

Changing narratives of prostate cancer 1990-2010

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Abstract

Prostate cancer (PCa) is a unique and controversial disease. This is at least due to the high prevalence of latent disease, increasing amounts of which is being diagnosed, most of which is indolent and not lead to death, and for which treatment carries significant risks. An increasing concern in medical sociology is how various social structures and actors contribute to the diagnosis and experience of conditions. For PCa, these include print media as an information source for men with prostate cancer (MWPCa), and PCa organisations (PCaOrgs) which have recently emerged in the UK. Yet, there is a distinct lack of UK studies of print media representation of PCa, of PCaOrgs, interaction between the two, and how any of this may impact on the experience of MWPCa. This thesis aims to address this deficit by drawing on narrative and framing theory to study 201 illness narratives of PCa across time: 140 illness narratives of MWPCa in UK newspapers 1990-2010; 20 with MWPCa interviewed in each of 2000 and 2010; and 21 with advocates around PCaOrgs in 2010. I ask: how have PCaOrgs and the UK print media been a force for change in the UK regarding how PCa is addressed and experienced by MWPCa? And more broadly what does this say about narrative structure and form. My findings indicate that though PCaOrgs and print media told stories of injustice around PCa, the substantive focus of this injustice changed over time—from PCa as “neglected” and “taboo” in the 1990s to other “pockets of injustice” since 2000. While one might expect that this to lessen any interactional difficulty that MWPCa experience in disclosing their illness, my study suggests this may not be so. My findings show how ideas of resonance and dissonance contribute to understanding the recursive and repetitive language around PCa.

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Acronyms

APA	Association for Prostate Awareness
BPH	Benign Prostatic Hyperplasia
CKWIC	Comparative Keyword in Context
DEP	Dominant Epidemiological Paradigm
DIPEX	Database of Individual Patient Experience
EHM	Embodied Health Movement
ERSPC	European Randomised Study of Screening for Prostate Cancer
GP	General Practitioner
HSM	Health Social Movement
HTO	Healthtalkonline
LUTS	Lower Urinary Tract Symptoms
MWPCa	Man/Men With Prostate Cancer
NBCC	National Breast Cancer Coalition
NICE	National Institute for Health and Care Excellence
NPCC	National Prostate Cancer Coalition (now renamed ZERO)
NSC	National Screening Committee
PCa	Prostate Cancer
PCaA	Prostate Cancer Advocate
PCaHSM	Prostate Cancer Health Social Movement
PCaOrg	Prostate Cancer Organisation
PCaSO	Prostate Cancer Support Organisation
PCRMP	Prostate Cancer Risk Management Programme
PCT	Primary Care Trust
PIP	Participant Information Pack
PLCO	Prostate, Lung, Colorectal and Ovarian (Cancer Screening Trial)
PRCF	Prostate Cancer Research Foundation
Protect	Prostate testing for cancer and treatment
PSA	Prostate Specific Antigen
TPCC	The Prostate Cancer Charity

Chapter 1 Introduction

The prostate, a small gland near a man's bladder with a role in producing semen, has been described both as 'the breast that got lost' (Kedrowski and Sarow, 2007: 135) and 'the problematic third testicle' (Oliffe, 2009: 33). Like the breast and the testicle, the prostate does not just biologically 'hang out' somewhere but is rather embodied in a cultural, social and medical setting. The cancer associated with the prostate, prostate cancer (PCa), is 'a unique and controversial disease' (Mazhar and Waxman, 2002: 594) with it seeming that 'everyone from the Lockerbie bomber to Adrian Mole (aged 39¼) has prostate cancer' (Profumo and Dinneen, 2010: 730). This controversy has its foundation in the 'major discrepancy between the true prevalence of prostate cancer (PC), the incidence of diagnosed PC and PC specific mortality' (Wolters et al., 2012: 108). What this means is that there is a high prevalence of latent PCa, an increasing amount of which is being diagnosed but of which a minority will cause mortality (Wolters et al., 2012: 109). On top of this, PCa is also controversial because it is the only human cancer, that while curable, may not need to be cured and for which the 'curing' may cause significant risks of urinary incontinence and impotence (Parker, 2004). Further, despite PCa often having 'a very indolent history' (Parker, 2004: 102), there were 10,837 PCa deaths in 2012 (Cancer Research UK, 2013a). Though deaths in men with non-lethal prostate tumours in the USA have been attributed in error to PCa, such error is thought to be less likely the case for the UK (Cancer Research UK, 2013a).

I begin this chapter, and thesis, with an overview of PCa in terms of recent trends in its prevalence, testing and screening, symptoms, diagnosis, known risk factors, and management and forms of treatment as this provides more substance to this ostensibly controversial condition. I continue by giving a brief indication of social actors and structures around PCa in the UK in order to define my research questions and aims. Finally I give an overview of my study design, data collection and data analysis.

1.1 Overview of prostate cancer

1.1.1 Morbidity and mortality trends

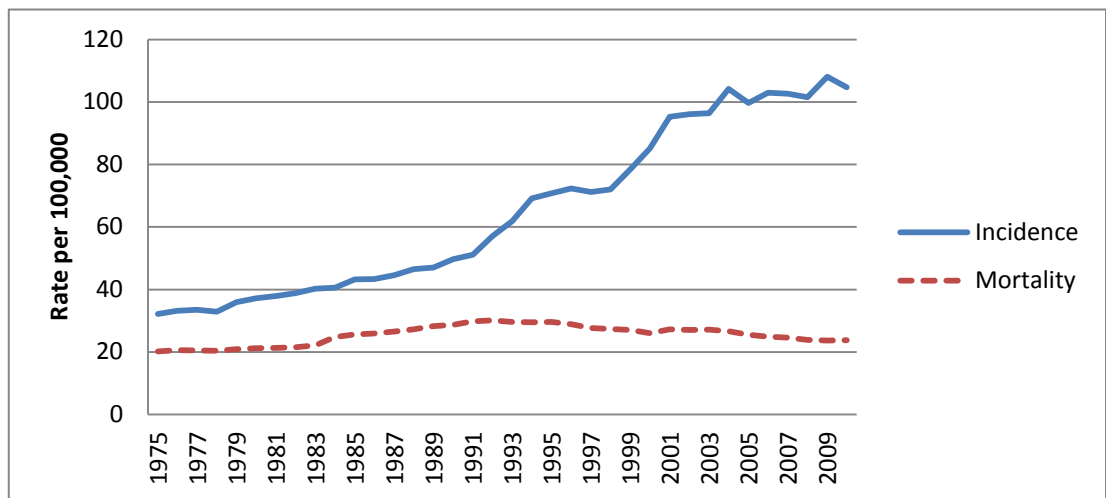
Excluding non-melanoma skin cancer, PCa is the fourth most commonly diagnosed cancer in the UK (after lung, colorectal and breast cancers) (Cancer Research UK, 2013b). It is the most frequently diagnosed cancer among men in the UK with an estimated 41,000 new cases diagnosed in 2010 and 900,000 worldwide in 2008 (Cancer Research UK, 2013c). The latest 5 year average survival rates¹ approach 82% (ranging from 92% in those aged 60-69 to 60% in those aged 80-99) (Cancer Research UK, 2013d). An estimated prevalence of over 250,000 men living with PCa in the UK in 2008 (Maddams et al., 2009) is predicted to more than treble to 830,000 (approximately 2.3% of the male population) by 2040 (Maddams et al., 2012).

These morbidity statistics indicate a huge increase in PCa incidence rates not reflected in mortality rates. Oliffe and Thorne (2007: 149) propose the likelihood that PCa will become a chronic, long-term illness for many men in Australia and Canada, the geographical context of their study on PCa and masculinities. This is because the proportion of elderly men in these countries is increasing and while PCa is the most commonly diagnosed male cancer, its mortality rate is significantly lower than its incidence rate. Given the above statistics on the morbidity and mortality rates of PCa, this may also be true of PCa in the United Kingdom. After lung cancer PCa is the second most common cause of cancer death in men in the UK accounting for 10,837 deaths in 2012 (Cancer Research UK, 2013a). Figure 1.1² shows the incidence rates in Great Britain (GB) alongside the mortality rates in the United Kingdom (UK) from 1975:

¹ Gigerenzer and Wegwarth (2013) argue that survival rates can mislead and that mortality rates are better used to communicate the benefits of screening for 2 reasons: 1) lead time bias - earlier detection means the time of diagnosis is earlier which alone increases 5 year survival rates; 2) screening increases overdiagnosis which in turn increases survival rates

² I was advised, through personal email communication from the CRUK Statistical Information Team (23-24 May 2012), to construct Figure 1.1 as a chart showing the incidence and mortality rates for PCa for GB alone 1975-2008 was no longer available on the CRUK website. More details of this correspondence and the original chart is shown in Appendix 1.

Figure 1.1. European age-standardised rates for incidence (GB) and mortality (UK) per 100,000 males, PCa, 1975-2010



(Cancer Research UK, 2013a; 2013c)

Figure 1.1 is very similar to a graph describing incidence and mortality rates in the USA (Welch et al., 2012: 57) which suggests that the area under the incidence curve represents a ‘tremendous amount of overdiagnosis’ (p. 57) in PCa. Overdiagnosis is defined in the context of PCa as ‘the diagnosis in men who would not have clinical symptoms during their lifetime’ (Schroder et al., 2009: 1327) or the diagnosis of a cancer that would never have been diagnosed in the absence of screening (Godtman et al., 2013: 102). More generally, Moynihan et al. (2012) note that:

Narrowly defined, overdiagnosis occurs when people without symptoms are diagnosed with a disease that ultimately will not cause them to experience symptoms or early death. More broadly defined, overdiagnosis refers to the related problems of overmedicalisation and subsequent overtreatment, diagnosis creep, shifting thresholds, and disease mongering, all processes helping to reclassify healthy people with mild problems or at low risk as sick. (Moynihan et al., 2012: 19)

Moynihan et al. (2012) go on to summarise four non-mutually exclusive contributory factors to overdiagnosis. These include overdiagnosis from ever widening disease definitions; screening detected overdiagnosis in people without symptoms; and the use of increasingly sensitive tests in those with symptoms.

1.1.2 Testing and screening

Much of the increase in incidence is attributed to the PSA test. Men with prostatic diseases, including PCa and benign prostatic hyperplasia (BPH), may have higher PSA levels both because of increased production of PSA and also distortions in the gland which allow PSA greater access to the circulation (Barry, 2001). In this way PSA is understood as a useful, though limited and controversial, biomarker for PCa (see Andriole et al., 2009; Barry, 2009; Collin et al., 2009; Schroder et al., 2009).

The effect of PSA testing on PCa related mortality remains unclear. The results from the European Randomized Study of Screening for Prostate Cancer (ERSPC) show a reduction in the rate of death from PCa in the screening group compared to the control group of 20% and absolute risk difference of 0.71 per 1000 men (Schroder et al., 2009). This conflicts with results, published in the same issue of *The New England Journal of Medicine*, from the United States Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial which shows no mortality gain (Andriole et al., 2009). An updated Cochrane review (Ilic et al., 2011) concludes from a meta-analysis of five randomised controlled trials (including ERSPC and PLCO) that PSA screening does not significantly reduce PCa mortality between men randomised to screening and control. Further, PCa specific mortality is not affected when men of different ages are screened and the number of men diagnosed with PCa is significantly higher in those randomised to screening rather than to control. The review also identifies harms of high rates of false-positive PSA results, overdiagnosis and adverse events associated with biopsies.

The mortality benefit found by Schroder et al. (2009) indicates a high risk of overdiagnosis with 1410 men needing to be screened and 48 treated to save one death from PCa. This leads to overtreatment which these authors identify as 'one of the major potential drawbacks of PSA screening' (2009: 106). Another drawback, 'compounded by messages (in the media and elsewhere)' (Welch and Black, 2010: 611) is the 'popularity paradox of screening: the more overdiagnosis that screening causes, the more people will feel they owe their lives to screening, and the more popular it will become' (Welch et al., 2012: 187). Writing in the *New York Times* (NYT), the man who discovered PSA in 1970 now says it is a 'hugely expensive public health disaster' (Ablin, 2010) and, referring to the ERSPC results (Schroder et al., 2009), 'that's 47 men who, in all likelihood, can no longer function sexually or stay out of the bathroom for long'

(Ablin, 2010). That Ablin has been told both to “shut up and sit down” (Hawkes, 2010: 340) and that his was ‘the number one requested article’ (p. 340) in the NYT indicates why this is ‘amongst the most debated topics in contemporary health care’ (Lane et al., 2010: 3095).

Adding to this debate, the diagnostic testing for PCa of men presenting with lower urinary tract symptoms (LUTS) or sexual dysfunction, or asymptomatic men ‘getting to be that age’ and opportunistically tested by their GP, is also described as de facto screening (Little et al., 2003; Collin et al., 2009; Drummond et al., 2009) or screening creeping in by the back door (Donovan et al., 2001). Currently, there is no known benefit of screening for PCa by PSA testing, digital rectal examination or any other method (Andriole et al., 2009). This has had direct implications in the decision, so far, by the UK National Screening Committee (NSC) not to recommend a systematic screening programme for PCa as ‘harms from prostate cancer screening using PSA are currently likely to outweigh the benefits’ (Mackie, 2010: 13). The Prostate Cancer Risk Management Programme (PCRMP), an NHS ‘informed choice programme’, currently stands in place of a national screening programme (Burford et al., 2010). There is though widespread agreement that national screening programmes are introduced due more to social movement advocacy than to clinical or epidemiological evidence (Brown et al., 2004; Jutel, 2009; Armstrong and Eborall, 2012; Faulkner, 2012; Welch et al., 2012).

1.1.3 Symptoms

A ‘symptom’ is not only ‘a bodily or mental phenomenon, circumstance, or change of condition arising from and accompanying a disease or infection and constituting an indication or evidence of it’ (Hsiao et al., 2007: E21) but is also considered as side-effects of treatment (p. E21.). The literature around symptoms of PCa is both scarce and ambiguous; scarce regarding the illness experience of men prior to diagnosis of PCa (see below for some exceptions) and ambiguous in the informing of those concerned with diagnosing PCa (Collin et al., 2008; Ito et al., 2013; Silberstein and Eastham, 2013; Weight, 2013; Weight et al., 2013).

The scarcity of the former is relieved somewhat by the incidental discussion of symptoms in research concerned with other aspects of the PCa illness experience, for example, treatment, testing or screening, or masculinity. A study of men with LUTS

without PCa reports that most of the men qualitatively interviewed, independent of race, social class or symptom severity, express a fear of PCa on presentation of LUTS (Brown et al., 2003). Zeliadt et al. (2008) report men not taking into account pre-diagnosis urinary symptoms when making decisions for surgical or non-surgical treatment for PCa. Chapple et al. (2002),¹ interviewing 52 men with prostate cancer (MWPCA), incidentally note that three quarters of these men consult their GP because of urinary symptoms.

The ambiguity of informing those concerned with diagnosing PCa is at least partly due to the long-standing debate and uncertainty regarding the association between BPH, LUTS and PCa (Weight, 2013) and also inconsistent evidence around sexual dysfunction and PCa. While PCa causes cells in the prostate to form tumours which may change the shape of the prostate gland, as men age their prostates may also enlarge causing BPH. If either a benign or cancerous prostate growth is large enough to press on the urethra it may cause symptoms of increased frequency, urgency or difficulty in passing urine; passing urine more often than usual especially at night; pain on passing urine; and blood in the urine or semen (Cancer Research UK, 2013e). The latter two symptoms are 'very rare' (Cancer Research UK, 2013e) in PCa and 'very early prostate cancer generally does not cause any symptoms at all' (Cancer Research UK, 2013e) (see forthcoming discussion of 'early' versus 'local' PCa §1.1.4). Symptoms of PCa which has spread may include pain in the hips, back, pelvis or other bony areas (Cancer Research UK, 2013e).

The sheer number of men who experience problematic voiding as they age means that LUTS are present in more than 50% of men aged over 60 and nearly 100% of men aged 90 (Weight, 2013). Men presenting with LUTS often, at their own or doctor's behest, have a PSA test or other PCa diagnostic tests and may be diagnosed with a low risk PCa (Collin et al., 2008; Ito et al., 2013; Silberstein and Eastham, 2013; Weight, 2013). Weight et al. (2013) find that men treated for their LUTS are not only more likely to be tested for PCa but also diagnosed with its localised form than men not treated for LUTS. However, they are no more likely to die from PCa or to be diagnosed with intermediate or high-risk cancer. The key, and controversial, issue Weight et al. (2013) highlight is whether men presenting with LUTS should be screened

¹ 20 of these men were matched along significant variables with 20 MWPCA for the purpose of this thesis

for PCa. They lament that their own and other extant data do not address this and it remains unclear whether the benefits of diagnosing these additional men with early PCa outweigh the associated harms.

Collin et al. report from two studies nested in the UK based 'Prostate testing for cancer and Treatment' (ProtecT) trial on the association between LUTS (2008) and sexual dysfunction (2009) with PCa. In the trial, men were invited to attend a prostate check and a PSA test with information collected before diagnosis on LUTS (specifically daytime and night-time frequency in urinating and urgency and hesitation) and sexual dysfunction (specifically erectile and ejaculatory dysfunction and sexual activity). Those with a PSA level ≥ 3.0 were invited to repeat the test, have a digital rectal examination (DRE) and a ten-core biopsy.

First, Collin et al. (2008) correct widespread misconceptions that the presence of LUTS means increased risk of PCa and that the lack of such symptoms indicates no cancer. The authors report: 1) a positive association between LUTS and a raised PSA among otherwise asymptomatic men; 2) that the lack of LUTS among men who have a raised PSA level indicates increased risk for PCa (see also the Ito et al., 2013 study on Japanese men); and 3) associations of LUTS with PCa did not differ between local or advanced disease. Their take-home message is that LUTS are more likely to be caused by benign rather than malignant prostate disease.

Second, Collin et al. (2009) investigate the inconsistent evidence around the association between sexual dysfunction and PCa. They suggest that evidence indicating the association of impotence with clinically detected PCa is likely to be biased given that men with impotence are more likely to present to their GP and undergo a PSA test and have PCa clinically detected. The authors suggest that such testing, controversially, equates to screening men with such symptoms. Also, they note that studies indicating that men diagnosed with PCa have more symptoms of sexual dysfunction may too be biased in that such a diagnosis is likely to have a psychological effect on their sexual function. From their own study they find only weak evidence for associations between sexual dysfunction and PSA detected PCa among British men aged 50-69. Furthermore, this weak association is found only in advanced PCa and not that localised to the prostate. They also report a positive correlation between LUTS and sexual dysfunction. Their take-home message here is that unlike LUTS, where the *lack* of such symptoms does indicate *greater* risk of PCa

and is thus of clinical utility in predicting individual risk of prostate cancer, the presence or lack of symptoms of sexual dysfunction does not provide such utility.

1.1.4 Diagnosis

The National Institute for Health and Clinical Excellence (NICE, 2008: 5) identifies three stages of cancer spread and growth: 1) localised PCa: cancer that is only in the prostate and has not spread; 2) locally advanced PCa: cancer that is in the prostate and has spread to surrounding tissues; and 3) metastatic (or advanced) PCa: cancer that is in the prostate and has spread to the lymph nodes, bones or other parts of the body. While NICE uses the more appropriate terminology of 'local' PCa, 'early' is still ubiquitous in the literature and on cancer websites. The Prostate Cancer Risk Management Programme (PCRMP) is ambiguous in its use of both 'early' and 'local', with its first use of early being in scare quotes (Burford et al., 2010: 8)¹. Writing about PCa but making a general observation, Faulkner notes that 'early' 'conveys an impression that there will be 'later' development of cancer associated with its initial detection' (2012: 11-12)². This 'impression' is in line with common sense notions that finding things early is valuable as it gives the opportunity to fix small problems before they become big (Welch et al., 2012). However, being recruited into a disease state 'earlier' is a form of 'diagnosis creep' (Aronowitz, 2009: 426) 'or leap' (Payer, 1992: 11) and potentially 'medicalising the previously healthy' (Aronowitz, 2009: 426).

Scholars concerned with the diagnosis and naming of a disease (Brown, 1990; Rosenberg, 1992; Chiong, 2004; Jutel, 2009) suggest that naming a disease 'does' work, for example in providing relief and conferring social legitimacy or collective identity to those ill (Chiong, 2004; Jutel, 2009). Rosenberg suggests that naming diseases involves a 'generation-specific repertoire of verbal constructs reflecting medicine's intellectual and institutional history' (1992: xiii) and so medicine's diagnoses may be understood as temporally situated according to the technologies and values available at a point in time (Jutel, 2009; see also Faulkner, 2012).

¹ My attention was drawn to this through personal correspondence with Alex Faulkner (24 April 2013)

² Also making this point is Jenny Donovan (personal correspondence 13 May 2013) who says she "should have" pursued 'the 'early' issue in published form"

1.1.5 Risk

There are three established risk factors for PCa: age; family history; and ethnicity (Cancer Research UK, 2013f). Other potential risk factors include the link between insulin-like growth factor-1 and related proteins with early life exposures that influence adult height (Lane et al., 2010; Cancer Research UK, 2013f); men with a previous cancer morbidity; and exposure to radiation (Cancer Research UK, 2013f). Factors known to decrease risk of PCa include diabetes (Lane et al., 2010; Cancer Research UK, 2013f); vitamins A, D, and E (found in foods containing lycopene, soy and selenium) (Cancer Research UK, 2013f); and the drugs warfarin and acetaminophen (Cancer Research UK, 2013f). While there is little literature around socio-economic deprivation and risk for PCa, McVey et al. (2010) observe a statistically significant difference between the most socio-economically deprived and the most affluent with those on low income more likely to choose watchful waiting as treatment for localised PCa. They suggest that such men may opt for this treatment because of the economic costs associated with treatment such as time off work and transport costs.

1.1.5.1 Age risk

There are two evident aspects of the risk of PCa around age. First, as men get older they are more likely to be diagnosed with PCa (Cancer Research UK, 2013c). Rates have continued to rise for men aged 45-54, 55-64 and 65-74 and decline for those aged 75-84 from the early 2000s and those aged 85+ from the mid-1990s. This may be due to diagnosis of early prostate cancers in younger men through PSA testing, leaving increasingly fewer cases which have not yet been diagnosed by the time men reach their 70s and 80s (Cancer Research UK, 2013c).

The second source of evidence for considering age risk and PCa is post-mortem data. Table 1.1 shows that approximately half of all men in their fifties have histological evidence of cancer in the prostate, which rises to 80% by age 80, but that only 3.8% of men will die from PCa (Sakr et al., 1996; as cited in Burford et al., 2010) (see also National Institute for Health and Clinical Excellence, 2008).

