise were mobilised through moralising discourses of responsibility. Using their expert knowledge, they perpetuated moralising talk about the importance of health responsibility for men, a discourse that is embedded in the 'informed choice' model that is advocated for and by men with regard to prostate cancer (Faulkner 2012). In doing this, men also sought to license and legitimise their expert status by treating expertise not as an 'objective' measure but rather as a value system, in that they sought to legitimate their expertise as a moral good.

The employment of a moral discourse by men was an important means of claiming authority for their expert claims. By sharing expertise, men could demonstrate their own moral worth and protect their moral status against possible charges of blame that can accompany chronic illness (Galvin 2002). Sharing expertise with others demonstrates good citizenship (Petersen and Lupton 1996) by showing a 'should care' attitude to health (Robertson 2006b). Men were demonstrating themselves to be *advocating* on behalf of other men and taking a *moral* position of responsibility in doing so. This position,

identified in this research, is termed here as men being *moral advocates*. The theme of responsibility and the position taken by many of the men in this research of being *moral advocates* are both returned to in Chapters Eight and Nine.

In the previous chapter men were identified as having concerns not only about their physical health but also about their moral status. In this chapter, men have been found to emphasise responsibility as a means of demonstrating moral authority over other men and thereby reclaiming or strengthening their masculinity. In the following chapter men's accounts of their experiences of treatment side effects and their reported management strategies to deal with these are examined, to further develop understandings of how men maintain their masculinity following treatment for prostate cancer.



# **Chapter Seven: The Experience and Management of Urinary Incontinence and Erectile Dysfunction**

## **7.1 Introduction**

In Chapter Five experiences of prostate cancer treatment side effects were identified as a common uncertainty that men faced. In this chapter these experiences are explored further and the ways in which men sought to manage these side effects are investigated. The side effects that are considered here are urinary incontinence (UI) and erectile dysfunction (ED) on the basis that these were the most commonly reported side effects that the men interviewed talked about. Much academic literature on these conditions comes from clinical, nursing, and psychological journals and there has been little sociological research exploring these conditions as treatment side effects for prostate cancer.

Urinary incontinence is symbolically loaded with meaning. Becoming incontinent as an adult can indicate frailty, loss of social capability (Isaksen 2002; Mitteness and Barker 1995), and cause feelings of embarrassment and shame to the sufferer (Eisenhandler 1993). For men, UI poses challenges to historically rooted assumptions that men should have control over their bodies (Jervis 2001) and it has been argued that men are more heavily reliant on being continent than women (Morgan 1993).

Urinary incontinence has been identified as a stigmatising condition for men following treatment for prostate cancer (Paterson 2000), yet their study was comprised of themes from just three interviews. Chapple and Ziebland (2002) have noted that UI can lead to a loss of the 'physically bounded body' (Lawton 1998: 131) but do not discuss the condition in greater depth. Some different techniques to cover stigma and pass as normal have been identified for men with UI more broadly, such as wearing dark clothing that disguises incontinence (Elstad et al. 2010). However, a gap remains to explore how men manage their UI as an iatrogenic side effect of prostate cancer treatment.

Erectile dysfunction (ED) is the other treatment side effect considered in this chapter. ED has received more attention within clinical and social research compared with UI, particularly in relation to masculinity. A failure to perform sexually can leave men feeling powerless (Potts 2000) and produce a newly subordinate masculine identity for men (Flood 2002; Lee and Owens 2002), although this is often rationalised as a failure of the body rather than a personal failing (Potts 2000). As a side effect of prostate cancer treatment, ED has been identified as a 'primary supportive care need' (Fergus et al. 2002: 304) for prostate cancer patients. Onset of ED can be distressing (Gray et al. 1997; Nelson et al. 2010) and lead to a perceived reduction in physical health and mental well-being (Bacon et al. 2002). Fergus et al. (2002: 310-11) found ED 'posed a threat to who men were' and contributed to 'diminished self-esteem and confidence'. In a sexualised masculine culture, ED was experienced as an 'invisible stigma' that was hidden from others, the thought of disclosure filled men with a sense of fear and shame that some men referred to as 'coming out' (ibid). Men have sought to respond to this symbolic threat by emphasising that ED resulting from treatment is a 'rationalized' (Oliffe 2005) 'trade-off' in order to live (Gray et al. 2000; Maliski et al. 2008). This serves as a means of playing down the significance of ED for their lives, that men often employed if they were unable to improve their sexual function as many men were not able to do (Fergus et al. 2002).

It will be important to consider how men's experiences of UI and ED fit with a sociological conception of stigma. A stigma is an aspect of a person that is socially ascribed as being discrediting (Goffman 1963; see Section 2.5). A distinction in the use of the term stigma has been drawn between enacted and felt stigma (Scambler and Hopkins 1986; Scambler 1989). Enacted stigma is the overt discrimination resulting from stigma as a result of its 'social unacceptability', whereas felt stigma is the feeling of shame or fear of potentially experiencing enacted stigma (Scambler 2009). How these terms may or may not apply to men's experiences of UI and how they relate to the term 'invisible stigma' that Fergus et al. (2002) use in describing ED will be explored in this chapter.

Men's rationalising ED as a failure of the body (Potts 2000) raises an important question as to how the onset of treatment side effects constitutes a disruption to embodied practices. Using the theoretical tools that have been advocated by Robertson et al. (2010): combining the theories of masculinities of Connell (2005), Watson (2000), and Robertson (2006b) offers a means of exploring how the experience and management of treatment side effects are related to men's embodied masculinities (see Sections 3.4 and 3.6 for further information). Furthermore, Crossley's (2006) notion of 'reflexive embodiment' (see Section 3.4) may also inform an understanding of embodied practices in this area.

Lastly, as this research has sought to examine men's experiences through the lens of chronic illness, Charmaz's (1994) theory of how masculine identity is maintained during chronic illness experience will also be drawn upon. Charmaz (1995: 268) has asserted that:

Illness can reduce a man's status in masculine hierarchies, shift his power relations with women and raise his self-doubts about masculinity'.

The onset of chronic illness can pose a range of 'identity dilemmas' for men (Charmaz 1994). These include the dilemma of either 'risking activity' or being resigned to 'forced passivity', of 'remaining independent' or 'becoming dependent', of 'maintaining dominance' or 'becoming subordinate', and 'preserving public persona' or 'acknowledging private feelings'. Importantly, however men choose to direct themselves in relation to these dilemmas there is always a cost (Charmaz 1994). Exploring men's experiences and management strategies in this way will provide further understanding of how men maintain masculinity following treatment for prostate cancer.

In Section 7.2 men's experiences of urinary incontinence are described. In Section 7.3 the management strategies that men employed and the importance of the strategies for maintaining masculinity are explored. In Section 7.4 men's experiences of erectile dysfunction are described. In Section 7.5 men's attempted strategies to manage their erectile dysfunction are

examined. Lastly, in Section 7.6, the management strategies adopted for both conditions are compared and discussed in relation to notions of embodiment and masculinity, to contribute to an understanding of how men manage UI and ED following treatment for prostate cancer.

## **7.2 Experiences of Urinary Incontinence**

Urinary problems may never occur for men treated for prostate cancer, or may occur but then cease entirely shortly following treatment, yet for more than half of the men interviewed urinary problems continued to varying degrees to be a concern for extended periods of time following treatment, if not indefinitely. Urinary problems posed significant challenges to how men went about their everyday lives.

The men who experienced urinary incontinence (UI) were very concerned with the shame and embarrassment that passing urine in public would cause them. Nigel's account below recalls an episode when the bag for his urinary sheath catheter (a device for collecting leaking urine) broke in a supermarket.

### ***Nigel***

*I used to like wearing shorts and then, can't wear shorts (because of urinary sheath catheter), so used to wear the cut-off jeans, so you've got enough fabric there to cover your bag, and all that sort of thing, but then you're out, I always remember I was dressed up like that and we went shopping in Sainsbury's (supermarket) and the bloody bag split*

### ***Interviewer***

*Oh no!*

### ***Nigel***

*(groans) my wife just, she was picking stuff off the shelves one minute, and then I was gone, I just ran*

**Interviewer**

*You just ran to the loo, or?*

**Nigel**

*I just ran, I phoned her on her phone, I said "I'm back in the car", she said "what are you doing", I said "the bloody bags split", "oh Christ", but that's sort of, that's embarrassing level, because nobody knew quite,*

**Interviewer**

*Yeah, what's happened*

**Nigel**

*Yeah, what's happened, 'he's wet himself', you know, 'what's up with him, is he some sort of drunkard or something?' (laughs) you know, which is natural enough I suppose really, you know.*

(67, RARP, Building Surveyor, Project Manager)

Nigel changed his usual style of dress to hide his urinary sheath catheter from others in public. His account shows a concern with what other strangers in public might think of him. This incontinence episode threatens a discrepancy between his virtual social identity, the impression Nigel gives, and his actual social identity (Goffman 1963). Nigel is concerned that others would see him as disreputable, as 'some sort of drunkard' rather than as a person with illness that he cannot control.

Geoff was also very concerned about others noticing his incontinence in public, as he describes here.

**Geoff**

*You become hyperaware of the fact that you are leaking, and it's probably brought about by the sort of the public perception of elderly smelly men and women who urinate a bit, and you've seen these people in the street, you know, people who are elderly and have an incontinence problem usually smell, it's just how it is ... and unless you've got a good regime of*

*pads, it does- and a good regime of showers and what have you, that smell stays with you*

(63, RP, RT, HT, Project Manager)

Geoff pays particular attention to the smell of urine and his concern with masking the smell 'that stays with you'. He also draws on a broader social stereotype, which other men drew upon as well, of 'elderly smelly men and women' who they associated public episodes of incontinence with.

Nigel and Geoff's accounts above demonstrate experiences of 'felt stigma' (Scambler 1989) in relation to their incontinence. Felt stigma is the feeling of shame or fear of potentially experiencing enacted stigma, where discrimination occurs against the social unacceptability of a person's stigmatising condition (Scambler 1989, 2009). Neither of these men make any reference to being discriminated against by others, yet both of their accounts show considerable efforts to avoid incontinent episodes being witnessed in public, either by running to the car or by a routine of frequent washing.

Experiences of felt stigma for urinary incontinence pose challenges for men in how they go about their everyday activities in public and still maintain their masculinity in doing so, while facing the worry and threat of incontinence. In the following section, some of the strategies men employed to manage their UI are explored.

### **7.3 Management Strategies for Urinary Incontinence**

Men sought to manage their incontinence in a variety of different ways. These different strategies and how these strategies are shaped by men's masculinity are explored within this section.

#### *7.3.1 Self-Monitoring as a Balancing Act*

Two of the most common methods of managing urinary incontinence were to wear incontinence pads or to wear a urinary sheath catheter over the penis to

collect leaking urine into a bag, usually tied around the leg or ankle. Whether using incontinence pads or urinary sheath catheters, monitoring the body is important in going about day-to-day living for these management strategies, whether that is in public space or domestically in the private sphere at home. This is illustrated in Clive and Nigel's accounts below. Clive used incontinence pads and describes the difficulties he encountered when going about domestic activities in and around his house, while Nigel describes the difficulties of using an external sheath catheter at his workplace.

**Clive**

*The [GPS] of the male, at the end of the male urethra, is not fixed like it is with a woman, its, you know, it moves around, and it's alright when I'm sat down, sedentary ... the bladder fills up, and then you can go to the toilet, but if you're outside, like occasionally I am, if- or on the computer and moving around and I'm in the garden and mowing or cutting or doing, once you start to concentrate on living, you forget, and occasionally, you know if you're under a car or you're moving around, then your body moves and your clothes move with you, and occasionally, you can find yourself leaking, just outside the area, which, believe it or not, it can happen, and so, um, occasionally I get caught out, um, I would be ill advised I think to go more than four hours without checking my pad*

(76, RP, RT, Electrical Engineer)

**Nigel**

*if you're doing any stretching about, that sort of thing, that's where I'd be careful, climbing up ladders and squeezing through gaps, if you stretch your leg and then all of a sudden something goes pop (referring to urinary sheath catheter and bag), and you go "oh no!"*

(67, RARP, Building Surveyor, Project Manager)

The movement of Clive's penis and his clothes in the course of his everyday activities left him prone to leaking 'outside the area' of bounded space that his incontinence pads constitute (Lawton 1998). The necessity for Clive to

monitor himself is clear from the 'ill advised(ness)' of going longer than four hours without checking his pad. Monitoring the body is shown to be a conscious, regulatory act, as Clive's account demonstrates where he says that when he starts 'to concentrate on living' he is liable to 'forget' about his pad and consequently finds himself 'leaking'. Nigel, too, has to be 'careful' in undertaking the once taken-for-granted physical activities required for his paid employment. The bodily practices that Clive and Nigel had previously taken for granted in going about daily mundane tasks become problematized with UI and consequently going about these activities requires constant attention in monitoring the body to try and avoid the leaking that can occur when attention slips. The importance of monitoring for embodied practices has been identified in relation to Crossley's (2006) notion of 'reflexive embodiment', where Schrock and Boyd (2006) have identified monitoring as a precursor before adopting new 'reflexive body techniques' (RBTs) in response to a desire to either maintain or modify the body.

Managing UI with incontinence pads or urinary sheath catheters relies to a large extent on men limiting their movements and strenuous exertions. Things are alright for Clive when 'sedentary' but when moving around the problem arises, while Nigel is troubled by the physically demanding activities involved in his paid employment. Watson (2000) has described 'pragmatic embodiment' as the primary mode that men occupy and demonstrate their masculinity through. It is important for men to be physically fit enough to fulfil and perform gendered functions and roles (ibid). For chronically ill men, one of the core dilemmas that they face to their masculine identity is of 'risking activity' or instead being forced into passivity (Charmaz 1994). For Clive and Nigel, engaging in everyday activities had become problematized and to risk engaging in activity required paying close attention by monitoring their leaking bodies.

Both Geoff and Dan, whose accounts are presented in the previous section and below, relied on incontinence pads on a daily basis to manage their UI. They both described acts of monitoring their bodies by paying attention to the physical feel of dampness on their skin, by physically checking to touch



whether pads were damp, and by checking to smell whether they could smell urine. The possibility of failing to pick up on bodily signs posed the threat of experiencing enacted stigma in public. Covering incontinence from others in public by engaging in constant monitoring put a strain on men's daily lives. This strain is evident in Dan's description of how his routine was drastically adapted by the need to check and change his incontinence pads 'six or seven times a day'.

**Dan**

*I used women's incontinence pads, they just happened to fit in my brand of underwear, that I wanted still to wear, umm, relatively unobtrusively. Meant that I had to change six or seven times a day*

**Interviewer**

*That's quite an undertaking*

**Dan**

*Oh it is, but, I never went anywhere without a man-bag with 3 sets of pants and Christ knows how many pads, like with your bag, mine would have been filled with underwear and pants.*

(66, RP, Consultant Anaesthetist)

Dan's account here shows the considerable extent to which men would go in order that they may be able to 'pass' as normal in daily public life. To manage this strain, Dan made some concessional changes to how he went about managing his incontinence. Here Dan describes how he changed his regular exercise routine from working out at the gym to swimming.

**Dan**

*I can say that swimming was great, the best exercise to do in front of people, because nobody knows you're incontinent ... I used to go to the gym, I was back to the gym about four months afterwards (following treatment), I knew I was going to leak so I put a clean pad on at the beginning, you know you're going to leak, and then you put a clean pad*

*on at the end, now if you start off with an empty bladder then you'll end up with an empty bladder and a wet pad, that's the practicalities of life, now for when you're swimming you're flat in the water you'll never leak, once you stand upright you can feel yourself possibly leaking, but seriously though you're just peeing down into the water. But for anyone who wants to do exercise, it gets- the whole of you is wet, so if you did dribble a bit, nobody's going to know, but it's those silly practicalities of life that make things bearable*

(66, RP, Consultant Anaesthetist)

Dan found it difficult to continue going to the gym after he became incontinent. He would have to change his pad before and after working out at the gym and even with an empty bladder he would still have leaked during the workout. By switching to swimming, Dan could be incontinent in front of people without them knowing, therefore his experience of felt stigma is reduced and the likelihood of enacted stigma occurring is also reduced. Swimming was an ideal activity for Dan, in that it enabled him to preserve important aspects of his masculine identity through doing it. He was able to remain active, be independent, and preserve his public persona, all of which are important 'identity dilemmas' for men facing chronic illness (Charmaz 1994). Furthermore, Dan is still able to show his continuing physical fitness and functioning, demonstrating his pragmatic embodiment (Watson 2000) and continuing masculinity despite the difficulties of his UI. However, swimming was still a second choice for Dan and was a concession to make it easier for him to manage his incontinence.

Another concession Dan made was to wearing women's incontinence pads, due to the poor fitting of the incontinence pads available to men generally, as the first of his two accounts above demonstrates. Dan's reported use of women's incontinence pads rather than men's pads was because they fit better with his underwear. Although Dan is generally dismissive of his using women's pads, there is some suggestion of his sensitivity to the issue in his use of the term 'man-bag' to describe how he carries his pads around in public. He

also later joked about a time when he left the bag full of pads in a boardroom after a meeting, although when asked what he would think if they had looked inside he replied defensively that he 'couldn't give a stuff, to be honest'. Other men also reported using women's incontinence pads or cutting up bigger pads into smaller pieces, as pads available to them were often large, nappy like, and more easily visible underneath clothing. However, wearing not just incontinence pads but *women's* incontinence pads evidently poses a profound threat to men's power and symbolic relations (Connell 2002, 2005), in that men's dominance is undermined by being required to use these pads and the symbolic connotations of being incontinent as an adult indicate both frailty and a loss of social capability (Isaksen 2002; Mitteness and Barker 1995).

Dan made concessions that threatened his power and symbolic gender relations (Connell 2002, 2005) and therefore his masculine identity. Yet this was done to maintain his capability of being active, independent, dominant, and to preserve his public persona (Charmaz 1994), as well as to continue fulfilling the gendered roles and functions of pragmatic embodiment (Watson 2000). This was true of other men managing UI with incontinence pads or urinary sheath catheters, where concessions in their activities were made in order to preserve masculine identity more broadly. Managing identity dilemmas in the wake of urinary incontinence puts considerable strain on men who try to continue exhibiting the masculine values Charmaz (1994) describes. However, as the accounts of Nigel and Dan suggest, the demands of engaging in public activity that accompany undertaking paid employment are more likely to be greater than for men who are retired and the extent of this strain will vary not only by the degree of intensity of UI but also by the stage men occupy in the life course.

Paying close and constant conscious attention through *monitoring* the leaking body is the primary means by which these men managed identity dilemmas and preserved masculine identity. However, when the strain of constant monitoring was too exhausting, men sought to make concessions to their condition in their daily activities. Further instances of this are explored in the following sub-section.

### 7.3.2 *Negotiating Public Spaces*

Travelling in public was a particularly important concern for men and managing incontinence while travelling required preparing in advance, as Algernon describes.

#### ***Algernon***

*We had a family gathering at the end of November, and that was- we had to legislate for the journey up to North-East London or, so, it was quite, yeah, so I had one of these milk churns in the car, in case of, which I had to use, not to drink milk, but- (both laugh)*

(73, RT, Researcher)

Algernon brought a large container to urinate in on a long trip travelling by car. The benefit of having a car allowed him to be able to travel and manage his continence with less chance of experiencing enacted stigma because of the relatively private space that a car affords when travelling in public. This is demonstrated further in Clive's account below.

#### ***Clive***

*I'm in John Lewis' restaurant, and their toilet was in the adjacent side of the floor, and I said "I need to go", and I got up to walk about, and I had completely voided (emptied his bladder) by the time I got there*

#### ***Interviewer***

*(gasps)*

#### ***Clive***

*And (Clive sighs heavily) and anyway ... we went out and we got a pair of trousers and underpants, as a back-up, in the boot of the car, so ... I changed in the car park, in the back of the car, we've got frosted windows, which I hadn't particularly wanted, but became a great benefit, that was*

*an upsetting point, and I can remember my son rang up that day, and I just broke down (suggesting that he was crying)*

(76, RP, RT, Electrical Engineer)

Clive's incontinence episode was particularly upsetting for him; he had already experienced other incidents like this but this one was 'the worst time of his life'. However, his car with its frosted windows became a private, safe space for him to escape potential discrimination from others in public.

Prior to treatment most of the men in this research had no physical impediments to their mobility, were physically active, and engaged in public activities without concern. Men had been able to go where they wanted and travel how and when they pleased. Moderate or severe urinary incontinence changed this for men. They were displaced from public spaces they had once felt comfortable in. These spaces came to be perceived as hazardous, just as Goffman describes in his notion of *umwelt* (Goffman 1971; see Section 3.4). As certain public spaces became associated with the feelings of fear and shame of felt stigma, with a perceived increased likelihood of enacted stigma occurring, men sought to avoid such spaces or find ways of traversing them with relative security.

Beyond travelling by car, further planning and preparation was required to engage in activities in public. Dan described how going shopping in his local town centre had become difficult because of the frequency and urgency with which he had to urinate. To help manage this, Dan had come to know every toilet in the town so that he would not be caught out by his incontinence. Andy, too, had to be prepared when going to the cinema, as he describes:

***Andy***

*I go (to the toilet) before I go in, and this is it you see, I go to the loo here, and when I get to the cinema I nip in and I don't really, but I nip in just to be safe, then before I come home, it depends, if I think oh I can make it*

*home alright its fine, then I don't, but, so that's the only downside, you're always thinking ahead*

(68, RTwHT, RP, Accountant)

Andy mapped out his toilet breaks in advance so that he could go out in public to the cinema to watch films with a reduced likelihood of having an incontinent episode. The inevitable 'downside' of this was that Andy had to pay considerable conscious attention to his body, as he was 'always thinking ahead'. These strategies match with those identified in Sub-Section 5.4.2 of men planning for uncertain future events. Persistent experiences of UI constitute an ongoing source of worry and concern for men as to how they deal with the possibility of incontinence occurring in public whenever they leave the house. This demonstrates that not only are men constantly occupied with monitoring their bodies but they are also frequently having to be mindful of future events and to engage in planning and preparing for how they will be managed.

Prior to the onset of their UI, men were largely free to go about in public without constraint. Yet following the onset of UI comes the constant threat of breaching the 'moral order' (Goffman 1971) in public. Feelings of fear and shame of experiencing discrimination from others were outweighed by the desire to maintain masculine identity, which motivated men to adopt strategies that allowed them to continue as much as possible the activities they had engaged in before the onset of UI. To be confined to the private and domestic sphere of the home poses a threat to men's symbolic and power relations (Connell 2002, 2005). Furthermore, embodied masculinity is demonstrated largely through men's capabilities to perform gendered roles and functions (Watson 2000), which frequently involve men engaging in activities in public. Engaging in public spaces is important for men to maintain their masculine identities, as an important 'identity dilemma' for men facing illness is preserving their 'public persona' (Charmaz 1994). By appearing in public, men are able to demonstrate to others how they are positioned in relation to the other identity dilemmas, showing that they are active,

independent, and remain dominant. In the next section men's experiences of erectile dysfunction as a treatment side effect of prostate cancer are explored.

#### **7.4 Experiences of Erectile Dysfunction**

Erectile dysfunction (ED) is another common side effect of treatment for prostate cancer, although the impact on men's lives compared with urinary incontinence is far less substantial. However, men commonly expressed feelings of sadness and shame about the loss of their sexual function, as Andy's account illustrates.

##### ***Andy***

*It does upset me, I think Jane (Andy's wife) thinks that I've just accepted it now, and I think she has, and I've said it hasn't upset me when it has, at times, especially when I hear jokes, if you're out talking and hear jokes, well not so much, people would joke, friends of ours wouldn't make a joke, but you hear it, people laugh, and I think 'seriously, no, I don't find it amusing'*

(68, RTwHT, RP, Accountant)

Andy's account demonstrates a reluctance to speak with his wife about how his ED was affecting them both, and this was common across the majority of men's accounts. For most of the men interviewed, sex before prostate cancer treatment was reported as being unproblematic. The onset of ED disrupted men's cathexis or emotional relations (Connell 2005) with their wives. The emotional energies or meanings that men attach to their relationships with their wives changed. For Andy, the experience of ED presented a barrier for both him and his wife to be able to talk about sex and this is a topic that is returned to in Section 7.6.

Andy's account also shows how the onset of ED poses a challenge to men's power relations (Connell 2005). His power and dominance as a man is undermined by the jokes that he hears others make that he takes offence to.

Shaun, too, described how his ED was upsetting for him but in much stronger terms.

**Shaun**

*There's a sense of its absence, of a subject when you've actually had this role, and that sense of, connection, is not in there in a sense ... and suddenly you're really a spinster, and then you think, well almost everybody else is part of this normal society, and you're sort of this slightly damaged good, and excluded from one aspect of life, I think that's the best way to put it, and I don't feel that it's made me go depressed or, no, but it's made me feel slightly detached from the rest of the world, that's why I described it*

(53, RARP, Commercial Manager)

For Shaun, there is a deeper sense of loss where he has become partially disconnected from the world around him and he considers himself to be broken in some way. The importance of his sexual potency for his masculinity and more broadly his engagement with the world is bound up in three of the four structures of gender relations: power, cathexis (emotional), and symbolic. Power and cathexis have already been discussed, but the huge symbolic importance of sexual potency within Western culture (Morgan 1993; Arneil 1999) cannot be understated, indeed this importance within a 'culture fraught with sexual competition and one-upmanship' is also observed by Fergus et al. (2002: 311) when discussing the 'invisible stigma' of ED. Fergus et al. (2002) also identified a sense of alienation with the rest of society that is evident in Shaun's account, where one of their participants felt like a 'lesser person' because of their ED. However, they do not interpret men's experiences in reference to Connell's (2005) theory of masculinities.

Fergus et al. (2002) also identify experiences of shame similar to those Andy and Shaun express, and these authors refer to this as an 'invisible stigma'. However, these experiences can also be considered, like UI, as instances of felt stigma (Scambler and Hopkins 1986). Having ED leaves these men in a discreditable state and the shame they feel about their condition is the same



as that for men with UI. Despite this, the degree and intensity of the experience of felt stigma is far less for ED than for UI. The threat of enacted stigma for UI is far greater, with there being a much greater likelihood of possibly having an incontinent episode in public, compared with the likelihood of ED being discovered unexpectedly in public, which could not feasibly occur without personal disclosure by the person with the condition or someone else who possessed that information.

Shaun's stronger sentiments compared with Andy's can be understood in relation to his comparatively younger age. Drawing interpretations based on men's ages is constrained by the disproportionate numbers of men in different age groups and then also the varying intervals since when they first received cancer treatment. However, it was commonly reported among comparatively older men within the sample that the impact of their ED on their lives was minimal (discussed further in Sub-Section 8.3.1). Furthermore, the impact of ED for the men in this research, all but two of whom were married, was mitigated by their being in long term marriages (discussed further in Sub-Sections 8.2.3 and 8.3.1). Previous research on how men and their wives manage prostate cancer has shown how partner relationships change and often result in greater emotional closeness following the loss of sexual potency that commonly accompanies treatment (Gray et al. 2000, 2002; Fergus et al. 2002; Bottorff et al. 2008). In the following section, men's attempts to manage and overcome their erectile dysfunction are explored.

## **7.5 Attempted Management Strategies for Erectile Dysfunction**

There are a variety of treatments for erectile dysfunction (ED), including Phosphodiesterase-5 (PDE-5) inhibitor drugs, such as Viagra and Cialis, vacuum pump systems, and a synthetic hormone called Alprostadil. PDE-5 drugs help to relax muscles in and around the penis so that blood can flow more freely. They are oral drugs that can take several hours or longer to take effect. Vacuum pumps work by drawing blood up into the penis and take a shorter period of time to take effect. Alprostadil can either be injected or used

as a urethral suppository. It has a rapid effect caused by a widening of blood vessels allowing greater blood flow to the penis.

The majority of the men who experienced erectile dysfunction trialled one or several of the treatments described above, either individually or in combinations. The degree of success in reducing ED was varied among men, but limited to no improvement were by a vast majority the most common outcomes that men reported. Jamie and Dan's accounts below show how improvements to sexual function could be achieved but were often conditional upon undesirable treatments or actions.

**Dan**

*It probably took about eighteen months before I had a reasonable, spontaneous erection and even now I use Cialis*

(66, RP, Consultant Anaesthetist)

**Jamie**

*If I hold the base myself, firmly, I can have penetrative sex, but it's not great, I don't really want to be holding that*

(53, RARP, Engineer)

Improvement in sexual function can be achieved but with difficulty. Jamie could have penetrative sex but it wasn't 'great' because he was required to firmly grip the base of his penis to sustain an erection. Dan could get an erection when taking Cialis but the time delay for the effect of the drug could make planning sexual activity with his wife difficult. A similar problem was faced by Chris when using a vacuum pump system.

**Chris**

*He (the doctor) suggested a vacuum pump, and I used that, and that was quite successful, certainly in creating an erection, and we were able to have intercourse using that, but, I don't think my wife was terribly enamoured by it, because it takes away the impromptu nature*

(73, RP, Day Trader, Banking)

The vacuum pump was effective in helping to achieve improved *sexual function*, yet this did not automatically translate to achieving improved *sexual activity* with partners. The loss of the 'impromptu nature' of sex was a commonly cited problem for those with ED and this has been observed in previous research (Gray et al. 2000, 2002; Fergus et al. 2002).

The problem of the loss of 'spontaneity' or 'impromptu(ness)' when engaging in sexual activity, or the problems of other conditional limitations on sexual activity, such as what Jamie describes, resulted in a decline of or total cessation in undertaking sexual activities for almost all of the men who sought to engage in them following treatment. In the following section, men's experiences and management strategies for both urinary incontinence and erectile dysfunction are interpreted together, employing notions of masculinity and embodiment, to better understand how management strategies are formed and sustained for these conditions.

## **7.6 Embodied Masculinity as a Facilitator and Barrier to Managing Treatment Side Effects**

Men's engagement with different strategies to manage their treatment side effects were shaped by their masculinity. Following the onset of UI, men commonly sought to undertake strategies that would reduce and completely stop their incontinence. One of these strategies is to undertake pelvic floor exercises to strengthen the muscles that control urination, as Arnold describes.