Table 1.1. Presence of PCa determined at autopsy

Age	20-29	30-39	40-49	50-59	60-69	70-79
Percentage of men in whom PCa was detected at autopsy	8	28	39	53	66	80
reproduced from Table 1 PRCMP (Burford et al. 2010: 10) originally sourced from Sakr et al. (1996)						

Table 1.1 also shows unexpected information which is confirmed by more recent autopsy studies seeking to identify the presence of unsuspected PCa in men who died from other unrelated causes (Powell et al., 2010; Soos et al., 2005). Soos et al. show ‘a surprisingly high prevalence of premalignant (HGPIN) and malignant [sic] disease in young men, starting in the third and fourth decades of life, and increasing steadily thereafter’ (2005: 739) and Powell et al. that sub-clinical PCa starts ‘as early as ages 20 to 29 years’ (Powell et al., 2010: 1793) in both black and white men. Similarly, Wolters et al. (2012: 109) draw attention to the high rates of incidentally detected PCa through radical cystoprostatectomy of patients treated for bladder cancer and who had no prior evidence of PCa. While such information may be important for the early detection of PCa, it also has implications for screening asymptomatic men as this would substantially increase the chance of detecting non-clinically relevant PCAs and inducing overtreatment (Wolters et al., 2012).

1.1.5.2 Family history

There is a large body of evidence indicating that men with a family history of PCa, or other cancers, are at increased risk themselves (Hemminki and Chen, 2005; Kicinski et al., 2011; Madersbacher et al., 2010). This risk is impacted further by the relatedness of the family member, the age of the MWPCA at diagnosis and the total number of family members affected (Madersbacher et al., 2010). Of note is that ‘family history’ does not necessarily imply a genetic or hereditary link but rather recognises the complex mix of environmental and genetic factors in an aggregation of cases within a family (Madersbacher et al., 2010). The PCa incidence rate for men whose fathers or brothers have PCa is 3.14 times and 2.35 times higher respectively than in other men with risk increasing if both father and brother have PCa and also if men are under 65 (Kicinski et al., 2011). There is also tentative evidence that risk increases somewhat for men with an affected second-degree relative. Further, a Swedish study finds that sons

with mothers diagnosed with breast or ovarian cancer have an increased risk of PCa (Hemminki and Chen, 2005).

1.1.5.3 Ethnicity

Incidence rates of PCa are lower for Caribbean and African men than for African-Americans and the latter have a 55% greater incidence than white Americans (Ben-Shlomo et al., 2008). The primary research of Ben-Shlomo et al.'s study shows that while the absolute risk for first generation all black, black African and black Caribbean men in the United Kingdom is less than for African-Americans, they still have an approximately three-fold greater risk of developing PCa than white men in the UK. This is more apparent for younger men. Kheirandish and Chinegwundoh (2011), in their study of incidence rates and presenting features among African-Caribbean, South-Asian and European men aged over fifty in North-east London, show that African-Caribbean men have three times greater risk of PCa than European men and that South-Asian men have the lowest incidence rates. A number of tentative explanations for this are suggested combining both environmental and genetic factors.

1.1.6 Management and forms of treatment

PCa is 'the only human cancer that is curable but which commonly does not need to be cured' (Parker, 2004: 101) and for which the 'curing' causes 'significant risks of urinary incontinence and impotence' (p. 101). Localised PCa is classified into risk groups defined by PSA level, biopsy Gleason score, and clinical T stage. Patients with low-risk localised disease face particularly difficult treatment choices which rest as much on opinion as on evidence (McVey et al., 2010). This is because the natural history of low risk localised PCa is not known, without any completed randomised controlled trials. A number of factors are considered when deciding on treatment for PCa. These include age and general health and how far the cancer has grown and spread (CRUK 2013d). The NICE (2008) guidelines indicate that potential treatments include:

- **Watchful waiting:** treatment is offered only when symptoms develop.
- **Active surveillance:** regular testing, with treatment only if and when necessary.
- **Radical prostatectomy:** surgery to remove the prostate.
- **Radical external beam radiotherapy:** radiation treatment directed at the prostate from outside the body to destroy cancer cells.

- **Brachytherapy:** radiotherapy treatment directed at the cancer from within the prostate. A substance that gives off radiation is placed in the prostate and the radiation destroys cancer cells.
- **Hormonal therapy:** medicines that reduce the production or block the effects of hormones which cause the cancer cells to grow.
- **Orchidectomy:** removal of the part of the testicles that produces the hormone testosterone which helps the cancer cells to grow.
- **Chemotherapy:** treatment with drugs to destroy cancer cells.
- **Palliative care:** aims to relieve the symptoms of cancer. This includes treatments for pain relief and practical support

(National Institute for Health and Clinical Excellence, 2008: 6)

In sum then, there are particular features of PCa which constitute it as a controversial condition. Autopsy studies show the prevalence of PCa in very young men (Soos et al. 2005; Powell et al. 2010) and other sources of high rates of incidentally detected PCa suggest that as PCa is now being looked for harder than ever before (Welch et al. 2012), it is likely to become an increasingly found and diagnosed disease. Given the high proportion of PCa that is indolent, the challenge facing practitioners is to distinguish men with 'clinically relevant cancers from those whose "disease" is destined merely to be an incidental histological event' (Parker, 2004: 101). While there is a common sense notion that finding things early is valuable (Welch et al., 2012), being recruited into a disease state 'earlier' is a form of 'diagnosis creep' (Aronowitz, 2009: 426). Such diagnosis creep potentially increases the chance of detecting non-clinically relevant PCas and inducing overtreatment (Wolters et al., 2012). Overtreatment would be of less importance, and controversy, if treatment had no morbidity, but this is not the case—radical treatment for PCa with its side effects of urinary incontinence and impotence can seriously impact a man's lifestyle (Parker, 2004: 102-3). Also, much of the increase in incidence of diagnosed PCa is attributed to a test which measures the blood level of prostate specific antigen (PSA), a glycoprotein produced almost exclusively by the prostate gland (Barry, 2001; Maddams et al., 2009; Maddams et al., 2012; Cancer Research UK, 2013c). The effect of PSA testing on PCa related mortality is unclear (Andriole et al. 2009; Schroeder et al. 2009), yet it is used as a de facto screening mechanism (Little et al., 2003; Collin et al., 2009; Drummond et

al., 2009). Additionally, there are misconceptions over whether symptoms of incontinence and impotence, common as men age, indicate an increased risk of PCa and whether their lack indicates no cancer (see for example Colin et al. 2008, 2009; Weight, 2013). Related to this is the question as to whether men presenting with lower urinary tract symptoms (LUTS) should be defacto screened for PCa (Weight et al. 2013).

1.2 Social actors and structures around PCa

Controversial illnesses have proved fruitful ground for conceptualising a ‘social diagnosis’ (Brown et al., 2011)—that which considers the variety of social structures and actors which might contribute to a diagnosis. In the UK, in the past twenty years the public visibility of PCa has increased as PCa organisations (PCaOrgs) have emerged to promote awareness of the condition and lobby for funding of services and research. The Prostate Cancer Research Foundation (PCRF) and The Prostate Cancer Charity (TPCC), for example, were established in 1993 and 1996 respectively¹. In recent years sociologists have become attentive to the impact of social movements around health on the experience of illness. Health social movements (HSMs) (Brown et al., 2004), or ‘disease-related social movements’ (Kedrowski and Sarow, 2007), are generally considered a major force for change in society at large regarding the way health issues are addressed and date back at least to concerns around occupational health during the Industrial Revolution (Brown et al., 2004; Kedrowski and Sarow, 2004). Contemporary scholarship pays attention to conditions such as Alzheimer’s Disease (Beard, 2004), HIV/AIDS (Spangler, 2000) breast cancer (Halebsky-Dimock, 2004; Klawiter, 2004; Kolker, 2004; Kedrowski and Sarow, 2007; Sulik, 2011), and mental health (Crossley and Crossley, 2001). Little attention though has been paid to PCa with research to date tending to focus not only on the USA but also comparing PCa with other illnesses—with breast cancer (Halebsky-Dimock, 2004; Kedrowski and Sarow, 2007) or with both HIV/AIDS and breast cancer (Spangler, 2000). Moreover, these

¹ In March 2011 the PCRF merged with Prostate UK to form Prostate Action. In June 2012 TPCC rebranded as Prostate Cancer UK and on 22 August 2012 it merged with the aforementioned Prostate Action because “by working together we can only be stronger, forming one unified force in the fight against prostate cancer and prostate disease. Speaking with a direct, singular voice we will be able to better achieve our aim of giving men's health the prominence it needs and address the legacy of neglect which surrounds prostate cancer” (<http://prostatecanceruk.org/news/merger> accessed 19/03/2013)

studies tend to highlight the lack of achievement of the potential PCa HSM when compared with other HSMs, concluding in part, for example, that the breast cancer movement benefitted from the experience and mobilisation of pre-existing networks of grassroots activists that had arisen in the context of the women's movement of the 1970s (Halebsky-Dimock, 2004; Kedrowski and Sarow, 2007).

PCaOrgs may then constitute part of the 'social diagnosis' (Brown et al., 2011) of PCa. Another social actant which may contribute to the diagnosis of PCa is print media. Print media is among the most relied on of sources of information regarding disease, illness, death and medicine for people in general (Clarke, 2004), and men with prostate cancer (MWPCa) in particular (Halpin et al., 2009). Yet, there are relatively few studies of print media representation of PCa (Halpin et al. 2009). Clarke's (1999; 2004) studies of PCa in contemporary 'mass print media' (1999: 58; 2004: 541), rather than considering print newspaper media, are instead limited to English language magazines in the United States and Canada from 1974-1995 (Clarke, 1999) and in Canada from 1996-2001 (Clarke, 2004). MacKenzie et al. (2007) analyse representations of PCa in Australian newspaper media and Halpin et al. (2009) do so in Canada. There are no studies of representation of PCa in the UK print media and consequentially none which compare how representation may have changed since the emergence of PCaOrgs into the UK in the mid-1990s.

1.3 Research questions and aims

PCa is the research 'flagship of men's cancer' (Wenger and Oliffe, 2013) and as such there are many studies describing various aspects of the experience of MWPCa (for example see Gray et al. 2000; Chapple and Ziebland, 2002; Oliffe, 2009; Broom, 2010; Mróz e al. 2013; Grunfeld et al., 2013). If, however, HSMs are a major force for change in a society regarding how health issues are addressed, the emergence of a potential PCa HSM in the mid-1990s may be relevant in the social diagnosis of this condition and may impact on the experience of MWPCa. Likewise, changes in the representation of PCa in the UK print media since the emergence of PCaOrgs may also impact on the experience of MWPCa. As yet though, there is a distinct lack of UK studies of print media representation of PCa, of HSM activity around PCa, the interaction between the two, and how any of this may impact on the experience of MWPCa.

Therefore, in this thesis I ask: how have PCaOrgs and the UK print media been a force for change in the UK regarding how PCa has been addressed and experienced by MWPCa? In answering this question I aim to investigate: 1) how key individuals within PCaOrgs describe how they have sought to address the condition of PCa; 2) the changes in how MWPCa describe their illness experience in research interviews over this time; and 3) the changes in how the UK national print media have represented the illness experience of MWPCa since the emergence of PCaOrgs in the UK in the mid-1990s.

1.4 Study design

Benford and Snow suggest that 'the very existence of a social movement indicates differences within a society regarding the meaning of some aspect of reality' (2000: 626). Whatever else HSMs do, they are likely to engage in work to affect interpretations of reality (Benford, 1997). The concept of framing is set forth as a way of understanding the complexities in how individuals and collectives interpret their world (Goffman, 1974; Entman, 1993). It is one of the foremost conceptual tools for understanding how social movement actors actively maintain, extend, transform or generate meaning to their attentive and bystander audiences (Snow and Benford, 1992); likewise it is used for understanding how the media produce meaning for their audience (Kitzinger, 2000; Brown et al., 2001; Philo, 2008). 'Frames matter', Polletta and Ho (2006: 203) insist, and so 'framing' theory offers a useful starting point for investigating how the media and actors around a potential PCa HSM may seek to produce or transform messages around aspects of PCa.

However, Polletta and Ho continue, 'the devil for social movement scholars is in showing how and when and how much [frames] matter' (2006: 203). In his study of how narratives justify military action, Smith (2005) suggests that understanding meaning through 'framing' has only 'nuisance value' and that the 'fragmentary nature of frame analysis permits only guerrilla warfare against the dominant paradigm. For cultural explanation to have an impact, what is required is some heavy artillery, not yet more scattered sniping' (p. 9). By this he means that it is structures within narrative which 'are pivotal as the bearers of meaning' (p. 14) and which make action 'legitimate and thinkable' (p. 3). The tendency of people to tell stories about themselves or others

is universal (Bury, 2001). Although not denying the possibility that these stories may indeed be ‘very much their own, (...) [people] do not make up these stories by themselves’ (Frank, 2010: 14). The close analysis of stories allows examination of the connections between biography and culture (Riessman, 2008) and what Giddens’s (1984) theory of structuration indicates as the recursive and repetitive nature of social practices common to both individual actors and social structures across space and time.

The method I used to answer the above research questions and address the research aims was to collect and analyse a variety of narratives—illness narratives which vary across time and type. First, I used qualitative open-ended interviews to understand how advocates around PCaOrgs narrated stories about PCa and sought to interpret this condition to attentive and bystander audiences since the emergence of these organisations in the mid-1990s. Second, I used qualitative open-ended interviews to understand how MWPCa narrated their illness experiences in primary research carried out in 2010-2011. I also, through my collaboration with the Health Experiences Research Group (HERG)¹ at Oxford University responsible for www.healthtalk.org, analysed illness narratives of MWPCa interviewed in 2000. This allowed me to compare how MWPCa narrated their illness experience in a contemporary setting with how they did so in a historical setting close to the advent of PCaOrgs into the UK. Third, I sampled the UK national print media for illness narratives of MWPCa 1990-2000 and 2000-2010. This corresponded to the two 10 year periods prior to each set of illness narrative interviews with MWPCa in 2000 and 2010.

1.5 Data collection

Access negotiations with the key advocates around PCaOrgs began in mid-October 2010 with the first interview in mid-November 2010 and the last in mid-April 2011. My access to my first participant was prompted by an opinion piece this participant had written about PCa in several prominent newspapers. Another initial contact was with a lobbyist who worked on behalf of a PCaOrg. I then ‘snowballed’ (Biernacki and

¹ HERG is formerly the DIPEX (Database of Individual Patient Experience) and www.healthtalk.org (formerly www.healthtalkonline.org) is its award winning website. Along with its sister website youthhealthtalk it allows public access to over 2000 people’s experiences of more than 60 health related illnesses and conditions

Waldorf, 1981) these participants by asking them to tell me of others whom they thought suitable to participate in my research and they each indicated several, sometimes mutual, potential people to contact. There were 21 participants recruited for this part of the research. These included 12 participants from five PCaOrgs; seven medical professionals who were influential in PCa awareness and often were also involved in PCaOrgs; and two public commentators/consultants around PCa.

The recruitment strategy for the interviews with MWPCa carried out in 2010 was adapted from that of the original HERG interviews in 2000 (Chapple and Ziebland, 2002). Access to these participants began in early May 2010 by first identifying specialist nurse gatekeepers at both Barts and The London and Belfast City hospitals and also a gatekeeper at a London PCaOrg. These gatekeepers acted as participant identification centres and distributed participant information packs to MWPCa attending the hospital or involved in the PCaOrg. Men were invited to return a reply slip for me to subsequently contact them. Though I interviewed 21 MWPCa for this part of my research one man later asked to be withdrawn. I then matched the remaining 20 MWPCa illness narratives along significant variables—age at diagnosis/age at interview and socio-economic status—with 20 illness narratives with MWPCa carried out around 2000 with HERG.

I used Nexis UK, a commercially available on-line database of newspaper articles to sample the media illness narratives. I retrieved all articles appearing in the English language UK national press from 01/06/1990 to 31/05/2010 (which were to at least some extent uploaded to Nexis 01/06/1990-31/05/1995 and fully uploaded thereafter) containing three or more mentions of the words 'prostate cancer' or 'cancer of the prostate' or 'prostatic cancer'—or various misspellings. This process led to a total of 306 articles which were then examined, using Hyden's (1997) typology, to determine which could be categorised as an 'illness narrative'. For the article to be included in the sample, I required it to predominantly (50% or more of its word content) depict 'events that have been experienced personally and pose problems for the individual in one way or another' (Hyden, 1997: 54); and/or to be 'a story the patient tells, and significant others retell, to give coherence to the distinctive events and long term course of suffering' (Kleinman, 1988: 49). This resulted in a final sample of 140 media narratives drawn across 2 time periods: 01/06/1990-31/05/2000 and 01/06/2000-31/05/2010.

1.6 Data analysis

The study design (§1.4) shows that I aim to investigate my research questions by collecting and analysing a variety of narratives. I use a narrative and framing theoretical framework as a sensitising tool (Blumer, 1954; Bowen, 2006; Charmaz, 2006) with which to approach this narrative data. Inasmuch as sensitising concepts draw attention to important aspects of the literature and the data, they may also be considered to be akin to the notion of 'keyness'. I use Wordsmith Tools software (Scott, 2013) to perform a comparative keyword in context (CKWIC) analysis of the two large data sets which comprise the media illness narratives of PCa. A CKWIC analysis is a way of inductively examining the words or phrases in one corpus, or body of data, which appear 'key', or statistically frequent (O'Halloran, 2010) when compared with another corpus. The CKWIC analysis gave an 'aerial view' (Seale and Charteris-Black, 2008: 456) of how the UK national print media represented the illness narratives of MWPCa since the emergence of PCaOrgs into the UK in the mid-1990s.

1.7 Structure of thesis

I now proceed by laying out in detail the theoretical background of this thesis in Chapter 2. In the main, I have drawn on conceptual frameworks around narrative and cultural framing theory. I did though use my initial interest around HSMs and the media as social actors around PCa as a compass rather than an anchor (Dixon-Woods et al., 2006) and continued to modify my enquiry in response to the emerging relevance of unexpected literatures during the data collection, analysis and writing up stages of the research process (Kelly, 2009). In Chapter 3 I more fully describe the study design, data collection and data analysis. I also provide a rationale for changes to the originally proposed thesis design. In Chapters 4, 5 and 6 I present my findings from the analysis of media illness narratives, advocates from around PCaOrgs, and MWPCa respectively. In Chapter 7 I discuss these findings and in Chapter 8 I offer some conclusions, discuss the limitations of the thesis and posit some potential avenues for future research.

Chapter 2 Literature review

2.1 Introduction

My aim in this chapter is to describe a range of concepts which shed light on how PCaOrgs and the UK print media have been a force for change in the UK regarding how PCa has been addressed and experienced by MWPCa. I first review aspects of the interaction between illness and disease, and focus particularly on the concept of social diagnosis and the role of health social movements and media as contributors to it. I follow this by reviewing framing and narrative theories.

2.2 The interaction between ‘disease’ and ‘illness’

Armstrong (2014) suggests that the influential thesis of Omran (1971), in explaining the emergence of chronic illness as due to the decline of infectious disease and an ageing population, has been accepted too uncritically in sociology of health and illness scholarship. Reliance on this explanation, he argues:

implicitly endorses its central assumption; that the diagnostic labels of any period reflect an underlying biological reality and that data in the historical record result from a medical perception largely uncontaminated by contemporary world views or theoretical frameworks. (Armstrong, 2014: 16)

Along similar lines, the long-standing distinction between illness and disease (Kleinman, 1988; Banks and Prior, 2001; Bury, 2001; Conrad and Barker, 2010) where ‘disease [is] (the biological condition) and illness (the social meaning of the condition)’ (Conrad and Barker, 2010: 567) is argued to be no longer appropriate (Rosenberg, 1992; Klawiter, 2004; Timmermans and Haas, 2008; Brown et al., 2011). Rather than being distinct, illness and disease are instead, ‘an interactive system, one in which the formal understanding of disease entities interacts with their manifestations in the lives of particular men and women’ (Rosenberg, 1992. xxiii). Timmermans and Haas (2008) lament the neglect of sociological inquiry into the ‘dialectic interaction between social life and specific diseases (...) and how social life matters for morbidity and mortality and vice versa’ (2008: 661). The repeated call for a sociology of diagnosis (Brown,

1990; Jutel, 2009; Brown et al., 2011; Jutel and Nettleton, 2011) does though suggest that this is not an utter neglect and that the 'powerful social tool' (Jutel, 2009: 278) of diagnosis is at least one 'salient juncture' (p. 278) between disease and illness. By this Jutel means that the:

Sociology of diagnosis has a salient role to play in understanding health, illness and disease – unpacking and identifying the play of interests which enter into discussions of what priorities should be set, and what goals attained. (Jutel, 2009: 294)

Brown et al.'s (2011) 'social diagnosis' concept 'considers both larger social structures, as well as the various social actors which contribute to the diagnosis' (Brown et al., 2011: 942). These include media and social movement actors (Brown, 1995; Brown et al., 2001; Brown and Zvestoski, 2004; Brown et al., 2004; Brown et al., 2012; Brown, 2013). A 'social diagnosis' is particularly conceptualised regarding illnesses with uncertainties and contestations around symptoms and aetiology, for example diseases such as fibromyalgia, Gulf War syndrome, chronic fatigue syndrome and environmental causes of breast cancer (Brown et al., 2011).

Jutel proposes that '[u]nderstanding the social frames within which diagnoses are generated, and grasping the impact of the label, is clinically powerful' (2009: 294). Not only *clinically* powerful though; Aronowitz (2009) cautions that naming certain diseases as 'cancer' rather than an underlying risk state (he highlights lobular carcinoma in situ) is 'semantic slippage' (p. 435) which results in those so 'diagnosed' adopting decision-making styles typically used in more advanced cancer states. He proposes that this at least includes the increasing numbers of women along the risk/disease continuum of breast cancer opting for prophylactic mastectomies (see also Henderson's (2013) account of Angelina Jolie's decision to have such surgery). One consequence of this is a 'larger and highly mobilised disease/risk population, resulting in an expanded market for interventions and greater clout for disease advocates' (Aronowitz, 2009: 417-8). Another consequence is that those with a poor prognosis are relatively more uncommon than in the past which 'makes the public face of some transformed diseases seem healthier and in general helps put a veneer of optimism onto the expanded group's identity' (p. 436). Aronowitz (2009) (see also Gillespie, 2012) argues that as increasing numbers of people are moved onto the risk/disease spectrum of any particular illness, the experience of being at risk of a

disease converges with the experience of the disease itself. This, he argues, is especially the case for chronic diseases, which PCa is argued to be (Doyle-Lindrud, 2007; Oliffe and Thorne, 2007; Oliffe, 2009).

Aronowitz (2009) suggests a variety of reasons for this including 'the recruitment of larger numbers into chronic disease diagnoses via new screening and diagnostic technology and disease definitions' (p. 417). Though Armstrong and Eborall (2012) argue that the sociology of screening is distinct from the sociology of diagnosis, it is likely, at least for a study of PCa, that screening is another salient juncture between disease and illness. This is because diagnostic testing for PCa of men spontaneously presenting to their general practitioner with sexual dysfunction or lower urinary tract symptoms (LUTS), or asymptomatic men 'getting to be that age', is described as de facto screening (Little et al., 2003; Collin et al., 2009; Drummond et al., 2009); screening which creeps in by the back door (Donovan et al., 2001).

In his revisionist account of chronic illness, Armstrong (2014) argues that the 'natural processes of ageing' (p. 15) related to physical and mental changes have been 'reconfigured and incorporated into a model of pathological disease (...) engender[ing] a new diagnosis of chronic illness' (p. 16). There are at least two important factors when considering the natural processes of ageing in engendering a diagnosis of PCa. First, the proportion of elderly men (aged 60-74 and 75+) in the UK is increasing (Office for National Statistics, 2013: Table A1-1). The long-standing debate regarding the association between benign prostate hyperplasia and LUTS and PCa (Collin et al., 2008; Weight, 2013; Weight et al., 2013) and also the inconsistent evidence around sexual dysfunction and PCa (Collin et al., 2009) are likely to mean both increased uncertainty in informing those concerned with the diagnosis of PCa and misconceptions for this ageing male population (§1.1.3). The question of whether men presenting with symptoms of such natural processes of ageing should be screened for PCa is likely to continue to be controversial as long as uncertainty regarding the benefits of diagnosing these additional men with early PCa outweighs the associated harms. Second, the differential between incidence and mortality is increasing with the consequence that more men are living longer with PCa. This is likely to result in a greater audience and clout for disease advocates and make the public face of PCa appear healthier (Aronowitz, 2009).

2.2.1 Interaction between ‘disease’ and ‘illness’: health social movements

Broadly speaking, social movements are considered to be a major force for change in society with their very existence suggesting differences around the meaning of some aspect of reality and a struggle between actors to invest this with a preferred meaning (Benford and Snow, 2000). Generally, social movements are concerned with collective action, at least some of which is extra-institutional, and goals or claims which are orientated to either promoting or resisting change (Snow et al., 2004). The locus of change is not only in political, corporate, religious institutions or the like, but also in ‘patterns of cultural authority, such as systems of beliefs or practices reflective of those beliefs’ (p. 9). Historical phenomena such as the rise of Christianity, the Reformation, the French, American and Russian revolutions are, at least to some extent, examples of social movements (p. 9). More recent exemplars are the labour movement (Fantasia and Stepan-Norris, 2007) and the women’s movement (Taylor and Whittier, 1995).

Like their non-health counterparts, ‘health social movements’ (HSMs), (Brown et al., 2004), or ‘disease-related social movements’ (Kedrowski and Sarow, 2007) are thought to be an important impetus for change in society regarding how health issues are addressed. HSMs date at least back to occupational health concerns during the Industrial Revolution. Kedrowski and Sarow (2007) review how the Black Lung and Brown Lung associations in the USA, comprising mainly workers and retirees with severe breathing problems from inhaling coal and cotton dust respectively, created compensation programs and better occupational health standards. Likewise, Brown et al. (2004) review how the women’s health movement altered medical conceptions of women and increased reproductive rights and also how the disability rights and mental health movements improved accessibility rights and decreased job discrimination.

HSMs are defined as ‘collective challenges to medical policy and politics, belief systems, research and practice that include an array of formal and informal organisations, supporters, networks of cooperation and media’ (Brown et al., 2004: 52) and take at least three, non-mutually exclusive, forms (Brown and Zavestoski, 2004; Brown et al., 2004). First, *health access movements* are mainly concerned with equitable access to healthcare and improved quality. Second, *constituency based*

movements address health inequity based on ethnicity, gender, class and sexuality (c.f. 'population-based groups' [Allsop et al., 2004]). Third, *embodied health movements* (EHMs) address disease, disability or illness experience by challenging science on causation, diagnosis, treatment and prevention. EHMs may also include constituents who are not ill but perceive themselves as vulnerable to the disease, for example, women who do not have breast cancer may be involved in activism around breast cancer. Brown et al. (2004) propose a strategic-advocacy¹ continuum according to whether the movement uses tactics such as education and advocacy or instead uses disruptive action to challenge existing medical paradigms.

While access and constituency based movements may typically challenge medical or scientific knowledge and practice and collaborate with scientists and health professionals in pursuing treatment, prevention, research and funding, EHMs are unique as they also introduce the embodied experience of people with the disease. Just as breast cancer does not happen to a disembodied breast 'hanging out somewhere' (p. 68), so also is the case for the 'lost breast' (Kedrowski and Sarow, 2007) of the prostate. A PCa EHM may then introduce '[d]isease narratives² [of MWPCa which] interweave organic disease processes with a bodily experience that is a function of social structures and cultural ways of knowing' (Brown et al., 2004: 67). EHMs may be considered 'boundary movements' (Brown et al., 2004: 63-5) as the narratives introduced may blur boundaries between lay and expert forms of knowledge: lay people becoming experts not only through their embodied illness experience but also by accessing knowledge through, for example, the internet enabling them to challenge their medical providers.

That the above 'types' of movement are non-mutually exclusive is clear when considering a potential PCa EHM is constituency based (the prostate gland is found only in men); it may seek greater access to services and quality of care; and seek to achieve this through men's embodied experience. Likewise, 'population-based' and 'condition-based' group 'types' (Allsop et al., 2004), concerned with specific populations or conditions respectively, may also be non-mutually exclusive. Though Spangler (2000) does not offer 'types' of social movements around disease/health, she proposes four main reasons for their emergence in the 1980s and 1990s: 1) the nature

¹ They describe it as 'strategic-agenda' continuum but the context instead indicates 'strategic-advocacy'

² Note the use of 'disease' rather than 'illness' narrative

of the diseases; 2) the degree of societal stigmatisation surrounding the diseases; 3) the governmental and medical organisational response; and 4) the particular communities affected. She suggests that these variables may account for: the different ways that organisations relate to government and medical institutions; the different methods and tactics used to achieve their organisational goals; and the speed of their emergence.

Another 'type' of social movement around health is a 'disease-related social movement' (Kedrowski and Sarow, 2007: 38). These are "'grassroots survivors' organisations" [GSOs] [...] or collection of organisations that focuses on a problem its activists believe is the responsibility of government to remedy' (p. 38). 'Survivor' is used rather than 'victim' as the latter implies one has succumbed to the disease when the key to activism is instead survivorship. Kedrowski and Sarow (2007) distinguish between groups populated by people with the disease and those populated by surrogates; 'medical professionals, family members, caregivers or philanthropists' (2007: 43). They argue both that survivors speak more powerfully about their experience and that the agenda of survivor organisations may be different to that of surrogates. They propose seven characteristics of successful GSOs, they: 1) form around long term health hazards; 2) adopt and use the organisational structures and practices of existing activist organisations; 3) offer their own experiences as evidence; 4) depend on an empowered and educated activist support base; 5) depend on the media and courts for keeping their issues alive and in the public's agenda; 6) depend on women as activist leaders; and 7) need financial and promotional support from business and industry to ensure long term viability (Kedrowski and Sarow, 2007: 52-60).

Kedrowski and Sarow (2007) describe the differing extent to which movements around breast cancer and PCa, the substantive context of their research in the USA, satisfy these characteristics. They argue that the breast cancer movement not only had the women's health and feminist movements as a foundation for their activism, they could also model the success of the AIDS movement, especially in adopting some of its more confrontational techniques. They were also able to use their selves as evidence, not only in their willingness to narrate their experience as persons with the disease, but also in how they could draw attention to the breast in ways not culturally acceptable for men to do so for the prostate. In contrast, the US PCa HSM fully shared

only the first characteristic and only partially shared the remaining six features¹. Unlike breast cancer, the US PCa HSM did not have a similar men's health movement as a model and many of the confrontational tactics of the AIDS movement were not considered options by the time the National Prostate Cancer Coalition (NPCC)² was formed in 1996. What the NPCC did have though was the opportunity to model itself on, or 'piggyback' (Kedrowski and Sarow, 2007: 153), the successes of breast cancer lobbyists in the National Breast Cancer Coalition (NBCC), founded in 1991. Despite this 'piggybacking', its 'grasstops' rather than grassroots origins made it hard to generate equivalent support (Halebsky-Dimock, 2004). Such modelling or 'piggybacking' is an example of social movement spillover where:

one movement can influence subsequent movements both from outside and from within: by altering the political and cultural conditions it confronts in the external environment, and by changing the individuals, groups, and norms within the movement itself. (Meyer and Whittier, 1994: 279)

Social movement spillover is useful in several ways. First, the goals and interests of one social movement may influence people in another to experience their illness as some form of inequality. Second, the success of some social movements may create, or remove, sympathetic allies for other social movements as per the examples above. Third, the way that activists articulate particular values or beliefs may have a beneficial effect on other social movements in that these articulations become 'culturally potent' (Kolker 2004: 827). Here proponents of new movements strategically bring their frames 'into alignment with potential recruits' pre-existing frames (...) [and] link their perspectives to widely-*resonant* beliefs or concerns' (Meyer and Whittier, 1994: 287 my emphasis - see §2.3.3) and thus make their messages recognisable by audiences as meaningful.

In the UK, in the past twenty years the public visibility of PCa has increased as PCa organisations (PCaOrgs) have emerged to promote awareness of the condition and lobby for funding of services and research. The Prostate Cancer Research Foundation (PCRF) and The Prostate Cancer Charity (TPCC), for example, were established in 1993 and 1996 respectively. In recent years there has been an increase in social movement studies which have focused on aspects of health and disease, for example, Alzheimer's

¹ Kedrowski and Sarow (2000: 60) present a table the details of which are ambiguously different from the accompanying text. Here I summarise my interpretation of their text which differs from the table

² Now renamed 'ZERO'

Disease (Beard, 2004), HIV/AIDS (Spangler, 2000) breast cancer (Halebsky-Dimock, 2004; Klawiter, 2004; Kolker, 2004; Kedrowski and Sarow, 2007; Sulik, 2011), and mental health (Crossley and Crossley, 2001). However, little attention has been paid to PCa, with research to date tending to focus not only on the USA but also comparing PCa with other illnesses, for example, breast cancer (Halebsky-Dimock, 2004; Kedrowski and Sarow, 2007) or with both HIV/AIDS and breast cancer (Spangler, 2000).

2.2.2 Interaction between ‘disease’ and ‘illness’: the media

Print media, as among the most relied on sources of information regarding disease, illness, death and medicine for people in general (Clarke, 2004), and men with prostate cancer (MWPCa) in particular (Halpin et al., 2009), is another potential contributor to the social diagnosis of PCa.

Studies of media production include both enquiries around the power of media producers and the power of others in influencing them (Seale, 2003). Philo (2008) contends against the trend to seriously neglect media power in favour of the power of a reflective resisting audience. He argues that a large proportion of media audiences relies on very traditional news sources and that ‘patterns of belief and understanding can be traced to [elite media producers]’ (2008: 542). Such repetitive patterns are seen in the idea of a media ‘boilerplate’ (Cotter, 2010), as though ‘seemingly throwaway material (...) repetitious, unattributed (...) and is potentially expendable as text (...) its role in framing a news story may also end up influencing public debate’ (Cotter, 2010: 171). Repetitive patterns are also seen in media templates (Kitzinger, 2000) which are used to (re)construct meaning over time for both journalists and audiences, retrospectively making salient particular aspects of past problems in explaining current events. Kitzinger (2000) shows through content analysis of media articles, interviews with journalists, and focus groups with audiences how the Cleveland child sex abuse scandal of the late 1980s was used as a template to help audiences and journalists make sense of the new events in Orkney in 1991. She suggests though that there is nothing innately problematic about journalists repeating historical analogies in templates as current happenings are not ahistorical. Indeed, the reconstruction of meaning from repeated texts is suggested as routine by Tannen

(2007) and Bakhtin (1981); where problems might arise though is when journalists, and audiences, unquestioningly accept templates from prior events as ‘truth’ for new events.

Studies of media reception include investigation of the media audience’s reception of news coverage of which two salient studies are Gamson (1992) and Kitzinger (2000). Gamson (1992) finds that people are neither “passive” nor “dumb” but ‘negotiate with media messages in complicated ways that vary from issue to issue’ (1992: 4). Kitzinger (2000) finds that, with some minority resistance and variation, particular phrases provoke ‘a set of powerful pre-packaged associations’ (2000: 70) creating images which “fitted” (p. 70) (see also Kitzinger and Miller, 1992) with audiences prior conceptions. Seale (2003) provides an overview of audience theory which includes such negotiation and resistance of audiences. He also notes how audiences seek emotional stimulation through entertaining dramatised contrasts which exploit oppositions between, say, good and evil, men and women or, as in Kitzinger’s study, ‘innocence and incompetence’ (Seale, 2003: 519). Audiences, having had repeated exposure to a variety of played-out forms, such as boilerplates (Cotter, 2010) or media templates (Kitzinger, 2000), have expectations of how they will be ‘entertained’ by media producers. This ‘entertainment’ though is not solely achieved by meeting their expectations but rather by an ‘entertaining disruption of expectations’ (Seale, 2002: 36). Indeed, there is an imperative for media producers to disrupt, or ‘twitch’ the plot from time to time in order to retain audiences’ interest’ (p. 36). ‘Twitching’ may also constitute a ‘reversal’ where previously established polarities ‘may suddenly be reversed, so that evil and good swap places’ (p. 36). Such ‘reversals’ become normal and imply a continual need for ‘twitching’. Later in this chapter (§2.3.3.1) I explore more fully the concept of repetition and also introduce the concept of interest and propose that these are instrumental in ‘twitching’ the plot for the ‘entertainment’ of media audiences.

2.2.2.1 The media representation of prostate cancer

The existing literature in the media and health field is weighted towards studies of representation (Seale, 2003), often involving analysis of which ideas or themes are discursively dominant in media content. Although PCa is the research ‘flagship of men’s cancer’ (Wenger and Oliffe, 2013) and print media are popular as an

information source for disease and illness, for people in general (Clarke, 2004) and MWPCa in particular (Halpin et al., 2009), there are relatively few studies of the representation of PCa within this medium (Halpin et al., 2009.). Clarke's (1999; 2004) studies of PCa in contemporary 'mass print media' (1999: 58; 2004: 541), rather than considering print newspaper media, are instead limited to English language magazines in the United States and Canada from 1974-1995 (Clarke, 1999) and in Canada from 1996-2001 (Clarke, 2004). Despite this limitation, and also that her sample sizes are small, there are interesting findings from these studies which I outline below. Two other studies (MacKenzie et al., 2007; Halpin et al., 2009) analyse representations of PCa in Australian and Canadian newspaper media respectively. There are no studies of the representation of PCa in the UK print media.

Clarke's (1999) study involves analysis of a 'paucity' (p. 70) of all 36 articles containing representations of PCa from three magazine database sources from 1974-1995 (only one of which extends to the whole sample period). She conducts a 'manifest' and 'latent' thematic analysis. 'Manifest' analysis focuses on meanings 'evident on the surface' (p. 63) or 'obvious intent of the overall article' (p. 65). 'Latent' analysis allows meaning to be subject to the legitimate and critical interpretation of the researcher and their particular biases, ideologies and knowledge of the wider discursive context. This, Clark suggests, correspond to both quantitative (counting the number of times that manifest themes appear) and qualitative (considering the underlying, or latent, meaning of the articles) analysis. Her manifest findings indicate that the predominant focus of these articles was on the importance of early detection followed by the increasing incidence of PCa. The 'latent' analysis includes findings that PCa is relatively neglected when compared with breast cancer; not because of its relative incidence in the population, but because of advocacy around breast cancer and the consequential lack of funding for PCa and attention to it by medical science and the media.

The primary concern of Clarke (2004) is to update her earlier research (Clarke, 1999) and compare representation of PCa with that of breast and testicular cancers. Here she analyses 19 articles on PCa in 10 Canadian mass print magazines. Of first note, again, is the scarcity of articles around prostate (19 articles) and testicular (11 articles) cancers relative to breast cancer (approximately 174 articles). She again conducts a manifest and latent thematic analysis with her findings inherently including

comparisons of PCa with breast cancer. Ideas of 'family' around PCa primarily focus on the MWPCa and his wife and how they cope with incontinence and impotence. In contrast, 'family' connections for women with breast cancer are much broader. Her other findings include comparisons with breast cancer activism and 'felt injustices' (p. 548) around the funding for research for PCa when compared to that for breast cancer or AIDS. Journalists explain that this is because men are not understood as 'victims' in the same way that women or gay men are and thus not offered similar public support. Further, journalists position women as helping their spouses to 'lose their shame' in bringing that disease 'out of the shadows' (p. 548).

Halpin et al. (2009) also conduct a manifest and latent thematic analysis on their sample from two English language Canadian national newspapers. Their initial sample of 817 articles containing the phrase 'prostate cancer' is reduced by approximately 50% after an initial manifest analysis excluded 'peripheral' articles making only superficial reference to PCa; such articles were not included in the subsequent latent analysis. The remaining articles were coded into three non-mutually exclusive categories of 96 'illness perspective' articles (focussing, for example, on information about men diagnosed and treated or who had died from PCa); 199 'medical perspective' articles (focusing, for example, on research, and new developments in screening); and 122 supplementary articles (focusing for example on men's diet, health behaviour and fundraising and awareness of PCa). They find four themes across their data (p. 159): "manufacturing the treatment imperative" from the medical perspective category; "the good fight" in the illness perspective category; and a "money for the cure" and "boys' and girls' cancer" in the supplementary category. Their conclusions include the observation that readers are offered only:

a truncated illness trajectory that privileged recovery and biomedically-derived 'cures'. As a result, only the beginning story ('men can get PC') and the ending ('men can die of PC') is detailed. There is no middle story about, 'living with PC'. (Halpin et al, 2009: 164)

This 'truncated' illness perspective meant there were no accounts of treatment side effects in their data. They also conclude that socially advantaged and health complacent men are positioned in a 'struggle for fundraising equity against women' (p. 164). Alongside this macro-level gender struggle, paradoxically on a micro-level, women were positioned as those who do, and should, look after the health of their

men. They suggest that this 'myopic presentation of health (...) [of elite men] encourages a myopic performance of health' (p. 164) extended across all masculinities.

Finally, MacKenzie et al. (2007) examine media coverage of PCa screening in Australia. Their sample included 388 print media articles from Australian capital city newspapers between February 2003 and December 2006 and 42 television items from Sydney television news over a similar period. Unlike Clarke (1999; 2004) and Halpin et al. (2009) they conduct a 'framing analysis'; focusing on categorising attributed or paraphrased quotes from named individuals as either a positive or negative framing of PCa screening. They find that the Australian print and television discourse on PCa during the sampled four year period was very supportive of PCa screening with 86% of all quotes categorised as positive. They conclude that the average consumer of news in Australia would find it difficult to believe that PCa screening was not a sensible thing to do. This is despite the real lack of scientific evidence and the almost universal tendency of those responsible for national screening programmes to not recommend PCa screening.

2.2.3 Masculinities and prostate cancer

The case made for the interaction between the social category of 'illness' and the pathological category of 'disease' and how it matters for morbidity and mortality (Timmermans and Haas, 2008) is also made for the interaction between the biological category of sex and the social category of gender (Annandale, 2013). While the social experiences of men and women provide a 'template' (Courtenay, 2009: 13) for how they choose to adopt various social behaviours and beliefs, '[u]nlike the presumably innocent effects of wearing lipstick or wearing a tie, the use of health-related beliefs and behaviours to define oneself as a woman or a man has a profound impact on one's health and longevity' (p. 13). Courtenay (2009) argues that men are not 'passive victims of a socially prescribed role (...) [but are instead] active agents in constructing and reconstructing dominant forms of masculinity' (p. 12). Dominant constructions of masculinity are conceptualised as hegemonic masculinity:

the socially dominant gender construction that subordinates femininities as well as other forms of masculinity, and reflects and shapes men's social relationships with women and other men, (...) [it] include[s] the denial of weakness or vulnerability, emotional and physical control, the appearance of being strong and robust, dismissal of any need for help, a ceaseless interest in

sex, the display of aggressive behaviour, and physical dominance (Courtenay 2009: 14).

Men demonstrate hegemonic masculinity around their health when, for example, they brag about how long it is since they have seen a doctor; refuse to take sick leave from work; or believe that talking to others about their illness presents them as weak [Courtenay, 2009: 14.]. Though hegemonic masculinity is understood as normative behaviour and not conceived as that which patterns all men's behaviour, it, or at least this definition, has been heavily criticised. These criticisms include the lack of attention to differences within and between the gender categories and how patterns of masculinity vary at least by place, class and generation (for a fuller review of these criticisms see Connell and Messerschmidt, 2005).

Sociological attention to the doing of gender and PCa begins to address, or at least recognises, some of these criticisms. Oliffe (2009) proposes three important factors when thinking about PCa and masculinity: 1) age is a risk factor for PCa; 2) the increasing differential between incidence and mortality means more men are living longer with PCa and, as yet, with no preventable cause or cure, PCa will unfold as a chronic illness; and 3) as PCa incidence varies geographically and ethnically men's experiences of PCa will be diverse. Oliffe's first two factors indicate that attention needs to be paid at least to how elderly men may construct plural masculinities. I suggest though that limiting attention to elderly men is likely to become increasingly incongruous. This is because autopsy studies show incidence of PCa in very young men (Soos et al., 2005; Powell et al., 2010) and given that PCa is being looked for harder than ever before (Welch et al., 2012) it is likely to be more frequently found in younger men.

MWPCa draw on a range of masculine ideals: denying illness, stoicism, and respecting the expertise of their physician (Chapple and Ziebland, 2002¹; Mróz et al., 2013). MWPCa discuss their reluctance to consult doctors; the embarrassment and inconvenience of incontinence; the impact of tiredness on their ability to work and play sport; and the impact of impotence (Chapple and Ziebland, 2002). The impact of impotence on masculinity differs though according to the treatment men receive: those receiving surgery describe impotence as a 'small price to pay' (p. 831); men

¹ 20 of these interviews are included in this present research

receiving hormone treatment describe how they feel physically and psychologically changed.

The construction of masculinities also differs according to the context in which the talk occurs. Chapple and Ziebland (2002) draw conclusions which reinforce the idea that masculinity is socially constructed with men saying that their 'macho' image is impacted by their illness. Mróz, Oliffe and Davison (2013) show how masculinities are co-constructed in the dyadic patient-physician communication encounter in the specific context of men, diagnosed with low risk PCa, choosing active surveillance as a treatment. They note that active surveillance occupies a unique position within cancer communication with the physician able to combine the bad news of '(you have prostate cancer) with some, albeit provisional, good news (i.e. you don't have to be treated just yet)' (p. 85). Broom (2010) examines the complexities between PCa and masculinities in Australian men before, during and after treatment. His stated context is that "younger men are now developing prostate cancer, and many die of the disease and not with it" (Broom, 2010: 180, citing Frydenberg et al., 1998¹; Broom, 2004²). He concludes that for the majority of men the exposure of their bodies to biomedical investigations and treatments threatens their enactment of masculinity around potency and continence control. In addition, he observes the 'code of silence' (p. 195) surrounding men's illness.

In sum, in this section I have shown how illness and disease can no longer be considered to be distinct given that 'social life matters for morbidity and mortality and vice versa' (Timmermans and Hass, 2008: 661) and the biological category of sex matters for the social category of gender and vice versa (Annandale, 2013). I show the usefulness of the concept of 'social diagnosis' (Brown et al., 2011) in its consideration of how media and social movement actors might contribute to a diagnosis. I note that although in recent years there has been an increase in social movement studies which have focused on aspects of health and disease, little attention has been paid to PCa. Likewise, studies of media representation of PCa are limited, both numerically and geographically, with as yet no study of such representation in the UK.