### ***Arnold***

*I went back to one of the cancer support nurses (because Arnold initially doubted the efficacy of pelvic floor exercises) and she said "well that's quite normal, but just keep banging on with your pelvic floor exercises", I had to by then start wearing pads, which I hadn't before, well I did for the first two weeks after the op, and then I tried and I was normal at that stage, didn't use them, but then I found that I had to start using them*

*again, and I got a bit concerned about it all, as one does at this, thinking 'well is this temporary or what?', anyway I persisted with the pelvic floor exercises and it gradually got better, and now it's, probably 95% ok ... I persisted with the pelvic floor exercises for months and months and months, until I was almost normal*

(83, RP, Royal Air Force Pilot)

For Arnold, the potential to regain control of when he urinates combined with the threat of his UI worsening was motivation to continue with his pelvic floor exercises. Arnold's dedication in persisting 'for months and months' with pelvic floor exercises is illustrative of how some men would be willing to submit themselves to new disciplined physical routines in order to improve their continence. The same measure of importance is also evident in Chris' account.

**Chris**

*I did use pads, more as a precaution than anything else, and I questioned myself whether it was right or not, because I told myself that the sooner that I could stop using pads the greater that the, not desire, the greater the possibility of me being able to sort out incontinence problems, because I said to myself that, I would be forced- with pads, yeah, there's always the reassurance that it's there, and therefore if you leak it doesn't matter too much, you've just got to change the pad when you get home, if you're out, but if you don't have the pad then there's a greater incentive to try to control things*

(73, RP, Day Trader, Banking)

For Chris, the use of incontinence pads partly constituted a concession to his body being limited by UI. By removing the safety barrier of incontinence pads, Chris 'forced' himself into improving his continence with the threat of negative consequences of the enacted stigma he would face if he was incontinent in public to motivate him.

Both Arnold and Chris' accounts serve to demonstrate their masculinity. Arnold's persistence in the face of adversity was eventually successful, while Chris' not wearing incontinence pads forced his incontinence to improve. The desire to reclaim control of the body to maintain masculinity is undoubtedly a powerful motivator to undertake these actions. However, their accounts suggest that it was their desire to return to normal and their force of will that were key to their success, and demonstrate how they have reclaimed mastery and dominance over their bodies, thereby maintaining masculinity.

Engaging in physically active strategies of pelvic floor exercises and going out in public without incontinence pads served Arnold and Chris well. Unfortunately, such strategies were not always effective and often men who attempted them would give them up in the course of time and would be resigned to having to wear incontinence pads or urinary sheath catheters, to *manage* rather than *resolve* their incontinence.

For erectile dysfunction, the situation is very different. Instead of trying to prevent or limit the body from leaking, as in the case for UI, overcoming erectile dysfunction is about trying to achieve and sustain a bodily effect. Furthermore, as described in Section 7.5, there is a significant gap between achieving adequate sexual function and being able to have satisfying penetrative sex. The disruption of the taken-for-granted routines of the sexual encounter resulted in reduced regularity or total cessation of sexual activity for almost all of the men. However, there was a notable exception to this within the sample.

Clarence was able to improve his erectile function by taking the drug Cialis and sometimes using a vacuum pump. Unlike most of the other men with ED, Clarence had problems with his erectile function before his prostate cancer treatment, therefore the onset of his ED was slower and less dramatic than it was for others. This may go some way in explaining how Clarence continued to engage in satisfying sexual activity with his wife following his treatment, yet

other practices he described may also be important for sustaining sexual activity when experiencing ED.

**Clarence**

*So on the whole we've had quite an acceptable sexual life ... you get organised, I mean what we do is that we have a sort of appointment system*

(74, RARP, Management Consultant)

By setting up an 'appointment system' Clarence and his wife established a new routine and a new habitual structure by which to better accommodate Clarence's new level of erectile function. Although there may be a price for adopting a schedule for sexual activity, with the loss of 'spontaneity' or 'atmosphere' that comes with having to plan sexual intercourse, Clarence emphasised how the appointment system reduced the pressure on his wife of not knowing whether affectionate behaviour may be construed as a desire to have sex or not.

**Clarence**

*Some women are worried by the potential idea that their husbands are going to be wanting sex, for example, and they may concern themselves that every night he might want sex, and therefore every night they're a bit tense, or every morning, whatever it is, and the net result is if you come to an arrangement where you are going to have it at a certain regularity, at a certain sort of time,*

**Interviewer**

*It takes away that stress*

**Clarence**

*they know, that all the rest of the time, there's going to be nothing like that, so any cuddling and kissing and stuff is not going to lead to that, for the rest of the time, it actually leads to an improvement, and it might well lead to an improvement for anybody, but um, it does for us anyway*

Furthermore, Clarence also ascribes his success to the frequent and open communication between him and his wife and his flexible approach to the sexual activities that he and his wife engage in, as the following two accounts show.

***Clarence***

*I have involved my wife in absolutely every stage of the process ... if you encounter a few problems you can just talk about it and overcome them*

***Clarence***

*You have to learn to be a little more flexible, in the way that you tackle sex ... in respect to the activities that you do are not quite so prescribed if you like, there's more masturbation and mutual masturbation and things like that involved*

By acknowledging the problem of ED, communicating effectively and regularly with his wife, routinizing sexual encounters, and adapting sexual practices, Clarence was able to sustain sexual activity with his wife. Arnold and Chris' accounts further above in relation to UI showed an association with masculine values as being a benefit for successfully addressing UI. By contrast, Clarence's account transgresses masculine norms, where sharing his feelings about his ED and sharing the power of decision-making and approach to the problem with his wife can be interpreted as weakening associations with cathexis and power relations (Connell 2005), according to Western conventions of hegemonic masculine ideals. That other men had not been able to form and sustain new behaviours to continue having satisfying sex demonstrates how masculine norms can serve as a barrier for adopting successful management strategies for ED.

Interpreting men's behaviours in relation to both urinary incontinence and erectile dysfunction together has also provided some insights into factors that facilitate or bar the adoption of management strategies to address these conditions. The first factor is the level of desire men have to manage their

condition and the second factor is the degree of routine with which a new management strategy is to be undertaken.

For UI, there is a strong desire to not experience felt or enacted stigma, so men adopt management strategies to reduce feelings of the former by reducing the likelihood of the latter. For ED, there is a desire to improve function but this is much less compared with UI. Furthermore, there is very little chance that men with ED would experience discrimination from others, primarily because there is almost no chance that others will discover that men have ED unless they are told so.

As for the adoption of routinized management strategies, urination occurs so frequently that it is comparatively easier to form new management strategies for UI and sustain them over time, as the regularity of urination lends itself to the formation of new habitual behaviours. This is compared with ED, where men's sexual activity with their wives will occur less regularly and more sporadically, at 'impromptu' moments, which is not conducive to the formation or sustainment of new habitual behaviours.

These factors are inextricably linked to masculine identity (Charmaz 1994) and the structures of gender relations (Connell 2005) that shape men's masculinity. The desire to address treatment side effects has been found to be largely motivated by men seeking to maintain masculine identity by seeking to address 'identity dilemmas' (Charmaz 1994). Furthermore, the disruption of men's bodily routines resulted in previously taken-for-granted bodily practices becoming problematized. The structures of gender relations also play an important role in constraining and shaping how men manage their treatment side-effects. These conditions challenged men's power and cathexis relations particularly and how men either acquiesced to or transgressed hegemonic masculine norms played an important role in determining how men were or were not able to form and sustain management strategies for their conditions.



## 7.7 Conclusion

This chapter has examined men's experiences of urinary incontinence (UI) and erectile dysfunction (ED) and explored the management strategies adopted to address these treatment side effects.

For urinary incontinence, men were found to experience felt stigma (Scambler and Hopkins 1986; Scambler 1989). The most common strategies men employed to manage UI, using incontinence pads and urinary sheath catheters, were found to conflict with the gendered roles and expectations that were important to their everyday lives. A core 'identity dilemma' (Charmaz 1994) that arose as a result of UI was the challenge of either 'risking activity' or accepting 'forced passivity' (ibid). These management strategies relied upon minimising bodily movement and strenuous effort, which goes against the primary mode of male embodiment, that of the physically active 'pragmatic' mode (Watson 2000). To balance this identity dilemma, close and constant self-monitoring of leaking bodies was required to engage in activity with reduced likelihood of having urine leak. Having to pay constant attention to the body and to changing pads and emptying full bags of urine put a strain on men's lives. In response, some men made concessions to their UI by curtailing or changing some of their activities to ease this strain, accepting some loss of masculinity to preserve masculinity more broadly. Bearing in mind the attempts men have made to demonstrate their masculinity within interviews, as have been considered in Chapters Five and Six, it is possible that men may have curtailed their activities even further than they expressed in these accounts.

Another necessary strategy for managing UI, in addition to having to constantly monitor the body, was planning trips out into public spaces in advance. Engaging in public spaces could become problematic following onset of UI, where incontinence episodes posed a threat to the 'moral order' (Goffman 1971) of public relations. Maintaining their masculinity required men to continue carrying out their gendered roles and functions (Watson 2000), which frequently necessitated men going beyond the private sphere,

either to engage in paid employment or for everyday and leisure activities. Engaging in public space is identified here as being particularly important for maintaining masculine identity following onset of UI, as it is key to all four of the masculine 'identity dilemmas' that Charmaz (1994) identifies. Being able to 'preserve public persona' requires a demonstration of normalcy in public and to engage in regular activities in public is a way of demonstrating 'activity', 'independence' and 'dominance' to others and to oneself.

Erectile dysfunction posed significant challenges to men's masculinity, as other authors have previously observed (Gray et al. 2000, 2002; Fergus et al. 2002), particularly at the 'power' and 'cathexis' levels of gender relations (Connell 2005). The problems of ED are difficult to address because taken-for-granted, habitual bodily practices of sexual activity are disrupted and comfortable routines of sex are no longer possible to follow. This led to almost all the men with ED reporting that they had ceased engaging in penetrative sex with their wives. Men also experienced felt stigma for their ED although this was experienced to far less a degree or intensity than UI was, largely because this was an 'invisible stigma' (Fergus et al. 2002) that was unlikely to be discovered by others unless disclosed by the bearer of ED.

Men's accounts of overcoming UI by undertaking pelvic floor exercises were found to draw upon masculine values of persistence and forcefulness, emphasising their power relations (Connell 2005) over their bodies. However, masculine norms have been identified as a possible barrier to effectively addressing ED, where open communication, shared decision-making, and scheduling were successful strategies for one man but go against traditional hegemonic masculine behaviours towards spouses. This shows how structures of gender relations (Connell 2005) shape the adoption of management strategies for treatment side effects, where acquiescing or transgressing hegemonic masculine norms of how to behave can facilitate or serve as an obstacle to the successful management of side effects.

Comparing UI and ED experiences and management strategies together has identified two factors that may facilitate or restrict the adoption and

sustainment of new health behaviours for managing treatment side effects. The first factor is the desire or motivation to address a concern and the second factor is the routineness with which that concern is to be addressed. These factors are intrinsically linked with masculinity. In this research, motivation to address side effects has been associated with the desire to maintain masculinity. Furthermore, the routine, habitual behaviours that have been disrupted by treatment side effects have problematized men's embodied masculinities.

To draw out and theorise the second factor a little further, Schrock and Boyd (2006) have suggested that closely monitoring the body is a precursor to the adoption of reflexive body techniques (RBTs) (Crossley 2006; see Section 3.4). The degree of monitoring required for UI shaped the adoption of incontinence pad and urinary sheath catheter use, which can be understood as RBTs for maintaining the unruly body. Without a high level of regularity with which a bodily concern arises, close monitoring of the body will be irregular and this is not conducive to the formation of new RBTs. This offers an explanation as to why men were predominantly unable to reclaim old or find new routines of sexual activity, as there was no bodily concern to regularly monitor. Erectile dysfunction is an absence, rather than the constant concern of an unwanted presence, as in the case of leaking urine for urinary incontinence. This finding provides further evidence to support Schrock and Boyd's (2006) suggestion of the importance of monitoring as a precursor to adopting new RBTs.

In this chapter, seeking to preserve masculinity has been found to be an important concern for men in managing their treatment side effects. In the following chapter, men's strategies of seeking to preserve their masculinity are explored further in the ways that they sought to normalise their prostate cancer illness experiences more broadly.

# Chapter Eight: Normalising the Impact of Prostate Cancer

## 8.1 Introduction

In this chapter, the ways that men sought to maintain their masculinity by seeking to normalise their experiences of prostate cancer are explored. This is done by exploring how men spoke about and represented other social actors in their lives, as well as exploring the common discourses or ways of talking men were found to employ to explain and normalise their prostate cancer experiences.

Seeking to normalise illness when talking about it is a way of managing illness through 'style' (Bury 1991). Normalisation is at its most basic definition a behavioural attempt at maintaining a normal life (Weiner 1975). It is a combination of mental activity and social behavioural strategies (Royer 1995; Sanderson et al. 2011), and has a moral dimension, in seeking to sustain the qualities that make up who people are (Sanderson et al. 2011, 2015). This moral component of seeking to preserve identity that is threatened by illness plays an important but understudied role. Particularly for chronic illnesses, being seen as not addressing one's illness can lead to charges of being a 'moral failure' by others (Galvin 2002) and there is a general expectation for chronically ill people to present themselves as being moral, virtuous, and attentive to their health (Williams 1993). More recent studies have identified how moral dimensions play an important role in shaping normalisation efforts (Sanderson et al. 2011; Sanderson et al. 2015).

Minimising can be understood as a form of normalising and is a way of playing down the extent of a problem. For older people who suffer a decline in health, minimising is a common strategy to emphasise continuing capability and independence, often in the form of drawing social comparisons with other older people who are worse off than themselves (Meadows and Davidson 2006; Frisby 2004). Gray et al.'s (2000) psychological study observed that couples managing prostate cancer seek to minimise the impact of cancer by

limiting who knows about the condition and by seeking to carry on their lives as normal.

Morality often takes a prominent role in health talk among lay people (Blaxter 1993, 1997; Backett 1992; Cornwell 1984; Herzlich and Pierret 1987), particularly among older people (Jolanki 2004). Demonstrating independence, self-care, and being physically and socially active are often expressed in health talk as constituting good health (Jolanki 2004: 498). Furthermore, health talk is often structured around discourses of agency, being able to do something about your health, or fate, not being able to; with agency discourses being preferred and facilitating moralising talk that emphasises the rightness of a person's own behaviour (Jolanki 2004). These have come to be described as 'moral repertoires', that are either 'individualistic' (agency) or 'fate' based (Jolanki 2005). For chronic illness management, Bury (1991) has identified how 'style' is a strategy whereby people seek to present themselves and features in a certain way, drawing on 'cultural repertoires' (1991: 462) to make sense of the impact of illness. How men seek to normalise their experiences of prostate cancer by drawing on broader cultural and moral discourses may offer insights into how men maintain their masculinity following treatment for prostate cancer.

Normalising the impacts of illness and incorporating these into everyday life can be easier when compliance with illness management aligns well with hegemonic masculine values (Williams, C. 2000). She found that men are more often likely to resist incorporating illness into their identities, instead preferring to cover their illness and pass as normal to others where possible. If the nature of the illness and the visibility of symptoms can allow men to do this, then they may be more willing to follow medical advice, as she found with young adults with diabetes and asthma. However, older men may be further swayed to follow medical guidance by trends over the life course towards caring more about their health and controlling their health behaviours (Robertson 2006b). Returning to normal is an important goal following treatment for cancer and normalisation efforts in this respect have been found to be inherently gendered (Hilton 1996; Wenger and Oliffe 2014). However,

the relationship between masculinity and efforts to normalise experiences following treatment for prostate cancer warrants sociological attention, particularly drawing on the theoretical toolbox described in Chapter Three.

In Section 8.2, the different social actors that men refer to in their stories about their illness are examined. How these men referred to other social actors offers an understanding of how men seek to normalise themselves and minimise the impact of their illness in relation to others. Then, in Section 8.3, common discourses that men employed to minimise the impact of prostate cancer treatment side effects in their health talk are identified and their relationships to broader cultural and moral repertoires are discussed.

## **8.2 Social Actors**

Men referred to other social actors within their stories to emphasise their own normality and minimise the degree of difficulty that they faced in comparison with others. Some common groups of people who were referred to by men are explored within this section, including other men who attended support groups, other men outside of support groups, men's own wives, and their children when men were either divorced or widowed. Each of these types of social actor that were referred to will now be discussed in turn.

### *8.2.1 Other Men Attending a Support Group*

Attending a support group offers men a variety of benefits, providing them with different forms of knowledge and support (see Chapters Five and Six) but also helping men to normalise their experiences of prostate cancer, as William and Nigel describe.

#### ***William***

*You sit round and you say what's wrong with you and what happened to you, that sort of thing, and you get people who've had the prostate removed, you get people who've had radiotherapy, and they all seem to*

*have different experiences- slightly different experiences, and I think it's very reassuring for people*

(83, RTwHT, Architect/Lighting Design Consultant)

***Nigel***

*I went and immediately it's 'oh come on in', and there's all these guys there, and they're talking about issues and problems that I'd had, and so it's commonplace, you know*

(67, RARP, Building Surveyor, Project Manager)

Already in Chapters Five and Six, support groups have been identified as sites where personal experiences of cancer are shared with other men. In these chapters this practice has respectively been understood as a means of disseminating information for managing uncertainty and as a form of expertise. However, support groups could also be places where men felt reassured that they were not the only people going through the same ordeal, that such experiences are 'commonplace', and that the differences in people's experiences were often only 'slightly different'.

This practice allowed men to acquire more context within which to represent their illness in their speech in relation to others. When interviewees were asked about the problems they faced they were able to moderate their answers by diminishing the extent of them in comparison with other men who attend their support group. This is evident in Paul and Matthew's accounts below.

***Paul***

*I think, when I see others there (at the support group) and I think 'my god' you know, and when I hear some of their PSA readings I think 'my god, mine's undetectable, that's quite frighteningly high'*

(67, RTwHT, Telecommunications Manager)

**Matthew**

*You know we've people in the group who are on blood- things I can't remember the names of the drugs, but there's two drugs, and they're not, they're not very well, they're fairly cheerful, and get about but they're not very good*

(77, WaW, RP, RT, Sales)

Accounts such as Paul's and Matthew's served to normalise their own experiences by drawing social comparisons between themselves and others (Meadows and Davidson 2006; Frisby 2004). The problems that others face are juxtaposed against themselves as being a 'normal' prostate cancer patient or survivor, these others have worse problems and are more outlying and abnormal than they are.

**8.2.2 Other Men Outside of Support Groups**

Attending a support group gave men additional context to represent their experiences of prostate cancer and reposition themselves as normal. Support group encounters showed men that they could maintain some degree of normality and masculinity can be retained. Consequently, emphasising and demonstrating these facts to other men beyond support group settings was an important task.

**Geoff**

*I made a big play with people about it (prostate cancer), you know, I've had it, and these are the impacts that it has on your life, so I've kind of been a bit of an advocate in that sense, with the people that I've worked with, so that they're aware of the issues that come with prostate cancer and the need for the testing and being aware*

(63, RP, RT, HT, Project Manager)



**Nigel**

*I went round sort of, a bit like I was an evangelist I was banging the drum and preaching the gospel [at] work, and this sort of thing, you know, get yourselves checked and everything else, and we did a little presentation which was quite good ... to guys in the office, and people out in the field, if they want to come along, to, hear about prostate cancer, because it is probably the most common cancer that men get, then don't be afraid of it, come along and I'll explain my experiences and anything else*

(67, RARP, Building Surveyor, Project Manager)

For chronically ill men, preserving a sense of self often involves minimising the visibility of your condition to others (Charmaz 1994). Yet for Geoff and Nigel, making their condition known to others played an important role in normalising their cancer experiences. By promoting responsibility for one's health, by being 'aware', men were able to emphasise the normality of prostate cancer as a common cancer that might affect anyone. It has been suggested that as men age they shift in their relationship with health and hegemonic masculine values towards caring more and controlling health behaviours more (Robertson 2006b) and both traits can be seen to strong degrees in these men's accounts. Their actions here are a further illustration of the *moral advocate* position, outlined in Chapter Six, indeed Geoff uses the term 'advocate' to describe himself. This position of being a good citizen and an expert serves to preserve and emphasise a person's own moral status and this is identified as an important means of maintaining masculinity for these men.

Support group spaces, then, can provide men with a basis from which to reorient their relationship with hegemonic masculinity. This position is further recognisable in how men talk about other men who do not occupy the same position, evident in the accounts of Ben and Peter below.

**Ben**

*I do meet friends and say "well what's your PSA level?", and they say "I don't know, I never looked", and I say "well aren't you going to ask?", and*

*they say “no I don’t like-” you know, you do get people who you might say are in denial, but, have consigned themselves to the care of the experts*

(68, HT, ChT, LPD, Cost and Works Accountant)

**Peter**

*We used to have a lady come around here every month, to collect for cancer research, but I know her husband got it (prostate cancer) about the same time as I did, and he won’t talk to anybody about it*

**Interviewer**

*Really?*

**Peter**

*He won’t say anything about it, doesn’t talk to his wife about it, and I met him up at hospital, and said “hello”, but he didn’t want to talk about it.*

(72, RP, RTwHT, Engineering Manager)

In their accounts, Peter and Ben represent other men with prostate cancer who do not attend support groups as strange or out of the ordinary people. Ben uses the phrase ‘you do get people’ to mark these men out as the exception and out of the ordinary and by positioning them as ‘in denial’ represents them as not taking ownership or responsibility for their health. Peter’s account was presented in a conspiratorial, almost gossipy way, again serving to mark out his neighbour as abnormal and other.

Such men were treated as odd or deviant cases that did not conform to the same values of being informed about one’s health and prepared for health crises that the men interviewed often espoused. By positioning these men as different in their accounts, men are seeking to position themselves and their actions as normal and in adherence to hegemonic masculine values. Yet more than this, these men’s talk serves to moralise the issue of responsibility for one’s own health. In Chapter Five, the healthicizing (Conrad 1987; Zola 1972; Armstrong 1995) forces that encourage prostate cancer detection were considered as contributing to at least some of the men in this research first

being diagnosed with prostate cancer. Following treatment, men can become *moral advocates* of prostate cancer awareness, as was identified in Chapter Six, and in taking on this role these men can contribute further to the healthicization of prostate cancer surveillance, by moralising health responsibility in their talk to others.

### 8.2.3 Wives

Another important type of social actor that men referred to in their accounts were their wives. The term 'wives' is used here because all men in the sample were married to women, rather than co-habiting as partners, except two men who were unmarried, one was widowed and the other was divorced. Previous research has identified the key role that the wives of men with prostate cancer play in helping men to manage the disruption caused by diagnosis and treatment (Gray et al. 2000; Bottorff et al. 2008) and therefore my research was not designed to investigate this topic. However, given that most men interviewed were married, most had been married for considerable periods of time, and that men frequently spoke about their wives, questions were incorporated into the interviews to ask about how men perceived their wife's role in their cancer experiences. The ways in which men represented their wives when talking about them not only offered a way of normalising their experiences but also offered means of demonstrating their masculinity in other ways.

By referring to their wives within their accounts, some men were able to convey the emotional aspects of their illness experiences by describing the support that their wives provided. Here Andy describes the period shortly following his diagnosis.

#### **Andy**

*We (Andy and Jane, his wife) came out, sat in the car park, and we both had five minutes (crying), as you can imagine, and I said I think I better [call the children] and my son of course, in that sense, you know male to*

*male, so she said "oh I'll phone (Carol, Andy and Jane's daughter) and tell her".*

(68, RTwHT, RP, Accountant)

Some men were able to speak about the emotional impact of their cancer experiences, though often these were represented in matter-of-fact ways, just as Andy's account above does. Where Andy says 'as you can imagine' he emphasises the normality of such an action in such a situation. Andy's emotional expression in his account here is further legitimised by his wife's presence and the account quickly moves from the emotional experience to one of action, to calling his son to tell him. Just as Robertson (2007) and Robertson et al. (2010) have described, pragmatic embodiment (Watson 2000) is the primary mode through which experiential or emotional embodiment (ibid) is constituted (see Section 3.6). By first fulfilling his role as a husband, by being there with and for his wife, and then reinforcing this by acting to tell his son the news, fulfilling his role as a father as a 'male to male thing', he is fulfilling his gendered roles of husband and father. This serves to legitimise how he was feeling as expressed in the account.

Edward also draws on traditional gender roles as a means of demonstrating his masculinity. On receiving his diagnosis, Edward goes to watch a cricket match with his son, leaving his female relatives at home upset together.

***Edward***

*When they told me Mary (Edward's wife) got very upset over it, I wasn't too- the thing that bothered me, I was going to see a Twenty20 (cricket) match, Norfolk, and I was more concerned about missing that, than that (the diagnosis) actually (Interviewer laughs), so, um, we made it, and I left Mary with her daughter in law and granddaughter, and the son and I went off to a cricket match and had a few beers, and, left the girls very upset*

(79, RTwHT, Manager for British Rail)

Edward employs humour here to downplay the significance of the diagnosis, a common strategy by men in interviews (Chapple and Ziebland 2004). Edward's account positions himself as unconcerned with his health and more concerned with sport, both staple facets of Western conceptions of masculinity (Courtenay 2000), which he juxtaposes against the 'feminine' values of being caring and emotional that his female family members exemplify in this story. This serves to emphasise Edward's own masculinity in contrast to their feminine care. Like Andy's account above, Edward emphasises a continuation of life as normal, by getting on with things and showing that his masculinity is not disrupted but is continuing as it was before the diagnosis.

Ian also juxtaposes himself with his wife and her behaviour, describing her as 'too caring' at times.

***Ian***

*Oh brilliant, yeah, very much so, very caring, too caring (both laugh) no I don't mean that really ... No, no she is- I mean, women like to be mothers don't they (Ian laughs)*

(78, RTwHT, Technical Director Aviation Industry)

This account accentuates the gendered role of his wife as caring, which by contrast shows Ian to be un- or less caring and therefore more masculine. By emphasising their wives' and their own gendered roles, men are reaffirming the continuity of their gendered roles and this is a way of demonstrating continuing pragmatic embodiment and social fitness (Watson 2000).

The gendered roles of both men and women that are represented in these men's accounts were also institutionalised within the support group (Support Group 2) that these men participated in. Jonathan describes how 'when we come to Christmas, the ladies put on a self-service table'. Furthermore, when describing his wife, Joe says:

**Joe**

*As a committee member's wife it is her expected duty to make the teas and coffees (both laugh), but er, I think she enjoys it (the group meetings) as well, maybe not quite so much as I do.*

(67, RP, Project Manager IT Industry)

When I attended a meeting at Support Group 2 in seeking to recruit more men to my study, I observed that many of the women at the meeting, before the presentation by a medical professional began, were working in the kitchen to prepare teas for others while some women, but mostly men, chatted in the main room (see Appendix 6). The background or backstage domestic caring practices of these women that are described in men's accounts were then, at least to the very limited exposure of being witnessed first-hand by the researcher on one occasion, represented with some accuracy. This finding reflects research on prostate cancer support groups (PCSGs) and women conducted in Canada (Bottorff et al. 2008) and further demonstrates the important supportive roles that men's wives play in helping their husbands manage the impacts of prostate cancer diagnosis and treatment.

These accounts importantly show how normalisation of illness is shaped by masculinity. Men sought to contrast their masculinity against the femininity of their wives' care to emphasise their masculinity and demonstrate a continuation of gender roles for themselves and their wives. In doing this, men were able to demonstrate a continuation of their pragmatic masculine embodiment and continuing social fitness (Watson 2000). Experiential (emotional) embodiment was constituted through pragmatic embodiment for some men, where emotions were expressed and legitimised through actions of being there for their family members. Emphasising masculinity in this way serves to demonstrate continuity as it minimises the disruption caused by prostate cancer.

#### 8.2.4 *Children of Divorced or Widowed Men*

There were two men in this research who were not married at the point of being interviewed. Both were single and had been for at least ten years, one being widowed and the other divorced. With only two cases, any patterns by which these men sought to normalise their cancer experiences, compared to married men, can only be the subject of speculation. Yet these contrasting cases provide some indication of the importance of long term partners for normalising prostate cancer.

Lucas had been divorced more than twenty years before he was diagnosed and had two young adult daughters who he had raised as a single parent for most of their lives. Earlier in the interview, Lucas had described how his daughter had reprimanded him for always taking everything on himself and not sharing his problems with his daughters.

***Lucas***

*I think that I just felt that I was being, trying to be strong, and do what you do, my kind of upbringing said*

***Interviewer***

*Like stoic, sort of-?*

***Lucas***

*Yeah, stoic, yeah, get on with it, that's the way you're brought up to manage these things, and I'd been strong, because of what I said about the single parent, running my home and my job and my life*

(66, RARP, Engineer/Risk Analyst)

Lucas uses his daughters to represent himself as being 'strong' by taking on difficult tasks by himself, thereby portraying himself as masculine through his stoicism and self-reliance, both facets of a broader Western conception of masculinity.

The same is true of William, as shown in his account here describing how he went through his treatment without telling family members he was ill.

**William**

*I didn't say anything to my family until I was cleared*

**Interviewer**

*Did you not? Oh.*

**William**

*Oh no, certainly not ... I knew jolly well what I was doing, because my daughter in law is one of those people who hones in on illness, and I thought I'm just not going to tell them.*

...

**Interviewer**

*It's a very- very different attitude to the ones I've seen before, but as a widower I would have thought that you'd be more reliant on family and friends, but?*

**William**

*Well I was an only child, and I was orphaned when I was nine.*

**Interviewer**

*Oh really? Oh.*

**William**

*Well not completely, my father was killed when I was nine from the war, and um, I was brought up to rely on myself, so yes, and so [it's nice to have people around] and things, and I do now get as much support as I need from the children, but um, I don't rely on- I try not to rely on other people*

(83, RTwHT, Architect/Lighting Design Consultant)



In both Lucas and William's cases their accounts draw upon their upbringing and how they learned self-dependence from an early age. Again, these accounts are normalising, by showing that they were prepared to deal with prostate cancer by themselves from their early years' experiences. By doing this, Lucas and William are emphasising their masculinity by demonstrating values of stoicism and self-reliance.

Without wives to depend upon, emphasising stoicism and self-reliance are important. In Lucas and William's accounts, the social actors most often referred to are their children. Stoicism is emphasised further in the way they spoke about their children, by describing how they did not want to be a burden on them and in seeking to care for their children as parents. Furthermore, their children and children-in-laws' 'feminine' expressions of caring are juxtaposed against Lucas and William's emphases on self-reliance, rather than the general expectation of such support from men's wives that was evident in the accounts explored in Sub-Section 8.2.3.

Yet these men, despite their displays of stoicism, undoubtedly found it more difficult to cope with their cancer experiences than the married men, as Lucas' account of being discharged from hospital early testifies to.