¹ Broom cites Frydenberg as sole author but it is a three-authored paper

² Broom 2004 also cites Frydenberg 1998. I was unable to access Frydenberg et al.'s paper to understand the claim that younger men in Australia are dying of rather than with prostate cancer

2.3 Framing theory

The concept of framing is set forth as a way of understanding the complexities in how individuals and collectives interpret their world (Goffman, 1974; Entman, 1993). It is common in both every day and academic discourse (Snow and Benford, 1992) and is often tacitly understood rather than explicitly defined (Entman, 1993). Its 'omnipresence across the social sciences and humanities' (p. 51) is shown by its various terminology such as "paradigms', 'stereotypes' [and] 'schemata'" (Fowler, 1991: 17). A schema (or frame) 'is a chunk of unconscious knowledge, shared within a group of people and drawn upon in the process of making sense of the world' (Fowler, 1991: 43 c.f. Goffman 1974). The utility of the framing concept for this present study has its foundation in its use as an explanatory factor in the study of social movements. The Goffmanian concept of framing was revived in an influential approach to the study of social movements (c.f. Snow et al., 1986; Gamson et al., 1992; Snow and Benford, 1992, 2000). Benford and Snow suggest that 'the very existence of a social movement indicates differences within a society regarding the meaning of some aspect of reality' (2000: 626). Actors around social movements are argued to be:

actively engaged in the production and maintenance of meaning for constituents, antagonists, and bystanders or observers (...) involv[ing] the amplification and extension of extant meanings, the transformation of old meanings, and the generation of new meanings (Snow and Benford, 1992: 136)

Such work by social movement actors suggests that though frames may be 'chunk[s] of unconscious knowledge' (Fowler, 1991: 43), they may also be consciously drawn upon. Known cultural frames may be strategically sought in order to focus attention on particular aspects of reality to elevate them in salience (Entman, 1993) 'by placement or repetition, or by associating them with culturally familiar symbols' (p. 53). This bears similarities to the beneficial consequence of social movement spillover where new actors strategically bring their messages into line with their potential audience's pre-existing frames (Meyer and Whittier, 1994).

2.3.1 Strategic frame alignment processes

Much of the work of social movement theorists in understanding frames and framing activity has centred on strategic frame alignment processes¹ (bridging, extension, amplification, and transformation) (Benford and Snow, 2000; Snow et al., 1986) Gamson 1988).

Frame bridging is ‘the linkage of two or more ideologically congruent but structurally unconnected frames regarding a particular issue or problem’ (Snow et al., 1986: 467). This can occur either across social movement organisations or towards a ‘probable adherent pool’ (p. 468). It is the most prevalent of the strategic frame alignment processes and is effected mainly by ‘organisational outreach and information diffusion through interpersonal or intergroup networks, the mass media, the telephone, and direct mail’ (p. 468.). Peace movement organisations, for example, may develop mailing lists from records of individuals attending events sponsored by like-minded organisations and then assume that those individuals are likely to share the aims and values of the peace movement.

Frame extension refers to the situation when the current programmes of a social movement organisation do not fit with the interests of potential adherents who may need to be ‘hooked’ to position their interests alongside that of the SM. This involves the extension of the boundaries of interest of the social movement organisation to incorporate the issues presumed to be of importance to potential participants. For example, rock and punk bands have been used to draw attention of otherwise indifferent individuals to disarmament rallies (Snow et al., 1986).

Frame amplification involves ‘the idealization, embellishment, clarification, or invigoration of existing values or beliefs’ (Benford and Snow, 2000: 624). Values are understood as ‘modes of conduct or states of existence that are thought worthy of protection and promotion’ (Snow et al., 1986: 469) and beliefs as ‘ideational elements that cognitively support or impede action in pursuit of desired values’ (p. 469-470). Beliefs include: stereotypical ideas about antagonists or targets of influence; the seriousness of the problem; who or what is to blame; and the necessity and efficacy of any corrective action (p. 469-470.). Stereotypic beliefs about homeless men as

¹ Snow et al. (1986) use ‘frame alignment’ to describe what Benford and Snow (2000) later refer to as ‘strategic processes’ and so I have amalgamated the two phrases

alcoholic and mentally and morally deranged were amplified to mobilise a neighbourhood against proposed local homeless shelters (p. 469-470.). Breast cancer activists drew upon commonly held values and beliefs around 'family' and 'fairness' in the early 1990s to create three interconnecting and culturally relevant frames which moved breast cancer from a problem of individual women to a public problem in need of social and institutional address: 1) breast cancer as an 'epidemic' with unacceptable rates of incidence in the young and old; 2) a 'gender equity' frame; and 3) a 'threat to the family' frame (Kolker 2004). The first two of these justified demands to increase funding and portrayed women as the sole victim. The third highlighted the importance of family in American discourse and meant that 'the pool of victims impacted by the disease expanded significantly to include the entire family' (p. 831) with breast cancer 'victims' and 'survivors' appellated with new identities of 'wives', 'mothers', 'sisters' and so on.

Frame transformation is a redefining of 'activities, events, and biographies that are already meaningful from the standpoint of some primary framework, in terms of another framework' (Snow et al., 1986: 474). Frame transformation is contingent on an interpretive change which includes the adoption of injustice frames and a corresponding shift in attribution of blame from the individual self to an external other. Social movement actors are argued to construct a compelling sense of injustice around an existing authoritative view of reality, provide a solution, and demand correction or eradication of the exposed injustice. In this way frames:

1. Highlight, or diagnose, some aspect of social life as problematic and/or unjust in need of change
2. Propose a solution, or make a prognosis, for the diagnosed problem specifying what needs to be done
3. Make diagnostic attributions of blame by identifying a culpable adversarial 'they' (or an internalised 'we') of individual, collective or structural agents responsible for the problem
4. Make prognostic attributions by identifying an internalised 'we' or externalised 'they' who will bring change by engaging in corrective action to resolve the problem

(Gamson et al., 1992; Snow and Benford, 1992)

In adopting an injustice frame, a condition previously understood as tragic is subsequently defined as unjust, for example, the tragic loss of a loved son by a careless driver may be redefined as an injustice demanding increased judicial penalties.

2.3.2 Framing hazards

The inevitable struggle between actors to invest aspects of reality with a preferred meaning suggests the likelihood that frames will be contested (Benford and Snow, 2000) or subject to what Snow and Lessor (2010) have recently described as ‘framing hazards’. Various such contested processes or hazards confronting those engaged in framing activities have been identified including: counter-framing; framing disputes; framing errors or misframings; framing shifts; ambiguous events; and dialectic tension between frames and events (Benford and Snow, 2000; Snow and Lessor, 2010).

Counterframing by movement opponents can result in rebuttals or undermining of a frame and generate further re-framing in an attempt to ‘ward off, contain, limit or reverse potential damage to the movement’s previous claims or attributes’ (Hunt and Benford, 1994 as cited by Benford and Snow, 2000: 626). Benford and Snow (2000) lament the lack of progress made on what shapes the outcome. Though they suggest that the winners engaged frames which were more resonant they do not provide an answer as to why and how this may be so.

Frame disputes have been examined mainly in terms of intramovement disagreements over the meaning of some present or projected future aspect of reality. This is exemplified in the three competing framings of obesity in the United States: the anti-obesity or obesity as risky behaviour frame and within the individual’s control; the obesity as a disease frame and beyond the individual’s control; and obesity as fat acceptance or body diversity frame where less social discrimination on size is needed (Snow and Lessor, 2010: 289-90). Each poses different problematisations of obesity, attribution of causes and actions for solution.

Framing errors occur when collective action is based on erroneous beliefs as, for example, in the changing ways that the disease pellagra was dealt with in the early 1900s. Despite the fact that malnutrition was found to be the cause of pellagra in 1914, the disease was framed as hereditary in a report by the Pellagra Commission in 1917, this not changing until after the Great Depression when many previously self-sufficient people succumbed to the disease. *Ambiguity*, common in medical diagnostic

uncertainty, may occur when there are questions as to what could possibly be going on in a particular event or when deciding between two or more potentially plausible explanations for what is going on (Snow and Lessor, 2010). A *dialectic tension* between frames and events is evident when initial framings legitimate some form of action but in turn transform the ideas and beliefs that make up the original frames so that such action is no longer efficacious. *Frame shifts* are generally preceded by new or unanticipated events and occur when one frame, rather than being transformed, is displaced by another. The susceptibility of a dominant frame to displacement is contingent on the extent to which it is falsifiable and may thus be prevalent in the health and medicine sector because of its reliance on empirical evidence (Snow and Lessor, 2010).

2.3.3 Frame resonance: ‘half the battle’ yet only ‘half the story’

what texts ‘do’ we all ultimately realise, they do in the resonance achieved between the words themselves and the worlds that surround them, elicit them, and are reflected and transformed by them (Charon, 2006: 113)

Frame resonance is understood as the “‘fit’ between frames and audiences’ previous beliefs, worldviews, and life experiences’ (Kitzinger and Miller, 1992; Kitzinger, 2000; Williams, 2004: 105). It incorporates the various strategic frame alignment processes and is seen as crucial in understanding why some frames and framing efforts are more successful than others (Snow and Benford, 1988; Benford and Snow, 2000). Though there is a necessity for communicators to construct frames which ‘ring true’, ‘fit’, or ‘hit home’ with an audience’s previous frames, there are risks as well as benefits in so doing.

Achieving resonance is advantageous as it allows challenging actors to ‘peer into the actions and histories of other challenging groups’ (Steinberg, 1999: 752) and ‘borrow’ their discourse in order ‘to articulate identities, grievances, and goals where there are gaps and silence in the discursive field in which they are fighting their own struggle’ (p. 752). Likewise, Turner describes how a sense of injustice ‘can become the leaven for vast social changes because (...) other organisable segments of society can see many of their own problems in the terms set forth by [other] activists’ (1969: 399). A new racist white supremacist, for example, described achieving resonance with

familiar civil rights language as “half the battle” (Berbrier, 1998: 432) in legitimising ‘the idea that whites have a right to organise, just like blacks, Hispanics and Jews’ (p. 432.). Steinberg (1999) insists that it is very difficult for actors to construct truly new oppositional symbols and that oppositional discourse is more likely to be appropriated, or reproduced, from other familiar hegemonic discourses and inflected with the intended meaning of the new actors. In contrast, Polletta and Ho assert that activists ‘sometimes invent new frames’ (2006: 194) arguing that neither women liberation activists seeking to radically challenge gender norms nor dissidents challenging the communist regime in Poland had social movement discourse to appropriate. They subsequently indicate though that the political challengers in Poland invoked both moral frames from the Catholic Church and civil rights discourse, and that the women’s liberation activists appropriated, with a gender twist, civil rights discourse from the 1950s.

Though seeking resonance is “half the battle” (Berbrier, 1998: 432) it is also ‘only half the story’ (Ferree, 2003: 306)—this is at least because the familiar and ‘common sense’ properties of resonant discourse potentially constitute it as hegemonic. Ferree (2003) describes the structured and institutionalised nature of hegemonic discourses, or ‘discursive hegemony’ (Steinberg, 1999) as discursive opportunity structures (DOS): ‘*institutionally anchored ways of thinking that provide a gradient of relative political acceptability to specific packages of ideas*’ (Ferree 2003: 309, emphases in original). Such institutional structures include a media DOS (Ferree, 2003; Koopmans and Olzak, 2004) and a judiciary DOS (McCammon et al., 2007). They may also include an epidemiological DOS, or a dominant epidemiological paradigm (DEP) (Brown et al., 2004), defined as ‘the pre-existing institutional [including science, government, private sector, media, and academia] beliefs and practices that shape the discovery and understanding of a disease [and] also shape the illness experience for the affected population’ (Brown et al. 2004: 61). As such an epidemiological DOS/DEP may also be understood as a dominant public narrative around health, illness or disease which allows some ideas to reign as ‘common sense’ while marginalising others.

In her study on abortion, Ferree (2003) argues that framemakers may instead opt for ‘nonresonant’ (p. 305) language, which ‘is by definition radical’ (p. 203), as an alternative and viable way both to achieve success and restructure hegemonic ideas.

She defines resonance and radicalism, respectively, as the mutually affirming or contradictory *'interaction of a frame with a discursive opportunity structure supportive of the terms of its argument'* (2003: 310, emphases in original). This then points to a potential combination of resonant and non-resonant language as an approach to successful framing. Also suggestive of this is Koopmans and Olzak's (2004) understanding of resonance as that which provokes either negative or supportive reactions—what they term consonance and dissonance—both 'hitting home' but in a 'familiar' and 'alerting' way respectively. Along these lines Polletta (2006) argues, in relation to stories rather than frames, that though 'stories must hew to familiar plotlines, a story that was so familiar as to be entirely predictable would be no story at all' (p. 10). Thus, it would indeed seem that though resonance may be 'half the battle' (Berbrier, 1998) in successful framing it still is 'only half the story' (Ferree, 2003). Something more is thus at stake in successful framing and looking more closely at what might constitute elements of resonance and non-resonance may shed some light on what this is.

2.3.3.1 The role of emotion and repetition in resonance

2.3.3.1.1 Emotion

Emotions like those which accompany a sense of injustice, or others such as compassion, shame, guilt and anger, play a part in the 'real reason[ing]' (Lakoff, 2010: 72) of everyday framing. Rather than understanding 'appeals to reason' as unemotional, instead 'real reason (...) requires emotion; uses the "logic" of frames, metaphors, and narratives' (p. 72). In their analysis of policymaking deliberations around resource allocations in primary health care, Russell and Greenhalgh (2011) find that a rhetorical approach to policy-making decisions does not 'occlude emotions (...) as elements that get in the way of rational decision-making, but rather sees them as integral to persuasion of an audience' (p. 60). Russell and Greenhalgh thus identify a paradoxical tension between 'appeals to reason' through robust evidence and appeals to emotions in decision-makers' arguments. Similarly, but outside of the policy arena, Kedrowski and Sarow (2007) suggest that 'the masses are not interested in the particular details of policy or appeals to reason; rather they respond to emotion [and] language that appeals to the "moral codes" embedded in our understanding has the

greatest resonance' (p. 165). Kedrowski and Sarow are concerned with what interests 'the masses' (p. 165)—and, by extension, with what interests the media as a means of access to these masses. I look now particularly at the particular emotions of 'injustice' and 'interest'.

Injustice, as a "hot' emotion' (Gamson, 1992: 7), has coloured all major social movements in each main historical era (Turner, 1969). Injustice is not merely about recognising, or experiencing, a misfortune such as poverty or illness and petitioning for help. Rather, it is 'moral indignation' (Gamson, 1992: 7), or 'sense of outrage against a system productive of such misfortunes' (Turner, 1969: 391) and action for their correction or eradication. In other words, instead of relying on the goodwill of others to address a problem, you instead demand what you claim is right, your right or a right. Significant social movements have both depended upon and promoted a 'normative revision' (p. 390) in how a 'substantial group of people look at some misfortune, seeing it no longer as a misfortune warranting charitable consideration but as an injustice which is intolerable in society' (p. 390). This involves changing ideas of what people view as unjust in any society; for example, the change in conceiving oneself as individually 'unlucky' in experiencing a particular event (or illness), to acquiring a consciousness of actors responsible for the perceived harm.

A common view of 'interest' is as a collective motive for social action; 'interest groups', like social movements, usually have goals which are similarly orientated towards either promoting or resisting change (Snow et al., 2004). An alternative view of interest¹ is that of 'the curious emotion', one of a number of knowledge emotions, by Silvia (2008). Silvia argues that 'interest' displays all the components normally associated with emotions: physiological changes in facial and vocal expressions; patterns of cognitive appraisal, subjective qualities; and an adaptive role across a lifespan (2008: 57). He asserts that 'emotions come from subjective evaluations of events: People appraise an event's meaning and these appraisals bring about emotions' (p. 58). He suggests that interest results from two such appraisals:

1. An evaluation of an event's novelty-complexity: 'evaluating an event as new, unexpected, complex, hard to process, surprising, mysterious or obscure' (p. 58)

¹ I became aware of this understanding of 'interest' as a relevant concept to review in the literature only upon analysis of the data.

2. An evaluation of an event's comprehensibility. This less obvious coping-potential appraisal 'involves people considering whether they have the skills, knowledge, and resources to deal with an event' (p. 58)

Thus with 'interest', 'people are "dealing with" an unexpected and complex event – they are trying to understand it. In short, if people appraise an event as new and as comprehensible then they will find it interesting' (p. 58). Further, comprehension and novelty are hinges between interest and other knowledge related emotions such as boredom and confusion or uncertainty. If an event is novel and comprehensible it is interesting but if it is novel and incomprehensible it is confusing (p. 58). By extension, if an event is comprehensible but not novel then it is boring. The addition of novelty onto the familiar is also evidence of how media producers "twitch" the plot from time to time in order to retain audiences' *interest*' (Seale, 2002: 36, emphasis added) (§2.2.2). An event's comprehensibility, or the coping-potential required for an event, may also be related to its 'familiarity' and this is discussed alongside repetition below.

2.3.3.1.2 Repetition

Polletta proposes that 'stories resonate through a combination of familiarity, pleasurable surprise, and emotional identification' (1998b: 425). The above discussion around 'interest' and injustice begin to address the surprise and emotional elements of Polletta's proposal. 'Familiarity' is argued to result from repetition, a discursive strategy at the heart of all discourse (Tannen, 2007: 49), and which gives talk 'a character of familiarity, making the discourse sound right [and] is a verbal analogue to the pleasure associated with familiar pleasurable surroundings' (p. 62). Unlike Kedrowski and Sarow (2004) in their negation of the significance of 'particular details', Tannen instead shows how 'the particularity and familiarity of detail makes it possible for both speakers and hearers to refer to their memories and construct images of scenes: people in relation to each other engaged in recognizable activities' (2007: 134) and that this is essential in forcefully dramatising the emotional impact of an event (p. 159). These images 'fire the individual imagination' (p. 134) precisely because they are constructed as recognisable through familiar details. Tannen proposes that there are three ways of thinking about repetition:

- self-repetition or allo-repetition (the repetition of others)
- a fixity-novelty continuum with a play between the fixed and the novel from exact repetition through to paraphrase
- a temporal continuum from synchronic (immediate) to diachronic (delayed) repetition – between the near and distant verbal environment

(Tannen, 2007: 63)

These interrelating forms of repetition indicate that language is more pre-patterned than one may think or prefer. Rather than this view of language favouring structure over agency, it instead addresses the ‘delicate balance between the individual and the social’ (Tannen, 2007: 99). Repetition thus has something to say about how the ‘individual speaks through the group and the group speaks through the individual’ (p. 100). Perhaps it is the repetition of others’ language, through the accumulation of prior text that led Snow and Benford to argue, using the language of the Bakhtin circle, that frames are a “dialogical’ phenomenon; their essence resides “not within us but between us” [addressing] the interindividual, interactional and contested process of framing’ (Snow and Benford, 2005: 207).

The common reporting of the thoughts, ideas or speech of others is typically referred to as ‘reported speech’. However Tannen insists that this term is ‘grossly misleading as one cannot speak another’s words and have them remain primarily the other’s words’ (2007: 104). She instead refers to this phenomenon as ‘constructed dialogue (...) a recontextualisation of words in a current discourse’ (p. 17) and is a discursive strategy which enhances the speaker’s ‘credibility as they present positive images of themselves and negative images of their opponents’ (p. 18). Thus, utterances spoken by someone else and repeated in some form by another speaker cease to be those of the speaker to whom they are attributed and are appropriated by the speaker repeating them. Further, everyday language and its ‘accumulation of prior texts’ (Tannen, 2007: 49, 103) involves taking words which have existed ‘in other people’s mouths, in other people’s contexts, serving other people’s intentions’ (Bakhtin, 1981: 294) and making them serve our own intentions in our own contexts.

The essence of such a line of theoretical enquiry is also reflected in the attention to the ‘cracks in the frame’ (Steinberg, 1998: 847 see also Snow and Benford, 2005), or shortcomings in practice if not in theory, of the framing literature (see Benford, 1997

for an insider's critique). These at least include the tendency of frame analysis to yield more descriptive heat than analytical light (Benford, 1997) by producing lists of frames like lists of themes and also to 'psychologise what is sociological' (p. 420). Steinberg shows how 'tilting the frame with a discursive turn' (1998: 862) addresses such 'cracks' and allows framing to be seen as a dialogic process (see also Bakhtin, 1981). In addition to recognising the implied dialogue with at least one other voice, and potential 'heteroglossia' (Bakhtin 1981) or 'multi-voicedness', Steinberg argues a dialogic focus addresses the insufficient attention given to how actors use discursive skills to delegitimize other's version of the truth by 'snatching their words from their mouths' (Steinberg, 1999: 772) and appropriating them with one's own twist for one's own purpose.

In sum, this section has shown the usefulness of the framing concept for understanding how individuals and collectives interpret their world (Goffman, 1974; Entman, 1993). This concept, as presented here, focuses on the activities of social movement actors and how they seek to produce or transform meaning around some aspect of reality (Benford and Snow, 2000). It helpfully identifies a range of features that contribute to understanding how new social movement actors might seek to construct their desired messages to audiences—frame amplification, transformation, resonance; contested processes of framing; ideas around emotions like injustice and 'interest'; repetition and the dialogical nature of framing. As such, and given that all 'meaning can be gleaned only by reference to a set of culturally familiar scenarios (scripts or frames)' (Fillmore (1976, 1985) cited by Tannen 2007: 54), it offers a useful starting point for analysing how actors around a potential PCa HSM may seek to produce or transform messages around aspects of PCa. Smith (2005) though suggests that understanding meaning through frame analysis has only 'nuisance value' and that the 'fragmentary nature of frame analysis permits only guerrilla warfare against the dominant paradigm (...) what is required is some heavy artillery, not yet more scattered sniping' (Smith, 2005: 10). By this he means that it is structures within narrative which 'are pivotal as the bearers of meaning' (p. 14) and which make action 'legitimate and thinkable' (p. 3)—'people make sense of the world with stories and act accordingly' (p. 18). Likewise Polletta (1998a) suggests that the narrative "captures the action-compelling character of the discourse around the sit-ins better than does the concept of frames by virtue of narrative's combination of familiarity and

undecidability, convention and novelty, and truth (representing reality) and fiction (constituting reality)” (p. 152).

2.4 Telling stories: narrative theory

The poetic notion that ‘The universe is made of stories, not atoms (Rukeyser, 1994: 135) recognises the universal tendency of human beings to tell stories about themselves or others (Bury, 2001). Close analysis of stories allows examination of the connections between biography and culture (Riessman, 2008) and the recursive and repetitive nature of social practices common to both individual actors and social structures across space and time (Giddens, 1984). My research aim in this thesis is to collect and analyse a variety of narratives—illness narratives which vary across time and type—to answer the research question of whether PCaOrgs or the UK print media have been a force for change in the UK regarding how PCa has been experienced by MWPCa. My aim in this section is to describe different aspects of narrative theory including the debates around it, how narratives are defined, the different types of narratives and the forms and structures which they are composed of.

2.4.1 Illness narratives

The increasing focus on the lay perspective of illness—sometimes termed ‘pathographies’ (Hyden, 1997; McKay and Bonner, 2002), ‘disease narratives’ (Brown et al., 2004) but more often ‘illness narratives’—began to emerge over the last thirty years or so (Hyden, 1997; Mishler, 2005) as a legitimate source of sociological enquiry into the ‘voice that was strong enough to stand up against the voice of medicine’ (Hyden, 1997: 49). Thomas (2010) though suggests that any sociological enquiry into illness narratives sooner or later encounters the well-known ‘storm in the academic teacup’ (Morse, 2001: 587)—of which there are several elements. Examination of illness narratives is claimed to: privilege story-telling over story-analysing and the ostensibly authentic feelings and experiences of the participant over other forms of data; romanticise illness sufferers as heroes in contrast with villainous doctors; and lack methodological and analytical rigour (Atkinson, 1997 reproduced in 2006).

The crux of this debate may reflect tension between public and professional sociologies (Thomas, 2010; Bury and Monaghan 2013a); the former concerned with

producing extra-academic knowledge for patient groups, the latter with producing academic knowledge for peers. Public and professional sociologies are though interfacing ‘ideal types, each of which is internally complex’ (Burawoy, 2004: 1609). This is not least because professional knowledge is instrumental for public knowledge—an effective public sociology depends upon a professional sociology in providing ‘legitimacy, expertise, distinctive problem definitions, relevant bodies of knowledge, and techniques for analyzing data’ (p. 1610). Correspondingly, Burawoy argues, the engagement of public sociologists in political and moral concerns beyond the academy makes the pursuit of methodological and theoretical coherence all the more worthy.

Responding to Atkinson’s (1997, reproduced in 2006) claims, Frank (2000) argues that though ‘narrative’ suggests structures within stories which a knowledgeable story-analyst may seek, story-tellers do not usually think of themselves as telling narratives and subsequently do not consciously adhere to any structures. Focusing on narrative structures may then privilege the story-analyst standpoint and risk excluding what is most important to storytellers, for example argues Frank (2000), their self-recuperation, self-preservation and remoralisation (p. 354). Frank’s later work though suggests that while ‘people tell stories that are very much their own (...) they do not make up these stories by themselves (2010: 14)—thereby indicating that when illness sufferers offer, say, moral accounts of themselves, they may, albeit unconsciously, draw on available and acceptable ways, or structures, of telling and knowing. Though ‘narrative’ evades a definitive explanation (Riessman, 2008), Table 2.1 exemplifies some common components:

Table 2.1 Common components in definitions of narrative

Author	Understanding	Components
Kleinman 1988: 49	‘The illness narrative is a story the patient tells, and significant others retell, to give coherence to the distinctive events and long term course of suffering. The plot lines, core metaphors, and rhetorical devices that structure the illness narrative are drawn from cultural and personal models for arranging experiences in meaningful ways and for effectively communicating those	<ol style="list-style-type: none"> 1. Simultaneously positioning of narrative and story 2. Telling stories 3. Giving coherence to events 4. Creating a plot 5. Using metaphors and other figures of speech 6. Drawing on cultural and personal resources 7. Recognising audience

	meanings’.	
Hyden, 1997: 49	‘we create frames for understanding and judgment and link them to the everyday circumstances of our lives by drawing on divers [sic] moral and political discourses. The narrative's importance lies in its being one of the main forms through which we perceive, experience, and judge our actions and the course and value of our lives’.	<ol style="list-style-type: none"> 1. Drawing on cultural resources to link with individual circumstances 2. Simultaneously positioning of frame and narrative
Bury, 2001: 264	‘The telling of stories, whether about oneself or others, is universal. The development of language in human life, in both evolutionary and individual terms, leads to the elaborate use of metaphors and other figures of speech, and thus narrative form. All human cultures (or cultural segments) rely on such symbolic repertoires in order to achieve a minimum of social integration’.	<ol style="list-style-type: none"> 1. Telling stories 2. Simultaneously positioning narrative and story 3. Using metaphors and other figures of speech 4. Drawing on cultural resources to integrate socially 5. Creating, sustaining and restoring meaning in everyday life
Riessman, 2008: 3, 105	<p>‘in everyday storytelling, a speaker connects events into a sequence that is consequential for later action and for the meanings that the speaker wants listeners to take away from the story. Events perceived by the speaker as important are selected, organized, connected and evaluated as meaningful for a particular audience’</p> <p>‘stories don’t fall from the sky (or emerge from the innermost “self”); they are composed and received in contexts – interactional, historical, institutional, and discursive – to name a view. Stories are social artefacts, telling us as much about society and culture as they do about a person or group.’</p>	<ol style="list-style-type: none"> 1. Temporal ordering of events 2. Creating plot 3. Recognizing audience 4. Selecting salient events 5. Organizing, connecting and evaluating events
Frank, 2010: 25-26	‘One thing happens in consequence of another (....) [tick tock] each <i>tick</i> creates an expectation for the corresponding <i>tock</i> to follow’	<ol style="list-style-type: none"> 1. Recognizing audience 2. Temporal ordering of events – tock follows tick
Czarnisaskwa, 2004: 5	‘[people do not] tell stories as they please and, in so doing, shape their	<ol style="list-style-type: none"> 1. Telling stories less agency 2. Drawing on cultural

	lives as they see fit. (...) we are never the sole authors of our own narratives; in every conversation a positioning takes place (Davies and Harre 1991) which is accepted, rejected, or improved upon by the partners in the conversation'	resources 3. Recognising audience 4. Co-construction of story
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Table 2.1 shows the commonalities in how a variety of authors have understood narratives. These at least include: a temporal ordering of events; involving the audience in the co-construction of meaning; drawing on circulating cultural, political or moral ways of speaking; and creating a plot. The often simultaneous positioning of 'narrative' and 'story' shows that there is not a consistent distinction between these terms; I thus use these terms interchangeably throughout this thesis.

2.4.2 Narrative types

Hyden (1997) draws attention to the relationship between the narrator, the narrative, and the illness and proposes three types of illness narratives: 1) illness as narrative; 2) narrative about illness; and 3) narrative as illness. First, an 'illness as narrative' is where the narrator, illness and narrative may be combined in one person depicting 'events that have been experienced personally and pose problems for the individual in one way or another' (1997: 54). Second, in a 'narrative about illness', knowledge and ideas are conveyed by a narrator about an illness. Third, a 'narrative as illness' refers to situations in which (an insufficient) narrative, or indeed an inability to create a narrative, indicates an illness, for example, a brain injured person unable to tie together particular experiences and events.

2.4.3 Narrative forms and analysis

I now draw on Bury's (2001) three types of non-mutually exclusive narrative form: contingent, moral and core and use this as a basis for understanding how narratives are analysed. I use the ideas of several other narrative and literary scholars to build upon this basis (for example: Bakhtin, 1986; Bury and Monaghan, 2013a; Frank, 2010; Hyden, 1997; Kelly and Dickinson, 1997; Polletta, 2006; Riessman, 2008; Tannen, 2007).

2.4.3.1 Contingent narratives

Contingent narratives address 'beliefs and knowledge about factors that influence the onset of disorder, its emerging symptoms, and its immediate or 'proximate' effects on the body, self and others' (Bury, 2001: 268). They thus deal with the immediate temporal unfolding of the illness from its onset, the strategies used to manage its effects and the relationship between those ill and those they interact with (Bury and Monaghan, 2013a). Bury (2001) suggests that Hyden's (1997) 'illness as narratives' and 'narratives about illness' types may be constructed within the same narrative when respondents' stories combine their lay beliefs with increasing familiarity with medical knowledge. Bury goes on to suggest that contingent narratives are concerned with how an ill person manages the effects of the illness on family and friends and includes aspects of: 1) normalisation; 2) coping; and 3) the strategic management of illness.

First, normalisation, Bury (2001) proposes, may be achieved either in the maintenance of one's pre-illness identity or the incorporation of illness into a changed identity. Maintaining one's pre-illness identity means that when people tell stories of themselves they are unlikely to disclose aspects of their illness. In contrast, people are more likely to disclose a variety of aspects of their illness when they seek to incorporate their illness into a changed identity. Second, people's talk about how they cope with illness deals with the practical management of interactional issues of disclosing illness to family and friends. Bury (2001) suggests that coping talk may be performative in that it allows a preferred, likely virtuous, self to be presented to others. Though he does not reference it directly, Bury's observation is similar to that which Wilkinson and Kitinger (2000) argue is a moral imperative for women with breast cancer to 'think positive'. Wilkinson and Kitinger (2000) show how the 'positive thinking' talk of these women is 'interactionally occasioned' (2000: 809) in using a 'taken-for-granted piece of cultural knowledge' (2000: 802) to enable the disclosure and convenient 'wrapping up' (2000: 803) of troubles telling; in turn relieving the 'listeners of a potential conversational burden' (2000: 805). Third, the strategic management of illness includes describing the pacing of work and home activities and the mobilisation of social support.

2.4.3.1.1 Disclosing illness and prostate cancer

There are few studies which consider how MWPCa disclose their illness. The most salient of these is a Canadian longitudinal study focusing on how MWPCa opting for surgery as treatment, and their spouses, manage decisions about telling or not telling others in their social and business networks (Gray et al., 2000). These authors propose that, given the massive increase in media coverage¹ and corresponding public awareness in the decade preceding the publication of their article, 'prostate cancer has ceased to be hidden to public gaze' (2000: 274). If so, there are consequences for how MWPCa may feel about disclosing their illness to others and for the stigma associated with a cancer diagnosis (Muzzin et al., 1994). Muzzin et al. (1994) characterise people with cancer as having 'a 'living-dying' experience' (p. 1201), being 'faced with the intolerable incompatibility of life and death' (p. 1201). These authors argue that this is at least because of the social stigma that others attribute to people with cancer and the subsequent problems that such people might have when interacting with others. People with cancer, they argue, might then choose to not disclose their diagnosis when they are interacting with particular groups of people. Goffman (1963) understands stigma as a mark of disapproval; either visible and discrediting or invisible and discreditable. Some marks of cancer are visible with the possessors of such marks discredited, for example hair loss as a result of chemotherapy; other marks though are invisible with the possessors instead discreditable, for example, impotence and incontinence resulting from radical prostatectomy or hormone treatment for PCa. The challenge for the discredited is to 'manage impressions'; for the discreditable to 'manage information'.

Gray et al. (2000) hypothesise that MWPCa are beginning to be seen in a positive manner similar to that for women with breast cancer and that it may be less socially dangerous for men to acknowledge their health status to friends and acquaintances. This is despite their recognition that PCa potentially constitutes the double stigma of life threatening illness and sexual dysfunction related to treatment.

Gray et al. (2000) conduct interviews with MWPCa and their spouses simultaneously and separately: pre-surgery; 8-10 weeks post-surgery; and 11-13

¹ They explicitly reference Clarke (1999) in support of their argument that media coverage has greatly increased. However, this is a misinterpretation of Clarke's sample size who instead laments "the very few articles on prostate cancer in the media over the time period covered" (Clarke, 1999: 70) and their "paucity" (p. 70) when compared with articles on breast cancer.

months post-surgery. The primary concern is on how men share information with others, besides their spouse, about their diagnosis and ongoing condition. They find that most MWPCa avoid disclosure about their illness where possible to others other than their spouse. The strategies men use for disclosing include concern with who needs to know; whether the men themselves need information from others; and an imperative to warn others. Men, for example, feel obligated to be open with their family; to prepare them for their potential death during or after surgery; and to warn them of familial risk of PCa. Among employed men, bosses or colleagues are also often perceived as needing to know for organisational purposes. Some men feel that disclosing their illness introduces awkwardness into friend and work relationships as often people do not know how to be helpful, presenting an unwelcome disturbance to pre-illness relationships. Men do not disclose their PCa to certain audiences: anyone outside of their circle of intimates; those who do not need to know; those they think would make a joke of it; and those whom they feel are vulnerable in some way, for example, frail mothers or those suffering themselves. While acknowledging that others may want to be supportive there is a mixed response to its receipt with some men enduring the help for the benefit of those offering help. Factors influencing this limited disclosure are a perceived low need of support; fear of the stigma associated with sexual dysfunction; the need to minimize threat of the illness to aid their coping; practical necessities in the workplace; and the desire to avoid burdening others.

Grunfeld et al., (2013), in their study of men's experience of working after treatment for PCa, explored differences in how MWPCa disclose to their colleagues. They found that some men are reluctant to disclose to their colleagues because they are embarrassed and worried that they may be stigmatised. Men are also concerned not to be seen as seeking sympathy or causing others to be embarrassed: "[p]eople just don't know what to think when you've got those things, cancer. As soon as people think that they think "Oh my God, you're going to be dead within a few weeks" or something" (p. 78). The authors though do not further discuss how men show their awareness of any interactional difficulty.

2.4.3.2 Moral narratives

Moral narratives have evaluative aspects as 'sufferers seek to account for and perhaps justify themselves in the altered relations of body, self and society brought about by

illness' (Bury, 2001: 274). Narrators may attribute culpability to the self, shift blame to an external Other or, indeed, do both. Hyden describes how a suicidal man attempts to understand his illness by shifting blame from himself to his parents: the potential genetic predisposition for mental illness from his father and the high expectations upon him by his mother (1997: 58-9). Moral narratives also include the pursuit of a virtuous presentation of self. This may involve distancing oneself from the 'dirty' side of illness; from being seen as a burden to others; or seen as a failure in the face of illness.

2.4.3.3 Core narratives and genres

Core narratives are instrumental in both contingent and moral narrative forms in making available particular language to narrate the moral self and concepts of disease and illness. People construct core narratives 'within cultural settings which provide specific forms of language, clichés, motifs, references and other elements of linguistic and symbolic repertoires which allow and constrain what is said and how it is expressed' (Bury, 2001: 278). Bury (2001) ostensibly agrees with Frank (2000) that when people tell stories they may unconsciously draw on core narratives; people's narratives may then be more 'pre-patterned' (Tannen, 2007) than they think. Such pre-patterning can happen when people draw on culturally available 'genres' (Bury, 2001: 278), or "genres of expression' (Bury and Monaghan, 2013a: 81) through which the narrator 'emplots' herself in a more or less dramatic fashion' (p. 81). These may be epic, heroic, tragic, romantic, comic or ironic, or didactic (Bury, 2001) or apocalyptic (Smith, 2005).

The suggestion that romantic genres are a struggle for personal meaning and identity (Kelly and Dickinson, 1997) is rather vague and seemingly redundant, not least given that narratives, generally, whatever the genre used, are considered to be sites for constructing and contesting identity (Riessman, 2008; Bury and Monaghan, 2013a). Drawing upon a heroic narrative is common, for example with media accounts typically describing those suffering from serious illness in terms of a 'courageous 'fight' by the sufferer' (Kelly and Dickinson 1997: 268) (see the media portrayal of children suffering from cancer in heroic terms (Dixon-Woods et al., 2003)). Similar to the romantic genre though, at least as understood by Kelly and Dickinson, the heroic genre is somewhat

lacking in specificity, seeming to fit within both tragic and romantic genres. More useful is Smith's (2005) explanation of a romantic-tragic genre continuum:

Where tragic frames exist the corresponding structure of feeling is not one that sustains activism or violent struggle. There is an amplified awareness of suffering, an atmosphere of pathos, and a belief that human motivations are misguided and can lead only to poor outcomes. If tragedy involves a futile struggle against the fates, the ubiquity of bad choices, the inevitable failure of heroic actions, and the horror of consequent suffering, the essence of romance is the triumph of the hero over adversity. Not necessarily about love, this is a fundamentally optimistic genre marked by the belief that actions can make a difference and that change for the better is in the air. In romance the hero is motivated by high ideals and overcomes a series of obstacles, challenges, and enemies associated with powers deemed evil. (Smith, 2005:25-26)

The romantic genre, continues Smith, is inspirational for social movements as it carries with it a hope that a wrong, or a wrongdoing antagonist, may be subject to successful negotiation to become good. Bury notes that people are not necessarily consistent in their use of genres and move say from tragic to ironic or heroic to comic as they see fit. This will, he suggests, mainly 'depend on the context in which the narrative is being constructed and presented, and on the intentional acts which they help to constitute' (Bury, 2001: 280).

Comedic or ironic genres may include mocking of the self or others (Kelly and Dickinson, 1997) with irony an aspect of both comedy and tragedy, and comedy sharing features of a romantic genre (Smith, 2005). Kelly and Dickinson (1997) argue that humour is a narrative device which renders the suffering of the ill person commonplace and which functions to spare 'the reader/listener pain, since the humour signals that the suffering is not to be taken seriously' (1997: 268). In this way the narrator creates a social distance from the suffering providing a practical intersubjective cue for the listener/reader to do likewise (p. 270). To this extent then, I suspect that comedic and ironic genres are instrumental in contingent narratives of coping (Bury, 2001) and may likewise allow the convenient disclosure and 'wrapping up' of troubles (Wilkinson and Kitzinger, 2000).

Epic genres involve an identification with or defence of existing social values (Kelly and Dickinson, 1997). The defence of a social value bears though, in my view, similarities to a moral narrative. In their study of how personal storytelling functions as a mechanism of socialisation in families, Miller, Wiley, Fung and Liang (1997) show how didactic narratives are used to convey moral and social standards. Inasmuch as

this is so, didactic genres, or forms, of narrative are at least instrumental in moral narratives.

Whatever genre people use, it is always open to negotiation, always “at risk”, (Bury, 2001: 279) in the everyday interactions people face, particularly with their family (p. 279.). To this extent then, narratives are ‘co-authored’ (Williams, 1984: 181) in that they are ‘bounded by and constructed in relationship with various individual people and organisations’ (p. 181.). Aspects of co-authorship are also seen when narrator and listener actively create ‘emplotment’ (Hyden, 1997: 61) when they seek ‘to understand and articulate the illness and the illness events as a meaningful whole’ (p. 61). ‘Stories work to *emplot* lives’, argues Frank (2010: 10, emphasis in original), by making ‘some particular future not only plausible but also compelling’ (p. 10)—Polletta and Ho (2006) make a similar point regarding the work of frames in ‘advancing a compelling point of view’ (p. 186). Although Hyden (1997) limits ‘emplotment’ to participants in oral narratives, Crossley and Crossley (2001) convincingly show, through written texts, how the mental health ‘voice’ changes over time with the changing anticipation of its audience’s reception. Ideas of co-authorship and emplotment also suggest that stories are dialogical—there is always an implied dialogue with at least one other voice in any narrative and potentially a ‘heteroglossia’ (Bakhtin 1981; see also Riessman, 2008: 107). Bakhtin (1986) points out that speakers, hearers, writers and readers all orientate to an actively responsive understanding and anticipate their audience’s agreement. Similarly, Frank (2010) borrows the term “recipient-designed” (p. 90) from conversation analysis in his observation that ‘storytelling is tailored to fit the expected response of the listener(s), including the listener’s apparent needs and purposes, sense of humour, likes and dislikes, and readiness to approve or disain’ (Frank, 2010: 90; see also Riessman, 2008: 106).

In sum, Bury provides three useful means for thinking about how narratives might be analysed: contingent, moral and core narrative forms. Core narratives are instrumental for the other narrative forms in that they provide pre-patterned common sense language, including genres, which the speaker draws on in the expectation that his/her intended audience does likewise in their interpretation. Narrators are not though consistent in how they use this pre-patterned language with their use always open to audience negotiation in everyday interaction. In this way, narratives are co-authored or emplotted as speakers anticipate their audience’s reaction – sympathetic,

objectionable or otherwise – and respond accordingly in the story they tell. Narratives are thus then also dialogic in that there is always an implied dialogue with at least one other voice. The pre-patterned, or repetitious, language of core narratives is used in moral and contingent narratives. Moral illness narratives seek to account for an illness, attribute blame, pursue a virtuous self and create distance from undesired aspects of the illness. Contingent narratives, though paying attention to the immediate temporal unfolding of the illness and its implications for managing work, home and other activities, also contain moral aspects. Narrators seek to normalise their pre/post illness identity and to manage interactional issues of disclosing illness to others and to create a social distance from being a burden, interactional or otherwise to others.

2.4.4 Some shortfalls in the illness narrative literature

Hyden (1997) proposes gaps that are insufficiently addressed in the literature: 1) studies comparing illness narratives in the mass media with illness narratives constructed by the afflicted; and 2) studies comparing how illness narratives may vary over time and social context. Dixon-Woods et al. (2003) and Crossley and Crossley (2001) have since somewhat alleviated this deficiency. Dixon-Woods et al. (2003) compare newspaper and parent's accounts of childhood cancer¹. They analyse 42 articles with significant coverage of a child with cancer which occurred during a specific week in 1999 and compare accounts of childhood cancer therein with narrative accounts from 20 mothers in England asked to 'tell the story' of their child's cancer. They find that though parents and newspaper accounts draw on common discourses about parenting, childhood and illness, they also differ significantly. Crossley and Crossley (2001) explain how the 'voice' of those diagnosed as mentally ill changed between the 1950s and 1990s. They show that when such 'voices' speak they accommodate an anticipated audience. In the 1950s the mental health 'voice' anticipated, and was shaped by, an unsympathetic, hostile and critical audience. In the 1990s, largely due to the work of the anti-psychiatry and survivor social movements and spillover from feminism and black liberation movements, the audience of the mentally ill 'voice' was prepared to listen in a new way.

¹ Although even here the parents are still surrogates for their children although the parents are giving their narrative of caring for their children

2.5 Summary

In this chapter I have shown how illness and disease can no longer be considered to be distinct given that 'social life matters for morbidity and mortality and vice versa' (Timmermans and Hass, 2008: 661). I show how a 'social diagnosis' (Brown et al., 2011) considers how HSM actors might contribute to the diagnosis of a health condition inasmuch as they are actively involved in the production and transformation of meaning. In the past twenty years, the public visibility of PCa has increased as PCaOrgs, as a potential HSM, have appeared in the UK. Despite this, and an increase in social movement studies which have focused on aspects of health and disease, little attention has been paid to PCa with no studies of how the emergence of PCaOrgs in the UK may produce or transform meaning around PCa. A social diagnosis also considers how the media might contribute to the diagnosis of a condition. Print media are among the most relied on sources of information regarding disease, illness, death and medicine for people in general (Clarke, 2004), and MWPCa in particular (Halpin et al., 2009). There are though relatively few studies of print media representation of PCa (Halpin et al. 2009) with as yet no study of such representation in the UK and thus none comparing how this representation may have changed since the emergence of PCaOrgs in the UK. Furthermore, there are no studies about how changing representations of PCa by PCaOrgs and the media may impact on the experience of MWPCa.

I have also shown that the tendency of people to tell stories is universal and the sociological examination of these stories sheds light on the repetitive nature of social practices over time. The way people—or organisations or the media—tell stories about illness has been an increasing source of enquiry in the sociology of health and illness over the last thirty years. There are though still gaps in this literature, for example, studies comparing illness narratives in the mass media with illness narratives constructed by the afflicted and studies comparing how illness narratives may vary over time and social context (Hyden, 1997). The sociological attention to illness narratives is despite contentious academic debate over the privileging of narrative data over other types of data. The crux of this debate relates to the ostensible tension between producing knowledge which addresses public concerns and producing knowledge which advances academic theoretical and methodological expertise.