### **Lucas**

*I had one night (in the hospital), and then I was discharged, without any notice ... and I said, "I just want to ask you, are you thinking of doing that?, I have no personal provisions in place to cope with being discharged today", and she ranted at me a bit about this, "you're deemed to be fit by a consultant to be discharged", and that's her intention, and then I did things and I thought 'right I've got to start making phone calls', to get one of my daughters to change her circumstances or get off work at short notice or something, ... I said (to the hospital matron) "I know where you're coming from, you know where I'm coming from, I'm distressed, I'm angry, I'm anxious about being discharged, and you're going to discharge me today aren't you", and I turned and walked away from her ... if you don't have any other, a wife or a partner or somebody at home, ready to*

*look after you, just reading and waiting for when you walk out, then, then it's a big event.*

(66, RARP, Engineer/Risk Analyst)

Lucas' account illustrates the degree of importance of the role that spouses can play in post-treatment care. His account juxtaposes Andy's account in Sub-Section 8.2.3, where by fulfilling his role as a husband Andy was offered a legitimate route to express his emotions. Lucas, by contrast, was in a distressing situation but on his own was forced to solely rely upon his pragmatic embodiment where he emphasises how he 'did things' to plan for being discharged, yet Lucas went on to describe how he then went home to an empty house. Lucas later described how he had a network of friends beyond his family but would not use them to 'cry on their shoulder' or share his emotional burden. He also asserted that he felt it was important not to 'bottle things up' although this was in relation to his having cried during the interview. By not having a partner to legitimise his emotional expressions with and through, Lucas' emotional expression was constrained by masculine norms.

Having identified how different social actors were represented in men's accounts to normalise prostate cancer experiences and to emphasise and maintain masculinity, the common themes which men drew upon in attempting to minimise the impact of their treatment side effects will be discussed.

### **8.3 Common Discourses for Minimising the Impact of Treatment Side Effects**

In Chapter Seven, men's accounts of the strategies they employed to manage their treatment side effects were explored. In this section the different common themes that men drew upon to minimise the impacts of the common treatment side effects urinary incontinence (UI) and erectile dysfunction (ED) are explored. These discourses, or ways of talking, served to downplay the

impact of treatment side effects on their lives, but were also ways of making sense of their experiences. They have been categorised into three forms: 'the ageing discourse', 'the chance discourse' and 'the choosing life discourse'. These discourses are also examined in relation to broader moral repertoires (Jolanki 2004, 2005) and are discussed in turn.

### 8.3.1 *The Ageing Discourse*

For erectile dysfunction, a dominant discourse emerged in men's accounts as a way of making sense of their side effect while also minimising the impact of it. This discourse was one of ageing, or getting older, in which sexual activity is understood as something that will diminish as a natural part of growing older.

#### ***Lionel***

*I think somebody once said, if you, when you get married, and you (referring to interviewer) can try this, get a jar, put it beside the bed, and put a pebble in it every time you make love to your wife, and, in the first year put a pebble in every time, and then after that for the rest of your life, take a pebble out, every time you make love to your wife, and you will never empty the jar (both laugh)*

(66, RP, Chartered Accountant)

Lionel's story emphasises that sex in married life is much more a staple of early married life. For the men interviewed, the association of sexual activity with spouses is particularly important given that all but two of the participants were married and had been for long periods of time. Therefore, the diminishing of sexual activity *in married life* is particularly important. This is important because men could minimise the impact of their ED on the premise that 1) when you get older your sexual activity will diminish naturally, and 2) when you have been married for a long time you have seen and done it all before.

The way that this discourse was drawn upon was found to vary depending on the age of the person engaging in that discourse. Some men, who were comparatively older than the rest of the sample, in their late seventies or early eighties, reported a decline in sexual activity prior to treatment for prostate cancer.

**Edward**

*I mean I'm 79, so really, I don't know, I know, it's not interfered with that side (sexual activity) really, but then I've got to say its eased off anyway prior to knowing about the treatment, I honestly don't know, because we'd very nearly stopped beforehand anyway, so it's, I think, a lot of us lose our, 'get up and go' as they call it, and, you know at that age, so whether it (treatment) has affected it (sexual activity) I don't know*

(79, RTwHT, Manager for British Rail)

Edward's account relies heavily on the fact that he had reached an age where his sexual activity had declined, even before he had been treated. In this way, his age had already rendered the impact of ED to be minimal.

Arnold, who was seventy-five at the time of treatment, not only drew upon his age but also upon the co-morbidities that accompanied his ageing to make sense of a decline in his erectile function. Arnold had diabetes which he saw as a compounding factor in reducing his erectile function and which he drew upon to emphasise the natural part of his decline in erectile function. By contrast, men who were comparatively younger struggled at times to employ an ageing discourse, as is evident in Chris' account.

**Interviewer**

*Is it something that you waited, to get back into after, I mean, did you wait long after you had the treatment, before you tried (to have sex)?*

**Chris**

*Um, probably, three months, and then we may have just thought well let's see, and it didn't happen, there was no reaction, um, so I think that's*

*probably the answer to your question, there wasn't any resentment, there wasn't any concern, and it may be partly age, you know, I was 60- what 64 when I had the operation, and I wasn't past it, and plenty of chaps are still making love to their wives and having full intercourse at 75, 85, maybe not much older than that, but nevertheless, you know alright, the frequency decreases and perhaps the, but the desire is probably still there, and I think men, well I believe that some men probably say to themselves at some stage in their lives, well you know I'd love to make love to you but I really don't feel I'm up for it, it's not going to be satisfying for either you or me and therefore it slowly reduces in intensity and frequency, I think even at 64 that had probably started to happen with us, you know we've had our children*

(73, RP, Day Trader, Banking)

Chris' attempt at employing an ageing discourse here is partial and conflicted. On the one hand, he presents his desire to engage in sexual activity as reducing because of age and his decline in erectile function as 'partly age' as well. Yet on the other, he describes how at the time of treatment he 'wasn't past it' and that men who were much older than him still had sex, although he presents it as being no longer necessary or as important to have sex with his wife.

For urinary incontinence, the situation was considerably different. UI was not a culturally expected experience for men, particularly at the mid- and later life stages, and lead to experiences of 'premature ageing' (Bury 1982; Singer 1974). Clive, who was one of the older participants of this research, attempted to employ an ageing discourse, shown below. However, this was the only observed instance of this.

**Clive**

*I'm 70 years old, you know eventually you're going to get a bit of incontinence when you get older, with or without the benefit of prostate surgery*

(76, RP, RT, Electrical Engineer)

This is likely because a decline in urinary continence has such a marked effect on daily life and that the significant and rapid decline in urinary function contrasted with expectations about continence levels for other men of similar ages, particularly when compared with expectations of decline of sexual function and sexual activity regarding ED.

An ageing discourse can be understood as a form of the 'fate' moral repertoire (Jolanki 2005). Men represent their ED as something that they cannot control but also as something which is not their fault, because it is part of a natural decline in sexual activity that comes with age so it does not matter that much, the significance is minimised. Employing this discourse allows men to be released from the responsibility of not having preserved their erectile function. This frees men from potential discourses of blame from others of their not virtuously working to manage and maintain their erectile function, which they might be subjected to. Either through potential interviewer questions or through talk with others. This discourse is similar to the next discourse, the chance discourse, in not only minimising the impact of illness but also in the approach taken regarding responsibility for illness.

### 8.3.2 *The Chance Discourse*

A discourse of chance or luck assisted some men in representing their own experiences of treatment side effects in relation to other men's experiences. Here Clive and Arnold talk about their improved urinary function following treatment for prostate cancer.

#### ***Clive***

*Yeah I think I'm very lucky, \*very very\* lucky, because I listen to some of the stories of some of the guys in the prostate group, and I'm so lucky it's untrue*

(76, RP, RT, Electrical Engineer)

**Arnold**

*I'm pretty well normal, you know I'm very very lucky, because I know other people who aren't, and it's a wretched business*

(83, RP, Royal Air Force Pilot)

Clive and Arnold's accounts show two ways that men can employ a chance discourse to minimise the impact of side effects and normalise their experiences of them. The first, shown in Clive's account, is Clive's minimising the impact of his urinary incontinence in comparison with other men he knows who are in a worse situation. This is the same kind of drawing of social comparisons commonly observed in qualitative research on ageing (Meadows and Davidson 2006; Frisby 2004), also observed in Sub-Section 8.2.1 further above. The second, shown in Arnold's account, is where Arnold has negligible or no urinary incontinence as a result of treatment and therefore employs a chance discourse to play down the success of his treatment compared to other men who have worse side effects than him, to emphasise humility and exceptionalism. Arnold is emphasising his normality as a man, rather than a man treated for prostate cancer.

Treatment side effects can be difficult to bring under control and making sense of this can be difficult for men. Nigel, in trying to improve his urinary incontinence, found the suggested therapy of pelvic floor exercises to be a 'waste of time'. He then proceeded to tell a story about a man who he was in hospital with and who had the same operation as him on the same day. This man had far worse side effects than him, from which Nigel concludes:

**Nigel**

*Well there we are, more or less the same day, same operation, totally different outcomes*

**Interviewer**

*Yeah it just plays out differently with everyone*

***Nigel***

*Yeah it's just the luck of the draw really, how it comes out*

(67, RARP, Building Surveyor, Project Manager)

In not being able to make sense of why his treatment outcome was different from another man's, Nigel falls back on the chance discourse of treatment outcomes being 'the luck of the draw'. The use of phrasing around the concept of 'luck' has been identified as a way by which people make sense of the socio-economic and political structures that govern their lives (Davison et al. 1991; Backett 1992). Jolanki (2004) asserts that discourses of agency are preferred to those of fate. In not being able to make sense of different treatment outcomes in terms of them being shaped by individual choice, Nigel falls back on a 'fate' repertoire of chance, which to some degree can make sense of his experiences that he cannot fully make sense of.

As the most common side effect among the men interviewed, ED was heavily emphasised as being the normal outcome for treatment, while those that do experience a return of erectile function were the 'very lucky' or 'very rare' cases, much more so than for UI.

***Matthew***

*I can't get an erection, those that tell you they can I'm not sure they can, unless they're very lucky*

(77, WaW, RP, RT, Sales)

***Joe***

*People very rarely get full potency back, afterwards*

(67, RP, Project Manager, IT Industry)

By positioning others as rare or lucky cases these men are able to represent themselves as normal prostate cancer patients or survivors.

The chance discourse is another form of the 'fate' moral repertoire (Jolanki 2005). In this instance, as for the ageing discourse, it serves to present



oneself as normal in relation to others but also to protect against possible charges of blame from others. Ageing and chance discourses position men as the subjects of circumstances beyond their control, thereby presenting them as blameless for their treatment side effects, the third and final discourse observed in this research, the choosing life discourse, is premised on taking personal responsibility for one's health.

### 8.3.3 *The Choosing Life Discourse*

Discourses of ageing or chance emphasise blamelessness for an illness situation, which is beyond a person's control. The choosing life discourse, by contrast, emphasises the opposite and takes ownership of responsibility for one's health. This discourse involves men drawing on treatment decisions or other past actions to justify and affirm their current situations, and in so doing make sense of the side effects they were experiencing.

Here, Lucas minimises the impact of his treatment side effects as a 'small by-product' of 'saving your life', while Chris sought to be 'rid of the cancer and the worries and concerns that might cause'.

#### **Lucas**

*I've always said to people who've asked, the doctors and nurses, it's inconvenient but it's entirely manageable, and it's a small by-product from having something which is saving your life, you know from the surgery, so that was always a comfortable perspective*

(66, RARP, Engineer/Risk Analyst)

#### **Chris**

*I think the view of us both (Chris and Victoria, his wife) was, if it means that you're going to get rid of the cancer and the worries and concerns that might cause then that's (erectile dysfunction) something we'll live with, there are ways of addressing this issue*

(73, RP, Day Trader, Banking)

Chris and Lucas here make sense of their side effects by representing them as necessary evils required in the course of saving their lives. This discourse presents them as stoic men who sacrificed aspects of their bodily function for their own survival.

However, the strength of the choosing life discourse in part rests upon a confidence in previous decisions or in making the 'right choice', a concern that was common for men that was identified in Sub-Section 5.3.4. Chris employed a choosing life discourse in his interview, yet he also described times when he had doubts as to whether he made the right choice.

**Chris**

*I think he (Chris' consultant) was leaning towards the watch and wait, the monitoring situation, and it was only me that decided that yes, I could have a radical (prostatectomy), but, was it something that I wanted to have, and on balance, yes, at the time I thought it was, now subsequently, and this may be important from the point of view of your study, because of the fact that, and this is where the impotence I suppose comes into it, there are times when I do say to myself now, maybe it was the wrong decision, maybe I should have gone for the watch and wait*

**Interviewer**

*Yeah*

**Chris**

*And perhaps things would have worked out alright and perhaps I could have retained more potency for longer than I did, um, and I ask myself that question occasionally, um, I obviously [come down] and say to myself well, I got rid of the cancer, I'm living with the impotence, just leave it at that, but the other occasion, perhaps when I'm feeling particularly frustrated ... I mean when I look at a pretty girl in the street, when I look at my wife, you know I sometimes, yes of course I think to myself, gosh, I wish I could do something about this, um, but other than a kiss or a cuddle*

*with my wife- not with the girl on the street (both laugh), you know I say to myself well, I just have to make do with that, and live with that*

(73, RP, Day Trader, Banking)

Chris confesses to a sense of internal conflict as to whether he made the right treatment decision and demonstrates that his decision was a sacrifice which he has suffered or paid a price for. Chris employs humour to dispel his doubts and emphasise his stoic position as having to 'make do' and live with his ED. Chris' account demonstrates how employing the choosing life discourse can be facilitated by reinterpreting biomedical knowledge, the strategy for managing uncertainties identified in Sub-Section 5.4.1. Adopting a discourse dependent on personal agency comes with taking responsibility for one's decisions and this can involve having to engage with uncertainties about having made the 'right choice' or not.

Yet despite this potential constraint in employing the choosing life discourse, this discourse was also one which could be well defended because it was presented from a unique perspective, as Andy makes clear when describing a newspaper article he had read.

***Andy***

*I read an article in the paper about a guy who, they were talking about prostate cancer and he was a journalist, and ... he said "if I was incontinent" he said "and if I couldn't have sex, then I'd prefer to be dead", and that's how the article ended, and I thought 'that's naivety beyond belief, because when you come close to meeting your maker you take a whole different approach to life', and that's the way we've (Andy and Jane, his wife) looked at it, that's the way we've dealt with it, yeah we've, you know, the sexual side, it's important, or has been important, but it's not as important as saving your life*

(68, RTwHT, RP, Accountant)

Andy represents the journalist as someone who cannot understand what having prostate cancer is like and the closeness of coming to death that

accompanies it because he has not experienced it first hand and therefore that the journalist is in no fit position to make a judgement. Andy's contributory expertise of prostate cancer privileges his experience over the views of others and serves to defend and strengthen his choosing life discourse.

'Choosing life' by opting for treatment may have caused disruptions to normal life and to masculinity, yet choosing life offered ways for men to maintain masculinity more broadly, by men realigning themselves with different hegemonic masculine values, as Lucas and Clive's accounts demonstrate.

***Interviewer***

*Did you find the loss of sexual function to be quite a difficult thing?*

***Lucas***

*I think that I just, yeah, I think I just put it into perspective, tried to be a bit clinical about it and say the important thing is saving my life, and my health, you know, I've got energy and vigour in other ways, and quality of life in other ways, so um, I think that [I] should, get on with it, as a sad by-product, really, yeah*

(66, RARP, Engineer/Risk Analyst)

Lucas describes that while he may no longer have good erectile function, he has 'energy and vigour' and 'quality of life in other ways'. He may have lost out in terms of his 'symbolic relations' (Connell 2002, 2005) in losing erectile function, yet was able to remain active and preserve his public persona (Charmaz 1994) in his social life, by maintaining other social roles, such as being active with local voluntary groups.

***Clive***

*The concept of all this work (further interventions to improve continence) is more worrying and, but, I am without cancer, at the end of the day, and I discussed this with my wife before and said [what do you-], so I think I'm- I've got the option, we could have surgery and remove it, and hope*

*they get it all away, and um, hopefully, I will survive, and, we can be part of our grandchildren's life*

(76, RP, RT, Electrical Engineer)

Clive, facing challenging urinary troubles, emphasises his pragmatic embodiment (Watson 2000) by highlighting the importance of maintaining his gendered roles as a husband and grandfather. The 'we' Clive uses to describe his treatment options was a language pattern frequently used by other men in this research and further exemplifies the importance that men's wives play in the management of prostate cancer (see Sub-Section 8.2.3). Men's use of the choosing life discourse frequently relies on the 'we', where men are not just choosing life for themselves but also implicitly for their wives as well. In this way, men's treatment choices are represented as stoic, in that their chronic difficulties following treatment are a necessary cost of continuing to be there for their dependent families. This behaviour is consistent with Noone and Stephen's (2008) notion of the legitimated user, where the concerns of wives about their husbands' health legitimates men's engagement with health care.

The choosing life discourse is an 'individualistic' moral repertoire (Jolanki 2005). Discourses of agency are generally preferred to ones of fate and beliefs about health being a result of individual choices may lead to moralising talk about health (Jolanki 2004), evident in Sub-Section 8.2.2. The choosing life discourse allowed men to realign their masculine values by emphasising stoicism when describing their actions in order that they may continue to fulfil their gendered roles. Just as was demonstrated in the previous chapter, accepting concessions in the loss of masculinity from illness allowed men to emphasise different aspects of masculinity as being more important in their lives, such as remaining socially active and continuing to play an important familial role.

## 8.4 Conclusion

This chapter has examined the different ways that men sought to normalise the impacts of prostate cancer and in doing so preserve their moral status and maintain their masculinity. Normalising was undertaken through reference to different social actors and by drawing on common themes, which also served to help make sense of their situations.

Throughout the findings chapters of this research, prostate cancer support groups (PCSGs) have been found to play a key role for men in managing prostate cancer. In this chapter, PCSGs served as sites where men were able to make sense of their cancer experiences by normalising them in comparison with other men. Men could represent themselves as normal prostate cancer patients or survivors, by comparing themselves with men who were worse off than they were within their support group. This kind of social comparison is a common strategy for resisting ageing (Meadows and Davidson 2006; Frisby 2004).

Participants also sought to normalise their experiences by contrasting themselves with other men who had prostate cancer but did not attend a PCSG, as well as with men who were not responsible for managing their own health. These sorts of men were described as being strange and difficult to comprehend and in this way the participants' talk was moralising towards these other men (Jolanki 2004, 2005).

Wives of men with prostate cancer undoubtedly play an important role in helping men to normalise prostate cancer. Previous research has identified the approaches that wives take to support their husbands emotionally and practically (Gray et al. 2000; Bottorff et al. 2008) and men's accounts about their wives in my research supports these findings. The way that men spoke about their wives, too, played an important role for men in helping them to normalise their situation. Men emphasised their masculinity by juxtaposing their stoicism in the face of prostate cancer against their wives' femininity, displayed through their reported responses of care, concern, and upset. When referring to their wives in their accounts, men also emphasised the gender

roles of themselves and their wives. Demonstrating their continuing adherence and fulfilment of pragmatic embodiment (Watson 2000) by being good husbands and fathers shows a continuation of masculinity despite the disruption caused by prostate cancer. In some instances, being a good father or husband was a way for men to mobilise pragmatic embodiment into legitimised expressions of experiential (emotional) embodiment (Robertson et al. 2010) of being upset about their illness experience. For men with no partner, stoicism was also emphasised through stories about the importance of self-reliance. Their stoicism was juxtaposed against the caring of their female children or children-in-law and was further emphasised by stressing that it was not their children's responsibility to look after them.

More than simply trying to normalise cancer experiences, men also drew on common discourses to try and make sense of the disruption caused by treatment side effects. First, an ageing discourse was described, where men emphasised the naturalness of their decline in sexual activity, so that the onset of their ED was not so important. For UI, this discourse was almost entirely absent, likely due to the perceived unnaturalness of the condition for the ages of the men experiencing the condition, which commonly caused a perceived 'premature ageing' (Bury 1982; Singer 1974) among men. This discourse is identified as being a form of the 'fate' moral repertoire (Jolanki 2004, 2005).

The chance discourse is another form of the 'fate' moral repertoire (Jolanki 2004, 2005). Just as men employed social comparison in relation to other social actors, they also compared the outcomes of their treatments, in relation to treatment side effects, with other men in terms of chance or luck. This was done in one of two ways, men who had better treatment outcomes emphasised how lucky they were, thereby emphasising their exceptionalism but through the humility of being lucky. Whereas men who had poorer treatment outcomes emphasised that others were extremely lucky and that others' luck was a rare occurrence, thereby emphasising their own state as normal for prostate cancer patients. For ED, almost all men drew on the latter approach, whereas for UI both approaches were employed.

Both the ageing and chance discourses drew on the notion of fate and were in this way disempowered, in that men's accounts emphasised that they could not control their illness situation. However, employing these discourses could help free men from a sense of responsibility for their illness situation and protect them against possible charges of blame for their conditions. Employing these discourses served to demonstrate to others that they were *blameless* for their situations.

The last discourse that was observed is the choosing life discourse. Unlike the ageing and chance discourse, this discourse drew upon an 'individualistic', rather than 'fate', moral repertoire (Jolanki 2004, 2005). This kind of discourse is empowered and emphasises agency, in that men had made a choice to have treatment. However, this discourse was frequently accompanied by accounts of uncertainties about whether they had made the 'right choice' in their treatment. Despite this, the choosing life discourse was an empowering one. Accepting the loss of masculinity that comes with treatment, men realigned their relationships with hegemonic masculine values to emphasise their masculinity in other ways. They were able to emphasise their stoicism by accepting the costs of treatment, in order to continue to maintain their gender roles as husbands, fathers, and grandfathers. They were also able to maintain active social lives and preserve their public personas, thereby addressing important identity dilemmas that can arise with chronic illness (Charmaz 1994), even though they lost out in other areas, just as has been observed in Chapter Seven.

Combinations of discourses have been drawn on at different points within a single interview to minimise the impact of treatment side effects in different, strategic ways to best emphasise normality and demonstrate masculinity. These strategies are reminiscent of Wetherell and Edley's (1999) work where men seek to position themselves in their talk in relation to hegemonic masculinity. The findings of this research show how men's normalising talk and employment of 'moral repertoires' (Jolanki 2004, 2005) are important strategies for maintaining and demonstrating masculinity in the wake of illness.



Demonstrating masculinity in the wake of illness is largely defined in relation to illness. Throughout the empirical findings chapters, demonstrating moral status has been identified as an important concern for men. Protecting against being subjected to blame by others, by presenting oneself as blameless and by moralising health responsibility through health talk, have all been identified as important strategies to normalise illness. These strategies are employed to preserve moral status and thereby maintain masculinity. This further highlights the importance of understanding the relationship between morality and normalisation in seeking to better understand illness experiences and behaviours, as Sanderson et al. (2011, 2015) have previously recognised, but also raises the importance of masculinity in relation to these two concepts as well. The ways in which these strategies for managing the chronic dimensions of illness relate to one another and to broader theories of masculinities are discussed in the final chapter.

## **Chapter Nine: Discussion and Conclusion**

### **9.1 Introduction**

The focus of this research has been to explore men's experiences and management strategies following treatment for prostate cancer. This research has built on previous qualitative research on prostate cancer (Chapple and Ziebland 2002; Oliffe 2005, 2009a; Broom 2004, 2009; Kelly 2009) by exploring some of the chronic aspects of men's illness experiences following prostate cancer treatment, which have previously received comparatively less attention than earlier stages of the illness trajectory.

29 men, recruited from two prostate cancer support groups (PCSGs), were interviewed about their experiences of diagnosis, treatment, and their lives following treatment. Qualitative, open interviewing yielded rich data about the concerns and difficulties of post-treatment life, including managing the fear of cancer recurrence and common treatment side effects, as well as the ways by which men sought to manage these concerns.

This chapter discusses the key findings of the research and draws conclusions from these findings. The key findings presented in the previous four empirical chapters are summarised in Section 9.2. Then, the ways that these findings contribute more broadly to sociological knowledge are discussed in Section 9.3. Following this, some of the main limitations and strengths of the study are explored in Section 9.4. Future research possibilities are then examined in Section 9.5 and lastly some concluding remarks are offered in Section 9.6.

### **9.2 Key Findings**

In this section the key findings of the research are summarised. These findings are split into four sections, each reflecting the findings of the previous four empirical chapters.

### 9.2.1 *Uncertainties and Uncertainty Management*

In Chapter Five, men's experiences of uncertainty following treatment for prostate cancer were examined. This research posed the questions *what uncertainties do men face following treatment for prostate cancer?* And, *how are these uncertainties managed?*

Despite common expectations that uncertainties experienced prior to treatment would be resolved following treatment (Bell and Kazanjian 2011), not only did such uncertainties commonly persist following treatment but also new uncertainties were identified. Four common uncertainties were identified in men's accounts of their experiences following treatment for prostate cancer.

The first uncertainty is a fear of cancer recurrence that comes from continued PSA testing following treatment. Men monitored their PSA tests following treatment and if their PSA tests became a cause for concern then they set thresholds for their PSA level, which if exceeded would prompt them to seek further information and guidance from medical professionals.

The second uncertainty is a fear of cancer recurrence that comes from unexplained bodily symptoms that were interpreted as possible signs of cancer recurring. This fear can be understood as a loss of 'health competence' (Horlick-Jones 2011) where the initial diagnosis of cancer with few or no symptoms led men to doubt the reliability of their body to inform them when they are ill.

The third uncertainty concerns treatment side effects following prostate cancer treatment. Treatment side effects bring new uncertainties, including concerns with what caused a new symptom, how severe a symptom would be, and how long it would last. Particularly in the case of urinary incontinence (UI), men described feeling vulnerable to UI returning and being a problem that would be harder to manage in old age. This uncertainty and the previous two forms of uncertainty are concerns with the *physical threats* of illness to the physical functioning of the body.

The fourth and last uncertainty is a concern with whether men had made the 'right' choice in opting to treat their prostate cancer. This fourth uncertainty is different in that it is concerned with a *moral threat* posed by the question of whether men had made the 'right' or 'wrong' choice.

Three strategies were identified to manage these uncertainties. The first strategy of reinterpreting biomedical knowledge was in response to the moral threat of men not knowing whether they had made the 'right' treatment decision. Men reinterpreted biomedical knowledge they had received prior to or shortly following treatment to make sense of their current situations, sometimes to justify their treatment decisions but at other times to critique them. Brown and de Graaf (2013) identified a strategy of imagining different futures as a means of managing extreme uncertainty for people with poor cancer prognoses. Instead of managing uncertain futures, the men in this research *reimagined uncertain pasts* as a means of managing uncertainty. By reconstructing the past through the lens of the present, men sought to make sense of and affirm their present situations.

The second strategy for managing post-treatment uncertainties involves planning for possible uncertain future events. Men described plans for future treatments they required or may require at a later point and these accounts recognise a long-term approach of *management* of cancer would be required, rather than to resolve concerns altogether as men often expect prior to treatment (Bell and Kazanjian 2011). Both *reinterpretation* and *planning* are identified as nuanced strategies that proceed from an overarching strategy of vigilance (Weitz 1989), where men use the knowledge they have acquired for their illness in different ways to manage the uncertainties they face.

The third strategy for managing uncertainties involves engaging in PCSG attendance. Vigilance as a strategy for managing uncertainty involves seeking knowledge to better understand illness and find ways to most effectively deal with it and any future problems that may arise in relation to it (Weitz 1989; Schneider and Conrad 1983; Comaroff and Maguire 1981). PCSGs offer access to a range of experiential and clinical forms of knowledge, both

from men who had followed different treatment or non-treatment pathways and received varying outcomes from these, and from medical professionals who regularly gave presentations at support group meetings. PCSGs are termed *vigilance networks* in this research for the important role they play in the acquisition of useful and relevant knowledge for men. How these findings relate to the findings of Oliffe et al. (2011) on the role of PCSGs on men's experiences of prostate cancer is discussed in Section 5.5.

Men have been found to face a range of uncertainties following treatment, not just pertaining to concerns with the physical functioning of their bodies relating to prostate cancer and iatrogenic side effects, but also concerning the threat to their moral status that treatment for prostate cancer poses. To manage these uncertainties, men have drawn on strategies of vigilance (Weitz 1989) centred around the knowledge that PCSGs provide. Begetting from vigilance, strategies using the knowledge acquired from vigilance to *plan* futures or *reinterpret* pasts were found to be useful in managing uncertainty. A sustained concern with vigilance demonstrates the chronic nature of prostate cancer that persists as a concern long after treatment. Another outcome of vigilance is the acquisition of specialist prostate cancer knowledge, which was examined in Chapter Six and the key findings for which are discussed in the following sub-section.

### 9.2.2 Patient Expertise

In Chapter Six, patient expertise was explored as another important theme of chronic illness research. The following questions were posed: *what forms of specialist expertise do men possess regarding prostate cancer? How do men acquire their expertise? And, how do men use their expertise?*

The men in this research have been found to possess a range of specialist expertises for prostate cancer. Men possessed contributory, interactional, and special interactional expertise for prostate cancer, all important forms of specialist expertise from Collins' (2014) recent schema for classifying different forms of expertise. These forms of expertise were

acquired through personal experience of illness, through interactions with medical practitioners in clinical encounters, and when interacting and engaging in activities at PCSGs with medical practitioners and current and former patients and cancer survivors. The extensive levels of expertise men were found to possess in this research provides further evidence that prostate cancer may be understood as a chronic illness (Bell and Kazanjian 2011) that requires management for extended periods of time after treatment.

Men learned to use some of the expert discourse of prostate cancer, demonstrating that they possessed some interactional expertise. However, men also possessed knowledge about prostate cancer beyond the remit of knowledge required for the management of illness. Furthermore, men engaged in activities at support group meetings where they were immersed in the expert discourse of prostate cancer and even played a participatory role in scrutinising scientific knowledge presented to them. This 'strange role' (Collins 2014: 116) that these men occupied demonstrates that these men possessed 'special interactional expertise'. That these men were found to possess special interactional expertise is a significant break from Collins' characterisation of this expertise being the preserve of researchers, science writers, and journalists. This is discussed further in Sub-Section 9.3.2.