All of the literature reviewed in this chapter helpfully points to the range of influences that may shed light on how the research question asked in §1.3: how have PCaOrgs and the UK print media been a force for change in the UK regarding how PCa has been addressed and experienced by MWPCa? And, more broadly, what might this reveal about the form and function of narratives? This literature then offers a useful starting point for 1) how key individuals within PCaOrgs describe how they have sought to address the condition of PCa; 2) the changes in how MWPCa describe their illness experience in research interview over this time; and 3) the changes in how the UK national print media have represented the illness experience of MWPCa from the emergence of PCaOrgs in the UK in the mid-1990s.

Chapter 3 Methods and methodology

3.1 Introduction

In this thesis I ask: how have PCaOrgs and the UK print media been a force for change in the UK regarding how PCa has been addressed and experienced by MWPCa? In answering this question I aim to investigate: 1) how key individuals within PCaOrgs describe how they have sought to address the condition of PCa; 2) the changes in how MWPCa describe their illness experience in research interviews over this time; and 3) the changes in how the UK national print media have represented the illness experience of MWPCa since the emergence of PCaOrgs in the UK in the mid-1990s. The methods I used to answer the above research questions and address the research aims involved collecting and analysing a variety of illness narratives. I proceed in this chapter to first describe my research design. I follow this by describing the methodology underpinning the methods. I show the broad support in the literature for engaging with narratives in such a way that the research enquiry itself plays a major part in analytic decisions (Spicer, 2012). Finally, I describe the methods I use to collect and analyse each of the three sets of data. Here, I present the specific research questions and aims for the particular data set and lay out the various research steps for each of the data sets: recruitment or sampling, ethical approval, data collection, transcription and analysis.

3.2 Development of research design

The original methodological design for this thesis included investigation: 1) of the changing public image of PCa over time (through UK print media articles and health documents from NHS, government and PCaOrgs sources); 2) of the impact on the experience of PCa (through five focus groups with MWPCa and their intimate family members); and 3) of PCaOrgs (through interviewing leading figures within PCaOrgs) (Appendix 2). A combination of opportunity and necessity led to three changes in this

design. First, focus group interviews with MWPCa and intimate family members¹ were changed to individual interviews with MWPCa around 2000-2001 and 2010-2012². This was due to an early collaboration with the Health Experiences Research Group (HERG) at Oxford University responsible for www.healthtalk.org which enabled access to 52 transcripts of narrative interviews with MWPCa in 2000. Access to this secondary data prompted the research possibility that similar individual interviews with MWPCa could be carried out in 2010 and compared with those in 2000—resulting in data about the experience of MWPCa through research interviews over time. While not ideal timing regarding the advent of PCaOrgs in the UK (in the mid-1990s), access to transcripts of MWPCa interviewed in 2000 was valuable in offering contemporary data on the experience of PCa close to this advent. Thus, though focus group data—where group members through agreement and disagreement ‘enthusiastically extend, elaborate, or embroider an initially sketchy account: for example through the consensual piling up of fine detail’ (Wilkinson, 2004: 180-1) would be lost—other interesting analytic comparisons were enabled.

One such interesting analytic comparison was between the ‘(mass³) mediated nature of [the] personal experience’ (Seale, 2003: 513) of MWPCa and that mediated through research interviews with MWPCa. Though boundaries between ‘hard’ and ‘soft’ media stories are blurred (Henderson and Kitzinger, 1999), sampling for ‘soft’ illness narrative articles over ‘hard’ articles—say about new drugs—offered a better comparative ‘fit’ with the rest of the research design. This was because it allowed a ‘human face’ (p. 570) to the media representation of PCa. Thus, the second change in the original research design was to sample the UK media for illness narratives of MWPCa from 1990-2000 and from 2000-2010. This corresponded to the two 10 year periods prior to each set of illness narrative interviews with MWPCa in 2000 and 2010.

¹ The original design also envisaged that some focus group participants would be African or African-Caribbean in order to explore how ethnically-based cultural differences may influence the degree to which the collective identity ‘offered’ to these individuals is taken up. A condition of the funding though was that this group should not be focussed on. A statement from Clive Seale, the funding applicant; ‘I am happy to confirm that, although I wanted to include Afro-Caribbean [participants], the funders were quite insistent that a condition of funding was that we should not focus on this group. I was quite frustrated about this at the time and tried to persuade them, but they insisted on this’ (personal correspondence, 15 January 2014).

² For ease of reference I henceforth refer to the 2000-2001 and 2010-2012 fieldwork as ‘2000 and ‘2010’ respectfully

³ Seale mainly focuses on “traditional popular ‘mass’ media” (p. 516) although he recognises that promotion of ‘scripts’ or ‘ways of thinking’ are increasingly found in ‘new’ media such as the internet.

Thus, the first change from conducting focus groups to conducting individual interviews and the second change from sampling all UK print media articles of PCa to sampling illness narratives of MWPCa sat alongside a third originally envisioned and unchanged source of data—narrative interviews with advocates around prostate cancer (PCaA) (Appendix 2). These two changes were though consequential for the fourth originally envisioned source of data (Appendix 2) regarding the quantity and type of data in the study. The first change meant an increase in data from 5 focus groups to 40 individual interviews (20 each from 2000 and 2010). The second change meant a reduction in data from sampling all articles around PCa in the UK national print media to only those containing illness narratives. Though this second change meant a reduction in the number of media articles analysed, the proposed method of analysis of these articles also changed from a straightforward comparative keyword analysis in context to one which paid additional qualitative attention to the narrative structure of these articles. Thus, on balance, this still represented far more data and subsequent analysis than originally envisaged. This then led to a third change—not to sample health policy documents concerning PCa from NHS, government or PCaOrg sources. Though a valuable research enquiry, it was not practical to proceed because of the extra time needed for data collection, analysis, discussion and the space needed in this thesis. Table 3.1 summarises the research design and is indicative of the research data which will be fully described in §3.4.

Table 3.1. Summary of research design and data

Data	No. of Narratives and Time Period	
	Early	Late
Illness narratives of MWPCa in the UK national print media	39 (1990-2000)	101 (2000-2010)
Illness narratives of MWPCa in research interviews	20 ¹ (2000)	20 (2010)
Narratives by prostate cancer advocates	0	21 (2010)
¹ Interviews by HERG for www.healthtalk.org matched along demographic variables (age at diagnosis/age at interview and socio-economic— see Table 3.9) of MWPCa interviewed in 2010		

Table 3.1 shows the quantity of narratives collected and analysed for this thesis. It also indicates the diachronic and typological (Hyden, 1997) range of these narratives to include: different time periods; illness narratives constructed both in research

interview and by journalists writing in UK national print media; and narratives about illness constructed in research interview.

3.3 Methodology

Here I show the broad support in the literature to engage with narratives not in an ‘undisciplined, anything goes atmosphere’ (Coffey and Atkinson, 1996: 194) but rather, where the research enquiry itself plays a major part in analytic decisions (Spicer, 2012). Although many researchers traditionally apply either a quantitative or qualitative methodology to data collection and analysis, the ‘ability to innovate [in combining such methods] lies at the heart of creative research practice’ (Spicer, 2012: 490). It also responds to Riessman’s encouragement to ‘innovate and transgress the borders’ (2008: 18) of incumbent narrative analytic traditions such as thematic and structural analysis and newer methods such as dialogic analysis. My research enquiry is to discover the extent to which PCaOrgs and the UK print media have been a force for change in the UK regarding how PCa has been addressed and experienced by MWPCa. I investigate this enquiry by examining: 1) how key individuals within PCaOrgs describe how they have sought to address the condition of PCa; the changes in how MWPCa describe their illness experience in research interviews over this time; and 3) the changes in how the UK national print media has represented the illness experience of MWPCa since the emergence of PCaOrgs in the UK in the mid-1990s.

3.3.1 Sensitising concepts

The literature review in Chapter 2 provides possible ‘sensitizing concepts’ (Blumer, 1954; Bowen, 2006; Charmaz, 2006) with which to approach narrative data. Sensitising concepts ‘suggest directions along which to look’ (Blumer, 1954: 7) during the iterative process of reviewing literature and developing the analysis and provide ‘initial ideas to pursue and sensitize you to ask particular kinds of questions about your topic’ (Charmaz, 2006: 16). They are ‘points of departure for developing, rather than limiting, our ideas’ (p. 17). One, rather unfounded, criticism though of using sensitising concepts is that they may disrupt an inductive approach to the data (Glaser, 1992)—where ‘patterns, themes, and categories of analysis come from the data; they emerge out of the data rather than being imposed on them prior to data collection and

analysis' (Patton, 1980: 306). However, analysis is also an 'inductive–deductive interplay (...) [where] [r]esearchers start with a topic of interest, collect data and allow relevant ideas to develop' (McGhee et al., 2007: 335)—a process enabled by use of sensitising concepts.

While the concepts in Chapter 2 provided initial ideas to pursue in investigating my thesis, and indeed iteratively helped to form it, in sensitising me to what questions to ask of the literature and my data (Charmaz, 2006), I remained open to the emerging relevance of other particular and unexpected literatures (Kelly, 2009). This was particularly exemplified in my discovery of the importance of the concept 'interest' during analysis. I used NVIVO (v9) software as a means to manage data from the MWPCa and PCaA interviews. One tool within this software is a 'query' facility which, as I shall explain below, is useful to systematically search the entire dataset if one has an analytic hunch about, or is sensitised to, a particular word or concept. Already sensitised to the idea that emotions may be important in my data (Turner, 1969; Gamson, 1992; Seale, 1993; Klawiter, 2004; Tannen, 2007; Lakoff, 2010), I inserted a list of emotions provided by Wikipedia¹ into the NVIVO query facility. When the PCaA data were so queried, of immediate note was the accumulation of data around 'interest' across the 21 interviews, for example (emphasis added):

I'd write for grants to the cancer charities for research money and get no, get nothing, and it seemed that there was no central government *interest* also in prostate cancer in the way that there was an *interest* in breast cancer (PCa-MP/2)²

I think what has changed is the angle that the media is *interested* in. (...) So although they are still very interested in prostate cancer as an issue, it's not about the hidden nature of the disease. It's not about the legacy of neglect. (...) so I think the issues have changed from the media perspective, what really *interests* them and what they're going to run with (PCa-ORG/3/1)

the media is not stupid and they start to question that kind of thing, and to sustain their *interest* you have to refresh the cause (PCa-ORG/3/2)

those with a, what might or might not be a vested *interest* will continue to try and stimulate the idea that, there is some sort of there is a benefit to be gained, by detecting more prostate cancers (PCa-MP/1)

¹ See Lupton's blog (Lupton, 2013) on her recognition of academic's use of Wikipedia as a reference source and her encouragement for academics to use this platform to contribute to their body of knowledge.

² See §3.4.2.1.1 for an explanation of this and other anonymised identifiers used in this section

This was surprising—not least because ‘interest’ was not immediately obvious as an emotion—and it prompted an investigation of the concept in the academic literature. This proved convincing regarding the status of ‘interest’ as an emotion; it also subsequently led to its theoretical and analytical importance in relation to ‘resonance’. My ensuing analytic attention on ‘interest’, and the discussion above on sensitising concepts in general, bears some similarities to what Frank describes as ‘artfulness’ (2010: 114), and what McGhee et al. (2007) might like to describe as inductive–deductive interplay, by Williams (1984) in: “The Genesis of Chronic Illness: Narrative Re-construction”. Frank proposes that Williams’s ‘artful’ use of ‘Bill’s’ question: ““How the *hell* have I come to be like this?”” (Frank, 2010: 114; Williams, 1984) implies that Williams’s analytic interest arose inductively from his interviews. Instead, Frank continues, Williams’s decision to focus on the genesis of chronic illness likely derived as much from concepts about narrative and illness as spontaneously from his interviews.

3.3.2 Comparative keyword in context analysis

Inasmuch as sensitising concepts draw attention to important aspects of the literature and the data, they may also be considered to be somewhat akin to the notion of ‘keyness’. Qualitatively speaking, ‘key’ words are determined ‘after a scholarly, interpretive investigation of [their] resonance within a system of ideas’ (Seale et al., 2006: 2581). Key words have ‘available and developing meanings’ (Williams, 1976: 13) with people making both explicit and implicit connections in their meaning-making in their ‘ways not only of discussing but of seeing many of [their] central experiences’ (p. 13.). ‘Keyness’, is not only understood qualitatively but also quantitatively (Stubbs, 1996; Baker, 2006) where it indicates the salience, or ‘proportional statistical frequency’ (O’Halloran, 2010: 215) of a word within a text.

Comparative keyword in context (CKWIC) analysis is a way of inductively examining the words or phrases in one corpus, or body of data, which appear ‘key’, or statistically frequent (O’Halloran, 2010) when compared with another corpus. It is a conjoint quantitative and qualitative analytic method which reduces ‘arbitrariness in what is selected as salient’ (p. 215) and which is ‘particularly suitable for use with large volumes of qualitative data where the systematic detection of differences between groups is a primary analytic purpose’ (Seale et al., 2006: 2577-8). A word is

determined as quantitatively significantly 'key' by taking into account the size of each corpus, the frequencies of each word within them and then carrying out a statistical test of difference in frequency of words with the significance of this difference measured by a probability (p) value. Two means commonly used to determine the significance of keywords are the chi-square test and log-likelihood statistic (Rayson et al., 2004); the choice of which one to use is indicated by their reliability for at least the size and ratio of the compared corpora. The choice of p value is indicative of not only the amount of confidence that may be had that the word is key due to the conscious or unconscious choice of the author rather than by chance (Baker, 2006) but also by the number of keywords the investigator deems necessary for analysis.

In as much as CKWIC is a quantitative analytic method it may be considered to be a specialised form of content analysis. Content analysis is a quantitative method for analysing text for the 'frequency of specific terms, narratives or concepts' (Seale and Tonkiss, 2012: 460). It may though not only be used for producing simple counts but combined with other methods to produce a more interpretive analysis of meaning in context (p.464). It is frequently used for analysing print or television media content, policy documents and political speeches. Studies using content analysis often use Nexis, or some other database, to search for data and some method of computer assisted data analysis software to examine a variety of substantive topics. Such studies include examining: how worldwide print media valorised men and women with cancer (Seale, 2002); obesity framing in the New York Times and prime time television news (Lawrence 2004); the effect of media portrayals of removal of human tissue from children for biomedical purposes on subsequent registrations with the UK Children's Cancer Study Group tumour bank (Seale et al. 2005); coverage of Herceptin in UK national print news (Wilson et al., 2008); and changes in 'cancer' portrayal over time in major Canadian daily newspapers Henry et al. (2012).

Like content analysis, studies using CKWIC analysis often use Nexis to search for data and computer assisted software to examine a variety of topics. Also, like a more interpretive content analysis, CKWIC combines statistical quantitative and qualitative notions of keyness as it 'reduces arbitrariness in what is selected as salient' (O'Halloran 2010: 215) and worthy of further investigation. Thus CKWIC and content analysis may both be 'a more purely inductive approach than that of the qualitative analyst who deploys inference at a much earlier stage' (Seale et al., 2006: 2581). Where CKWIC

differs from an interpretive content analysis is that it inductively examines words or phrases in one corpus which appear 'key' when compared with another corpus and is particularly suitable for research questions where the detection of differences between texts is a principal research enquiry (Seale et al., 2006). CKWIC analysis is used in a variety of health and social contexts: the relevance of gender in online cancer support groups comparing breast and prostate cancer experience (Seale et al., 2006); differences in pro- and anti-hunt arguments in parliamentary debates (Baker, 2006); media constructions of sleep and sleep disorders (Seale et al., 2007); interaction of class and gender (Seale and Charteris-Black, 2008); changing media portrayal of anorexia (Shepherd and Seale, 2010); comparisons between formal and informal weaning advice to first time mothers (Moore, Milligan, Rivas, and Goff, 2012); and how people with osteoarthritis use 'pain' words in their experience of knee and hip pain and how men and women use 'pain' words differently (Gooberman-Hill, French, Dieppe, and Hawker, 2009).

3.4 Methods

The substantive focus of this section is on the methods used to collect and analyse a variety of narratives concerned with PCa (total n=200): illness narratives of MWPCa from the UK print media 1990-2010 (n=140); illness narratives from research interviews with MWPCa in 2000 (n=20) and in 2010 (n=20); and narratives about illness from actors around PCaOrgs in 2010 (n=21). This section is laid out in two parts: first I describe the processes involved in collecting the data for these three sets of narratives; second I describe how I analysed each dataset.

3.4.1 Data collection

3.4.1.1 Data collection: media illness narratives of MWPCa 1990-2010

My research question asks how PCaOrgs and the UK print media have been a force for change regarding how PCa has been addressed and experienced by MWPCa since the emergence of PCaOrgs in the UK in the mid-1990s. I aim to answer this question by exploring changes in how the media have represented the illness experience of

MWPCa. I now describe how I sampled the 140 illness narratives from the UK print media 1990-2010.

3.4.1.1.1 Sampling illness narratives of MWPCa in UK print media

A final sample of 140 media narratives was drawn across 2 time periods: 01/06/1990-31/05/2000 and 01/06/2000-31/05/2010. Of note is that I originally sampled by 4 five year time periods: 1) 01/06/1990-31/05/1995; 2) 01/06/1995-31/05/2000; 3) 01/06/2000-31/05/2005; and 4) 01/06/2005-31/05/2010. While the original sampling frame allowed a more nuanced examination of media framing of PCa when there was little, if any, activity from UK PCaOrgs¹, the dual time period sampling frame provided a better fit with the overall research design.

I used Nexis UK, a commercially available on-line database of newspaper articles, to retrieve all articles appearing in the English language UK national press from 01/06/1990 to 31/05/2010 containing three or more mentions of the words ‘prostate cancer’ or ‘cancer of the prostate’ or ‘prostatic cancer’ with no section of the newspaper excluded. To allow for misspellings of ‘prostate’, for example prostrate and postrate, I also searched for articles containing three or more mentions of these phrases with the misspelled words. No graphics were included as Nexis UK reproduces text only. This process retrieved 1,271 articles across 18 newspapers (or 21 if Sunday equivalents are distinct) and their distribution is shown in Table 3.2. Of note, while broadsheet newspapers and their Sunday equivalents were accessible separately, for example Sunday Times and Times (rows 2-3), many non-broadsheets were combined with their Sunday equivalent, for example, Daily Mail and Sunday Mail (row 7).

Table 3.2. All media articles drawn by newspaper across time

	Newspaper	01/06/1990 - 31/05/2000	01/06/2000 - 31/05/2010	Total
1.	Guardian	32	51	83
2.	Sunday Times	12	27	39
3.	Times	56	129	185
4.	Independent	24	57	81
5.	Independent on Sunday	3	5	8
6.	Observer	7 ¹	29	36
7.	Daily Mail & Sunday Mail	54 ¹	300	354
8.	People	1 ¹	4	5

¹ The Prostate Cancer Research Foundation (PCRF) and The Prostate Cancer Charity (TPCC), for example, were established in 1993 and 1996 respectively - see first note in § 1.2

9.	Mirror & Sunday Mirror	26 ¹	117	143
10.	Business	1 ²	0	1
11.	News of the World	0 ²	4	4
12.	Daily Express	2 ²	132	134
13.	Sunday Express	1 ²	14	15
14.	Sun	1 ²	82	83
15.	Daily Telegraph	*	78	78
16.	Sunday Telegraph	*	8	8
17.	Daily Star & Sunday Star	*	8	8
18.	Morning Star	*	6	6
	Total articles	220	1051	1271
¹ not fully uploaded 01/06/1990-31/05/1995 but fully uploaded 01/06/1995-31/05/2000				
² not uploaded at all 01/06/1990-31/05/1995 and not fully uploaded 01/06/1995-31/05/2000				
*not uploaded at all 01/06/1990-31/05/2000				

Each of these 1271 articles were scan read in order to select those containing any coverage of the life or death of a named MWPCa. Table 3.3 shows the distribution of the resulting 427 articles across 12 newspapers (combining newspapers where relevant with their Sunday equivalents) across time. Therefore, of all the articles sampled in the UK national newspapers available online via the Nexis UK database containing three or more mentions of key phrases around PCa, slightly over one third referenced the life or death of a MWPCa.

Table 3.3. Coverage of life and death of MWPCa across all online UK national newspapers (01/06/1990-31/05/2010)

	Newspaper	01/06/1990-31/05/2000	01/06/2000-31/05/2010	Total
1.	Times & Sunday Times	23	51	74
2.	Independent & Independent on Sunday	6	21	27
3.	Guardian & Observer	14 ¹	28	42
4.	Daily Mail & Sunday Mail	34 ¹	82	116
5.	The Mirror & Sunday Mirror	13 ¹	30	43
6.	People	0 ¹	4	4
7.	Business	1 ²	0	1
8.	The Sun & News of the World	1 ²	40	41
9.	Daily Express & Sunday Express	1 ²	49	50
10.	Daily & Sunday Telegraph	*	27 ³	27
11.	Daily Star & Sunday Star	*	2 ³	2
12.	Morning Star	*	0 ³	0
	Total	93	334	427
¹ not fully uploaded 01/06/1990-31/05/1995 but fully uploaded 01/06/1995-31/05/2000				
² not uploaded at all 01/06/1990-31/05/1995 and not fully uploaded 01/06/1995-31/05/2000				
³ not fully uploaded 01/06/2000-31/05/2005				
*not uploaded at all 01/06/1990-31/05/2000				

However, Table 3.2 and Table 3.3 show that not all newspapers were uploaded to the Nexis UK database in the earlier time periods. Rows 1-2 show that only two newspapers (or four with Sunday equivalent) were uploaded at the start of the sampling period on 01/06/1990. Rows 3-6 show that a further four (or seven with

Sunday equivalent) were uploaded to Nexis by 01/06/1995. In order to examine changes in the media illness narratives of MWPCa in UK national print media over time, this study sampled only those six newspapers (or 11 with Sunday equivalent) which were at least to some extent uploaded 01/06/1990-31/05/1995 and fully uploaded thereafter. Thus, the 121 articles containing three or more mentions of key phrases around PCa (rows 7-12 Table 3.3) are excluded from this analysis leaving a total of 306 articles (Table 3.5).

3.4.1.1.2 Taking account of the excluded data

Paying attention to the potential impact of the exclusion of these articles on the dataset, Table 3.4 shows that sampling Nexis UK for all articles in the UK national press for three or more mentions of key phrases around PCa, resulted in 934 articles across the six newspapers (combined with Sunday equivalent where relevant) which were at least to some extent uploaded to Nexis between 01/06/1990-31/05/1995. Thus, of the original 1271 articles 337 articles were excluded as the relevant newspapers were not uploaded to Nexis UK to some extent in the earliest time period.

Table 3.4. All sampled articles in newspapers uploaded to some extent 01/06/1990-31/05/1995

	Newspaper	01/06/1990-31/05/2000	01/06/2000-31/05/2010	Total
1.	Times & Sunday Times	68	156	224
2.	Independent & Independent on Sunday	27	62	89
3.	Guardian and Observer	39 ¹	80	119
4.	Daily Mail & Mail on Sunday	54 ¹	300	354
5.	Mirror & Sunday Mirror	26 ¹	117	143
6.	People	1 ¹	4	5
	Total articles	215	719	934
¹ not fully uploaded 01/06/1990-31/05/1995 but fully uploaded 01/06/1995-31/05/2000				

Table 3.5 shows the distribution of these 934 articles containing any coverage of the life or death of a MWPCa across these newspapers.