Acquiring specialist prostate cancer expertise has been facilitated by the specialist expertises men had previously acquired from their current or former paid employment. The large proportion of men who had managerial employment training or skilled technical proficiency in their former or current employment can be understood as having 'referred' expertise (Collins 2014; Collins and Evans 2007). Acquired from their paid employment, men possessed interactional expertise that helped them to learn the technical language of prostate cancer, thereby facilitating their acquisition of interactional expertise for prostate cancer with other men and with medical professionals. The scientific backgrounds of many of these men's employment or education is identified as an additional facilitator, driving men's acquisition of knowledge as a personal interest beyond the acquisition of knowledge simply for managing illness. These identified factors that facilitate the

acquisition of expertise are rooted in men's 'production relations' (Connell 2005).

When men had acquired specialist prostate cancer expertise they were often keen to share knowledge with other men. Sharing this expertise is a way of demonstrating their own masculinity, with expertise serving as a form of 'power relations' (Connell 2005) over other men. The question of how men share expertise raises another question, namely of how men claim authority for their expertise.

Men's expertise was given a degree of 'license' (Prior 2003) both by and within PCSGs, by imposing informal limits on what forms of expertise men were permitted to share. Men emphasised the importance of not giving 'medical advice' and that they were limited to sharing their contributory expertise of their own experiences of illness. This constitutes a kind of communal licensing of expertise, where a degree of internal regulation within PCSGs provides some legitimacy to the expert claims of the men within the groups. Community outreach activities arranged by Support Group 2, where information and awareness is provided by men to members of the public beyond support group encounters within public spaces, contributed further to men's legitimacy claims of expertise in this group.

Claims to prostate cancer expertise were also made by employing moralising discourses of responsibility. Using their expert knowledge, men perpetuated moralising talk about the importance of health responsibility for men, a discourse that is embedded in the 'informed choice' model for prostate cancer management that is advocated for and by men (Faulkner 2012). In doing this, men also sought to license and legitimise their expert status by treating expertise not as an 'objective' measure but rather as a value system, in that they sought to legitimise their expertise as a moral good. This finding demonstrates how the men in this research can be understood as 'savvy social actors' (Brown et al. 2004: 64) in being able to fluidly move between and blur the line between lay and expert status. Just as men took their 'referred expertise' (Collins and Evans 2007; Collins 2014) from their paid employment

to facilitate the acquisition of specialist prostate cancer expertise, they also shared their new expertise with others within and beyond support group settings, which served to demonstrate their 'power relations' (Connell 2005) over others.

Lastly, by sharing expertise and employing a moral discourse of responsibility to support claims of expertise, men were able to demonstrate their own moral worth and protect their moral status against possible charges of blame that can accompany chronic illness (Galvin 2002). Sharing expertise with others demonstrates 'good citizenship' (Petersen and Lupton 1996) by showing a 'should care' attitude to health (Robertson 2006b). Men were demonstrating themselves to be *advocating* on behalf of other men and taking a *moral* position of responsibility in doing so. This position, identified in this research, is termed here as men being *moral advocates*. This is discussed further in Sub-Sections 9.3.3 and 9.3.4.

In Chapter Six, men were found to possess substantive forms of specialist expertise for prostate cancer. These forms and high levels of expertise were found to be facilitated by men's 'referred expertise' (Collins 2014; Collins and Evans 2007) and a scientific interest in prostate cancer, both rooted in men's 'production relations' (Connell 2005). Lastly, men have been found to use their expertise to demonstrate their 'power relations' over others to maintain their masculinity following treatment for prostate cancer. Building on this finding that expertise serves to maintain masculinity, Chapter Seven explored how men managed treatment side effects and sought to maintain their masculinity while doing so. These findings are summarised in the following sub-section.

### 9.2.3 *The Experience and Management of Treatment Side Effects*

In Chapter Seven men's experiences of the treatment side effects urinary incontinence (UI) and erectile dysfunction (ED) were explored and the strategies that men adopted to manage these side effects were examined. This



research posed the following research question: *how do men manage treatment side effects for prostate cancer?*

For urinary incontinence, men were found to experience felt stigma (Scambler and Hopkins 1986; Scambler 1989). The most common strategies men employed to manage UI, using incontinence pads and urinary sheath catheters, were found to conflict with carrying out gendered roles and expectations in everyday lives. These management strategies rely on minimising bodily movement and strenuous effort, which go against the primary mode of male embodiment, that of the physically active 'pragmatic' mode (Watson 2000). A core masculine 'identity dilemma' (Charmaz 1994) that arises as a result of UI is the challenge of either 'risking activity' or accepting 'forced passivity (ibid). To balance this identity dilemma, close and constant self-monitoring of leaking bodies is required to engage in activity. Self-monitoring reduces the likelihood of having urine leak. However, having to pay constant attention to the body and being required to change pads and empty full bags of urine puts a strain on men's lives. In response, some men made concessions to their UI by curtailing or changing some of their activities to ease this strain, accepting some loss of masculinity to preserve masculinity more broadly.

In addition to having to monitor the body, planning trips out into public spaces in advance is another management strategy for UI. Engaging in public spaces could become problematic following onset of UI, where incontinence episodes posed a threat to the 'moral order' (Goffman 1971) of public relations. Maintaining their masculinity required men to continue carrying out their gendered roles and functions (Watson 2000), which frequently necessitated men to go beyond the private sphere, either to engage in paid employment, or for everyday and leisure activities. Engaging in public space is identified here as being particularly important for maintaining masculine identity, as it is key to all four of the masculine 'identity dilemmas' that Charmaz (1994) identifies. Being able to 'preserve public persona' requires a demonstration of normalcy in public and to engage in regular activities in

public is a way of demonstrating 'activity', 'independence' and 'dominance' to others and to oneself.

Men experienced felt stigma for their erectile dysfunction, although this was experienced to far less a degree or intensity than it was for UI, largely because this was an 'invisible stigma' (Fergus et al. 2002) that was unlikely to be discovered by others unless disclosed by the bearer of ED. Erectile dysfunction posed significant challenges to men's masculinity, as other authors have previously observed (Gray et al. 2000, 2002; Fergus et al. 2002), particularly at the 'power' and 'cathexis' levels of gender relations (Connell 2005). The problems of ED are difficult to address because taken-for-granted, habitual bodily practices of sexual activity are disrupted and comfortable routines of sex are no longer possible to follow. This led to almost all the men with ED reporting that they had ceased engaging in penetrative sex with their wives.

Men's accounts of overcoming UI by undertaking pelvic floor exercises were found to draw upon masculine values of persistence and forcefulness, emphasising their 'power relations' (Connell 2005) over their bodies. However, masculine norms are identified as a possible barrier to effectively addressing ED, where open communication, shared decision-making, and scheduling sexual encounters were successful strategies for one man but go against traditional hegemonic masculine behaviours towards spouses. This shows how structures of gender relations (Connell 2005) can shape the adoption of management strategies for treatment side effects, where acquiescing to or transgressing hegemonic masculine behavioural norms can facilitate or serve as an obstacle to the successful management of side effects.

Comparing UI and ED experiences and management strategies together has identified two factors that may facilitate or restrict the adoption and sustainment of new health behaviours for managing treatment side effects. The first factor is the desire or motivation to address a concern and the second factor is the routineness with which that concern is to be addressed. These factors are intrinsically linked with masculinity. Within Chapter Seven,

motivation to address treatment side effects has been found to be linked with seeking to maintain masculinity. Furthermore, the routine, habitual behaviours that have been disrupted by treatment side effects have problematized men's embodied masculinities.

The second factor identified in the paragraph above, concerning the routineness with which a bodily concern is attended to, is shaped by monitoring the body. Schrock and Boyd (2006) have suggested that closely monitoring the body is a precursor to the adoption of reflexive body techniques (RBTs) (Crossley 2006; see Section 3.4). The degree of monitoring required for UI shaped the adoption of incontinence pad and urinary sheath catheter use, which can both be understood as RBTs for maintaining the unruly body. Without a high level of regularity with which a bodily concern arises, close monitoring of the body will be irregular and this is not conducive to the formation of new RBTs. This offers an explanation as to why men were predominantly unable to reclaim old or find new routines of sexual activity, as the bodily concern of achieving an erection did not require regular monitoring or attention. Erectile dysfunction is an absence, rather than the constant concern of an unwanted presence, as in the case of leaking urine for urinary incontinence. This finding provides further evidence to support Schrock and Boyd's claim of the importance of monitoring as a precursor to adopting new RBTs.

In Chapter Seven, men's management strategies for their treatment side effects have been found to be shaped and motivated by a desire to preserve masculinity. In Chapter Eight, men's strategies of seeking to preserve their masculinity were explored further in the ways that they sought to normalise their prostate cancer illness experiences and these findings are discussed in the following sub-section.

#### *9.2.4 Normalising Prostate Cancer*

In Chapter Eight, the different ways that men sought to normalise the impacts of prostate cancer and in doing so maintain their masculinity were explored.

The following research questions were posed: *how do men normalise the impact of treatment for prostate cancer? How do men maintain their moral status following treatment for prostate cancer?* And, the overarching question of this research, *how do men maintain their masculinity following treatment for prostate cancer?*

Two important strategies of normalising were employed by men, the first was undertaken through reference to different social actors to draw comparisons that emphasised their normality by referring to similarities or differences between themselves and others. The second strategy involved drawing on common themes to explain treatment side effects, which also served to help men make sense of their situations.

Throughout the findings chapters of this research, prostate cancer support groups (PCSGs) have been found to play a key role for men in managing prostate cancer. In Chapter Eight, PCSGs were found to serve as sites where men could normalise their cancer experiences by comparing them with other men's experiences. By identifying how their experiences compared with other men's, participants could represent themselves as normal prostate cancer patients or survivors, compared with other men who were worse off than they were within their support group.

Normalising through comparison was also undertaken with men beyond PCSGs, where participants sought to contrast themselves with other men who had prostate cancer but did not attend a PCSG, as well as with men who were not responsible for managing their own health. These sorts of men were described as being strange and difficult to comprehend and, in this way, participants' talk was moralising about these other men (Jolanki 2004, 2005).

Wives of men with prostate cancer play an important role in helping to manage the illness, offering both emotional and practical support to their husbands (Gray et al. 2000; Bottorff et al. 2008) and men's accounts about their wives in my research support these findings. The way that men spoke about their wives also played an important role for men in helping them to normalise their situation. Men emphasised their masculinity by juxtaposing

their stoicism in the face of prostate cancer against their wives' femininity, displayed through their reported responses of care, concern, and upset. When referring to their wives in their accounts, men also emphasised the gender roles they and their wives occupied. By demonstrating their continuing adherence and fulfilment of pragmatic embodiment (Watson 2000) by being good husbands and fathers, men showed a continuation of their masculinity despite the disruption caused by prostate cancer. In some instances, being a good father or husband served to legitimise expressions of emotional embodiment (Robertson et al. 2010) of being upset about their illness experience. For men without partners, stoicism was also emphasised through stories about the importance of self-reliance. Their stoicism was juxtaposed against the caring of their female children or children-in-law and was further emphasised by stressing that it was not their children's responsibility to look after them.

Men also drew on common discourses to try and make sense of the disruption caused by treatment side effects. First, an ageing discourse was observed, where men emphasised the naturalness of their decline in sexual activity because of their age, so that the onset of their ED was not so important. For UI, this discourse was almost entirely absent, likely due to the perceived unnaturalness of the condition for the ages of the men experiencing it, which commonly caused a perceived 'premature ageing' (Bury 1982; Singer 1974) among men. This discourse is identified as being a form of the 'fate' moral repertoire (Jolanki 2004, 2005).

The chance discourse is another form of the 'fate' moral repertoire (Jolanki 2004, 2005). Just as men employed social comparison in relation to other social actors, they also compared the outcomes of their treatments, in relation to treatment side effects, with other men in terms of chance or luck. This was done in one of two ways, men who had better treatment outcomes emphasised how lucky they were, thereby showing their exceptionalism but through the humility of being lucky. Whereas men who had poorer treatment outcomes emphasised that others were extremely lucky and that others' luck was a rare occurrence, thereby emphasising their own state as normal for

prostate cancer patients. For ED, almost all men drew on the latter approach, whereas for UI both approaches were employed.

Both the ageing and chance discourses drew on the notion of fate and were in this way disempowered discourses, in that men's accounts emphasised that they could not control their illness situations. However, employing these discourses could help free men from a sense of responsibility for their illness situation and protect them against possible charges of blame for their conditions. Employing these discourses served to demonstrate to others that they were *blameless* for their situations, which in turn served to preserve moral status.

The last discourse that was observed is the choosing life discourse. Unlike the ageing and chance discourses, the choosing life discourse drew upon an 'individualistic', rather than 'fate', moral repertoire (Jolanki 2004, 2005). This kind of discourse is empowered and emphasises agency, in that men had made a choice to have treatment. However, this discourse was frequently accompanied by accounts of uncertainties about whether they had made the 'right choice' in their treatment. Despite this, the choosing life discourse was an empowering one. Accepting a loss of masculinity that comes with treatment, men realigned their relationships with hegemonic masculine values to emphasise their masculinity in other ways. They were able to emphasise stoicism by accepting the costs of treatment, in order to continue to maintain their gender roles as husbands, fathers, and grandfathers. They were also able to maintain active social lives and preserve their public personas, thereby addressing important 'identity dilemmas' that come with chronic illness (Charmaz 1994), even though they lost out in other areas, just as has been observed in Chapter Seven.

These normalising strategies are reminiscent of Wetherell and Edley's (1999) work where men seek to position themselves in their talk in relation to hegemonic masculinity. The findings of this research show how men position themselves as normal, good patients by employing normalising talk in relation to other social actors and by drawing on 'moral repertoires' (Jolanki 2004,

2005) in order to demonstrate continuing masculinity and moral status in the wake of illness.

Demonstrating masculinity in the wake of illness is largely defined in relation to illness. Throughout the empirical findings chapters, demonstrating moral status has been identified as an important concern for men. Protecting against being subjected to blame by others, by presenting oneself as blameless and by moralising the importance of health responsibility within health talk, have all been identified as important strategies to normalise illness. These strategies are employed to preserve moral status and thereby maintain masculinity. This further highlights the importance of understanding the relationship between morality and normalisation in seeking to better understand illness experiences and behaviours, as Sanderson et al. (2011, 2015) have previously recognised, but also raises the importance of masculinity in relation to these two concepts as well. The relationship between these strategies and the preservation of masculinity is discussed further in Sub-Sections 9.3.4 and 9.3.5.

### **9.3 Contribution to Sociological Knowledge**

This research has explored the chronic dimensions of illness experience following treatment for prostate cancer and the ways in which a specific set of well educated, professionally employed, middle aged and later life men addressed these concerns. Key features of chronic illness experience and strategies for chronic illness management have been identified in men's accounts. Although men were keen to emphasise there was little disruption to their lives as a result of prostate cancer diagnosis and treatment, men experienced a range of uncertainties and varying degrees of felt stigma for their treatment side effects. Men sought to manage these ongoing concerns with chronic illness management strategies in order to preserve moral status and masculinity. In this section, important themes identified within this research are discussed in greater detail. The concepts of vigilance, patient expertise, morality, and masculinity are all subjects of attention.

### 9.3.1 *Theorising Vigilance*

Weitz's (1989) notion of uncertainty management as being a choice between vigilance towards or avoidance of an uncertainty serves as a basic framework for understanding uncertainty management. However, the concept of vigilance particularly has been shown in this research to have great potential for development to better understand how uncertainties are managed. Brown and de Graaf (2013) have identified how imagining different possible futures helps to manage the tensions of an extremely uncertain present. In this research, *reinterpretation* of the past has been identified as a strategy that proceeds from vigilance. Knowledge acquired about prostate cancer is used by men to reinterpret past events and make sense of them. Uncertainties remain about whether the 'right' choice was made and imagining how different scenarios may have turned out helps men to moderate these uncertainties. Another strategy proceeding from vigilance identified in this research is *planning* for possible uncertain future events. Again, knowledge acquired through vigilance serves to enable effective planning to address events that are likely to arise and to learn about possibilities that might not have been foreseen if men were not being vigilant in learning more about their illness.

The concept of *vigilance networks* has also been posited in this research. PCSGs have been identified as being important for managing uncertainty by providing a network of contacts who can be called upon to provide a range of clinical and experiential knowledge. Men often referred to acquiring knowledge through online sources, but one problem with this is having too much information available and not knowing what information to trust. PCSGs serve an important role of being able to narrow down the information that men required when they first attended a PCSG meeting with their concerns. Members of support groups would direct new attendees to speak to people who had experienced certain problems or who had undertaken certain treatments, providing new attendees with appropriate information that was relevant to their concerns. Crucially, these networks persisted over time, if new problems arose for men then they could engage with their network and be directed to appropriate knowledge to address them. Furthermore, engaging



in knowledge acquisition was possible within PCSGs for the sake of being prepared for possible problems that may arise in the future. This approach to understanding vigilance is to view it not as an individual activity but as a communal one. This communal approach to vigilance can be interpreted as being symptomatic of a broader societal concern with risk (Beck 1992) and of an increasing moral necessity of attending to risks (Roth 2010).

With the increasing dominance of risk playing a mediating role in everyday life, there is a more urgent need to have appropriate theoretical resources to explain how uncertainties are managed. Indeed, uncertainty remains undertheorized compared with risk within sociology (Zinn 2008) and researchers have often assumed risk to be the dominant explanatory factor in explaining decision-making and other health behaviours for managing illness, yet people will draw upon a range of resources as well as risk to manage uncertainty (ibid). Exploring Weitz's (1989) concept of vigilance in this research has yielded not only two sub-strategies that proceed from vigilance, which offer more nuanced understandings of how uncertainty is managed, but also a notion of vigilance which is undertaken communally. Further research in this area could provide a better understanding of men's management strategies and decision-making in a state of uncertainty. Particularly as the broader context explored in Section 5.2 suggests the importance of experiences of uncertainty and perceived vulnerability (Gillespie 2012) to illness in shaping men's decisions about how to manage prostate cancer. In the following sub-section the nature of patient expertise, a product of vigilance, is discussed in greater depth.

### *9.3.2 Determining Expert Status*

Men's strategies of vigilance and engagement with vigilance networks played an important role in the acquisition of specialist expertises (Collins 2014) of prostate cancer. Questions about the forms and levels of expertise men possess and how this expertise is used by men have been addressed in this research. These questions can inform broader questions about the nature of patient

expertise, regarding how this term can be defined and addressing the implications of what using such a term might be.

A problem with defining patient expertise can be identified in previous approaches to the subject. Collins' (2014) schema for conceptualising expertise seeks to answer questions of how knowledge is acquired, how such knowledge can be classified as different forms of expertise, how people can discern to make decisions based on available knowledge, and which forms of expertise are the most informed, rigorous, and reliable. These are all important questions to understand expertise in theoretical terms. Collins' work shows that lay people can possess substantive levels of knowledge, which Collins terms 'expertise'. Lay people can possess interactional and contributory expertise, both required to be an 'expert' in the wider, everyday understanding of the term, however lay people will almost always not possess these forms of expertise to the levels required to be an 'expert' in the popular use of the term, as they will not have the intensive, formalised training that is required.

Prior (2003), by contrast, addresses the question of how to define lay or patient expertise and addresses the challenge of treating lay knowledge as 'expertise', in that this term falls into a problematic miscomprehension of how lay knowledge is understood and treated by lay people in relation to expert knowledge. These considerations address the practical concerns of how expertise is understood and treated on a broader, public scale, more than defining expertise in a theoretical sense. Prior (2003) therefore argues that to be called an expert a person must possess the required expertise but must also possess appropriate 'license' to share that expertise.

The findings of this research serve to blur any neat categorisations that either Collins (2014) or Prior (2003) offer. The men in this research possess contributory, interactional, and special interactional expertise regarding prostate cancer. Importantly, Collins (2014) is not addressing the question of *lay or patient expertise* in this work but instead the question of *expertise* in general terms; however, the special interactional expertise men were found to possess in my research marks these men out as possessing remarkable levels

of expertise beyond those that Collins anticipates for lay people. Furthermore, while the men in my research possessed no formal 'license' (Prior 2003) for their expertise, they have been found to communally produce their own license within PCSGs as a means of legitimising their sharing of knowledge with others. This raises important questions of how can these different forms of licensing be discerned from one another, what forms of expert license can be considered legitimate, and how can such a judgement be made? However, the finding of men engaging in communal licensing confounds Prior's (2003) distinction between lay person and expert.

The men in this research have been identified as 'savvy social actors' (Brown et al. 2004: 64) who have blurred distinctions between lay and expert knowledge in different ways. Men have claimed authority to advise other men by drawing on their own experiential knowledge to inform others and have employed moralising language to give credence to their actions. By doing this, men's expertise is not treated as 'objective' knowledge but rather is value laden, the sharing of expertise with others becomes a moral good, a way of 'giving back', and advice is framed within the language of responsibility.

Blurring the lines between lay person and expert also involved not representing their knowledge as 'expertise' but rather as 'advice' or 'awareness'. To return to the question of 'license', the men in this research were able to circumvent the problem of overstepping their license, as their expertise was referred to either in terms of relating personal experience or was couched in the moral language of information you *should* know or *should* make yourself aware of. An informal process of regulation of how expertise was shared occurred within PCSGs. Furthermore, while no formal licensing is offered by state institutions for men at PCSGs, which a medical doctor is licensed by (this is the specific example of licensing that Prior refers to), there have been no institutional actions to curtail PCSG activities in providing or limiting expertise. Likely this is because there is a gap in provision of care for men following treatment for prostate cancer and therefore the state relies upon voluntarily-run PCSGs to fill this gap (Kickbusch and Hatch 1983; Kelleher 2006).

This blurring between lay and expert knowledge makes forming a definition of patient expertise more difficult than previous efforts have had to contend with. In line with previous authors (Prior 2003; Collins and Evans 2002) I agree that terms such as 'lay expert' or 'expert patient' should not be used too freely and not without a clear frame of reference. To use the term 'lay expert' or 'expert patient' may serve to distort lay public understandings of the term and contribute to a decline in public trust in professional experts and scientific knowledge. The use of the term 'expert' and 'expertise' in this research has been primarily based on Collins' (2014) usage.

However, it is important not to ignore the substantive levels of specialist expertise that the men in this research possessed. Such levels are not enough for these men to be treated the same as doctors, nurses, or other medical professionals but at the same time they are more substantial than what might be expected for an informed patient. Furthermore, that these men also possessed an informal degree of license for their expertise, the question of whether these men are lay or patient experts, terms which have been used synonymously here, in the purely academic rather than lay public meaning of the terms, has been opened again by this research, where Prior's (2003) work has previously sought to resolve it.

Within internet research the term 'apomediation' (Eysenbach 2008) has been coined to describe a process whereby intermediaries, for example medical practitioners, are increasingly bypassed in favour of 'apomediarities', groups or networks that discuss and filter knowledge. People must engage with intermediaries to access services but apomediarities stand apart from this relationship and offer guidance as to which services to access. Eysenbach (2008) observes a process of transition from the traditional model of intermediaries being the gatekeepers of knowledge towards apomediarities taking an increasing role in lay and expert relationships and this has implications for how credibility of knowledge is judged. The men in this research can be viewed to some extent to take on the role of apomediators, where they directed men to different knowledge areas based on the relevance of such knowledge to their situations. However, the men in this research went

further than just being filters of knowledge, as they were acting as experts by engaging in at least some of the activities that experts engage in and generating a degree of license among themselves for their expertise. Therefore, the question remains of how to define the knowledge statuses of these men. In dealing practically with the lay public understanding of the term 'expert', a preferable term to refer to the men in this research of *knowledge providers* is posited as an alternative. This doesn't resolve the debate of what an 'expert patient' constitutes but seeks to recognise the expert activities and license generation these men engaged in. It is undoubtedly problematic to label these men as experts, even if the means of drawing categories or distinctions between lay people and experts are becoming increasingly blurred.

PCSGs have been identified as playing a crucial role in facilitating the acquisition of expertise and license for men. Self-help groups have been identified as places where people can engage in a 'moral-practical form of reasoning' in how they speak to make sense of chronic illness experiences in ways that are meaningfully aligned with their everyday lived experiences. In this research, the moral component of this reasoning has been identified as having been mobilised and as playing a large role within men's talk, both during and beyond PCSG encounters. This is discussed further in Sub-Sections 9.3.3 and 9.3.4.

### *9.3.3 Preserving Moral Status*

Morality has emerged as a consistent theme throughout the findings of this research. The broader context of prostate cancer surveillance has been discussed in Chapter Five, with national policy in this area being focussed towards a strategy of 'informed choice' for men's access to diagnostic testing for prostate cancer (Faulkner 2012; Chief Medical Officer 2009; Public Health England 2016). Arguably, this kind of strategy contributes to a process of 'healthicization' (Zola 1972; Conrad 1987; Armstrong 1995) for monitoring prostate health, in that this previously medical issue is becoming advanced as

a behavioural one, where there is a moral obligation to engage with health surveillance for prostate health.

Moralisation in the area of prostate health surveillance has significant implications for men's health care experiences and decisions. It can give new meanings to the language of risk employed in medical terminologies and this can shape how biomedical diagnostic testing for prostate cancer is perceived and interpreted. As Roth (2010: 469) notes: 'increasingly, what people know to be true, good, right, healthy or dangerous is communicated through the language of risk'. Furthermore, moral worthiness is increasingly judged by people's adherence to risk and surveillance regimens (Roth 2010; Hunt 2003). Therefore, moral meanings can be understood as being bound up within such surveillance regimens. Indeed, prostate and broader health surveillance practices drew some of the men in this research into a trajectory towards being diagnosed, often without men having ever presented with symptoms. Furthermore, the meanings imbued in these diagnostic tests foster a perceived vulnerability by men, a sense of being especially prone or susceptible to prostate cancer disease (Gillespie 2012).

After treatment, moral concerns persist with the uncertainty of whether opting for their specific treatment was the 'right' choice. Men employed 'moral repertoires' (Jolanki 2004, 2005) to account for their situations, particularly where they faced persistent iatrogenic side effects following treatment. In this way, men were able to position themselves either as being responsible but as ultimately being blameless for their continuing side effects by employing a 'fate' repertoire, or as being responsible by demonstrating accountability for their actions, through making a choice to have treatment, by employing an 'individualistic' repertoire (Jolanki 2004, 2005). In some cases, men also took on the role of being a *moral advocate* using the specialist prostate cancer expertise they had acquired to engage in moralising talk about being responsible for their own health and advocating for other men to check their prostate health.

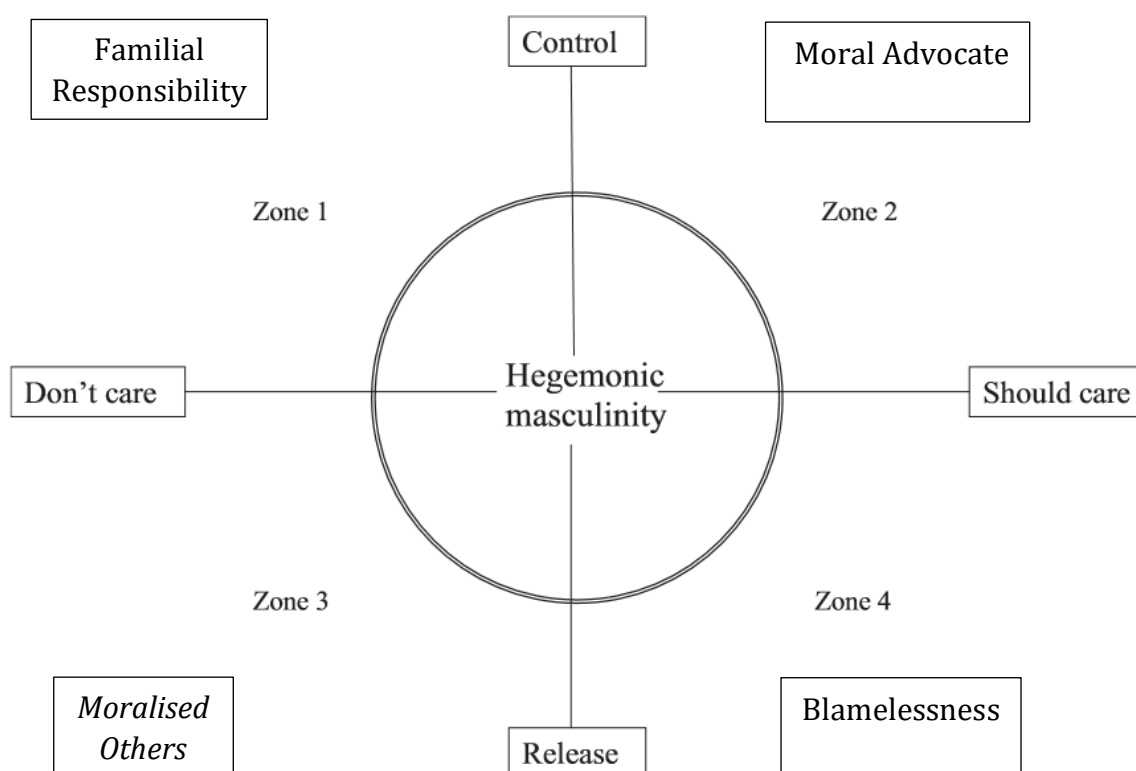
There is almost a moral cycle evident in these behaviours, although moral progression may be a more appropriate term. Some of the men's experiences of being diagnosed with prostate cancer and subsequently treated for it may have been shaped, to varying degrees, by prostate health surveillance becoming an increasingly moralised issue. Then, after being diagnosed and receiving treatment, these men engaged with moral concerns they faced following treatment, which lead them to adopt moral positions and engage in moralising talk towards others. This moralising of responsibility for prostate health to a small extent feeds back to men who have not yet engaged in prostate health surveillance, as one man reported that a PSA testing drive he had been involved in organising at his local rotary club was attended by more than 500 men in a single one-day event. Throughout all the findings chapters, but particularly Chapters Six and Eight, adopting a moral position has been identified as an important strategy for maintaining masculinity. In the following sub-section, this relationship between morality and masculinity is explored and discussed further.

#### *9.3.4 Moral Positioning to Preserve Masculinity*

In seeking to comprehend the relationship between men's employment of moralising talk and their attempts to maintain their masculinity, key works by Robertson (2006b, 2007) are drawn upon. Robertson (2007) has observed that the management of health has a moral element that is usually discussed in terms of 'responsibility' and for those experiencing chronic illness the issue of morality is a particularly important one (see also Galvin 2002; Williams 1993). However, how health talk that draws on notions of responsibility relates to hegemonic masculinity remains open for theorisation. This relationship is explored by returning to Robertson's (2006b) conceptual model for theorising the relationship between health and hegemonic masculinity that was discussed in Chapter Three (Section 3.6) and is reproduced with annotations in Figure 9.1.

To recap, Robertson's (2006b) model represents a way of understanding men's health behaviours by how they position themselves in relation to hegemonic masculine values. His model positions men in relation to two axes. The first axis addresses how men seek to control and moderate their health behaviours or be released from controlling them, thereby being free to engage in what might be regarded as risky or excessive behaviours. The second axis addresses competing public discourses that men face, on the one hand 'that 'real' men do not care about health' and on the other 'that the pursuit of health is a moral requirement for good citizenship' (Robertson 2006b: 178).

**Figure 9.1 Annotations to Robertson's Model of the Relationship between Health and Hegemonic Masculinity Showing the Moral Positioning of Men Treated for Prostate Cancer**



(Annotations to Source: Robertson 2006b: 186)



The different ways that men sought to represent themselves in this research can be interpreted as seeking to position themselves in relation to hegemonic masculinity on this model, where men were found to position themselves within three out of the four zones, all except zone 3.

In zone 2, men represent themselves as being in control in managing illness and as caring about the management of health and illness. It was in this zone that more than half of men interviewed sought to position themselves. Here men drew on the 'individualistic' moral repertoire (Jolanki 2005) in employing a *choosing life* discourse, discussed in Chapter Eight. These men emphasised the moral position of their decisions to opt for treatment as being the 'right thing' to do as good, dutiful citizens for the sake of survival and were in this way *moral advocates*.

In both controlling and caring about one's health, as these men in zone 2 expressed, there is perhaps a danger of controlling or caring for one's health too much, and therefore perhaps a greater necessity to legitimate or explain oneself in this respect (Robertson 2003, 2006b, 2007). This is where being a *moral advocate* becomes particularly important. These men justify and legitimise their controlling behaviours and caring attitudes through the moral status that having prostate cancer expertise and possessing the 'license' (Prior 2003) that attending a cancer support group provides. Men's knowledge sharing and health promoting activities offer them a position from which to legitimately care about health and moralise to others the virtues of being vigilant and caring about health generally and the risk of prostate cancer specifically. Importantly, this finding offers empirical evidence to support earlier suggestions that men will move towards greater control and greater caring about health over the life course (Robertson 2006b, 2007) and that PCSGs serve a role in facilitating this transition (Olliffe et al. 2011).

In zone 1, men represent themselves as being in control in managing illness but as not caring about the management of health and illness. This was the second most common zone men positioned themselves in, with just under a quarter of the sample positioning themselves here. In Chapter Eight this was

observed in men's accounts who also drew on the 'individualistic' moral repertoire (Jolanki 2005) in the *choosing life* discourse, the same as the men in zone 2. In this zone, however, men controlled their health behaviours for the claimed purpose of continuing to fulfil their gendered familial roles and obligations that are so important to men's embodied masculinity (Watson 2000). Instead of emphasising a broader moral responsibility, these men drew more specifically on a discourse of *familial responsibility*. There was a tension here for these men who felt an expectation to not care about their health but were required to do so. This can be understood as an extension of Noone and Stephens' (2008) 'legitimated user' position, where men seek to balance the don't care–should care dichotomy (Robertson 2006b, 2007) when utilising healthcare by framing it as being occasional and therefore legitimate. This has been linked to marital status (Davidson and Meadows 2009), where wives legitimise men's illnesses and engagement with healthcare services (Robertson 2003, 2007) and it is perhaps no coincidence that within my research all but two of the men were long term married.

In zone 4, men represent themselves as caring about their health but emphasise a release from the responsibility of the damaging impacts of their illness, most notably in the form of treatment side effects that they found difficult to control or manage. The remaining men in the sample, not found in zones 1 or 2, were located in this zone. In this zone men drew upon the 'fate' moral repertoire (Jolanki 2005) either employing *ageing* or *chance* discourses, examined in Chapter Eight. Here men sought to position themselves as *blameless* following the onset of treatment side effects. This positioning is a way of protecting themselves from moralising discourses of blame and experiences of personal shame, where men seek to absolve themselves of the responsibility for their potentially stigmatising symptoms.

Lastly, none of the men interviewed sought to position themselves in zone 3, where men feel less obligated to control their health behaviours but instead enjoy the release of 'risky' behaviours and also don't care about their health or about illness. Many of the men who were positioned in zone 2 and who emphasised their roles as *moral advocates* by engaging in moralising talk

about health sought to position generalised other men (who they would refer to in passing), who did not take ownership of and care about their health, within zone 3. These are *moralised others* and this term has been italicised in Figure 9.1 to reflect that these are not men who were interviewed in this research but are described by men within the sample. This kind of talk, as men's references to other social actors (described in Chapter Eight) suggests, served as a form of social comparison by which men could better position themselves as moral, responsible agents in contrast to men who were not.

Men drew heavily on moral repertoires (Jolanki 2004, 2005) to emphasise *responsibility* or freedom from responsibility through *blamelessness*, in order to account for their illness situation. Shame and blame are powerful moralising forces (Scambler 2009) and attempts to make sense of shame and defend themselves against blame were evident in men's accounts. The moral repertoires men employed appeared well rehearsed, likely facilitated by conversations at support group meetings. Put within a broader context, moral repertoires can be understood as part of Bury's (1991: 462) notion of 'style', of drawing on 'cultural repertoires' in accounting for illness and presenting illness to others in particular, strategic ways.

Sanderson et al. (2015) found that self-blaming for illness was a barrier to normalisation. In Chapter Eight, men were found to have some success in normalising the impacts of cancer by drawing comparisons between themselves and others. However, normalising treatment side effects was more complicated. Men experienced felt stigma for urinary incontinence and erectile dysfunction and this presented a barrier to normalisation. Instead the impacts of these conditions were minimised and experiences of these conditions had to be accounted for and justified by employing moral repertoires.

Protecting against being subjected to blame by others, by presenting oneself as being blameless and by moralising health responsibility through health talk, have been identified as important strategies as part of efforts to minimise and normalise illness. Morality, then, plays a significant role in shaping normalising practices, just as Sanderson et al. (2011, 2015) have

suggested, and importantly this was driven by concerns with maintaining masculinity for the men in this research, as has been identified in Figure 9.1 above.

Charmaz's (1994) framework presents the key to understanding the importance of morality for maintaining masculine identity. In Chapter Seven, engaging in public was identified as important for maintaining all four of Charmaz's masculine 'identity dilemmas', where men could show to others that they were still active, independent, dominant, and possessed a reputable public persona. Although some men's trips into public spaces often required monitoring of the body and planning to do this without incontinent episodes occurring. Men will therefore go to a great deal of effort to maintain normality, despite the disruption of prostate cancer, in order to preserve public persona, or moral status, which is an important component of masculine identity. Furthermore, the ways that men seek to morally position themselves and others in their talk shows the importance to men of representing themselves as having reputable moral statuses when facing illness, in order to maintain masculinity. The relationship between chronic illness and morality has received some attention (Charmaz 1994, 1995; Rich 2006; Galvin 2002; Goffman 1963; Erikson 1966), however the relationship between masculinity, (chronic) illness, and morality remains an undertheorized area. The contribution of this research of applying Robertson's model to the case of (chronic) illness, and examining how different forms of moral repertoires shape men's positioning in relation to Robertson's model, offers a framework by which to theorise how morality, illness, and masculinity intersect. In the following sub-section, the ways that men maintained their masculinity following prostate cancer are explored in broader terms.

### 9.3.5 *Maintaining Masculinity*

The primary question of this research has asked *how do men maintain their masculinity following treatment for prostate cancer?* In the previous sub-section, drawing on different moral repertoires to mobilise notions of

responsibility in different ways has been identified as important for maintaining masculinity following treatment for prostate cancer. However, throughout this research other theories of masculinities have been drawn upon to answer this question and these are discussed here.

Throughout this research men's relationships with broader structures of gender relations (Connell 2002, 2005) have been identified as changing in response to prostate cancer illness and treatment. These structures of gender relations: power, production, cathexis, and symbolic (discussed in Sections 3.2 and 3.7) are all important components of men's masculinity, embedded in men's everyday lives. The changes observed in each of these structures are discussed in turn.

Power relations are the ways by which men maintain authority over other men and over women in the gender order. As has already been discussed in the previous sub-section (see also Sub-Sections 9.2.3 and 9.2.4), prostate cancer related illness can pose a challenge to moral status, where men experience shame and are concerned with being blamed for their treatment side effects. A state of illness is a weakened state; to be confined to the domestic sphere and become more dependent on one's wife poses a threat of loss of authority and dominance. In response to this, men acquired knowledge through different vigilance strategies and developed specialist prostate cancer expertise. Adopting the role of *moral advocate* served to preserve men's power relations, where engaging in moralising talk was a means of claiming authority for their expert claims.

Production relations address gender divisions of labour. This was not often directly related to men's prostate cancer in this research. Men were at varying points in their paid employment careers, a minority were still working or partly working, while the majority had retired already or were at the point of retiring when they were diagnosed with prostate cancer. The loss of production relations can be difficult for men to deal with when they retire (Meadows and Davidson 2006). However, for some men PCSGs played an important role in counteracting the loss of production relations. The

administrative roles of running the support groups, that a significant minority of men interviewed currently or previously had been involved with, offered a form of meaningful work, not very dissimilar from the work they had engaged in for their paid employment. More broadly, men were often actively involved in community and special interest groups where they served on committees. This kind of work can be viewed as an extension or reclamation of production relations for men, by continuing to be productive, active, and engage in meaningful work. More directly in relation to prostate cancer, men's historic relationships with production relations served an important role in facilitating the restoration of power relations. In Chapter Six, men were found to draw on the 'referred' expertise (Collins 2014) of their current or former paid employment to facilitate the acquisition of specialist prostate cancer expertise, which strengthened men's power relations.

Cathexis or emotional relations are the emotional energies and meanings that are attached to people or objects and the practices associated with these. Changes to men's cathexis relations have not been examined in great depth in this research. Previous research on how men and their wives manage prostate cancer has shown how partner relationships change with a decline in sexual activity to a focus on greater emotional closeness following the loss of sexual potency that predominantly accompanies treatment (Gray et al. 2000, 2002; Fergus et al. 2002; Bottorff et al. 2008). This has also been observed as a broader pattern of ageing (Potts et al. 2006) and this process is likely sped up by treatment for prostate cancer. However, this research has found that the ways that men spoke about their wives in their accounts served to bolster their masculinity by emphasising their own masculinity in comparison and contrast to their wives' femininity.

Prostate cancer will for most men significantly disrupt 'symbolic relations', where the side effects of treatment result in a loss of continence and sexual potency. Most importantly to control one's own continence, but also to be sexually potent, both possess huge symbolic importance for being a man. They go to the core of men's pragmatic and normative modes of embodiment (Watson 2000) and are therefore very important to men's embodied sense of

self. To reorient their symbolic relations, men emphasise certain symbolic values that are important masculine virtues, namely morality, stoicism, and responsibility, over other hegemonic masculine values associated with younger men, such as physical strength and sexual virility.

Following prostate cancer diagnosis and treatment, men seek to restore and reorient their relationships with the structures of gender relations as best they can. Men's relationships change most with symbolic and cathexis relations where they seek to form new associations where different values are privileged over those that have been lost. For some men, production relations could be adapted and partially sustained through taking on voluntary activities that involved similar forms of work to their paid employment. However, sustaining power relations is identified as being particularly important for men and acquiring expert knowledge and using this to sustain dominance and moral authority over other men played an important role in this. Sustaining power relations also relies on balancing masculine 'identity dilemmas' (Charmaz 1994) and to remain dominant has been associated with preserving public persona, which relies on being active and independent beyond the private sphere of the home. To show continuing power relations and masculinity, men minimised the disruption of prostate cancer treatment in their accounts with stories which showed themselves continuing to fulfil their gendered roles and obligations and remaining physically and socially fit (Watson 2000), which are all values closely associated to Charmaz's (1994) masculine 'identity dilemmas'.

These findings provide further evidence to support the assertion that men remain structurally situated within the same dominant ideology as younger men and therefore seek to continue aligning themselves with hegemonic masculine values as they age (Meadows and Davidson 2006; Solimeo 2008; Davidson and Meadows 2009). Rather than embrace alternative, non-hegemonic masculinities, the men in this research drew upon available resources to renegotiate their masculinity, accepting concessions in some areas while seeking to maximise their masculinity in others. Acquiring expert knowledge played a crucial role in providing moral authority that was

a key facilitating factor in restoring power relations, which was particularly important in maintaining masculine identity which has been identified as being heavily dependent upon being able to preserve 'public persona' (Charmaz 1994).

Lastly, it is important to emphasise that PCSGs play a very significant role in facilitating the reorientation and restoration of masculinities in each of these four structures of gender relations. PCSGs facilitate the acquisition of expertises, serve to mitigate changes in employment status by offering work-like activities, offer information that can help to mitigate the impacts of treatment side effects on married life, and are the legitimising institutions that provide the basis for adopting a position as a *moral advocate*, where certain symbolic masculine values can be emphasised over others.

#### **9.4 Strengths and Limitations of the Research**

This research study could be considered limited in several aspects of its design. A key potential limitation is that men were recruited through two prostate cancer support groups in the South East of England. Therefore, the sample is more indicative of men who attend a PCSG rather than the broader population of men who are diagnosed and treated for prostate cancer. There have been a range of studies that have previously recruited men from PCSGs (Olliffe et al. 2011; Bell and Kazanjian 2011; Broom 2004; Chapple and Ziebland 2002).

Recruiting from support groups can lead to a sample skewed towards certain demographic characteristics. Dominant characteristics for men from the US and Canada, which have been identified from previous studies based on recruitment from PCSGs, include men being white, well educated, and in their late sixties (Breau and Norman 2003; Gregoire et al. 1997; Krizek et al.; 1999; Steginga et al. 2001; Coreil and Behal 1999). These demographics are also echoed in more recent research from other first world nations (Broom 2009) and are closely mirrored within my own sample. Importantly, the age demographic is largely determined by the nature of the condition. Furthermore, the demographics of my sample are shaped, to a degree, by the



demographic makeup of the prosperous areas that satellite London where the two support groups were based. Men from lower educational and socio-economic status groups are poorly represented in my sample, and men from different ethnic groups are not represented at all. However, these groups are well represented in the urban centres where the support groups were based. These factors impose a limit as to how generalizable the findings of this research can be and these findings are specific to men who are well educated from managerial or senior technical occupational groups.

Recruiting from a wider pool of PCSGs might have served to broaden diversity in the sample, yet finding new recruitment sites proved to be difficult. Furthermore, the success in recruiting from the two support groups, particularly Support Group 2, discouraged further efforts in finding new recruitment sites.

Recruiting from support groups also brought constraints not just of homogeneity but of variability, too. One instance of this was the different periods of time that had elapsed between men receiving their diagnoses, undertaking their primary treatments, their subsequent experiences resulting from diagnosis and treatments, and their being interviewed for this research. The variation in these time intervals for men posed some difficulties in making comparisons between men. These varying intervals were addressed by paying consideration to the time that had passed since different treatments and procedures had been undertaken when reviewing men's accounts, but also by acknowledging their current circumstances to seek to appreciate how past events were represented by men through the lens of current and near future concerns. Understanding the *context* within which men's health talk occurs is important, particularly when treating the ways that men talk and how they represent themselves as masculine within interviews as data (Olliffe 2009b).

Despite some limitations, recruiting from support groups afforded a range of benefits in addressing the research questions that have been posed in this research. Having attended support group meetings before, men were more open to talking about their experiences than they might have been had

they not attended a support group before. Recruiting from PCSGs also provided a sample of men who were at varying intervals following primary treatment, as discussed in the paragraph above, yet this offered a way to better understand areas of interest to this research. In seeking to understand the chronic dimensions of post-treatment experiences, exploring men's experiences at varying intervals following treatment offered insights into men's changing experiences and evolving management strategies over time. For instance, this informed an understanding of how the acquisition of specialist knowledge changed from a primary concern with knowledge related to illness to an emerging wider interest in prostate cancer beyond knowledge necessary for the management of the illness. Lastly, the homogeneity of the sample provides a stronger basis for making claims about the specific group of men that was recruited for this research.

Interviewing men also posed challenges for the research. Previous methodological research on interviewing men has recognised how men's presentations of themselves as masculine within interviews is important and part of this involves them talking about their actions and representing them as if they were the rational thing to do (OliFFE and Mroz 2005; Schwalbe and Wolkomir 2001, 2002; see Sub-Section 4.5.2) The men in this research had high degrees of health literacy and often specialist expertise in prostate cancer and these factors can only have reinforced their normalising talk in support of their choices and actions. Efforts to treat as data and examine how men emphasised their masculinity in different ways, as well as to look beyond these self-presentations, have been described in Sub-Section 4.5.2.

Balancing concerns of rapport and interview flow against critically challenging interviewees' accounts is a difficult process, yet where possible I have attempted to address contradictions and probe presumed implicit meanings in men's accounts. In some cases, this led men to voice concerns about having made the 'wrong choice' in their illness management decisions and expressing the difficulties they faced regarding their treatment side effects. More broadly, men's accounts that have represented themselves in masculine ways have been interpreted as data that has been analysed within

this research. Such accounts have been treated with caution, recognising the broader context of the interviewees' past experiences, present lives, and how the interview encounter is a joint co-construction of data between interviewer and interviewee. This is reflected in aspects of the findings of this research, where the reinterpretation of past knowledge and previous events is recognised as being framed through men's present lives and given new meaning in their current contexts (see Sub-Sections 5.4.1 and 8.3.3).

## **9.5 Recommendations for Future Research**

There are a range of areas where future sociological research could further develop the findings presented in this research. First, some of the areas of sociological interest are explored and then broader health policy concerns are addressed.

The concept of vigilance (Weitz 1989) utilised in this research has proved to be a useful one for understanding men's uncertainty management strategies. The notion of *vigilance networks* advanced in this research could be developed further in future research. Examining a wider range of support groups could inform an understanding of how vigilance networks operate and how they are formed and sustained over extended periods of time. Certain support group practices may play an important role here. For instance, although not discussed in the findings of this research, one support group took records of attendance and monitored for prolonged absences of people, whereupon they would contact such people to check up on their welfare. It is a reasonable surmise that this kind of practice could strengthen social ties within PCSGs and help to sustain support groups over the longer term. Further empirical research is required to explore commonalities and differences between different PCSG practices.

Vigilance also warrants attention among men with prostate cancer who do not attend PCSGs. The men in this research were found to possess a range of specialist expertises that are not common among lay people. By investigating different groups of men, especially according to class and

education level, both within and beyond support group membership, it may be possible to better understand the factors that facilitate the acquisition of specialist prostate cancer expertise and how unique or commonplace the situation was for the specific group of men in my research.

Future research exploring the concept of 'patient expertise' will need to address the newly unravelled categorisations that have previously sought to distinguish lay people from experts. The questions posed in Sub-Section 9.3.2 of how can different forms of 'licensing' (Prior 2003) of expertise be discerned from one another, what forms of expert license can be considered legitimate, and how can such a judgement be made, are identified as potential directions for future research. These are questions that to a large extent go beyond the micro interactional level. The communal license that men created together for their expertise in this research was aligned with the dominant expertise of medical practitioners, rather than posed as a direct challenge to it, and was also on so small a scale as to not be a subject of significant public controversy. In a world that is currently struggling with the challenges of a supposed climate of 'post-truth', where professional experts are being rejected and dismissed, understanding the mechanisms by which groups of lay people create and license their own expert statuses is a particularly important concern.

Morality has been largely marginalised and absent from sociological debates over recent decades (Hitlin and Vaisey 2010), although there has been some attention within the sociology of health and illness (Galvin 2002; Williams 1993; Robertson 2007). This research has offered a template for understanding the role of morality in maintaining masculinity in the wake of illness. To test the robustness of this new model, future research could be undertaken to explore the moral positioning of ill men who are much younger, to explore how they draw upon or reject notions of responsibility in their accounts. Exploring how middle aged and later life ill men of lower educational attainment and socio-economic background engage in moralising talk and how this compares with the sample of men in this research may also offer further insights into men's relationships with hegemonic masculinity in a state of

illness. Investigations in these areas may also offer insight into how unique or commonplace positioning oneself as a *moral advocate* is for men, particularly beyond support group settings that have been identified as playing a key role for men in taking such a position within this research. The importance of morality for maintaining masculinity in later life and old age may also have broader relevance beyond the field of health and illness, to better understand ageing masculinities and men's experiences and behaviours in other aspects of men's everyday lives.

Prostate cancer and treatment are often represented within mainstream print media in ways that emphasise the curative properties of biomedicine and downplay the negative aspects of treatment (Halpin et al. 2009). The time after treatment for prostate cancer remains, to some degree, ignored and invisible, both in research and public perception. In this research, examining the time after treatment identified the importance of treatment side effects in shaping men's experiences. More empirical research is recommended to explore men's experiences of urinary incontinence (UI) following treatment for prostate cancer. The small number of previous studies on UI as a prostate cancer treatment side effect have either employed a quantitative design (Korfage et al. 2006; Bhojani et al. 2008), or have only paid cursory attention to UI (Chapple and Ziebland 2002; Broom 2009; Oliffe 2009a). There is perhaps a reluctance by both interviewer and interviewee to talk about this condition, which could explain why it has received limited attention in prostate cancer literature to date. My research identified a diversity of difficulties that men experienced in managing this condition, as well as a range of different clinical pathways to address the issue, each with their own unique facets that warrant attention. For instance, the pelvic sling and artificial urinary sphincter are both interventions to manage UI, the meanings that men attach to which have thus far been unexplored in sociological research.

Further qualitative research is also recommended to explore experiences of bowel incontinence. There were too few instances reported in my research to discuss these experiences, yet the few reports that were given

showed that men were often surprised and alarmed by the onset of bowel incontinence and were unsure whether it was related to their cancer treatment or another new problem. Like urinary incontinence, bowel incontinence has received limited attention in qualitative social research, despite being a common side effect of treatment for prostate cancer.

With regard to health policy, my research adds to the weight of evidence that is already shifting policy for prostate cancer management in the UK. There is an increasing drive by medical professionals to encourage men who have low PSA levels or who are assessed as having 'low risk' prostate cancer to undertake surveillance options for managing their cancer, rather than having surgical or radiotherapy treatment. The ongoing concerns that men face often long after treatment, in the form of uncertainties, treatment side effects, and disrupted masculinities provides further evidence for the preference of encouraging men to follow non-treatment, surveillance regimens rather than primary treatment options where appropriate. For health policy to succeed in this transition, more research is required to build on the works of Gillespie (2012, 2015) and Biddle et al. (2015) to understand how men manage the uncertainties of living with the possibility of having a malignant cancer.

In addition, more refined and nuanced techniques and new biomedical tests are being developed for prostate cancer diagnosis, with increasing sensitivity to be able to detect not only tumour size but also discern between fast and slow growing tumours. Such tests would have the potential to be not just diagnostic but also *prognostic* in their design. They would ideally serve to reduce the number of unnecessary intensive treatments by being able to predict the speed and extent of cancer growth. Yet how such tests might produce uncertainties that shape decisions for how to manage prostate cancer warrants investigation.

Lastly, the findings of this research have shown the importance of PCSGs in supporting men to deal with the concerns they face following treatment. It is unlikely that state funding will be forthcoming soon to support

the work that voluntarily-run PCSGs do. However, men from both the support groups in my research reported some inconsistency in receiving information about their local support group, which in some cases delayed their first encounters with their local group. These two groups may not be representative of other support groups, yet one possible improvement to health policy might be for hospitals and medical practitioners to provide more consistent and formalised signposting to local support groups that may be able to provide support that clinical services do not currently supply. For the two PCSGs in this research the onus was on them to provide information leaflets about their organisations to hospitals for dissemination and for some patients treated privately these information leaflets were not provided by their consultants. Access to such groups is by no means universal and is by fortune of geographic locality, however providing signposting to services where they exist locally offers a relatively low cost way of offering greater access to voluntary support services.

## **9.6 Concluding Remarks**

The findings of my research have contributed to sociological knowledge in the fields of illness, health, uncertainty, expertise, morality, and masculinity. These findings have advanced our understanding of how prostate cancer can be understood as a chronic illness, in terms of how men experience and manage their post-treatment lives. These findings inform our understanding of how men maintain their masculinity following treatment for prostate cancer.

This research has shown how Weitz's (1989) concept of vigilance can be developed to explore how strategies such as reinterpreting past events and planning for future events can emerge from and be reinforced by vigilance. The concept has also been developed to form a new concept of *vigilance networks*, which recognises how uncertainty management is not just an individualistic strategy but also one that can be undertaken communally.

This research has challenged previous attempts to draw clear distinctions between lay and expert knowledge and statuses by identifying

levels of expertise and expert activities engaged in by the men in this research that overstep previously identified boundaries between lay and expert people (Prior 2003; Collins 2014). These men have been sensitively termed *knowledge providers*, although without using such terminology they are effectively operating as experts on a small scale and in a constrained, informally self-regulated manner. An effective schema to distinguish between lay and expert status remains an important sociological concern.

The importance of maintaining masculinity following treatment has been demonstrated in this research, clearly identified in the management strategies men report employing when dealing with treatment side effects. Men's urinary incontinence experiences have been shown to challenge important masculine 'identity dilemmas' (Charmaz 1994), where physical activity poses a threat to leaking which requires constant and close monitoring. Being able to demonstrate masculinity involves engagement in public space, where being active, independent, and remaining dominant can be demonstrated to others while preserving public persona (Charmaz 1994). Engaging in public space also allows men to demonstrate their continuing fulfilment of gendered roles and obligations (Watson 2000) but being able to do this required close monitoring and planning in advance of engagement into safe public spaces.

It has been shown that men seek to normalise their post-treatment prostate cancer experiences by drawing social comparisons between different social actors and by employing 'moral repertoires' (Jolanki 2004, 2005). These combined strategies allow men to emphasise different notions of responsibility in their accounts to morally position themselves in relation to their illness experiences and their masculinity. My research has provided a template in relation to Robertson's (2006b) model to understand how men position themselves in relation to illness, rather than health, and hegemonic masculinity. These positions involve seeking to demonstrate responsibility or blamelessness, thereby protecting against possible charges of blame for illness by others and demonstrating moral status to others. This finding contributes



to our understanding of how men maintain masculinity following the onset of illness.

Overall this research has shown that prostate cancer poses significant challenges to masculinity, threatening men's relationships with the structures of gender relations (Connell 2005), yet PCSGs play an important facilitating role in assisting men to realign their relationships with these structures by emphasising different values and making concessions to the activities they engage in. Of all the structures of gender relations, power relations are sustained and reinforced the most, with a concern and emphasis on morality in men's talk and reported actions used to preserve moral status and reputation, which is important for maintaining dominance over others and sustaining masculine identity more broadly.

## Bibliography

- Abend, G. (2010) 'What's new and what's old about the new sociology of morality.' In Hitlin, S. and Vaisey, S. (Eds) *Handbook of the Sociology of Morality*, 561-584. New York: Springer.
- Abouassaly, R., Lane, B. R., Lakin, M. N., Klein, E. A. and Gill, I. S. (2006) 'Ejaculatory urine incontinence after radical prostatectomy.' *Urology*, 68 (6): 1248-52.
- Adamson, C. (1997) 'Existential and clinical uncertainty in the medical encounter: an idiographic account of an illness trajectory defined by Inflammatory Bowel Disease and Avascular Necrosis.' *Sociology of Health and Illness*, 19 (2): 133-59.
- Akazaki, K. and Stemmermann, G. N. (1973) 'Comparative study of latent carcinoma of the prostate among Japanese in Japan and Hawaii.' *Journal of the National Cancer Institute*, 50 (5): 1137-1144.
- Anderson, R. and Bury, M. (Eds) (1988) *Living with Chronic Illness: The Experience of Patients and Their Families*. London: Unwin Hyman.
- Antonucci, T. C. and Akiyama, H. (1987) 'An examination of sex differences in social support among older men and women.' *Sex roles*, 17 (11-12): 737-749.
- Arber, S., Davidson, K. and Ginn, J. (2003) 'Changing approaches to gender and later life.' In Arber, S., Davidson, K. and Ginn, J. (Eds) *Gender and Ageing: Changing Roles and Relationships*, 1-14. Maidenhead: McGraw-Hill Education.
- Arksey, H. (1994) 'Expert and lay participation in the construction of medical knowledge.' *Sociology of Health and Illness*, 16 (4): 448-68.
- Arksey, H. (1998) *RSI and the Experts*. London: University College London Press.
- Armstrong, D. (1995) 'The rise of surveillance medicine.' *Sociology of Health and Illness*, 17 (3): 393-404.
- Arneil, B. (1999) *Politics and Feminism*. Oxford: Blackwell Publishers.
- Arrington, M. I. (2003) "'I don't want to be an artificial man": Narrative reconstruction of sexuality among prostate cancer survivors.' *Sexuality and Culture*, 7 (2): 30-58.
- Babchuck, N. (1978) 'Aging and primary relationships.' *International Journal of Aging and Human Development*, 9: 186-193.

- Backett, K. (1992) 'Taboos and excesses: lay health moralities in middle class families.' *Sociology of Health and Illness*, 14 (2): 255-274.
- Bacon, C. G., Giovannucci, E., Testa, M., Glass, T. A. and Kawachi, I. (2002) 'The association of treatment-related symptoms with quality-of-life outcomes for localized prostate carcinoma patients.' *Cancer*, 94: 862-71.
- Barbuto, R., Biggeri, M., and Griffo, G. (2011) 'Life project, peer counselling and self-help groups as tools to expand capabilities, agency and human rights.' *ALTER-European Journal of Disability Research/Revue Européenne de Recherche sur le Handicap*, 5 (3): 192-205.
- Barry, M. J. (2001) 'Prostate-specific-antigen testing for early diagnosis of prostate cancer.' *New England Journal of Medicine*, 344 (18): 1373-1377.
- Beck, A. M., Robinson, J. W., and Carlson, L. E. (2009) 'Sexual intimacy in heterosexual couples after prostate cancer treatment: What we know and what we still need to learn.' *Urologic Oncology: Seminars and Original Investigations*, 27 (2): 137-143.
- Beck, U. (1992) *Risk Society: Towards a New Modernity*. London: Sage.
- Becker, M. H. (1986) 'The tyranny of health promotion.' *Public Health Reviews*, 14: 15-25.
- Bell, K. and Kazanjian, A. (2011) 'PSA testing: Molecular technologies and men's experience of prostate cancer survivorship.' *Health, Risk and Society*, 13 (2): 183-198.
- Benhabib, S. (1992) *Situating the Self: Gender, Community, and Postmodernism in Contemporary Ethics*. New York: Routledge.
- Bhojani, N., Perrotte, P., Jeldres, C., Suardi, N., Hutterer, G., Shariat, S. F. and Karakiewicz, P. I. (2008) 'The effect of comorbidities and socioeconomic status on sexual and urinary function in men undergoing prostate cancer screening.' *The Journal of Sexual Medicine*, 5 (3): 668-76.
- Biddle, C., Brasel, A., Underwood, W. and Orom, H. (2015) 'Experiences of uncertainty in men with an elevated PSA.' *American Journal of Men's Health*, 11 (1): 24-34.
- Blaxter, M. (1993) 'Why do the victims blame themselves?' In Radley, A. (Ed) *Worlds of Illness: Biographical and Cultural Perspectives on Health and Disease*. London: Routledge.
- Blaxter, M. (1997) 'Whose fault is it? People's own conceptions of the reasons for health inequalities.' *Social Science and Medicine*, 44 (6): 747-756.