Table 3.5. All sampled articles in newspapers uploaded to some extent 01/06/1990-31/05/1995 containing coverage of life and death of MWPCa

	Newspaper	01/06/1990-31/05/2000	01/06/2000-31/05/2010	Total
1.	Times & Sunday Times	23	51	74
2.	Independent & Independent on Sunday	6	21	27
3.	Guardian and Observer	14 ¹	28	42

4.	Daily Mail & Mail on Sunday	34 ¹	82	116
5.	Mirror & Sunday Mirror	13 ¹	30	43
6.	People	0 ¹	4	4
	Total	90	216	306
¹ not fully uploaded 01/06/1990-31/05/1995 but fully uploaded 01/06/1995-31/05/2000				

Therefore, Table 3.4 and Table 3.5 show that of the articles sampled across the 6 UK national newspapers uploaded to Nexis UK at least to some extent during the earliest time period (01/06/1990-31/05/1995) and containing three or more mentions of key phrases around PCa, approximately one third (306/934) of these made at least some reference to the life or death of a MWPCa. Similarly, rows 7-12 Table 3.3 indicate that just over one third (121/337) of the articles excluded through their relevant newspapers not being uploaded to Nexis UK in the earliest time period also contained content of the life or death of a MWPCa. In addition to this similarity, another noteworthy point regarding this excluded data is that only 3/121 articles (rows 7-9 Table 3.3 column 2) were from the first time period of 01/06/2000-31/05/2010 and thus provide minimal comparative interest for the research interviews with MWPCa in 2000. Further, given what is discussed below regarding the 46% reduction of these 306 articles to 140 illness narratives (or 15% of total articles), it is reasonable to assume that a similar proportion of these 121 articles would have contained illness narratives. Thus, the analysis in this thesis potentially excludes approximately 56 articles predominantly containing illness narratives of MWPCa and these would be almost exclusively from 01/06/2000-31/05/2010.

3.4.1.1.3 Refining sample for illness narratives

While each of the 306 articles indicated in Table 3.5 included at least some coverage of the life or death of a MWPCa, the extent to which this was informative about the experience of MWPCa varied widely. Some articles contained only one sentence of the life or death of a MWPCa, for example, “Major Ron is one of the lucky ones” (Mirror, 11/12/1998), while others contained several thousand words, for example “The Awesome Mr Ripley” (article title, Sunday Times, 23/10/2005). Using Hyden’s (1997) typology, these 306 articles were read again to determine which could be categorised as an ‘illness narrative’. The articles fell, to varying extents, into the first two of Hyden’s threefold typology. For the article to be included in the sample as an ‘illness as narrative’, I required it to predominantly (50% or more of its word content) depict ‘events that have been experienced personally and pose problems for the

individual in one way or another' (Hyden, 1997: 54); and/or to be 'a story the patient tells, and significant others retell, to give coherence to the distinctive events and long term course of suffering' (Kleinman, 1988: 49). Table 3.6 shows the distribution of these 'illness as narratives' and 'narratives about illness' across the six sets of newspapers and across all time periods.

Table 3.6. Total number of articles containing 'illness as narratives' and 'narratives about illness' across time

Time period	Newspaper	Predominantly illness as narrative ¹	Narrative about illness ²	Other ³	Total
01/06/1990-31/05/2000	Times & Sunday Times	9	14	0	23
	Independent & Independent on Sunday	1	5	0	6
	Guardian & Observer	5	6	3	14
	Daily Mail & Mail on Sunday	19	15	0	34
	Mirror & The Sunday Mirror	5	5	3	13
	The People	0	0	0	0
Total		39	45	6	90
01/06/2000-31/05/2010	Times & Sunday Times	16	28	7	51
	Independent & Independent on Sunday	8	10	3	21
	Guardian & Observer	13	10	5	28
	Daily Mail & Mail on Sunday	47	31	4	82
	Mirror & The Sunday Mirror	17	13	0	30
	The People	1	3	0	4
Total		102	95	19	216
Total across both time periods		141	140	25	306
¹ 50% or more 'illness as narrative' (11 contain less than 250 words (5 & 6 from each time period respectively)) ² less than 50% 'illness as narrative' and may contain narratives about prostate cancer or other health or illness narratives or fundraising or campaigning ³ Political contexts (which are less than 50% illness as narrative) or letters/obituaries					

Having now identified those articles which are predominantly 'illness as narratives', henceforth I dispose of Hyden's terminology and refer to these simply as illness narratives. McKay and Bonner (2002) suggest that there are marked differences between celebrity and non-celebrity illness narratives in that the former may be used to revive the flagging career, explain absences or announce forthcoming concerts. I suggest a similar argument could also be put forward for the illness narratives of politicians. While this may be so, my sampling procedure ensures that even those articles about celebrities or politicians are predominantly about their experience of PCa. Therefore, my sample includes articles which are predominantly illness narratives of MWPCa regardless of any celebrity or political status. Further Fakhri excludes narratives of less than 250 words in order to 'screen out short texts which might not include features of connected discourse' (1998: 451). I have though chosen to retain

these shorter narratives (5 and 6 in the respective time periods) if the illness narrative represents more than 50% of the word count in the article in which they appear.

In sum then, this sampling procedure has resulted in a final sample of 140 articles (note the one further exclusion in Table 3.7) which are predominantly about the illness narratives of MWPCa out of an original 934 articles containing key phrases around prostate cancer in 6 UK national newspapers between the specified dates in 1990-2010. Therefore, approximately 15% of the originally sampled articles, or 46% of the 306 articles containing coverage of the life or death of a MWPCa, were predominantly about the illness experience of MWPCa. Table 3.7 shows the distribution of these articles across the 6 newspapers and time.

Table 3.7. Total number of articles containing MWPCa illness narratives across time

	Newspaper	01/06/1990-31/05/2000	01/06/2000-31/05/2010	Total
1.	Times & Sunday Times	9	16	25
2.	Independent & Independent on Sunday	1	8	9
3.	Guardian and Observer	5 ¹	13	18
4.	Daily Mail & Mail on Sunday	19 ¹	47	66
5.	Mirror & Sunday Mirror	5 ¹	16*	21
6.	People	0 ¹	1	1
	Total	39	101	140
<small>¹not fully uploaded 01/06/1990-31/05/1995 but fully uploaded 01/06/1995-31/05/2000 *1 article (375 words) excluded due to it being in the Eire edition and thus not accessible to MWPCa in the UK</small>				

3.4.1.2 Data collection: ‘narratives about illness’ by PCa advocates

In this thesis I ask how PCaOrgs and the UK print media have been a force for change in the UK regarding how PCa has been addressed and experienced by MWPCa. I aim to answer this question by investigating how key individuals within PCaOrgs describe how they have sought to address the condition of PCa since the emergence of PCaOrgs in the UK in the mid-1990s. I now describe the data collection process for this data.

3.4.1.2.1 Recruitment

Recruitment negotiations with these participants began in mid-October 2010 with the first interview in mid-November 2010 and the last in mid-April 2011. My first contact was a freelance commentator on men and women’s health issues and previous head of policy and research in a PCaOrg. My access to this person was prompted by an opinion

piece they had written about PCa in several prominent newspapers. Another initial contact was with a public affairs consultant and lobbyist who worked on behalf of a PCaOrg. I then 'snowballed' (Biernacki and Waldorf, 1981) these interviewees by asking them to tell me of others whom they thought suitable to participate in my research and they each indicated several, sometimes common, potential contacts. 'Snowballing' contacts, a legitimate way of gaining access to the field, 'yields a study sample through referrals made among people who share or know of others who possess some characteristics that are of research interest' (Biernacki and Waldorf, 1981: 141). The researcher must 'develop and control the sample's initiation, progress and termination' (p. 143) and is, at least, responsible for initiating the referral chain by contacting participants and verifying the eligibility of those people identified by their current participants. This process proved unproblematic, perhaps because of the combination of my small sample size and the high number of potential eligible participants.

There were 21 participants recruited for this part of the research. These included two public commentators/consultants around PCa; seven medical professionals who were influential in PCa awareness and often were also involved in PCaOrgs; and twelve participants from 5 PCaOrgs. There was one public consultant and one public commentator each concerned with PCa. These were given the common pseudonym of PCa-PCa and a number relating to the order in which they were interviewed. For example, PCa-PC/2 indicates that this was the second commentator/consultant interviewed.

The seven medical professionals included three consultant urologists (from Barts and The London and Belfast City hospitals) and two consultant oncologists (from Hammersmith and Belfast City hospitals). There were five professors in total including three of the aforementioned consultants. All but one of these medical professionals also had very significant involvement in either PCa or men's health organisations as founders, presidents, or trustees (The Prostate Cancer Charity, Men against Cancer, European Men's Health Forum, Prostate Cancer Research Foundation, Prostate Action) or as organisation members (Men against Cancer, The Prostate Centre). These participants were given the common pseudonym of PCa-MP and a number relating to the order in which they were interviewed. For example, PCa-MP indicates that this

participant was a medical professional and was the second such professional interviewed.

Finally, the five PCaOrgs which participated in this research were: The Prostate Cancer Charity (now Prostate Cancer UK); The Prostate Cancer Support Federation; The Association for Prostate Awareness; Prostate Action; and Men against Cancer. The twelve participants in these PCaOrgs included two chief executives; two chairmen; one secretary; one head of media and public relations; one head of policy and campaigns; and five managers concerned with volunteer development; information; marketing communications; helpline; and African-Caribbean policy and development. These participants were given the common pseudonym of PCa-ORG; a number related to the particular PCaOrg; and where appropriate, a number relating to the number of participants interviewed in that organisation. For example, PCa-ORG/3/4 indicates that this participant worked for a PCaOrg, which was the third such organisation represented in this research and they were the fourth participant from this organisation.

3.4.1.2.2 Ethical approval

Research ethical approval was granted for this part of the research by Queen Mary University of London Research Ethics Committee (Ref: QMREC2010/27) in April 2010 (Appendix 4). Due to their public visibility there were particular potential risks for some of these participants. First, during interview they could describe publicly visible activities where anonymity may not be easy to ensure. Second, they could say something in their interview which, if published, could damage their own or someone else's reputation. In order to avert these potential risks I informed these participants in the information sent to them (Appendix 9) that I would send them a copy of the interview transcription for them to highlight passages that caused them concern and which they would prefer not to be published. In addition, they could require changes to particular passages in order that they may be written in a way that preserved their anonymity. Thus, they would have opportunity to check, amend and veto anything they said in the interview which they would prefer not to be included in reports arising from the study.

A further issue regarding ethics was my proposal to ask my participants "further questions on themes relevant to the research agenda". When I was informally

seeking advice from the research ethics committee administrator on how to complete my ethics application I was advised that it would be beneficial to include supplementary information with my ethics committee application regarding what these 'further questions' might be. Though it is methodologically unjustifiable to develop precise questions in a 'tell me the story about...' narrative interview, what was methodologically justifiable was to develop potential interview prompts which related to what I knew was relevant in the literature I had reviewed to that point. I thus submitted these potential interview prompts (Appendix 6) as supplementary material as indicative of what I may ask in interview if the participant did not already talk about them in the course of their narrative and if it seemed interactionally appropriate to do so. There was neither requirement for me to ask these questions nor to seek further ethical approval for any other question that I decided to ask.

3.4.1.2.3 Data collection

All participants gave their consent to participate in the research (Appendix 7). They were then invited to 'tell the story' of how they became involved with PCa and the organisations associated with it and their reflections on the history and future prospects of PCa awareness. The supplementary questions were used only if appropriate to the particular participant. The interviews lasted between 24 minutes and 2 hours with most lasting either around 30 minutes or 1 hour. Most interviews were held in the office of the interviewed participant although four were held in a cafe and one in the participant's home. All interviews were audio-recorded. In one instance I was asked to turn the recorder off as the participant wanted to say something 'off-the-record'. In another instance, the participant expressed confidence in saying something 'off-the-record' while the interview was being recorded; perhaps confident of the assurances given orally at the start of the interview and in the written information sheet regarding their review of the transcription. Many participants were confident they would not say anything in the interview that would identify themselves or others in a non-preferred way. In some instances the reason for this confidence was made explicit; that they were professional public orators. With one exception all participants wanted to review their transcription. The exception was the participant who expressed an 'off-the record' comment. Contextual notes were made of the interview for some of the participants and alongside the transcription of all.

3.4.1.2.4 Transcription

All interview recordings were initially transcribed to a stage similar to a “first pass” transcription (without intonation, emphasis, breathing, overlaps, etc.)’ (Hepburn and Potter, 2007: 175) by a professional transcription organisation¹. The transcriptions, while providing most of the content of the interview talk, still required checking for accuracy of this content and the addition of some other non-verbal indicators of interaction such as laughter; pauses of more than a few seconds; noticeable emphasis on words; and ‘ehm’s’, ‘er’s’ and the like and this constituted a stage 2 transcription (see Appendix 8 for the transcription notation). The words of both interview participants, that is, interviewer and interviewee, were recorded given the co-authored nature of the narrative. Of the 21 participants interviewed, 20 transcriptions were returned in August 2011 for review with an accompanying letter (Appendix 9). Of these 20, 6 neither acknowledged receipt of the transcription nor indicated any desired changes; 2 made no changes; 5 made minor changes only (defined as correction of typing errors or transcriber mishearing or removal of laughter or ehms/ers or the like); and 7 made major changes (defined as rewording or veto of talk).

3.4.1.3 **Data collection: illness narratives of MWPCa**

In this thesis I ask how PCaOrgs and the UK print media have been a force for change in the UK regarding how PCa has been addressed and experienced by MWPCa. In answering this question I aim to investigate changes in how MWPCa describe their illness experience in research interview from a time approximate to the emergence of PCaOrgs in the UK in the mid-1990s. Early on, the research saw collaboration with the Health Experience Research Group (HERG) at the Department of Primary Care Health Sciences, Oxford University, England. The HERG² is responsible for the research which appears on www.healthtalk.org, an award winning website, which along with www.youthhealthtalk.org allows public access to over 2,000 people’s experiences of more than 60 health related illnesses and conditions. Interviews take place in

¹ www.transcriptionsulike.co.uk. This was my own business enterprise during my PhD and so I personally completed all transcriptions.

²The HERG is formerly the DIPEX (Database of Individual Patient Experience) Research Group and www.healthtalk.org is formerly www.healthtalkonline.org

participants' homes or another preferred location. Interviews are audio-recorded for analysis, though they may also be filmed with participant consent.

This collaboration enabled access to 52 transcriptions of interviews with MWPCa in 2000-01 and in return I provided HERG with access to my interviews completed in 2010 to update www.healthtalk.org. Thus, the data were collected over two time periods: 1) 2000 by HERG; and in 2010 by me. Once the 2010 fieldwork period was completed, 20 of the interviews completed in 2000 were matched along significant variables (age at diagnosis/age at interview and socio-economic status – see Table 3.8) with those completed in 2010. Video, audio or transcription excerpts of some of the interviews with MWPCa over these two time periods are accessible on www.healthtalk.org (Appendix 10). The 2010 fieldwork with MWPCa took place in London and Belfast where I worked and lived respectively.

3.4.1.3.1 Recruitment

Table 3.8. Recruitment summary of MWPCa in 2010¹

Recruitment Site		Participant Packs	Reply slips	Interviews
Initial recruitment	Belfast City Hospital	129	7	6
	Barts Hospital	80	2	2
	APA ¹ London	40	1	0
	Casual contact	5	5	5
Subsequent snowball recruitment	From MWPCa interviews	3	0	0
	Advocate interview	5	0	0
	Advocate interview/ PCaSO ² SE England	25	3	1
	Advocate interview	5	0	0
	TPCC Voices	*	9	7
Total		292	27	21 (Belfast: 8 & London: 13)
¹ APA – Association for Prostate Awareness; ² PCaSO Prostate Cancer Support Organisation *recruitment information on TPCC website; web messages board; and email and print monthly bulletin Jun-Aug 2011 (Appendix 12)				

Table 3.8 summarises the recruitment for MWPCa in 2010. The recruitment strategy for the 2010 fieldwork was adapted from that of the original www.healthtalk.org interviews in 2000 (Chapple and Ziebland, 2002). Access began in early May 2010 by first identifying specialist nurse gatekeepers at both Barts and The London Hospital and Belfast City hospitals and also a gatekeeper at the Association for Prostate Awareness (APA) in east London. Access letters (Appendix 9) and sample participant information packs (PIPs) were sent to these gatekeepers in early May 2010 asking if

¹ See note 1 p.70

they would act as participant identification centres and distribute PIPs to MWPCa attending the hospital or support group. PIPs contained four documents: an introductory letter to the MWPCa (Appendix 9), a participant information booklet produced by HERG and adapted for this research; a document describing www.healthtalk.org; a reply slip (Appendix 11) and an addressed envelope¹. Men were invited to return the reply slip to me and I would subsequently contact them. In mid-May 2010 I began distributing PIPs to these gatekeepers and was very expectant regarding recruitment success given the number of packs distributed (Table 3.8); their willingness to take part; and also the support of their attendant consultants (two of who would also be interviewed as PCaA participants).

I made five casual contacts through friends and friends of friends and sent these men PIPs. I also 'snowballed' (Biernacki and Waldorf, 1981) these participants with those willing to do so taking PIPs for others. However, this was with limited success with the exception of those distributed through the Prostate Cancer Support Organisation (PCaSO). The most successful recruitment was through Prostate Cancer 'Voices'; a TPCC network aiming to facilitate user involvement in research and projects aimed at improving the experience of MWPCa (Appendix 12). This resulted in nine men contacting me and receiving PIPs and returning reply slips leading to seven MWPCa being interviewed.

3.4.1.3.2 Overcoming recruitment problems

My expectant success turned gradually to disappointment as between May-November 2010 I had received only eight reply slips and interviewed seven men. One reason for this was the delay in recruitment at Belfast City Hospital where the associated health trust had requested local ethical approval (Appendix 4) which was finally granted in November 2010.

In mid-November 2010 I met with the specialist nurse at Barts and The London after having asked her to reflect on whom she gave the PIP to. She found this an interesting task and said she only gave it to those men whom she thought would like to take part and whom she thought could describe their experience adequately. I replied that I understood this because, as a qualitative researcher, I seek people who are able

¹ The first 160 addressed envelopes were also stamped but I decided to stop this as it did not seem to be encouraging response and was using up valuable resources.

to reflect upon and describe their experience of illness (Morse, 2002). However, such a person is not always immediately apparent and so to the extent that she was giving the PIP only to ostensibly 'good' participants, she was potentially missing other reflective participants. We discussed the possibility, and problems, of giving packs out to all the men attending her clinic. Possibilities included putting a PIP with each set of notes but problems meant asking other nurses also to distribute packs as she would miss other men when attending to another patient. Also, some MWPCa attending her clinic did not speak good English and would not be able to adequately describe their experience. In addition, she expressed her uncertainty over how to introduce the pack. I had already given her a very short guiding script (Appendix 13) but she said she did not like to read it out. I assured her that she did not have to read this but merely use it as a guide to how she might introduce the research and PIP.

Between April-May 2011 I completed seven further interviews. These came from one casual contact, three from PCaSO (to which I recently sent information packs having already interviewed its chairman as part of the PCaA interviews) and three from Belfast City Hospital. The latter may have been as a result of a recent visit there to interview the consultant as a PCaA participant, deliver more PIPs, and speak briefly to the specialist nurse. When I informed this nurse of the recent increase in reply slips she responded, "I'm now adding in that you really appreciate their participation, maybe that's doing the trick!" (personal email communication) This response perhaps illustrates that persuading men to take part in this (or any?) research depends on personal interaction with somebody that they know and who can act as a mediator (Olliffe and Mróz, 2005). This is also exemplified in that all five of the casual contacts resulted in interviews (Table 3.8).

I gave two recruitment presentations to PCa support groups which also had the benefit of opportunities to practice communicating my research to a lay audience. The first was to an audience of approximately 30 (mostly men) at the annual general meeting of the APA support group in mid-November 2010. While my presentation was ostensibly well received and I personally distributed 15 PIPs, no man returned a reply slip. The second was to an audience of approximately 25 (almost exclusively men) at a PCa support group in September 2011 at a hospital near Belfast at the suggestion of the specialist nurse at Belfast City Hospital. Throughout the presentation there were both questions by the facilitator and members of the group and also discussion

between the men. In a way it reminded me of the interactive benefits of a focus group where group members through both agreement and disagreement 'enthusiastically extend, elaborate, or embroider an initially sketchy account: for example through the consensual piling up of fine detail' (Wilkinson, 2004: 180-1). One man in particular, probably aged in his mid-fifties and recovering from a recent operation to remove his prostate, shared his great distress from the treatment side effects. The other group members gave him advice, agreeing and disagreeing with each other over what was best. Many men mentioned their PSA level with one man talking of his 'watchful waiting' treatment approach and how he was controlling his PSA by diet. I had brought along several PIPs, but only one man took one and I did not subsequently receive a reply slip.

It may be the case that the decision to take part in my research was more daunting than taking part in a typical research interview. This was because potential participants were also asked to consider whether they would like the audio (or video if they consented) recording of their interview to be publically accessible on www.healthtalk.org.

3.4.1.3.3 Ethical approval

This part of the study was approved by the Berkshire Research Ethics Committee (Reference: 09/H0505/66) under 'Narratives of health and illness for www.healthtalkonline.org and www.youthtalkonline.org' (Appendix 4). The Belfast Health and Social Care Trust requested additional local Research Ethics Committee submission and this was approved before the Belfast fieldwork (Reference: 10142SZ-SP) (Appendix 4).

3.4.1.3.4 Data collection

This section relates to interviews with MWPCa completed in 2000 and 2010. 21 MWPCa participated in the 2010 fieldwork and interviews took place in men's homes (eight men living around Belfast) or in a meeting room at my London office (13 men living around London); were all interviewed by me; lasted on mean average 59 minutes (range 36-85 minutes); and gave consent for their interviews to be video-recorded (18 men) or audio-recorded (three men) (Appendix 7). These interviews were then

matched with 20¹ MWPCa interviewed in 2000 on age at diagnosis/age at interview and socio-economic variables (Table 3.9). The interviews in 2000 mostly took place in men's homes; lasted on mean average 62 minutes (range 23-128 minutes); all but one were interviewed by Alison Chapple of Healthtalkonline; and gave consent to be video-recorded (twelve men) or audio-recorded (eight men). Most men in both periods (all remaining 20 in 2010) were interviewed alone. All but two men interviewed in the 2010 fieldwork were of White European ethnicity² with one Black Caribbean and one Bangladeshi. I do not have specific data on the ethnicity of the men interviewed in 2000. The aggregate metadata of the original 52 men interviewed in 2000 indicates the majority of these were of White European ethnicity (49) and one each of Black Caribbean, Black Nigerian and Indian ethnicity (Chapple and Ziebland, 2002).

Table 3.9 shows the pseudonym, age at interview, age at diagnosis and socio-economic classification of each of the participants interviewed in 2010 and their matched participants interviewed in 2000. In the presentation of the findings and discussion all participants, and any other identified people or places, are given pseudonyms.