- Bloor, M. (1995a) 'A user's guide to contrasting theories of HIV-related risk behaviour.' In Gabe, J. (Ed) *Medicine, Health and Risk: Sociological Approaches*. Oxford: Blackwell Publishers.
- Bloor, M. (1995b) *The Sociology of HIV Transmission*. London: Sage.
- Boberg, E. W., Gustafson, D. H., Hawkins, R. P., Offord, K. P., Koch, C., Wen, K. Y., Kreutz, K. and Salner, A. (2003) 'Assessing the unmet information, support and care delivery needs of men with prostate cancer.' *Patient Education and Counseling*, 49 (3): 233-242.
- Bottorff, J. L., Oliffe, J. L., Halpin, M., Phillips, M., McLean, G. and Mroz, L. (2008) 'Women and prostate cancer support groups: The gender connect?' *Social Science and Medicine*, 66 (5): 1217-1227.
- Boyle, P., Robertson, C., Mazzeta, C., Keech, M., Hobbs F. D. R., Fourcade, R., Kiemeny, L. and Lee, C. (2003) 'The prevalence of male urinary incontinence in four centers: the UREPIK study.' *BJU International*, 92 (4): 409-14.
- Brannen, J. (1988) 'Research note: The study of sensitive subjects.' *The Sociological Review*, 36 (3): 552-563.
- Bray, F., Lortet-Tieulent, J., Ferlay, J., Forman, D. and Auvinen, A. (2010) 'Prostate cancer incidence and mortality trends in 37 European countries: An overview.' *European Journal of Cancer*, 46 (17): 3040-3052.
- Breau, R. H. and Norman, R. W. (2003) 'The role of self-help groups in educating and supporting patients with prostate cancer and interstitial cystitis.' *BJU International*, 92 (6): 602-606.
- British Sociological Association (2002) *Statement of Ethical Practice for the British Sociological Association*. Retrieved 12.02.2017 from <https://www.britsoc.co.uk/equality-diversity/statement-of-ethical-practice/>
- Brittain, K. R. and Shaw, C. (2007) 'The social consequences of living with and dealing with incontinence—A carers perspective.' *Social Science and Medicine*, 65 (6): 1274-1283.
- Broom, A. (2004) 'Prostate cancer and masculinity in Australian society: A case of stolen identity?' *International Journal of Men's Health*, 3 (2): 73-91.
- Broom, A. (2009) 'Prostate cancer and masculinities in Australia.' In Gough, B. and Robertson, S. (Eds) *Men, Masculinities and Health: Critical Perspectives*. Basingstoke: Palgrave Macmillan.

- Broom, A. and Cavenagh, J. (2010) 'Masculinity, moralities and being cared for: An exploration of experiences of living and dying in a hospice.' *Social Science and Medicine*, 71 (5): 869-876.
- Broom, A., Hand, K. and Tovey, P. (2009) 'The role of gender, environment and individual biography in shaping qualitative interview data.' *International Journal of Social Research Methodology*, 12 (1): 51-65.
- Brown, P. (1987) 'Popular epidemiology: Community response to toxic waste-induced disease in Woburn Massachusetts.' *Science, Technology and Human Values*, 12: 3-4: 78-85.
- Brown, P. and de Graaf, S. (2013) 'Considering a future which may not exist: the construction of time and expectations amidst advanced-stage cancer.' *Health, Risk and Society*, 15 (6): 1-18.
- Brown, P., Zavestoski, S., McCormick, S., Mayer, B., Morello-Frosch, R. and Gasior Altman, R. (2004) 'Embodied health movements: New approaches to social movements in health.' *Sociology of Health and Illness*, 26 (1): 50-80.
- Bryant, A. (2002) 'Re-grounding grounded theory.' *JITTA: Journal of Information Technology Theory and Application*, 4 (1): 25.
- Bryman, A. (2008) *Social Research Methods*. Oxford: Oxford University Press.
- Burt, J., Caelli, K., Moore, K. and Anderson, M. (2005) 'Radical prostatectomy: Men's experiences and postoperative needs.' *Journal of Clinical Nursing*, 14 (7): 883-90.
- Bury, M. (1982) 'Chronic illness as biographical disruption.' *Sociology of Health and Illness*, 4 (2): 167-82.
- Bury, M. (1988) 'Meanings at risk: The experience of arthritis.' In Anderson, R. and Bury, M. (Eds) *Living with Chronic Illness: The Experience of Patients and their Families*, 89-116. London: Unwin Hyman.
- Bury, M. (1991) 'The sociology of chronic illness: A review of research and prospects.' *Sociology of Health and Illness*, 13 (4): 451-68.
- Bury, M. (1997) *Health and Illness in a Changing Society*. London: Routledge.
- Bury, M. (2001) 'Illness narratives: fact or fiction?' *Sociology of Health and Illness*, 23 (3): 263-285.
- Busby, H., Williams, G. and Rogers, A. (1997) 'Bodies of knowledge: Lay and biomedical understandings of musculoskeletal disorders.' In Elston, M. A. (Ed) *The Sociology of Medical Science and Technology*, 79-99. Oxford: Blackwell.

- Butera, K. J. (2006) 'Manhunt: The challenge of enticing men to participate in a study on friendship.' *Qualitative inquiry*, 12 (6): 1262-1282.
- Byrne, B. (2004) 'Qualitative interviewing.' In Seale, C. (2004) *Researching Society and Culture*, 179-192. London: Sage.
- Calasanti, T. (2004) 'Feminist gerontology and old men.' *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 59 (6): S305-S314.
- Calasanti, T. and King, N. (2005) 'Firming the floppy penis: Age, class, and gender relations in the lives of old men.' *Men and Masculinities*, 8 (1): 3-23.
- Calnan, M. (1987) *Health and Illness: The Lay Perspective*. London: Tavistock.
- Cameron, E. and Bernardes, J. (1998) 'Gender and disadvantage in health: Men's health for a change.' *Sociology of Health and Illness*, 20 (5): 673-693.
- Campbell, C. (2006) 'Do today's sociologists really appreciate Weber's essay The Protestant Ethic and the Spirit of Capitalism?' *The Sociological Review*, 54 (2): 207-223.
- Cancer Research UK (2017a) 'Prostate cancer incidence statistics.' Retrieved 18.02.2017 from <http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/prostate-cancer/incidence>
- Cancer Research UK (2017b) 'Prostate cancer mortality statistics.' Retrieved 18.02.2017 from <http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/prostate-cancer/mortality>
- Cancer Research UK (2017c) 'Prostate cancer survival statistics.' Retrieved 18.02.2017 from <http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/prostate-cancer/survival>
- Carricaburu, D. and Pierret, J. (1995) 'From biographical disruption to biographical reinforcement: The case of HIV positive men.' *Sociology of Health and Illness*, 17 (1): 65-88.
- Carrigan, T., Connell, R. W. and Lee, J. (1985) 'Towards a new sociology of masculinity.' *Theory and Society*, 14 (5): 551-604.
- Carter, H. B. (2004) 'Prostate cancers in men with low PSA levels—must we find them?' *The New England Journal of Medicine*, 350 (22): 2292.
- Cassells, C. and Watt, E. (2003) 'The impact of incontinence on older spousal caregivers.' *Journal of Advanced Nursing*, 42 (6): 607-616.

- Cayless, S., Forbat, L., Illingworth, N., Hubbard, G. and Kearney, N. (2010) 'Men with prostate cancer over the first year of illness: Their experiences as biographical disruption.' *Support Care Cancer*, 18: 11-19.
- Center, M. M., Jemal, A., Lortet-Tieulent, J., Ward, E., Ferlay, J., Brawley, O. and Bray, F. (2012) 'International variation in prostate cancer incidence and mortality rates.' *European Urology*, 61 (6): 1079-1092.
- Chapple, A. and Ziebland, S. (2002) 'Prostate cancer: Embodied experience and perceptions of masculinity.' *Sociology of Health and Illness*, 24 (6): 820-841.
- Chapple, A. and Ziebland, S. (2004) 'The role of humor for men with testicular cancer.' *Qualitative Health Research*, 14 (8): 1123-1139.
- Charmaz, K. (1991) *Good Days, Bad Days: The Self in Chronic Illness and Time*. New Brunswick: Rutgers University Press.
- Charmaz, K. (1994) 'Identity dilemmas of chronically ill men.' *The Sociological Quarterly*, 35 (2): 269-288.
- Charmaz, K. (1995) The body, identity, and self. *The Sociological Quarterly*, 36 (4): 657-680.
- Charmaz, K. (2000) 'Experiencing chronic illness.' In Catalano, R., Pickett, K. E., Albrecht, G., Fitzpatrick, R. and Scrimshaw, S. (Eds) *Handbook of Social Studies in Health and Medicine*, 277-292. London: Sage.
- Charmaz, K. (2002) 'Grounded theory analysis.' In Gubrium, J. F. and Holstein, J. A. (Eds) *Handbook of Interview Research*, 675-694. Thousand Oaks: Sage.
- Charmaz, K. (2014) *Constructing Grounded Theory*. London: Sage.
- Chen, R. C., Clark, J. A. and Talcott, J. A. (2009) 'Individualizing quality-of-life outcomes reporting: How localized prostate cancer treatments affect patients with different levels of baseline urinary, bowel, and sexual function.' *Journal of Clinical Oncology*, 27 (24): 3916-3922.
- Chief Medical Officer (2009) 'Prostate Cancer Screening: Revised Prostate Cancer Risk Management Programme (PCRMP) Information Materials Now Available.' London: Department of Health. Retrieved 12.02.2017 from [http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/documents/digitalasset/dh\\_103140.pdf](http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_103140.pdf)
- Clarke, A. E., Mamo, L., Fosket, J., Fishman, J. and Shim, J. (Eds) (2010) *Biomedicalization: Technoscience, Health, and Illness in the US*. Durham: Duke University Press.

- Collins, H. (2014) *Are We All Scientific Experts Now?* Cambridge: Polity.
- Collins, H. and Evans, R. (2002) 'The third wave of science studies: Studies of expertise and experience.' *Social Studies of Science*, 32 (2): 235-96.
- Collins, H. and Evans, R. (2007) *Rethinking Expertise*. Chicago: University of Chicago Press.
- Collinson, D. and Hearn, J. (1994) 'Naming men as men: Implications for work, organization and management.' *Gender, Work and Organization*, 1 (1): 2-22.
- Comaroff, J. and Maguire, P. (1981) 'Ambiguity and the search for meaning: Childhood leukaemia in the modern clinical context.' *Social Science and Medicine. Part B: Medical Anthropology*, 15 (2): 115-123.
- Connell, R. W. (1983) *Which Way is Up? Essays on Class, Sex and Culture*. Boston: Allen and Unwin.
- Connell, R. W. (1987) *Gender and Power*. Cambridge: Polity.
- Connell, R. W. (2000) *The Men and the Boys*. Oakland: University of California Press.
- Connell, R. W. (2002) *Gender*. Cambridge: Polity.
- Connell, R. W. (2005) *Masculinities*. Cambridge: Polity.
- Connell, R. W. and Messerschmidt, J. W. (2005) 'Hegemonic masculinity: Rethinking the concept.' *Gender and Society*, 19 (6): 829-859.
- Conrad, P. (1987) 'Wellness in the work place: Potentials and pitfalls of work-site health promotion.' *The Milbank Quarterly*, 65 (2): 255-275.
- Corbin, J. and Strauss, A. (2008) *Basics of Qualitative Research*. London: Sage.
- Cordova, M. J., Giese-Davis, J., Golant, M., Kronnenwetter, C., Chang, V., McFarlin, S. and Spiegel, D. (2003) 'Mood disturbance in community cancer support groups: The role of emotional suppression and fighting spirit.' *Journal of Psychosomatic Research*, 55 (5): 461-467.
- Coreil, J. and Behal, R. (1999) 'Man to man prostate cancer support groups.' *Cancer Practice*, 7 (3): 122-129.
- Coreil, J., Wilke, J. and Pintado, I. (2004) 'Cultural models of illness and recovery in breast cancer support groups.' *Qualitative Health Research*, 14 (7): 905-923.



- Cornwell, J. (1984) *Hard-Earned Lives: Accounts of Health and Illness from East London*. London: Tavistock.
- Courtenay, W. (2000) 'Constructions of masculinity and their influence on men's well-being: A theory of gender and health.' *Social Science and Medicine*, 50 (10): 1385-1401.
- Courtenay, W. (2009) 'Theorizing masculinity and men's health.' In Broom, A. and Tovey, A. (Eds) *Men's Health: Body, Identity and Social Context*, 9-32. Chichester: John Wiley and Sons.
- Cox, S. and McKellin, W. (1999) "There's this thing in our family': Predictive testing and the construction of risk for Huntington Disease.' In Conrad, P. and Gabe, J. (Eds) *Sociological Perspectives on the New Genetics*. Malden: Blackwell Publishers.
- Crawford, R. (1977) 'You are dangerous to your health: The ideology and politics of victim blaming.' *International Journal of Health Services*, 7 (4): 663-80.
- Crawford, R. (1984) 'A cultural account of health.' In McKinlay, J. (Ed) *Issues in the Political Economy of Health Care*, 61-103. London: Tavistock.
- Crawford, R. (1994) 'The boundaries of the self and the unhealthy other: Reflections on health, culture and AIDS.' *Social Science and Medicine*, 38 (10): 1347-56.
- Crawford, R. (2000) 'The ritual of health promotion.' In Williams, S., Gabe, J. and Calnan, M. (Eds) *Health, Medicine and Society: Key Theories, Future Agendas*, 219-35. London: Routledge.
- Crossley, M. L. (2002a) 'The perils of health promotion and the 'barebacking' backlash.' *Health*, 6 (1): 47-68.
- Crossley, M. L. (2002b) "Could you please pass one of those health leaflets along?": Exploring health, morality and resistance through focus groups.' *Social Science and Medicine*, 55 (8): 1471-1483.
- Crossley, N. (1995) 'Body techniques, agency and intercorporeality: On Goffman's relations in public.' *Sociology*, 29 (1): 133-149.
- Crossley, N. (2006) *Reflexive Embodiment in Contemporary Society: The Body in Late Modern Society*. Maidenhead: McGraw-Hill Education.
- Crossley, N. (2007) 'Researching embodiment by way of 'body techniques'' *The Sociological Review*, 55 (S1): 80-94.

Dall'Era, M. A., Albertsen, P. C., Bangma, C., Carroll, P. R., Carter, H. B., Cooperberg, M. R., Freedland, S., Klotz, L., Parker, C. and Soloway, M. S. (2012) 'Active surveillance for prostate cancer: A systematic review of the literature.' *European Urology*, 62 (6): 976-983.

Damber, J. and Aus, G. (2008) 'Prostate Cancer.' *Lancet*, 371: 1710-21.

Daubenmier, J. J., Weidner, G., Marlin, R., Crutchfield, L., Dunn-Emke, S., Chi, C., Gao, B., Carroll, P. and Ornish, D. (2006) 'Lifestyle and health-related quality of life of men with prostate cancer managed with active surveillance.' *Urology*, 67 (1): 125-130.

Davidson, K. and Arber, S. (2003) 'Older men's health: A life course issue?' *Men's Health Journal*, 2 (3): 72-75.

Davidson, K. and Meadows, R. (2009) 'Older men's health: The role of marital status and masculinities.' In Gough, B. and Robertson, S. (Eds) *Men, Masculinities and Health: Critical Perspectives*, 109-124. Basingstoke: Palgrave Macmillan.

Davison, C., Smith, G. D. and Frankel, S. (1991) 'Lay epidemiology and the prevention paradox: The implications of coronary candidacy for health education.' *Sociology of Health and Illness*, 13: 1-19.

Denzin, N. K. and Lincoln, Y. S. (Eds) (2011) *The Sage Handbook of Qualitative Research*. Thousand Oaks, CA: Sage.

Department of Health (2004) 'Manual for Cancer Services.' London: Department of Health. Retrieved 12.02.2017 from [http://webarchive.nationalarchives.gov.uk/+www.dh.gov.uk/en/Healthcare/Cancer/DH\\_4135595](http://webarchive.nationalarchives.gov.uk/+www.dh.gov.uk/en/Healthcare/Cancer/DH_4135595)

Dingwall, R. (1976) *Aspects of Illness*. London: Martin Robertson.

Djulgovic, M., Beyth, R. J., Neuberger, M. M., Stoffs, T. J., Vieweg, J., Djulgovic, B. and Dahm, P. (2010) 'Screening for prostate cancer: Systematic review and meta-analysis of randomised control trials.' *British Medical Journal*, 341: 4538.

Donaldson, M. (1993) 'What is hegemonic masculinity?' *Theory and Society*, 22 (5): 643-57.

Eagleton, T. (2003) *After Theory*. London: Penguin.

Economic and Social Research Council (2015) *Framework for Research Ethics*. Retrieved 12.02.2017 from <http://www.esrc.ac.uk/files/funding/guidance-for-applicants/esrc-framework-for-research-ethics-2015/>

- Eisenhandler, S. A. (1992) 'Lifelong roles and cameo appearances: Elderly parents and relationships with adult children.' *Journal of Aging Studies*, 6 (3): 243-257.
- Eisenhandler, S. A. (1993) 'The social value of "physiological autonomy": Urinary incontinence and continence in a sample of older women.' *Journal of Women and Aging*, 4 (3): 45-58.
- Elstad, E. A., Taubenberger, S. P., Botelho, E.M. and Tennstedt, S. L. (2010) 'Beyond incontinence: The stigma of other urinary symptoms.' *Journal of Advanced Nursing*, 66 (11): 2460-70.
- Elwyn, G., Edwards, A., Kinnersley, P. and Grol, R. (2000) 'Shared decision-making and the concept of equipoise: Defining the 'competencies' of involving patients in health care choices.' *British Journal of General Practice*, 50: 892-99.
- Epstein, S. (1996) *Impure Science. Aids, Activism and the Politics of Knowledge*. Berkeley, CA: University of California Press.
- Erikson, K. (1966) *Wayward Puritans: A Study in the Sociology of Deviance*. London: Collier-Macmillan.
- Evans, J., Frank, B., Oliffe, J. L. and Gregory, D. (2011) 'Health, illness, men and masculinities (HIMM): A theoretical framework for understanding men and their health.' *Journal of Men's Health*, 8 (1): 7-15.
- Ewald, F. (1991) 'Insurance and risks.' In Burchell, G., Gordon, C. and Miller, P. (Eds) *The Foucault Effect: Studies in Governmentality*. London: Harvester.
- Eysenbach, G. (2008) 'Medicine 2.0: Social networking, collaboration, participation, apomediation, and openness.' *Journal of Medical Internet Research*, 10 (3): e22.
- Faircloth, C. A., Boylstein, C., Rittman, M., Young, M. E. and Gubrium, J. (2004) 'Sudden illness and biographical flow in narratives of stroke recovery.' *Sociology of Health and Illness*, 26 (2): 242-261.
- Fairhurst, E. (2003) 'New identities in ageing: Perspectives on age, gender and life after work. In Arber, S., Davidson, K. and Ginn, J. (Eds) *Gender and Ageing: Changing Roles and Relationships*. Maidenhead: McGraw-Hill Education.
- Faulkner, A. (2012) 'Resisting the screening imperative: Patienthood, population and the politics of prostate cancer detection technologies in the UK.' *Sociology of Health and Illness*, 34 (2): 221-233.

- Fergus, K. D., Gray, R. E. and Fitch, M. I. (2002) 'Sexual dysfunction and the preservation of manhood: Experiences of men with prostate cancer.' *Journal of Health Psychology*, 7 (3): 303-316.
- Ficarra, V., Novara, G., Galfano, A., Stringari, C., Baldassarre, R., Cavalleri, S. and Artibani, W. (2006) 'Twelve-month self-reported quality of life after retropubic radical prostatectomy: A prospective study with Rand 36-Item Health Survey (Short Form-36).' *BJU International*, 97 (2): 274-278.
- Fielding, N. and Thomas, H. (2008) 'Qualitative Interviewing.' In Gilbert, N. (Ed) *Researching Social Life*. London: Sage.
- Fleming, A. (1999) 'Older men in contemporary discourses on ageing: Absent bodies and invisible lives.' *Nursing inquiry*, 6 (1): 3-8.
- Flood, M. (2002) 'Between men and masculinity: An assessment of the term "masculinity" in recent scholarship on men.' In Pearce, S. and Muller, V. (Eds) *Manning the Next Millennium: Studies in Masculinities*, 203-213. Bentley: Black Swan Press.
- Fontana, A. and Frey, J. H. (2000) The interview: From structured questions to negotiated text. *Handbook of Qualitative Research*, 2: 645-672.
- Frisby, C. M. (2004) 'Does race matter? Effects of idealized images on African American women's perceptions of body esteem.' *Journal of Black Studies*, 34 (3): 323-347.
- Fultz, N. H. and Herzog, A. R. (2001) 'Self-reported social and emotional impact of urinary incontinence.' *Journal of the American Geriatrics Society*, 49 (7): 892-9.
- Gabe, J. (Ed) (1996) *Medicine, Health and Risk: Sociological Approaches*. London: Wiley-Blackwell.
- Gabe, J., Bury, M. and Elston, M. A. (Eds) (2004) *Key Concepts in Medical Sociology*. London: Sage.
- Gabe, J., Coveney, C. M. and Williams, S. J. (2016) 'Prescriptions and proscriptions: moralising sleep medicines.' *Sociology of Health and Illness*, 38 (4): 627-44.
- Gacci, M., Bartoletti, R., Figlioli, S., Sarti, E., Eisner, B., Boddi, V. and Rizzo, M. (2003) 'Urinary symptoms, quality of life and sexual function in patients with benign prostatic hypertrophy before and after prostatectomy: A prospective study. *BJU International*, 91 (3): 196-200.

- Galvin, R. (2002) 'Disturbing notions of chronic illness and individual responsibility: Towards a genealogy of morals.' *Health* 6 (2): 107-137.
- Geertz, C. (1973) *The Interpretation of Cultures*. New York: Basic Books.
- Gelmann, E. P. (2008) 'Complexities of prostate-cancer risk.' *The New England Journal of Medicine*, 358 (9): 961-963.
- Gerhardt, U. (1989) *Ideas About Illness: An Intellectual and Political History of Medical Sociology*. London: Macmillan.
- Gerschick, T. and Miller, A. (1995) 'Coming to terms: masculinity and physical disability.' In Sabo, D. and Gordon, D. F. (Eds) *Men's Health and Illness: Gender, Power and the Body*, 183-204. Thousand Oaks, CA: Sage.
- Gilleard, C. J. and Higgs, P. (2000) *Cultures of Ageing: Self, Citizen, and the Body*. Harlow: Pearson Education.
- Gillespie, C. (2012) 'The experience of risk as 'measured vulnerability': Health screening and lay uses of numerical risk.' *Sociology of Health and Illness*, 34 (2): 194-207.
- Gillespie, C. (2015) 'The risk experience: the social effects of health screening and the emergence of a proto-illness.' *Sociology of Health and Illness*, 37 (7): 973-987.
- Glaser, B. (2001) *The Grounded Theory Perspective: Conceptualization Contrasted with Description*. Mill Valley, CA: The Sociology Press.
- Glaser, B. and Strauss, A. (1967) *The Discovery of Grounded Theory: Strategies for Qualitative Research*. London: Weidenfeld and Nicholson.
- Goffman, E. (1959a) 'The moral career of the mental patient.' *Psychiatry*, 22 (2), 123-142.
- Goffman, E. (1959b) *The Presentation of Self in Everyday Life*. Garden City, NY: Anchor.
- Goffman, E. (1963) *Stigma: Notes on a Spoiled Identity*. New Jersey: Prentice-Hall.
- Goffman, E. (1971) *Relations in Public: Microstudies of the Public Order*. New York: Harper and Row.
- Gordon, D. (1995) 'Testicular cancer and masculinity.' In Sabo, D. and Gordon, D. (Eds) *Men's Health and Illness: Gender, Power and the Body*, 246-265. London: Sage.

- Gore, J. L., Krupski, T., Kwan, L., Maliski, S. and Litwin, M. S. (2005) 'Partnership status influences quality of life in low-income, uninsured men with prostate cancer.' *Cancer*, 104 (1): 191-198.
- Gough, B. (2006) 'Try to be healthy, but don't forgo your masculinity: Deconstructing men's health discourse in the media.' *Social Science and Medicine*, 63 (9): 2476-2488.
- Graham, J., Baker, M., Macbeth, F. and Titshall, V. (2008) 'Diagnosis and treatment of prostate cancer: Summary of NICE guidance.' *British Medical Journal*, 336: 610-612.
- Gramsci, A. (1971) *Selections from the Prison Notebooks*. (translated and edited by Quintin Hoare and Geoffrey Nowell Smith) London: Lawrence and Wishart.
- Gray, R. E., Fitch, M., Davis, C. and Phillips, C. (1996) 'Breast cancer and prostate cancer self-help groups: Reflections on differences.' *Psycho-Oncology*, 5 (2): 137-142.
- Gray, R. E., Fitch, M., Davis, C. and Phillips, C. (1997) 'Interviews with men with prostate cancer about their self-help group experience.' *Journal of Palliative Care*, 13: 15-21.
- Gray, R. E., Fitch, M., Phillips, C., Labrecque, M. and Fergus, K. (2000) 'Managing the impact of illness: The experiences of men with prostate cancer and their spouses.' *Journal of Health Psychology*, 5 (4): 531-548.
- Gray, R. E., Fitch, M., Phillips, C., Labrecque, M. and Fergus, K. (2002) 'Prostate cancer and erectile dysfunction: Men's experiences.' *International Journal of Men's Health*, 1 (1): 15.
- Gregoire, I., Kalogeropoulos, D. and Corcos, J. (1997) 'The effectiveness of a professionally led support group for men with prostate cancer.' *Urologic Nursing*, 17 (2): 58-66.
- Grönberg, H. (2003) 'Prostate Cancer Epidemiology.' *The Lancet*, 361: 859-864.
- Grosz, E. (1994) *Volatile Bodies: Toward a Corporeal Feminism*. Indianapolis: Indiana University Press.
- Gubrium, J. F. (1997) *Living and Dying at Murray Manor*. Charlottesville, VA: University of Virginia Press.
- Gutmann, M. C. (2006) *The Meanings of Macho: Being a Man in Mexico City*. Oakland: University of California Press.
- Halberstam, J. (1998) *Female Masculinity*. Durham: Duke University Press.

- Halpin, M., Phillips, M. and Oliffe, J. L. (2009) 'Prostate cancer stories in the Canadian print media: Representations of illness, disease and masculinities.' *Sociology of Health and Illness*, 31 (2): 155-169.
- Hamdy, F. C. (2016) 'The Prostate Testing for Cancer and Treatment ( ProtecT) study: what have we learnt?' *BJU International*, 118 (6): 843-843.
- Harrison, J., Maguire, P. and Pitceathly, C. (1995) 'Confiding in crisis: Gender differences in pattern of confiding among cancer patients.' *Social Science and Medicine*, 41 (9): 1255-1260.
- Hearn, J. (1995) 'Imaging the aging of men.' In Featherstone, M. and Wernick, A. (Eds) *Images of Aging: Cultural Representations of Later Life*, 97-115. London: Routledge.
- Hearn, J. (1996) *Is Masculinity Dead? A Critical Account of the Concepts of Masculinity and Masculinities*. Milton Keynes: Open University Press.
- Hearn, J. (2004) 'From hegemonic masculinity to the hegemony of men.' *Feminist Theory*, 5 (1): 49-72.
- Heijnsdijk, E., Wever, E., Auvinen, A., Hugosson, J., Ciatto, S., Nelen, V., Kwiatkowski, M., Villers, A., Páez, A., Moss, S., Marco, Z., Teuvo, T., Mäkinen, T., Carlsson, S., Korfage, I., Essink-Bot, M., Otto, S., Draisma, G., Bangma, C., Roobol, M., Schröder, F. and de Koning, H. (2012) 'Quality-of-life effects of prostate-specific antigen screening.' *The New England Journal of Medicine*, 367 (7): 595-605.
- Helgeson, V. (1995) 'Masculinity, men's roles and coronary heart disease.' In Sabo, D. and Gordon, D. (Eds) *Men's Health and Illness: Gender, Power and the Body*. London: Sage.
- Herskovits, E. J. and Mitteness, L. S. (1994) 'Transgressions and sickness in old age.' *Journal of Aging Studies*, 8 (3): 327-340.
- Herzlich, C. and Pierret, J. (1987): *Illness and Self in Society*. Baltimore: John Hopkins University Press.
- Hilton, B. A. (1996) 'Getting back to normal: The family experience during early stage breast cancer.' *Oncology Nursing Forum*, 23 (4): 605-614.
- Hitlin, S. and Vaisey, S. (Eds) (2010) *Handbook of the Sociology of Morality*. New York: Springer.
- Hockey, J. L. and James, A. (1993) *Growing Up and Growing Old: Ageing and Dependency in the Life Course*. London: Sage.

- Horlick-Jones, T. (2011) 'Understanding fear of cancer recurrence in terms of damage to 'everyday health competence'.' *Sociology of Health and Illness*, 33 (6): 884-898.
- Humphris, G. M. and Ozakinci, G. (2006) 'Psychological responses and support needs of patients following head and neck cancer.' *International Journal of Surgery*, 4 (1): 37-44.
- Humphris, G. M., Rogers, S., McNally, D., Lee-Jones, C., Brown, J. and Vaughan, D. (2003) 'Fear of recurrence and possible cases of anxiety and depression in orofacial cancer patients.' *International Journal of Oral and Maxillofacial Surgery*, 32 (5): 486-491.
- Hunt, A. (2003) 'Risk and moralization in everyday life.' In Ericson, R. V. and Doyle, A. (Eds) *Risk and Morality*, 165-92. Toronto: University of Toronto Press.
- Hutchinson, S., Marsiglio, W. and Cohan, M. (2002) 'Interviewing young men about sex and procreation: Methodological issues.' *Qualitative Health Research*, 12 (1): 42-60.
- Inside Health (2017) 'Prostate Cancer.' BBC Radio 4, 03.01.2017.
- Isaksen, L. W. (2002) 'Toward a sociology of (gendered) disgust: Images of bodily decay and the social organization of care work.' *Journal of Family Issues*, 23 (7): 791-811.
- Jani, A. B. and Hellman, S. (2003) 'Early prostate cancer: clinical decision-making.' *The Lancet*, 361: 1045-53.
- Jervis, L. (2001) 'The pollution of incontinence and the dirty work of caregiving in a US nursing home.' *Medical Anthropology Quarterly*, 15 (1): 84-99.
- Johansson, E., Steineck, G., Holmberg, L., Johansson, J. E., Nyberg, T., Ruutu, M. and Bill-Axelsson, A. (2011) 'Long-term quality-of-life outcomes after radical prostatectomy or watchful waiting: The Scandinavian Prostate Cancer Group-4 randomised trial.' *The Lancet Oncology*, 12 (9): 891-899.
- Johns, L. E. and Houlston, R. S. (2003) 'A systematic review and meta-analysis of familial prostate cancer risk.' *BJU International*, 91 (9): 789-794.
- Jolanki, O. (2004) 'Moral argumentation in talk about health and old age.' *Health*: 8 (4): 483-503.
- Jolanki, O. (2005) 'Health and Morality.' Paper presented at the 7<sup>th</sup> Conference of the European Sociological Association, Torun, Poland, 9<sup>th</sup>-12<sup>th</sup> September 2005.



- Jolanki, O., Jylhä, M., and Hervonen, A. (2000) 'Old age as a choice and as a necessity: Two interpretative repertoires.' *Journal of Aging Studies*, 14 (4): 359-372.
- Katz, D., Koppie, T. M., Wu, D., Meng, M. V., Grossfeld, G. D., Sadesky, N., Lubeck, D. and Carroll, P. R. (2002) 'Sociodemographic characteristics and health related quality of life in men attending prostate cancer support groups.' *The Journal of Urology*, 168 (5): 2092-2096.
- Keitel, M. A., Zevon, M. A., Rounds, J. B., Petrelli, N. J. and Karakousis, C. (1990) 'Spouse adjustment to cancer surgery: Distress and coping responses.' *Journal of Surgical Oncology*, 43 (3): 148-153.
- Kelleher, D. (1988) *Diabetes*. London: Routledge
- Kelleher, D. (2006) 'Self-help groups and their relationship to medicine.' In Kelleher, D., Gabe, J. and Williams, G. (Eds) *Challenging Medicine*. Oxford: Routledge.
- Kelly, D. (2009) 'Changed men: The embodied impact of prostate cancer.' *Qualitative Health Research*, 19 (2): 151-163.
- Kelly, M. P. (1991) 'Coping with an ileostomy.' *Social Science and Medicine*, 33 (2): 115-125.
- Kelly, M. P. (1992a) *Colitis*. London: Routledge.
- Kelly, M. P. (1992b) 'Self, identity and radical surgery'. *Sociology of Health and Illness* 14: 390-415.
- Kickbusch, I. and Hatch, S. (Eds) (1983) *Self-Help and Health in Europe: New Approaches in Health Care*. Copenhagen: World Health Organization.
- Kimmel, M. S. (1994) 'Masculinity as homophobia: Fear, shame and silence in the construction of gender inequality.' In Brod, H. and Kaufman, M. (Eds) *Theorizing Masculinities*, 119-142. Thousand Oaks, CA: Sage.
- Kirby, R. S. and Kirby, M. G. (1999) 'Impact of prostatic disease on men's health.' In Kirby, R. S., Kirby, M. G. and Farah, R. N. (Eds) *Men's Health*. Oxford: ISIS Medical Media.
- Kitzinger, C. (2004) 'Feminist approaches.' In Seale, C., Gobo, G., Gubrium, J. F. and Silverman, D. (Eds) *Qualitative Research Practice*, 125-140. London: Sage.
- Kitzinger, C. (2007) 'Editor's Introduction: The Promise of Conversation Analysis for Feminist Research.' *Feminism and Psychology*, 17 (2): 133-148.

- Klein, A. M. (1993) *Little Big Men: Bodybuilding Subculture and Gender Construction*. New York: Suny Press.
- Knafl, K. A. and Deatrck, J. A. (1986) 'How families manage chronic conditions: An analysis of the concept of normalisation.' *Research in Nursing and Health*, 9 (3): 215-222.
- Knight, F. (1921) *Risk, Uncertainty and Profit*. New York: Sentry Press.
- Korfage, I. J., Hak, T., de Koning, H. J. and Essink-Bot, M. L. (2006) 'Patients' perceptions of the side-effects of prostate cancer treatment—a qualitative interview study.' *Social Science and Medicine*, 63 (4): 911-919.
- Krizek, C., Roberts, C., Ragan, R., Ferrara, J. and Lord, B. (1999) 'Gender and cancer support group participation.' *Cancer Practice*, 7 (2): 86-92.
- Krongrad, A., Lai, H., Burke, M., Goodkin, K. and Lai, S. (1996) 'Marriage and mortality in prostate cancer.' *The Journal of Urology*, 156 (5): 1696-1700.
- Kunkel, E. J., Myers, R. E., Lartey, P. L. and Oyesanmi, O. (2000) 'Communicating effectively with the patient and family about treatment options for prostate cancer.' *Seminars in Urologic Oncology*, 18 (3): 233-240.
- Kvale, S. and Brinkmann, S. (2009) *InterViews: Learning the Craft of Qualitative Interviewing*. London: Sage.
- Lamb, B. W., Brown, K. F., Nagpal, K., Vincent, C., Green, J. S., and Sevdalis, N. (2011) 'Quality of care management decisions by multidisciplinary cancer teams: A systematic review.' *Annals of Surgical Oncology*, 18 (8): 2116-2125.
- Lawton, J. (1998) 'Contemporary hospice care: The sequestration of the unbounded body and 'dirty dying'.' *Sociology of Health and Illness*, 20 (2): 121-143.
- Lee, C. and Owens, R. G. (2002) *The Psychology of Men's Health*. Buckingham: Open University Press.
- Lee, D. (1997) 'Interviewing men: Vulnerabilities and dilemmas.' *Women's Studies International Forum*, 20 (4): 553-564.
- Leitzmann, M. F. and Rohrmann, S. (2012) 'Risk factors for the onset of prostatic cancer: Age, location, and behavioral correlates.' *Clinical Epidemiology*, 4: 1-11.
- Lesko, S. M., Rosenberg, L. and Shapiro, S. (1996) 'Family history and prostate cancer risk.' *American Journal of Epidemiology*, 144 (11): 1041-1047.

- Litwin, M. S., Hays, R. D., Fink, A., Ganz, P. A., Leake, B., Leach, G. E. and Brook, R. H. (1995) 'Quality-of-life outcomes in men treated for localized prostate cancer.' *JAMA*, 273 (2): 129-135.
- Longino Jr, C. F. and Lipman, A. (1983) 'The married, the formerly married and the never married: Support system differentials of older women in planned retirement communities.' *The International Journal of Aging and Human Development*, 15 (4): 285-297.
- Lumme-Sandt, K., Hervonen, A. and Jylha, M. (2000) 'Interpretative repertoires of medication among the oldest-old.' *Social Science and Medicine*, 50 (12): 1843-50.
- Maliski, S. L., Rivera, S., Connor, S., Lopez, G. and Litwin, M. S. (2008) 'Renegotiating masculine identity after prostate cancer treatment.' *Qualitative Health Research*, 18 (12): 1609-1620.
- Manderson, L. (2005) 'Boundary breaches: the body, sex and sexuality after stoma surgery.' *Social Science and Medicine*, 61 (2): 405-415.
- Manderson, L., Bennett, E. and Andajani-Sutjahjo, S. (2006) 'The social dynamics of the interview: Age, class, and gender.' *Qualitative Health Research*, 16 (10): 1317-1334.
- Manne, S. L. (2002) 'Prostate cancer support and advocacy groups: Their role for patients and family members.' *Seminars in Urologic Oncology*, 20 (1): 45-54.
- Marmot, M. (2006) 'Cancer and Health Inequalities: An introduction to current evidence.' London: Cancer Research UK.
- Marshall, V. W., Clarke, P. J. and Ballantyne, P. J. (2001) 'Instability in the retirement transition: Effects on health and well-being in a Canadian study.' *Research on Aging*, 23 (4): 379-409.
- Mason, J. (2002) *Qualitative Researching*. London: Sage.
- Mauss, M. (1979) 'Body Techniques.' *Sociology and Psychology: Essays*, 95-123. London: Routledge.
- McCallum, T. J., Moore, K. N. and Griffiths, D. (2001) 'Urinary incontinence after radical prostatectomy: Implications and urodynamics.' *Urologic Nursing*, 21 (2): 113-9.
- McCracken, G. (1988) *The Long Interview (Qualitative Research Methods, Volume 13)*. London: Sage.

- McKee, L. and O'Brien, M. (1983) 'Interviewing men: 'taking gender seriously'.' In Gamarnikow, E., Morgan, D., Purvis, J. and Taylorson, T. (Eds) *The Public and the Private*. London, Heinemann.
- McLeod, D. G. (2005) 'The effective management of biochemical recurrence in patients with prostate cancer.' *Urology*, 7 (5): S29-S36.
- Meadows, R. and Davidson, K. (2006) 'Maintaining manliness in later life: Hegemonic masculinities and emphasized femininities.' In Calasanti, T. M. and Slevin, K. F. (Eds) *Age Matters: Realigning Feminist Thinking*, 295-312. London: Routledge.
- Messerschmidt, J. W. (2004) *Flesh and Blood: Adolescent Gender Diversity and Violence*. Oxford: Rowman and Littlefield Publishers.
- Messner, M. A. (1995) *Power at Play: Sports and the Problem of Masculinity*. Boston: Beacon Press.
- Minichiello, V., Browne, J. and Kendig, H. (2000) 'Perceptions and consequences of ageism: Views of older people. *Ageing and Society*, 20 (3): 253-278.
- Mitchell, J. C. (1983) 'Case and situation analysis.' *The Sociological Review*, 31 (2): 187-211.
- Mitteness, L. S. and Barker, J. C. (1995) 'Stigmatizing a "normal" condition: Urinary incontinence in late life.' *Medical Anthropology Quarterly*, 9 (2): 188-210.
- Mols, F., Korfage, I. J., Vingerhoets, A. J., Kil, P. J., Coebergh, J. W., Essink-Bot, M. L. and Van de Poll-Franse, L. V. (2009) 'Bowel, urinary, and sexual problems among long-term prostate cancer survivors: A population-based study.' *International Journal of Radiation Oncology\* Biology\* Physics*, 73 (1): 30-38.
- Monaghan, L. (1999) 'Challenging medicine? Body building, drugs and risk.' *Sociology of Health and Illness*, 21 (6): 707-34.
- Monaghan, L. (2001) 'Looking good, feeling good: The embodied pleasures of vibrant physicality.' *Sociology of Health and Illness*, 23 (3): 330-356.
- Monaghan, L. and Gabe, J. (2015) 'Chronic illness as biographical contingency? Young people's experiences of asthma.' *Sociology of Health and Illness*, 37 (8): 1236-1253.
- Morgan, D. (1993) 'You too can have a body like mine': Reflections on the male body and masculinities.' In Scott, S. and Morgan, D. (Eds) *Body Matters: Essays on the Sociology of the Body*. London: The Falmer Press.

- Moynihan, C. (1986) 'Testicular cancer: The psychosocial problems of patients and their relatives.' *Cancer Surveys*, 6 (3): 477-510.
- Moynihan, C. (1998) 'Theories of masculinity.' *British Medical Journal*, 317 (7165): 1072-1075.
- Mullen, K. (1992) 'A question of balance: Health behaviour and work context among male Glaswegians.' *Sociology of Health and Illness*, 14 (1): 73-97.
- Mullen, K. (1993) *A Healthy Balance: Glaswegian Men Talking About Health, Tobacco and Alcohol*. Aldershot: Ashgate Publishing.
- National Cancer Intelligence Network (2009) 'Cancer Incidence and Survival By Major Ethnic Group, England, 2002-2006', London: National Cancer Intelligence Network. Retrieved 12.02.2017 from [http://www.ncin.org.uk/publications/reports/reports\\_archive](http://www.ncin.org.uk/publications/reports/reports_archive)
- National Cancer Intelligence Network (2014) 'Cancer by deprivation in England: Incidence, 1996-2010, Mortality 1997-2011.' London: National Cancer Intelligence Network. Retrieved 18.02.2017 from [http://www.ncin.org.uk/about\\_ncin/cancer\\_by\\_deprivation\\_in\\_england](http://www.ncin.org.uk/about_ncin/cancer_by_deprivation_in_england)
- Nelson, C. J., Deveci, S., Stasi, J., Scardino, P. T. and Mulhall, J. P. (2010) 'Sexual bother following radical prostatectomy.' *Journal of Sexual Medicine*, 7: 129-35.
- Nelson, W. G., De Marzo, A. M. and Isaacs, W. B. 'Mechanisms of Disease: Prostate Cancer.' (2003) *The New England Journal of Medicine*, 349 (4): 366-81.
- NHS Centre for Reviews and Dissemination (1997) 'Effectiveness Matters: Screening for Prostate Cancer.' *NHS Centre for Reviews and Dissemination, University of York*. 2 (2): 1-4. Retrieved 12.02.2017 from <https://www.york.ac.uk/media/crd/em22.pdf>
- Noaks, L. and Wincup, E. (2004) *Criminological Research: Understanding Qualitative Methods*. London: Sage.
- Noone, J. H. and Stephens, C. (2008) 'Men, masculine identities, and health care utilisation.' *Sociology of Health and Illness*, 30 (5): 711-725.
- Novara, G., Ficarra, V., Rosen, R. C., Artibani, W., Costello, A., Eastham, J. A., Graefen, M., Guazzoni, G., Shariat, S. F., Stolzenburg, J., Van Poppel, H., Zattoni, F., Montorsi, F., Mottrie, A. and Wilson, T. G. (2012) 'Systematic review and meta-analysis of perioperative outcomes and complications after robot-assisted radical prostatectomy.' *European Urology*, 62 (3): 431-452.

Oakley, A. (1981) 'Interviewing women: A contradiction in terms.' In Roberts, H. (Ed) *Doing Feminist Research*. London: Routledge and Paul Kegan.

Odendahl, T. and Shaw, A. M. (2002) 'Interviewing elites.' In Gubrium, J. F. and Holstein, J. A. (Eds) *Handbook of Interview Research: Context and Method*, 299-316. London: Sage.

Office for National Statistics (2013) 'Chapter 4: The Labour Market and Retirement.' London: Office for National Statistics. Retrieved 12.02.2017 from <http://webarchive.nationalarchives.gov.uk/20160105160709/http://ons.gov.uk/ons/rel/pensions/pension-trends/chapter-4--the-labour-market-and-retirement-2013-edition/art-pt2013ch4.html>

Oliffe, J. (2005) 'Constructions of masculinity following prostatectomy-induced impotence.' *Social Science and Medicine*, 60 (10): 2249-2259.

Oliffe, J. (2006a) 'Embodied masculinity and androgen deprivation therapy.' *Sociology of Health and Illness*, 28 (4): 410-432.

Oliffe, J. (2006b) 'Being screened for prostate cancer: A simple blood test or a commitment to treatment?' *Cancer Nursing*, 29 (1): 1-8.

Oliffe, J. (2009a) 'Positioning prostate cancer as the problematic third testicle.' In Broom, A. and Tovey, P. (Eds) *Men's Health: Body, Identity and Social Context*, 33-62. London: John Wiley and Sons.

Oliffe, J. (2009b) 'Bugging the cone of silence with men's health interviews.' In Gough, B. and Robertson, S. (Eds) *Men, Masculinities and Health: Critical Perspectives*, 67-89. Basingstoke: Palgrave Macmillan.

Oliffe, J. and Mroz, L. (2005) 'Men interviewing men about health and illness: Ten lessons learned.' *Journal of Men's Health and Gender* 2: 257-260.

Oliffe, J., Bottorff, J. L., McKenzie, M. M., Hislop, T. G., Gerbrandt, J. S. and Oglov, V. (2011) 'Prostate cancer support groups, health literacy and consumerism: Are community-based volunteers re-defining older men's health?' *Health* 15 (6): 555-570.

Palmer, M. H., Fogarty, L. A., Somerfield, M. R. and Powel, L. L. (2002) 'Incontinence after prostatectomy: coping with incontinence after prostate cancer surgery.' *Oncology Nursing Forum* 30 (2): 229-238.

Parsons, E. and Atkinson, P. (1992) 'Lay constructions of genetic risk.' *Sociology of Health and Illness*, 14: 437-455.

Parsons, E. and Atkinson, P. (1993) 'Genetic risk and reproduction.' *The Sociological Review*, 41 (4): 679-706.

- Parsons, E. and Atkinson, P. (2004) 'Lay constructions of genetic risk.' In Bury, M. and Gabe, J. (Eds) *The Sociology of Health and Illness: A Reader*. London: Routledge.
- Parsons, T. (1951) 'Illness and the role of the physician: A sociological perspective.' *American Journal of Orthopsychiatry*, 21 (3): 452-460.
- Paterson, J. (2000) 'Stigma associated with postprostatectomy urinary incontinence.' *Journal of Wound Ostomy and Continence Nursing*, 27 (3): 168-173.
- Patton, M. Q. (2002) *Qualitative Research and Evaluation Methods*. London: Sage.
- Peake, S. and Manderson, L. (2003) 'The constraints of a normal life: The management of urinary incontinence by middle aged women.' *Women and Health*, 37 (3): 37-51.
- Peake, S., Manderson, L. and Potts, H. (1999) "'Part and parcel of being a woman": Female urinary incontinence and constructions of control.' *Medical Anthropology Quarterly*, 13 (3): 267-285.
- Pease, B. (2002) *Men and Gender Relations*. Croydon: Tertiary Press.
- Peate, I. (2004) 'Men's attitudes towards health and the implications for nursing care.' *British Journal of Nursing*, 13 (9): 540-5.
- Penson, D. F., Feng, Z., Kuniyuki, A., McClerran, D., Albertsen, P. C., Deapen, D., Gilliland, F., Hoffman, R., Stephenson, R. A., Potosky, A. L. and Stanford, J. L. (2003) 'General quality of life 2 years following treatment for prostate cancer: What influences outcomes? Results from the prostate cancer outcomes study.' *Journal of Clinical Oncology*, 21 (6): 1147-1154.
- Petersen, A. (1997) 'Risk, governance and the new public health.' In Petersen, A. and Bunton, R. (Eds) *Foucault, Health and Medicine*, 189-206. London: Routledge.
- Petersen, A. and Lupton, D. (1996) *The New Public Health: Health and Self in the Age of Risk*. London: Sage.
- Petry, H., Berry, D. L., Spichiger, E., Kesselring, A., Gasser, T. C., Sulser, T. and Kiss, A. (2004) 'Response and experience after radical prostatectomy: Perceptions of married couples in Switzerland.' *International Journal of Nursing Studies*, 41 (5): 507-13.
- Pini, B. (2005) 'Interviewing men: Gender and the collection and interpretation of qualitative data.' *Journal of Sociology*, 41 (2): 201-216.

Pollock, K. (1993) 'Attitude of mind as a means of resisting illness.' In Radley, A. (Ed) *Worlds of Illness: Biographical and Cultural Perspectives on Health and Disease*, 49–70. London: Routledge.

Pope, C. and Mays, N. (Eds) (2008) *Qualitative Research in Health Care*. Oxford: John Wiley and Sons.

Potter, J. and Wetherell, M. (1987) *Discourse and Social Psychology: Beyond Attitudes and Behaviour*. London: Sage.

Potts, A. (2000) "'The Essence of the Hard On": Hegemonic masculinity and the cultural construction of "erectile dysfunction".' *Men and Masculinities*, 3 (1): 85-103.

Potts, A., Grace, V. M., Vares, T. and Gavey, N. (2006) "Sex for life? Men's counter-stories on 'erectile dysfunction', male sexuality and ageing.' *Sociology of Health and Illness*, 28 (3): 306-329.

Prior, L. (2003) 'Belief, knowledge and expertise: the emergence of the lay expert in medical sociology.' *Sociology of Health and Illness*, 25 (3): 41-57.

Prostate Cancer UK (2017a) 'The PSA Test.' Retrieved 18.02.2017 from <http://prostatecanceruk.org/prostate-information/prostate-tests/psa-test>

Prostate Cancer UK (2017b) 'Scans and TNM staging.' Retrieved 18.02.2017 from <http://prostatecanceruk.org/prostate-information/prostate-tests/scans-and-tnm-staging>

Prostate Cancer UK (2017c) 'Watchful waiting.' Retrieved 18.02.2017 from <http://prostatecanceruk.org/prostate-information/treatments/watchful-waiting>

Prostate Cancer UK (2017d) 'Active surveillance.' Retrieved 18.02.2017 from <http://prostatecanceruk.org/prostate-information/treatments/active-surveillance>

Prostate Cancer UK (2017e) 'External beam radiotherapy.' Retrieved 18.02.2017 from <http://prostatecanceruk.org/prostate-information/treatments/external-beam-radiotherapy>

Prostate Cancer UK (2017f) 'Permanent seed brachytherapy.' Retrieved 18.02.2017 from <http://prostatecanceruk.org/prostate-information/treatments/brachytherapy>

Prostate Cancer UK (2017g) 'Treatments.' Retrieved 18.02.2017 from <http://prostatecanceruk.org/prostate-information/treatments>



Prostate Cancer UK (2017h) 'New treatments.' Retrieved 18.02.2017 from <http://prostatecanceruk.org/prostate-information/treatments/new-treatments>

Prostate Cancer UK (2017i) 'Living with prostate cancer.' Retrieved 18.02.2017 from <http://prostatecanceruk.org/prostate-information/living-with-prostate-cancer>

Public Health England (2016) 'Prostate Cancer Risk Management Programme (PCRMP): Benefits and Risks of PSA Testing.' London: Department of Health. Retrieved 12.02.2017 from <https://www.gov.uk/government/publications/prostate-cancer-risk-management-programme-psa-test-benefits-and-risks/prostate-cancer-risk-management-programme-pcrmp-benefits-and-risks-of-psa-testing>

Rabeharisoa, V. (2003) 'The struggle against neuromuscular diseases in France and the emergence of the "partnership model" of patient organisation.' *Social Science and Medicine*, 57 (11): 2127-2136.

Radley, A. (1994) *Making Sense of Illness: The Social Psychology of Health and Disease*. London: Sage.

Radley, A. and Billig, M. (1996) 'Accounts of health and illness: Dilemmas and representations.' *Sociology of Health and Illness*, 18 (2): 220-240.

Reeve, B. B., Potosky, A. L. and Willis, G. B. (2006) 'Should function and bother be measured and reported separately for prostate cancer quality-of-life domains?' *Urology*, 68 (3): 599-603.

Renold, E. (2004) "'Other' boys: Negotiating non-hegemonic masculinities in the primary school.' *Gender and Education*, 16 (2): 247-265.

Renzetti, C. M. and Lee, R. M. (1993) *Researching Sensitive Topics*. London: Sage.

Rich, E. (2006) 'Anorexic dis(connection): Managing anorexia as an illness and an identity.' *Sociology of Health and Illness*, 28 (3): 284-305.

Roberts, K. and Clarke, C. (2009) 'Future disorientation following gynaecological cancer: women's conceptualisation of risk after a life threatening illness.' *Health, Risk and Society*, 11 (4): 353-366.

Robertson, S. (2003) 'Men managing health.' *Men's Health Journal*, 2 (4): 111-13.

Robertson, S. (2006a) "'I've been like a coiled spring this last week': Embodied masculinity and health.' *Sociology of Health and Illness*, 28 (4): 433-56.

- Robertson, S. (2006b) 'Not living life in too much of an excess': Lay men understanding health and well-being.' *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 10 (2): 175–89.
- Robertson, S. (2007) *Understanding Men and Health: Masculinities, Identity and Well-Being*. Maidenhead: McGraw-Hill Education.
- Robertson, S., Sheikh, K. and Moore, A. (2010) 'Embodied masculinities in the context of cardiac rehabilitation.' *Sociology of Health and Illness*, 32 (5): 695-710.
- Robinson, S. (2004) 'Uncertainty.' In Gabe, J., Bury, M. and Elston, M. A. (Eds) *Key Concepts in Medical Sociology*, 101-6. London: Sage.
- Roth, L. T. (2010) 'The moral construction of risk.' In Hitlin, S. and Vaisey, S. (Eds) *Handbook of the Sociology of Morality*, 469-484. New York: Springer.
- Roulston, K. (2010) 'Considering quality in qualitative interviewing.' *Qualitative Research*, 10 (2): 199-228.
- Royer, A. (1995) 'Living with chronic illness.' In Kronenfeld, J. (Ed) *Patients, Consumers, Providers, and Caregivers (Research in the Sociology of Health Care)*, 12: 25-48. Bingley: Emerald Group Publishing Limited.
- Royer, A. (2000) 'Uncertainty: a key characteristic of chronic illness and a major problem for managed care.' In Kronenfeld, J. (Ed) *Health, Illness, and use of Care: The Impact of Social Factors (Research in the Sociology of Health Care)* 18: 269-286. Bingley: Emerald Group Publishing Limited.
- Ryen, A. (2004) 'Ethical issues.' In Seale, C., Gobo, G., Gubrium, J. F. and Silverman, D. (Eds) *Qualitative Research Practice*, 230-247. London: Sage.
- Sabo, D. and Gordon, D. (Eds) (1995) *Men's Health and Illness: Gender, Power and the Body*. London: Sage.
- Sacco, E., Prayer-Galetti, T., Pinto, F., Fracalanza, S., Betto, G., Pagano, F. and Artibani, W. (2006) 'Urinary incontinence after radical prostatectomy: Incidence by definition, risk factor and temporal trend in a larger series with a long term follow-up.' *BJU International*, 97 (6): 1234-41.
- Saltonstall, R. (1993) 'Healthy bodies, social bodies: men's and women's concepts and practices of health in everyday life.' *Social Science and Medicine*, 36 (1): 7-14.
- Sanda, M. G., Dunn, R. L., Michalski, J., Sandler, H. M., Northouse, L., Hembroff, L., Lin, X., Greenfield, T. K., Litwin, M. S., Saigal, C. S., Mahadevan, A., Klein, E., Kibel, A., Pisters, L. L., Kuban, D., Kaplan, I., Wood, D., Ciezki, J., Shah, N. and Wei,

J. T. (2008) 'Quality of life and satisfaction with outcome among prostate-cancer survivors.' *New England Journal of Medicine*, 358 (12): 1250-1261.

Sanderson, T., Calnan, M. and Kumar, K. (2015) 'The moral experience of illness and its impact on normalisation: Examples from narratives with Punjabi women living with rheumatoid arthritis in the UK.' *Sociology of Health and Illness*, 37 (8): 1218-1235.

Sanderson, T., Calnan, M., Morris, M., Richards, P. and Hewlett, S. (2011) 'Shifting normalities: Interactions of changing conceptions of a normal life and the normalisation of symptoms in rheumatoid arthritis.' *Sociology of Health and Illness*, 33 (4): 618-633.

Sayer, A. (2011) *Why Things Matter to People: Social Science, Values and Ethical Life*. Cambridge: Cambridge University Press.

Scambler, G. (1989) *Epilepsy*. London: Routledge.

Scambler, G. (2009) 'Health-related stigma.' *Sociology of Health and Illness*, 31 (3): 441-455.

Scambler, G. and Hopkins, A. (1986) 'Being epileptic: Coming to terms with stigma.' *Sociology of Health and Illness*, 8 (1): 26-43.

Schneider, J. and Conrad, P. (1980) 'In the closet with illness: Epilepsy, stigma potential and information control.' *Social Problems*, 28 (1): 32-44.

Schneider, J. and Conrad, P. (1983) *Having Epilepsy: The Experience and Control of Illness*. Philadelphia: Temple University Press.

Schrock, D. and Boyd, E. M. (2006) 'Reflexive transempodiment.' In Waskul, D. and Vannini, P. (Eds) *Body/Embodiment: Symbolic Interactionism and the Sociology of the Body*, 51-66. Aldershot: Ashgate.

Schutz, A. (1970) *On Phenomenology and Social Relations: Selected Writings*. (Edited by Helmut R. Wagner). Chicago: University of Chicago Press.

Schwalbe, M. and Wolkomir, M. (2001) 'The masculine self as problem and resource in interview studies of men.' *Men and Masculinities*, 4 (1): 90-103.

Schwalbe, M. and Wolkomir, M. (2002) 'Interviewing Men.' In Gubrium, J. F. and Holstein, J. A. (Eds) *Handbook of Interview Research: Context and Method*. London: Sage.

Scott, A. and Wenger, G. C. (1995) 'Gender and social support networks in later life.' In Arber, S. and Ginn, J. (Eds) *Connecting Gender and Ageing: A Sociological Approach*, 158-72. Buckingham: Open University Press.

- Seale, C. (1999) 'Quality in qualitative research.' *Qualitative Inquiry*, 5 (4): 465-478.
- Seale, C. (2005) 'Using Computers to Analyse Qualitative Data.' In Silverman, D. (2005) (Ed) *Doing Qualitative Research: A Practical Handbook*. London: Sage.
- Seidler, V. J. (2006) *Transforming Masculinities: Men, Cultures, Bodies, Power, Sex and Love*. London: Routledge.
- Seidler, V. J. (2007) 'Masculinities, bodies, and emotional life.' *Men and Masculinities*, 10 (1): 9-21.
- Sestini, A. J. and Pakenham, K. I. (2000) 'Cancer of the prostate: A biopsychosocial review.' *Journal of Psychosocial Oncology*, 18 (1): 17-38.
- Shaw, I. (2008) 'Ethics and the practice of qualitative research.' *Qualitative Social Work*, 7 (4): 400-414.
- Silverman, D. (2005) *Doing Qualitative Research: A Practical Handbook*. London: Sage.
- Silverman, D. (2011) *Interpreting Qualitative Data: A Guide to the Principles of Qualitative Research*. London: Sage.
- Silverman, D. (2013) *Doing Qualitative Research: A Practical Handbook*. London: Sage.
- Singer, E. (1974) 'Premature social aging: The social-psychological consequences of a chronic illness.' *Social Science and Medicine (1967)* 8 (3): 143-151.
- Smith, B. and Sparkes, A. C. (2005) 'Men, sport, spinal cord injury, and narratives of hope.' *Social Science and Medicine*, 61 (5): 1095-1105.
- Smith, B. and Sparkes, A. C. (2008) 'Changing bodies, changing narratives and the consequences of tellability: A case study of becoming disabled through sport.' *Sociology of Health and Illness*, 30 (2): 217-236.
- Smith, C. (2003) *Moral, Believing Animals: Human Personhood and Culture*. Oxford: Oxford University Press.
- Smith, D. P., King, M. T., Egger, S., Berry, M. P., Stricker, P. D., Cozzi, P., Ward, J., O'Connell, D. L. and Armstrong, B. K. (2009) 'Quality of life three years after diagnosis of localised prostate cancer: population based cohort study.' *British Medical Journal*, 339 (4817): 1-12.

Smith, J. A., Braunack-Mayer, A., Wittert, G. and Warin, M. (2008) "'It's sort of like being a detective": Understanding how Australian men self-monitor their health prior to seeking help.' *BMC Health Services Research*, 8 (1): 56.

Soares, J. J., Macassa, G., Grossi, G. and Viitasara, E. (2008) 'Psychosocial correlates of hopelessness among men.' *Cognitive Behaviour Therapy*, 37 (1): 50-61.

Social Research Association (2003) *Ethical Guidelines*. Retrieved 12.02.2017 from <http://the-sra.org.uk/research-ethics/ethics-guidelines/>

Solimeo, S. (2008) 'Sex and gender in older adults' experience of Parkinson's disease.' *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 63 (1): S42-S48.

Sontag, S. (1988) *Illness as metaphor*. London: Macmillan.

Sox, H. C. (2012) 'Quality of Life and Guidelines for PSA Screening.' *The New England Journal of Medicine*, 367 (7): 669-671.

Sparkes, A. C. and Smith, B. (2002) 'Sport, spinal cord injury, embodied masculinities, and the dilemmas of narrative identity.' *Men and Masculinities*, 4 (3): 258-285.

Stanford, J. L., Feng, Z., Hamilton, A. S., Gilliland, F. D., Stephenson, R. A., Eley, J. W., Albertsen, P. C., Harlan, L. C. and Potosky, A. L. (2000) 'Urinary and sexual function after radical prostatectomy for clinically localized prostate cancer: The Prostate Cancer Outcomes Study'. *JAMA*, 283 (3): 354-360.

Stanley, L. and Wise, S. (1990) 'Method, methodology and epistemology in feminist research processes.' In Stanley, L. (Ed) *Feminist Praxis: Research, Theory and Epistemology in Feminist Sociology*. London: Routledge.

Steginga, S. K., Occhipinti, S., Dunn, J., Gardiner, R. A., Heathcote, P. and Yaxley, J. (2001) 'The supportive care needs of men with prostate cancer (2000).' *Psycho-Oncology*, 10 (1): 66-75.

Steinberg, G. D., Carter, B. S., Beaty, T. H., Childs, B. and Walsh, P. C. (1990) 'Family history and the risk of prostate cancer.' *The Prostate*, 17 (4): 337-347.

Steineck, G., Helgesen, F., Adolfsson, J., Dickman, P. W., Johansson, J. E., Norlén, B. J. and Holmberg, L. (2002) 'Quality of life after radical prostatectomy or watchful waiting.' *New England Journal of Medicine*, 347 (11): 790-796.

Sulik, G. A. (2009) 'Managing biomedical uncertainty: The technoscientific illness identity.' *Sociology of Health and Illness*, 31 (7): 1059-1076.

- Tannock, I. F. (2000) 'Eradication of a disease: how we cured asymptomatic prostate cancer.' *The Lancet Oncology*, 1: 17-19.
- Taylor, D. and Bury, M. (2007) 'Chronic illness, expert patients and care transition.' *Sociology of Health and Illness*, 29 (1): 27-45.
- Tewari, A., Sooriakumaran, P., Bloch, D. A., Seshadri-Kreaden, U., Hebert, A. E. and Wiklund, P. (2012) 'Positive surgical margin and perioperative complication rates of primary surgical treatments for prostate cancer: A systematic review and meta-analysis comparing retropubic, laparoscopic, and robotic prostatectomy.' *European Urology*, 62 (1): 1-15.
- Thompson, E. H. (1994) 'Older men as invisible in contemporary society.' In Thompson, E. H. (Ed) *Older Men's Lives*, 1-21. Thousand Oaks, CA: Sage.
- Thorne, S. E., Nyhlin, K. T., and Paterson, B. L. (2000) 'Attitudes toward patient expertise in chronic illness.' *International Journal of Nursing Studies*, 37 (4): 303-311.
- Trinh, Q. D., Sammon, J., Sun, M., Ravi, P., Ghani, K. R., Bianchi, M., Jeong, W., Shariat, S. F., Hansen, J., Schmitges, J., Jeldres, C., Rogers, C. G., Peabody, J. O., Montorsi, F., Menon, M. and Karakiewicz, P. I. (2012) 'Perioperative outcomes of robot-assisted radical prostatectomy compared with open radical prostatectomy: Results from the nationwide inpatient sample.' *European Urology*, 61 (4): 679-685.
- Turner, B. S. (1995) 'Aging and identity: Some reflections on the somatization of the self.' In Featherstone, M. and Wernick, A. (Eds) *Images of Aging: Cultural Representations of Later Life*, 245-60. London: Routledge.
- Turowetz, J. J. and Maynard, D. W. (2010) 'Morality in the social interactional and discursive world of everyday life.' In Hitlin, S. and Vaisey, S. (Eds) *Handbook of the Sociology of Morality*, 503-526. New York: Springer.
- Twigg, J. (2000) 'Carework as a form of bodywork.' *Ageing and Society*, 20 (4): 389-411.
- Tyson, M. D. and Penson, D. F. (2016) "Killing two birds with one stone": patient-reported quality-of-life outcomes from the Prostate Testing for Cancer and Treatment ( ProtecT) trial.' *BJU International*, 118 (6): 844-845.
- Ussher, J., Kirsten, L., Butow, P. and Sandoval, M. (2006) 'What do cancer support groups provide which other supportive relationships do not? The experience of peer support groups for people with cancer.' *Social Science and Medicine*, 62 (10): 2565-2576.

- Wallace, M. (2002) 'Uncertainty and quality of life of older men who undergo watchful waiting for prostate cancer.' *Oncology Nursing Forum*, 30 (2): 303-309.
- Warren, S. (1997) 'Who do these boys think they are? An investigation into the construction of masculinities in a primary classroom.' *International Journal of Inclusive Education*, 1 (2): 207-222.
- Watson, J. (2000) *Male Bodies: Health, Culture and Identity*. Buckingham: Open University Press.
- Weiner, C. (1975) 'Tolerating uncertainty: The burden of rheumatoid arthritis.' In Strauss, A. and Glaser, B. (Eds) *Chronic Illness and the Quality of Life*. St Louis, MO: Mosby.
- Weitz, R. (1989) 'Uncertainty and the lives of persons with AIDS.' *Journal of Health and Social Behavior*, 30 (3): 270-281.
- Wenger, G. C. (2002) 'Interviewing older people.' In Gubrium, J. F. and Holstein, J. A. (Eds) *Handbook of Interview Research: Context and Method*, 259-278. London: Sage.
- Wenger, L. M. and Oliffe, J. L. (2013) 'Moving Beyond the Prostate: Benefits in Broadening the Scope of Research on Men and Cancer.' *American Journal of Men's Health*, 7 (2): 138-141.
- Wenger, L. M. and Oliffe, J. L. (2014) 'Men managing cancer: A gender analysis.' *Sociology of Health and Illness*, 36 (1): 108-122.
- Wetherell, M. and Edley, N. (1999) 'Negotiating hegemonic masculinity: Imaginary positions and psycho-discursive practices.' *Feminism and Psychology*, 9 (3): 335-356.
- White, A. (2001) 'How men respond to illness.' *Men's Health Journal*, 1 (1): 18-19.
- Whitehead, S. M. (2002) *Men and Masculinities: Key Themes and New Directions*. Cambridge: Polity.
- Whitley, R. D. (1970) 'Black boxism and the sociology of science: A discussion of the major developments in the field.' *The Sociological Review*, 18 (S1): 61-92.
- Williams, C. L. and Heikes, E. J. (1993) 'The importance of researcher's gender in the in-depth interview: Evidence from two case studies of male nurses.' *Gender and Society*, 7 (2): 280-291.

- Williams, G. and Popay, J. (2006) 'Lay knowledge and the privilege of experience.' In Kelleher, D., Gabe, J., Williams, G. (Eds) *Challenging Medicine*. Oxford: Routledge.
- Williams, G. H. (1993) 'Chronic illness and the pursuit of virtue in everyday life.' In Radley, A. (Ed) *Worlds of Illness: Biographical and Cultural Perspectives on Health and Disease*. London: Routledge.
- Williams, K. C., Hicks, E. M., Chang, N., Connor, S. E. and Maliski, S. L. (2014) 'Purposeful normalization when caring for husbands recovering from prostate cancer.' *Qualitative Health Research*, 24 (3): 306-316.
- Williams, C. (2000) 'Doing health, doing gender: Teenagers, diabetes and asthma.' *Social Science and Medicine*, 50 (3): 387-396.
- Williams, S. (2000) 'Chronic illness as biographical disruption or biographical disruption as chronic illness? Reflections on a core concept.' *Sociology of Health and Illness*, 22 (1): 40-67.
- Williams, S. and Bendelow, G. (2000). "Recalcitrant bodies'? Children, cancer and the transgression of corporeal boundaries.' *Health* 4 (1): 51-71.
- Wilt, T. J., MacDonald, R., Rutks, I., Shamliyan, T. A., Taylor, B. C. and Kane, R. L. (2008) 'Systematic review: Comparative effectiveness and harms of treatments for clinically localized prostate cancer.' *Annals of Internal Medicine*, 148: 435-448.
- Wynne, B. (1996) 'May the sheep safely graze? A reflexive view of the expert-lay knowledge divide.' In Lash, S., Szerszynski, B. and Wynne, B. (Eds) *Risk, Environment and Modernity: Towards a New Ecology*, 44-83. London: Sage.
- Zeliadt, S. B., Ramsey, S. D., Penson, D. F., Hall, I. J., Ekwueme, D. U., Stroud, L. and Lee, J. W. (2006) 'Why do men choose one treatment over another? A review of patient decision making for localized prostate cancer.' *Cancer*, 106: 1865-74.
- Ziebland, S. (2004) 'The importance of being expert: the quest for cancer information on the internet.' *Social Science and Medicine*, 59 (9): 1783-1793.
- Zinn, J. O. (2005) 'The biographical approach: A better way to understand behaviour in health and illness.' *Health, Risk and Society*, 7 (1): 1-9.
- Zinn, J. O. (2008) 'Heading into the unknown: Everyday strategies for managing risk and uncertainty.' *Health, Risk and Society*, 10 (5): 439-450.
- Zola, I. K. (1972) 'Medicine as an institution of social control.' *The Sociological Review*, 20 (4): 487-504.



# Appendices

## Appendix 1: Participant Information Sheet



Centre for Criminology and Sociology

Royal Holloway, University of London

Egham, Surrey, TW20 0EX, UK

### **Study: Understanding men's recovery experiences following treatment for prostate cancer.**

I would like to invite you to take part in a research project. Before you decide, please read this sheet, it will explain why the research is being done and what it will involve for you. Please take the time to read the following information carefully and please feel free to ask any questions to me in person or via my contact information overleaf.

#### **What will happen to me if I take part?**

You will be asked to participate in a one-to-one interview with the student researcher. This interview will last between one and one and a half hours. It will take place at your home or at a public location of your choosing, arranged prior to the interview. During the interview a Dictaphone will be used to make an audio recording of the interview and the student researcher may take notes

of what is being said. The audio recording will afterwards be transcribed and used for analysis.

### **What is the purpose of the study?**

This study seeks to explore men's experiences of recovery from prostate cancer after having undergone treatment. This research aims to identify common themes in men's experiences of diagnosis and treatment of prostate cancer, whilst also investigating how these experiences might be important in shaping men's attitudes and lives following treatment.

### **Do I have to take part?**

No, you do not have to participate. You can withdraw at any time and may do so without giving a reason. Following the interview you have up to a month following the date of your interview to withdraw from the study if you wish to. If you do take part, you do not have to answer any question put to you and do not need to give any reason for your decision not to do so.

### **What are the risks and benefits?**

Risks – Discussions within the interview will address sensitive topics which could cause distress. If this were to occur then if you decide not to continue the Dictaphone would be turned off and the interview ended.

Benefits – Taking part in this study will assist and add to current knowledge of men’s experiences of prostate cancer following treatment and has potential policy implications for how health care is provided in this area.

**Will my taking part in the study be kept confidential?**

Yes. All of the information you give will be anonymised so that those reading reports from the research will not know who has contributed to it. Your signed consent form will also be stored separately from the responses you provide. Data will be stored securely in accordance with the Data Protection Act (1998).

**Contact details of researcher and supervisors**

**Student Researcher**

Richard Green

Email: [richard.green.2008@live.rhul.ac.uk](mailto:richard.green.2008@live.rhul.ac.uk)

Mobile: *(removed)*

**Supervisors**

Professor Jonathan Gabe – [j.gabe@rhul.ac.uk](mailto:j.gabe@rhul.ac.uk)

Dr. Rob Meadows – [r.meadows@surrey.ac.uk](mailto:r.meadows@surrey.ac.uk)

Professor Sara Arber – [s.arber@surrey.ac.uk](mailto:s.arber@surrey.ac.uk)

**Thank you for taking the time to read this information sheet, please keep this for reference and to contact us with any queries.**

## Appendix 2: Consent Form



**Study: Understanding men's recovery experiences following treatment for prostate cancer.**

**Student Researcher: Richard Green**

**Please read the following bullet points carefully and only mark each of the subsequent boxes with a ✓ if you agree with the corresponding statement.**

- I the undersigned voluntarily agree to take part in this study.
- I have read and understood the Information Sheet provided. I have been given a full explanation by the researcher of the nature, purpose, location and likely duration of the study, and of what I will be expected to do.
- I have been given the opportunity to ask questions on all aspects of the study and have understood and been satisfied with the information given as a result.
- I understand that all personal data relating to volunteers is held and processed in the strictest confidence, and in accordance with the Data Protection Act (1998). I agree that I will not seek to restrict the use of the results of the study on the understanding that my anonymity is preserved.
- I understand that I am free to withdraw from the study at any time without needing to justify my decision and without prejudice.
- I confirm that I have read and understood the above and freely consent to participating in this study. I have been given adequate time to consider my participation and agree to comply with the instructions and restrictions of the study.

Please read through the following points carefully and only tick each of the boxes if you agree with the statement that it corresponds to:

- I have read the information sheet about this study
- I have had the opportunity to ask questions
- I have received satisfactory answers to any questions
- I understand that I am free to withdraw from the study at any time, without giving a reason
- I agree to participate in this study

NB: This consent form will be stored separately from the responses you provide.

**Name of participant** .....

**Signed** .....

**Date** .....

**Name of researcher** .....

**Signed** .....

**Date** .....

### Appendix 3: Topic Guide

**Core Topics:** Everyday Life, Heuristics, Uncertainty, Uncertain Futures, Perceptions of Risk, Gender, Masculinity, Support Groups, Clinicians, Trust, Hope, Embodiment.

- To start, can you tell me a bit about how you were diagnosed with prostate cancer?
  - Was it a routine test that identified the cancer?
    - Did you ask for the test or was it something your doctor suggested you have?
  - Were you experiencing any symptoms?
    - How long were you experiencing symptoms before you sought medical advice?
    - Did you think it might be anything else?
    - Did you look into what the cause of the symptoms might be before you sought medical advice?
  - Did you know much about prostate cancer before you were diagnosed?
    - Had you at the time, or have you since, seen much in the media about prostate cancer? (Bob Monkhouse, Movember, Men United)
    - What information did the doctor/nurse tell you about prostate cancer?
  - What tests did you have to diagnose you?
    - What did each of these involve?
    - How do each of these tests work?

- What was your PSA score?
- What was your Gleason Score?
- What did your other tests show?
- Did you believe these tests to be reliable and accurate indicators for detecting prostate cancer?
- Who first told you that you had prostate cancer?
  - What were your initial feelings and first reactions when you were told this?
  - What information were you given about how prostate cancer would impact on you?
  - How were you feeling in the days/weeks following diagnosis?
  - What was happening in your life at the time and did the diagnosis have an effect on your personal and working life?
- How did you tell family/friends/work colleagues about the cancer?
  - What did you tell people when you were going through treatment and what do you say to people now when you talk about or are asked about your experiences?
- What did the doctor recommend in terms of treatment or non-treatment options?
  - How much time were you given to make a decision?
  - Did you look for additional information elsewhere, and if so where?
  - Were the opinions of important people around you significant in deciding on your course of treatment?

- Why did you decide to have the treatment that you did?
  - How long after your decision did treatment begin?
- What did the treatment involve?
  - How regularly? Was there any regular contact with different types of staff?
  - How did the treatment feel, both at the time and shortly following the treatment?
  - How did the treatment fit in with your personal/family and work life?
    - How, if at all, did things change in your personal/family and work life?
    - Did having treatment put any strain or pressure on your personal/family and work life?
    - How was your day-to-day life affected by the treatment?
- Were there any side effects to the treatment you had? **Key topics to consider: urinary incontinence, fluid retention, and sexual dysfunction.**
  - IF SO – Do you still face any persistent side effects up to the present day?
    - IF NOT – How long did it take for the side effects to diminish?
  - What sort of advice, recommendations, or prescribed medications did the doctor provide?
  - Have the side effects, at any point, had any impact on how you go about your day-to-day life?



- What were your experiences like in the days/weeks/months following your treatment?
  - And over the longer term, up to the present day, how have you found the recovery process?
- Has the treatment process made much of a difference to the way you live your everyday life?
- Are you still having tests and regular contact with doctors following your treatment?
  - IF SO, describe these events? How does it feel before attending them?
  - IF NOT, how long ago did tests and contact stop?
    - How did it feel not having regular appointments and contact with clinicians?
- What doctors/nurses/medical staff have you had contact with over the course of your illness?
  - How would you rate their service of care?
  - How much value do you place in their advice, recommendations, and/or skills?
- At what point did you first come in contact/become involved with your local prostate cancer support group?
  - How did you find out about the support group?
  - What services do the support group offer, and which have you used?
    - How useful have you found these services?
    - How will an average meeting go?

- What sorts of things are discussed at these meetings?
  - What do you think they could do better or what more do you think they could do for men following diagnosis and treatment for prostate cancer?
- Prostate cancer is solely a men's disease, I just wondered how you think your experiences might differ from say a woman's experiences facing breast cancer, for example?
  - What role has your spouse played in throughout your cancer experience?
- Do you know anyone else who has suffered from cancer?
  - Have you spoken with them about their experiences of cancer?
  - In what ways are they similar/different to your own experiences?
- How do you feel that some of your (male) friends would have coped if they had been in your position?
- What were some of your lowest and highest points throughout the treatment process?
- How do you view your future having undergone treatment for prostate cancer?
  - If you had the choice again, after being diagnosed with prostate cancer, would you change any of your decisions about treatment or any aspect of the experience as a whole?
  - Has the experience had any impact on any life plans you might have or have had for the future, or how you view your future?

#### **Appendix 4: Email Advert Sent to Support Group 1 Mailing List**

**(Please Note: The original contents of this email have been amended in italics to protect anonymity. This email was sent on my behalf by the Support Group leader.)**

Dear Sirs,

My name is Richard Green and I am the grandson of *(name)* (Norman to those who knew him), who helped to establish *(Support Group 1)*. He was successfully treated for prostate cancer but sadly passed away in 2009. My grandfather's experiences of prostate cancer have led me to do research on prostate cancer and I am writing to ask you to take part in my PhD research project.

I am seeking to interview men who have successfully completed treatment for prostate cancer, interviews would last approximately an hour at your own homes and I can be extremely flexible with regard to times and days to conduct interviews to fit around peoples' busy schedules.

My research project is particularly focussed on men's experiences after treatment for prostate cancer, concerning their experiences of the side effects of different treatments and looking at what recovery and getting back to normal means to men. I am very much hoping that some of you will be willing to share your prostate cancer stories with me.

I am in the middle of a three-year funded PhD studentship at Royal Holloway, University of London and in association with the University of Surrey. Attached to this email is an information sheet which provides some further details about my study and includes my contact details (please email: [Richard.Green.2008@live.rhul.ac.uk](mailto:Richard.Green.2008@live.rhul.ac.uk) or [r.j.green@surrey.ac.uk](mailto:r.j.green@surrey.ac.uk) and mobile: *(removed)*). I urge you to get in contact with me to ask any additional questions about my project, or better yet to agree to participate!

Thank you for taking the time to read this email, I hope to hear from you soon.

Many Thanks,

Richard Green

**Appendix 5: Email Advert Sent to Support Group 2 Mailing List**

**(Please Note: The original contents of this email have been amended in italics to protect anonymity. This email was sent by the Support Group leader.)**

Dear Member

At last Friday's (*Support Group*) meeting I talked about the Sociology PhD student, Richard Green, who had contacted me concerning his project. I repeat below his original email to me and have attached a pdf document giving more details of the project (*See Appendix 1*).

I had a very interesting hour and a half with him. He is highly intelligent (already got a BSc and an MSc!!) and was very easy to talk with. He wants to talk with men about their experiences before and after their treatment/diagnosis for prostate cancer - which to be honest is what we do with each other at many of the meetings.

Can I urge you to consider taking part in this study. He can easily be contacted by email or by phone - his details are on the information sheet. He is quite happy to come to your house for the interview to cause as little inconvenience as possible.

If I can help further, do either email or phone me.

Warmest wishes

(*Support Group Leader*)

-----

Dear (*Support Group Leader*),

I am a PhD student at Royal Holloway, University of London doing research on men's experiences of recovery following treatment for prostate cancer. I have so far been recruiting men to be interviewed for my study through (*Support Group 1*), however I am looking for more men to interview and am therefore writing to ask whether you might consider allowing me to advertise my study through your organisation, perhaps via your emailing list or newsletter, or at one of your group meetings?

My grandfather was diagnosed and successfully treated for prostate cancer about a decade ago and was active in helping and developing (*Support Group 1*), which is where my interest in prostate cancer started. Men's lives after completing treatment is an area that has generally received less attention in research compared to other areas like diagnosis and treatment. It is an area of study I am passionate about exploring and I am looking to make the research as strong as possible by interviewing as many men as possible. I have attached an information sheet about my research which can tell you a bit more about what I am doing, although if you have any additional questions I would urge you to contact me via this email address or by my contact number below, as it would be great to be able to explain more about my research and what I am hoping to achieve, either by email, phone or in person.

Thank you for taking the time to read this email, I look forward to hearing from you.

Many Thanks,

**Richard Green**

PhD Candidate  
Royal Holloway, University of London  
Mobile: (*removed*)

## **Appendix 6: Observations from Attending a Meeting at Support Group 2**

Various participants had previously encouraged me to come along to a meeting to find out how the support group operates and the experience was informative in seeing how the meetings play out in practice. The meeting I attended was in a community meeting hall in an urban area adjacent to the hospital that patients were most often referred to. This was reportedly for the convenience of medical practitioners who came to give talks at the support group meetings so that they would not have to travel far, as well as for other practical and financial reasons. The meeting place and the group meeting itself was not on NHS property or affiliated with the NHS.

Here follows a brief account of this support group visit, which is described from memory and from notes written during and shortly after the visit. At this support group meeting, chairs were laid out in rows facing a presentation stand at the back end of the room. Prior to the meeting officially beginning, attendees (a mixture of men and women, predominantly men) stood and sat around the edges of the arranged chairs and talked while drinking teas and coffees. At the entrance, two people registered attendance as people entered. I had previously been informed that this support group operated a policy of contacting attendees who had not attended for an extended series of meetings in a row, just to check that everything was going well for them. There were a group of solely women (as far as I could see) in a kitchen area off from the main hall separated by a doorway and large serving hatch from which teas and coffees were being served. When I arrived my gatekeeper, who was also the support group leader, came over to welcome me, got me a cup of tea, and introduced me to a few people to chat with. When the meeting began, I sat at the front and the support group leader introduced the main speaker, a secondary speaker, and myself – where he encouraged attendees to speak to me and take part in my research. The main speaker was a radiotherapy consultant, at the beginning of her talk she noted that since she had already given the same talk twice over the last two years, she would adopt a new strategy and instead presented an open Q&A session for approximately

45 minutes. The second speaker, a research nurse, then encouraged attendees to consider taking part in a research project she was working on – a trial of washable incontinence pads. At the end of the session attendees either left, chatted more, tidied up, or sought to speak to either of the speakers. Approximately eight people came to speak to me and asked me questions about my research and whether they might be viable participants. I wrote down the names and contact details of some of these men while others gave me their business cards. I then helped to tidy up, thanked the support group leader for inviting me to attend, wrote some notes and thoughts about the session while sitting in my car, and then left.

## **Appendix 7: List of Developed Codes**

**(Please Note: Indentations refer to sub-level codes)**

Bureaucracy

Cancer

Cancer Charities

Death

Depression

Diagnosis

Doctors

Doctors - Trust

Specialist Nurses

Engaging in risk discourse

Family History

Fitness

Forms of Capital

Benefits of the support group

Knowing People

Location

Other social groups

Religious

Retirement

Volunteering or Giving

Working Lives or Professions

Holidays

Media - Prostate Cancer

Medical Professionals - risk and support information

Men's Health Behaviours

Online support

Other health complaints

Pre-Diagnosis - Asymptomatic

Pre-Diagnosis - Symptomatic

Prostate Cancer Awareness

Public vs. Private NHS



Quality of Care

Recovery

Affecting Sleep

Emotional Aspects of Recovery

Faults with Care

Holiday Disruptions

Masculinity or Pride

Physical Recovery

Alternative Therapies

Disrupted Recovery - Further Interventions

Disrupted Recovery - Recurrence

Disrupted Recovery - Surgery Went Wrong

From Radiotherapy

Immediately after surgery

Recovery compared to other men

Stigma of catheter

Role or Experiences of Wives

Screening Controversy

Single Man

Sleep

Stories and Fantasies

Practical Professions

Risk Professions

Demonstrating Patient Expertise

Becoming an Expert – Learning from others

Contesting Medical Practitioners

Within Support Groups

Contesting Expert Knowledge

Definition of an Expert

Experiential Expertise - Knowing One's Body

Expert Knowledge as exacerbating uncertainties about past decisions

Expert Knowledge as minimising uncertainties about past decisions

Expert Knowledge as Uncertain - not sure about something

Expert Knowledge to justify restricted treatment options  
Expert Knowledge to minimise uncertainties in the present or future  
Expert Knowledge, Expert Decisions  
Expert Knowledge, Personal Decisions  
Professional Working Life Applied Expertise  
Self-Management  
Spreading Gospel of Prostate Cancer  
Support Groups Facilitating Expert Knowledge  
    Support Group Encounters Shaping Men's Choices  
    Medical Practitioners at Support Groups facilitating expert knowledge  
Taking ownership of health  
    Producing own data

#### Support Group

Committee Membership and Duties  
Community Outreach  
Giving Advice  
How the group is run  
Other Support Groups  
Support Group - Discovery  
Support Group - History  
Support Group - Purpose of attending  
Support Group - Literature

#### Taking injections

#### Taking pills

#### Talking to other people

#### Technical Interest

#### Treatment

Any other treatment  
Brachytherapy  
Diagnostic Techniques  
Comparing treatments  
Having a choice  
    Restricted Choice

Hormone Therapy  
Making the right choice  
Ongoing PSA tests  
Radical Prostatectomy  
Radiotherapy  
Robot-Assisted Radical Prostatectomy  
Side effects  
Trans-Urethral Resection (bore) of the Prostate  
Watch and Wait

#### Uncertainty

Lay theorising of causality of prostate cancer  
    Diet  
Management - Being Adaptive  
Management - Being Cautious  
Management - Being decisive or not waiting around  
Management - Being Fatalistic  
Management - Being or feeling in control  
Management - Being prepared for the unexpected  
Management - Being Proactive  
Management - Being Stoic  
Management - Diary  
Management - Doctors  
Management - Emotions  
Management - Engaging in risk discourse  
Management - Family  
Management - Food  
Management - Hope  
Management - Humour  
Management - Luck, fate, chance  
Management - Reflecting on life  
Management - Research and Documentation  
Management - Specialist Nurses  
Management - Talking to other men  
Management - Talking to professionals

## Uncertain Bodies

Ageing Male Body

Fear of cancer recurrence

Urinary infections

Unexplained Symptoms

Training or practicing the body

Sexual Dysfunction

Relating to radiation

Relating to Hormone Therapy

Rectal Incontinence

Monitoring of the self

Lay theorising of bodily processes

Interventions

Incontinence

Artificial Urinary Sphincter

Compared with sexual dysfunction

Comparing to other men

Compromising - Choosing Life

Conflicting treatments

Convene Catheter Experiences

Coping With Incontinence

Planning Ahead

Experiences of having a catheter in

Experiences of Incontinence

Expert Patientness

Fitness

Frequency - Toilet

Incontinence Pads

Increasingly extensive interventions

Lay Theorising of Bodily Processes

Limitations of Incontinence

Medical Professionals - risk and support info

Medication for Incontinence

Minor Incontinence

New Normal  
Pelvic Floor Exercises  
Pelvic Sling  
Penile Clamp  
Personal - Emotional  
Removing catheter after surgery  
Retention  
Scar Tissue and Strictures  
Self-Catheterising  
Stretching the urethra  
Super-pubic catheter  
Support Group  
The 'What If' Question  
Toilet - Sleep - Night  
Traumatic Experiences  
Worries for the Future

#### Uncertain Futures

Decline  
Embodied uncertain futures  
Fear of recurrence  
    Not Fear of recurrence  
Managing Uncertain Futures  
New Technology  
Survival

#### Uncertain Pasts

Uncertainty - Diagnosis  
Uncertainty - Recovery  
Uncertainty - Treatment

#### Unreliable Narratives

#### Working Life Disruptions