Table 3.9. Pseudonym and age characteristics of participants

Interviews in 2010			Interviews in 2000		
Pseudonym	Agel/AgeD	NS SOC 2010	Pseudonym	Agel/AgeD	NS SOC 2010
Alan	72/69	5	Aaron	70/66	5
Brian	64/64	2	Barry	66/66	2
Charlie	67/66	2	Calvin	65/63	2
Don	66/65	2	David	63/62	2
Ernie	73/67	1	Eddie *	72/65	2
Fred	51/50	3	Finlay	57/54	3
Graham	58/56	2	Gary	58/57	1
Hugh	62/57	2	Harry	63/56	2
Ivan	88/82	2	Ian	80/77	2
Joe	61/52	1	James	65/59	1
Keith	57/54	2	Karl*	59/59	3
Liam	70/65	2	Lawrence	70/67	2
Michael	68/65	2	Mark	69/67	2
Neil	53/47	2	Nathan*	51/50	2
Oscar	66/58	1	Oliver	63/59	1

¹ One MWPCa in 2010 withdrew on receipt of his transcript.

² Men self-identified as white/caucasian or white British/Irish/European/Latvian. I have no ethnic data for the 20 MWPCa interviewed in 2000 although 48 of the original 52 were White British

Peter	62/60	2	Paul	65/65	3
Quinn	67 /61	3	Quentin*	68/66	2
Robert	68 /54	2	Ralph	66/57	2
Sean	81/80	2	Sam*	83/81	5
Thomas	57/54	3	Taylor*	55/54	?
MWPCa 2010 interviews are matched with interviews in 2000 by AgeI/AgeD and then by occupation by ONS Standard Occupational Classification (SOC) 2010; *not a direct match either by occupation or AgeI or AgeD					

Men in both time periods were asked to ‘tell the story’ of their illness from when they first suspected they may have PCa to the present day. Further questions were asked to encourage more details of specific events in their narrative or to correct any misunderstanding. In addition, if not already elaborated on in their narrative, other questions were asked regarding, for example, diagnosis, treatment and side effects. To ensure some similarity with prompting questions asked in the earlier interviews I randomly selected 6/52 of the interview transcripts from 2000 and reviewed and categorised the questions asked by the interviewer. Table 3.10 summarises the similarities and differences of the sample of MWPCa in 2000 and 2010.

Table 3.10. Similarities and differences of MWPCa sample 2000 and 2010

Characteristics of MWPCa and interview		2010	2000 www.healthtalk.org
No. of MWPCa		20	20
Age at interview	50-59	5	5
	60-69	10	10
	70-79	3	3
	80-89	2	2
Ethnicity	White European	18	Most
	Black Caribbean	1	-
	Bangladeshi	1	-
Location of interview and interviewer		7 in homes of MWPCa in Belfast & 13 in AM’s London office (AM ¹)	Throughout the UK in homes of MWPCa (almost all AC ²)
Interview method		Interviews start with a ‘tell the story’ narrative followed by semi-structured questions on e.g. diagnosis, treatment & side effects if not mentioned. Random selection and categorization of questions asked in 2000 to give some similarity of questions asked in 2010	
Purpose of interview		To provide other MWPCa with up-to-date information about what PCa experience with some interviews contributing to www.healthtalk.org	
Mean length of interview		59 mins (range 36-85)	62 minutes (23-128 mins)
Video/audio recording		17 V & 3A	12 V & 8 A
Interviewed alone/partner		Alone	Alone (most?)
Transcription		AM	All rechecked by AM

3.4.1.3.5 Video recording

As noted earlier (§3.4.1.3), the www.healthtalk.org interviews with MWPCa in 2000 though audio-recorded for analysis, were also sometimes videoed with participant consent. Video, audio or transcription excerpts of interviews with MWPCa were then made accessible on www.healthtalk.org. As some of my interviews would be used to update www.healthtalk.org with the experience of MWPCa in 2010, I also asked my participants for consent to video their interview—for the explicit purpose that some video excerpts may be used on this website. Table 3.10 shows that 17 men gave consent for their interview to be videoed. Though there is increasing sociological attention to the role that visual aspects of interaction plays in the practical accomplishment of a social activity (Heath, 2004)—such as describing one’s experience of PCa—my research question did not require these visual aspects of interaction to be transcribed and analysed (Bailey, 2008). What was of methodological interest was that taking part in a video recorded interview was a different experience from an audio recorded interview. As discussed earlier, all narratives are implicitly co-authored as speakers anticipate the response of their co-present or non-present audience. The video recorder potentially served as a more explicit observable reminder to my participants of their non-present audience.

3.4.1.3.6 Transcription

All recordings from the 2010 MWPC fieldwork were similarly transcribed to the PCaA recordings (§3.4.1.2.4). As per standard policy for www.healthtalk.org all transcriptions were returned to the participant for their review. Of the 21 transcriptions, 8 were returned with no revisions, 8 with minor revisions and 4 with major. One participant withdrew during my follow up telephone call to him after his long delay in returning his transcription. In withdrawing he said that his illness was “a long time ago” and he no longer wanted to take part. The minor revisions mostly included corrections of my mis-hearings, mis-transcribing or mis-spellings, for example, one participant corrected my mis-transcribed “enema scan” to “MRI scan”. Revisions also categorised as minor were 2 participants who made small deletions of ehms or ehs; small corrections to their grammar; or small corrections to what they wanted to have said, for example,

“switch me to the zoladex, which blocks the +production+ (receptors)” or “I was laying there stark +naked+”¹.

While the minor revisions were a useful, very often correcting, exercise there were aspects of the major deletions which were of concern to the research and to which brief attention needs to be paid. 2/4 major revisions were from the oldest participants in the study. One retired high ranking professional spoke for about 15 minutes at the start of his interview about his wife’s illness and death and this text he deleted along with small amounts of other text regarding his wife and other family members. While this text was useful and interesting for me to serve as a context for this man’s experience, it was not necessarily relevant to the analysis and so excluding it was not problematic. A second elderly man, whom I experienced as a very difficult participant to the extent that I considered excluding his interview, expressed confusion with his transcript and significantly delayed its return. He made many additions/deletions to the first 1 ½ pages of his transcription and I suspect he may have liked to have completely rewritten it. I have reflected elsewhere on difficult moments in interviews (Montgomery, 2012) and so it is likely that I will similarly reflect on this difficult interview at a later time. One other participant made smaller and not so important deletions. A fourth participant made very significant deletions around his experience to the extent that I wrote to him to ask if he would reconsider these changes so that I might consider them in my analysis though they could still be excluded for www.healthtalk.org. He agreed that I could re-include some text while keeping other text excluded.

Returning the transcripts to participants is both a useful and ethical activity. It is useful as it enables appropriate corrections to be made to the transcript. It is ethical as it may help address the power imbalance between ‘interviewee’ and ‘interviewer’ in research interviews (Edwards and Mauthner 2002; Sinding and Aronson 2003; Liamputtong 2007). Returning the transcript to the participant may contribute to a joint creation of ‘liveable stories’ (Sinding and Aronson 2003: 115), that is stories which can be lived with after the researcher has gone. Perhaps the withdrawal of my one MWPCa and the problems that I’ve noted around one elderly MWPCa (at least around his perusal of the transcript) has something to do with having a story that can be lived with.

¹ +text+ was added text and ~~text~~ was text deleted by participants

It is also the policy of HERG to write short biographies of the participant and 'more about me' summaries which also appear on the website. While initially I began writing these and sending them to the participants with the transcriptions I stopped this as it proved too laborious particularly given that not all recordings would be chosen for www.healthtalk.org. I decided then to wait until HERG had chosen those participants whose recordings they wished to use to update their website before writing these biographies and summaries and sending them to the participants for their review and agreement (see the weblinks in Appendix 10).

With respect to the illness narratives of MWPCa interviewed in 2000, HERG enabled my access to 52 transcripts of MWPCa with corresponding demographic data from which I matched 20 MWPCa interviews with the 20 MWPCa interviewed in 2010. I subsequently asked HERG for access to the recordings of these 20 interviews so that I could check the transcriptions for accuracy and incorporate the interactional features that I included in the transcriptions from 2010. A data transfer agreement was obtained.

3.4.2 Data analysis

Here I describe how I analysed each of the three datasets of narratives.

3.4.2.1 Data analysis: comparative keyword in context analysis of media narratives

I now describe the CKWIC analysis of the sampled media illness narratives (§3.4.1.1.1). The CWIKC analytic framework allowed me to ask key practical questions of my media illness narrative data: 1) which words were significantly more frequently used by journalists when writing about MWPCa in 1990-2000 and 2000-2010; and 2) what 'aerial view' (Seale and Charteris-Black, 2008: 456) did this give of how the UK national print media represented the illness narratives of MWPCa since the emergence of PCaOrgs into the UK in the mid-1990s? There were five main steps in the CKWIC analysis: 1) creating word lists of each corpus of text; 2) identifying words significantly more frequent in one corpus when compared with another ($p < 0.01$); 3) constructing preliminary 'keyword sets' (O'Halloran 2010: 218), or themes (Seale et al., 2006), and assigning keywords to these; 4) doing an initial concordance analysis of identified

keywords to refine the sets; and 5) doing a further detailed concordance analysis of identified keywords in context.

3.4.2.1.1 CKWIC analysis: steps 1 – 2

Steps 1 and 2 involved inserting both corpora into Wordsmith Tools software (Scott, 2013). This allowed respective lists of words along with their frequencies and keywords to be created. The first column in Table 3.11 indicates the corpus under examination with the reference corpus it is compared with in parenthesis. The second and third columns respectively indicate the number of articles and words which constitute these corpora. The second column shows that there were 39 and 101 media articles containing illness narratives of MWPCa in 1990-2000 and 2000-2010 respectively, giving a total of 140 articles overall. The third column shows a respective 41,487 and 108,107 words in each corpus, giving a total of 149,594 words. Of note is the difference, though not problematic (Rayson et al., 2004), in the size of the two corpora.

Table 3.11. Characteristics of the 1990-2000 and 2000-2010 corpora

Corpus of print media narratives of MWPC	No. of articles	Words in corpus	Words in wordlist	Keywords ¹ p<0.01 (p<0.001)
1990-2000 (RC 2000-2010)	39	41487	4915	138 (84)
2000-2010 (RC 1990-2000)	101	108107	8894	118 (41)
Total	140	149594	13809	256 (125)

¹Log-likelihood statistic

Column 4 in Table 3.11 shows the number of words in each word list. The frequencies of the words in each wordlist were compared with each other to see which ones were 'key', that is, occurring statistically more often than would be expected by chance. The fifth column indicates the number of keywords identified at specified significance levels (p<0.01 and p<0.001) using the log-likelihood statistic. I chose the log-likelihood statistic over the chi-square test as it is used with accuracy for various combinations of size and of corpora (Rayson et al., 2004) and the chi-square test gave a much lower number of keywords than was useful for analysis when p<0.01. Row 1 column 5 in Table 1 shows that comparing the 1990-2000 in reference to the 2000-2010 corpus identified 138 keywords when p<0.01, 84 of which were also significant when p<0.001. Row 2 column 5 shows that comparing the 2000-2010 corpus with reference to the 1990-2000 corpus identified 118 positive keywords when p<0.01, 41 of which were

also significant when $p < 0.001$. The minimum frequency of keywords was set at 5 and 11 respectively in order to cover 0.01% of each corpus.

Appendix 3 shows all keywords identified in this process. Baker (2006) suggests that keyword lists tend to show up three types of words: 1) proper nouns; 2) grammatical or functional words; and 3) 'aboutness' words. The latter, being lexical words—nouns, verbs, adjectives and adverbs—are Baker suggests, the most interesting to analyse. Of note was, as Baker indicates, the high number of proper nouns, evident in male names. Also notable was the relative lack of functional words identified as key in each corpus; this may be because both corpora were from the similar genre of written narratives of MWPCa in print media.

3.4.2.1.2 CKWIC analysis: steps 3 – 4

Steps 3 and 4 in the CKWIC analytic process involved a move from a purely quantitative to a more qualitative analysis. Drawing on the constant comparative method (Charmaz, 2006) I constructed short and simple codes which stayed close to the data. These were first categorised into preliminary themes (Seale et al., 2006): the keywords *GBP* (Great British Pounds), *million* and *spent* intuitively seemed to be about money; *brachytherapy*, *procedure*, *anaesthetic*, *treatment*, *drug*, *Zoladex*, *Casodex*, and *operations* seemed to be about treatment; *risk* about risk; *wear* about clothing; *score* about sport; *PSA* about testing and so on. I constructed preliminary codes and compared the keywords with each other and the codes until as many as possible were categorised. I then examined the keywords in their context through the concordance provided by the software. This allowed me to see whether my intuition was right, needed refined or mistaken. Figure 3.1 shows the *GBP* concordance—each line shows *GBP* (1990-2000) with several words of context on either side.

Figure 3.1 Sample 'GBP concordance 1990-2000

N Concordance
 1 lived for the company and built it into a GBP 350 million empire. He was
 2 year before he died.' His Trust, valued at GBP 3.5 million, paid out GBP 1 million
 3 worried because each scan costs GBP 400. It looks as though I've got
 4 spent on finding a cure is derisory - GBP 47,000 last year, compared to
 5 spent on finding a cure is derisory - GBP 47,000 last year, compared with
 6 spent on finding a cure is derisory -GBP 47,000 last year. That is why the
 7 Manchester M60 3JD I am donating GBP to the Daily Mail Prostate Cancer
 8 . HERE'S HOW TO DONATE For every GBP raised by Mail readers the
 9 . HERE'S HOW TO DONATE For every GBP raised by Mail readers the
 10 charity received a cheque - for exactly GBP 47,000. I hope the money will help
 11 get there.' The Daily Mail launched its GBP 1million fundraising campaign - in
 12 out that the Government spent just GBP 47,000 a year on research into
 13 insurance. The blood test costs only GBP 15, and it is appalling that it is not
 14 spent on finding a cure is derisory - only GBP 47,000 last year, compared to
 15 8,000 men in the UK a year but only GBP 47,000 was spent researching it in
 16 of cancer prevention and cure. Yet only GBP 47,000 a year goes on prostate
 17 , valued at GBP 3.5 million, paid out GBP 1 million a year ago to the
 18 - 10,000 die every year - yet a pitiful GBP 47,000 was spent last year
 19 Mail has launched an appeal to raise GBP 1 million to rectify this scandalous
 20 Mail has launched an appeal to raise GBP 1 million to rectify this scandalous
 21 Mail has launched an appeal to raise GBP 1 million to rectify this scandalous
 22 Mail has launched an appeal to raise GBP 1 million. Sidney Swan was
 23 Mail has launched an appeal to raise GBP 1 million. Here, 58-year-old
 24 I vowed that, when I was better, I'd raise GBP 47,000 for prostate research and
 25 UK. I had one mission: to raise GBP 47,000. Through my job in
 26 the disease. At the same time, GBP 18 million was spent on Aids,
 27 GBP 47,000 last year, compared to GBP 18 million spent on Aids. The
 28 - GBP 47,000 last year, compared to GBP 18million spent on Aids, which
 29 by generous Mail readers - up to GBP 500,000 another pound will be
 30 Charitable Trust will match it up to GBP 500,000. The money raised will go
 31 Charitable Trust will match it up to GBP 500,000. The money raised will go
 32 by generous Mail readers - up to GBP 500,000 - another pound will be
 33 - GBP 47,000 last year, compared with GBP 18 million spent on Aids, which

Examining the keywords in their concordance was often enough to refine my categories, but if not then particular concordance lines were also viewed in their larger context. This process mainly resulted in two outcomes: the complete removal of a word from one theme to another; and/or the placing of a word in more than one theme if it was associated with two or more meanings. These words were marked with a * to indicate their 'split' status (Seale et al., 2006: 2582). An example of this process was with the keyword *wear* (2000-2010), originally categorised as '*Clothing*'. Examining *wear* in its context showed that seven of its ten relevant instances referred to issues around treatment side-effects: "I was also left incontinent and had to wear pads for three years" (Daily Mail, 01/11/2005); and "that removed most of the cancer, but it damaged my ability to stay sexually aroused. I prayed it was just a temporary effect, that it would eventually wear off and everything would be normal" (Daily Mail, 06/11/2001). In one instance it referred to a drug beginning to 'wear off'; in another to Megrahi, the man convicted of the Lockerbie bombing, who offered "to wear an electronic tag if freed" (Daily Mail, 15/11/2008). Only once did it refer to an item of

clothing in relation to Andy Ripley, a celebrity MWPCa, many years earlier. Thus, *wear* was removed from 'Clothing' and placed in 'Treatment side-effects'.

Likewise, *score* (2000-2010) was initially classified in 'Sports' but examining it in its context demonstrated that it was almost exclusively used to indicate either a Gleason or PSA *score* (§1.1.1). One of two instances of *score* in a sporting context did though indicate a pertinent gendered use:

Ladies easily discuss breast cancer, but you don't see a gathering of men in a pub talking about their prostates. They are talking about the latest page three girls or the cricket score because they think that any problem "down there," as they'd put it, is a nonmacho situation (Daily Mail, 27/07/2002)

I thus removed *score* 'Sports' and placed it in 'Tests and diagnosis'. Similarly, all but two instances of *race* (1990-2000) were associated with political contests in the USA, mostly regarding Rudolph Giuliani but also Bob Dole. One exception referred to a MWPCa comparing his outlook on life before and after PCa; the other was regarding a half marathon ran by a MWPCa to raise £47,000. Thus, though the meaning of *race* was as a sports word in all instances, this was as a metaphor for a political contest; it was thus categorised in, the subsequently excluded, 'Political practice'. Of note, *race* did not refer to ethnicity in any instance. Examples of 'split' words in 1990-2000 were *Mail**, *raise** and *Mail's**, due to their meaning around both raising awareness and raising money. *Launch** in 2000-2010 was used to describe launching a show or a book in the context of employment of MWPCa and launching awareness campaigns.

3.4.2.1.3 CKWIC analysis: step 5

The keywords were then examined in detail in their concordance using Wordsmith Tools (Scott, 2013) in order to discover analytic patterns. Collocation, informally defined as 'the company a word keeps' (Firth (1957) cited by Stubbs 1996: 173), provided a way of exploring the statistical tendency of words 'to co-occur with other words' (Stubbs 1996: 173). Figure 3.1 above shows the concordance for *GBP*. In order to help identify patterns in the concordance, these lines were, in the first instance, sorted alphabetically one space left of the keyword and then one space right, with any deviation from this sort noted. Sometimes particular patterns were only somewhat visible and a re-sort was needed to make them more visible. For example, "47,000"

was repeated often in Figure 3.1; a re-sort one space right then one space left (Figure 3.2) allowed all lines containing “47,000” to appear consecutively:

Figure 3.2 Partial 'GBP' keyword concordance 1990-2000: '47,000'

N Concordance

12 yet the amount spent on finding a cure is derisory - GBP 47,000 last year, compared with GBP 18

13 of money spent on finding a cure is derisory - GBP 47,000 last year, compared to GBP 18million

14 of money spent on finding a cure is derisory -GBP 47,000 last year. That is why the Daily Mail

15 week the charity received a cheque - for exactly GBP 47,000. I hope the money will help research

16 when I found out that the Government spent just GBP 47,000 a year on research into prostate

17 other forms of cancer prevention and cure. Yet only GBP 47,000 a year goes on prostate research.

18 the money spent on finding a cure is derisory - only GBP 47,000 last year, compared to GBP 18 million

19 cancer kills 8,000 men in the UK a year but only GBP 47,000 was spent researching it in 1998. It is

20 killer for men - 10,000 die every year - yet a pitiful GBP 47,000 was spent last year researching the

21 moment I vowed that, when I was better, I'd raise GBP 47,000 for prostate research and education,

22 Campaign UK. I had one mission: to raise GBP 47,000. Through my job in international

Table 3.12 shows the final thematic categories of keywords in UK print media when the media narratives of MWPCa in 1990-2000 were compared with those in 2000-2010. It begins to offer insights into how journalists wrote stories about the illness experience of MWPCa:

Table 3.12 Thematic categories of keywords

Keywords and themes across time ¹ (p<0.01)		
	1990-2000	2000-2010
1.	<p>Raising money for PCa: (GBP, million, spent, Mail*, raise*, Mail's*)</p> <p>No keywords</p> <p>No keywords</p> <p>Treatment side-effects: (sexuality, risks, greater)</p>	<p>No keywords</p> <p>Treatment types and procedures: (brachytherapy, procedure, robot, SPES, anaesthetic, keyhole, treatment, drug, trial, seeds, monitor, needles*, operations, work*, inoperable*, herbal, join, LRP, receive, robotic)</p> <p>Treatment policy and insurance: (Guildford, cover, PCT, policy)</p> <p>Treatment side-effects: (love, nerves, depression, again*, Zoladex, testicles, wear, Casodex)</p>
2.	<p>Being reluctant to talk: (taboo, quiet)</p> <p>Raising awareness: (Mail*, idea, raise*, Mail's*)</p> <p>Knowing about the prostate and prostate cancer (prostatic, studying, shaped, BPH,</p>	<p>Being reluctant to talk: (reasons)</p> <p>Raising awareness: (radio, launch*, diary)</p> <p>No keywords</p>

	tumour, surrounds, analysed, doughnut, slower, upper, enlarge, killer, develops, disease, capsule, hyperplasia, cancer)	
3.	Risks <u>Age risk</u> : (escalate, occur, age, young) <u>Genetic risk</u> : (genetic, history, link, gene) <u>Nutrition risk</u> : (vegetables, fruit, zinc, fats, oil, tofu, exposure, eat, vitamin, diet, meat, chemicals) Symptoms (urine, symptoms, water, frequently, stream, passing, signs, enlargement)	No keywords No keywords
4.	Tests and diagnosis : (examination, transrectal, medical, identifies, biopsy, rectal, reveal, digital, ultrasound, remains)	Tests and diagnosis ; (again*, score, needles* inoperable*, PSA*)
5.	Lifestyle <u>Employment</u> (biology) No keywords No keywords	Lifestyle <u>Employment</u> (presiding, launch*, return, TV, work*, Manchester*) <u>Sports</u> (England, rugby, game, Manchester*. rowing) <u>Emotion</u> (emotional)
6.	Actants (Margaret, Cliff, it, MFI, Magda, Myra goon, shadows, sister, family, I'd, Duchess, figure, pathologists, charitable, society, men, institute)	Actants (UK, she, Val, Maureen, Jackie, de, court, university, he, nurse, you're, Caroline, Liz, Bono, professor, doc, charity's, club, his)
7.	Other (charmed, even, almost, as, only, joke, all, happen, powerful, fortunately, soon)	Other (Stuff, park, November, testicular, allowed, around, final, later, on, either, road, tea, over, said, yes)
¹ Two categories of keywords are not included here (Political practice - 21 & 13 keywords in 1990-2000 and 2000-2010 respectively and NAMES OF MWPCa - 20 & 24 keywords in 1990-2000 and 2000-2010 respectively) *indicates a 'split' keyword (Seale et al., 2006: 2582) when contextual examination shows association with two or more themes		

Table 3.12 is arranged to show keywords in the 1990-2000 corpus when compared with 2000-2010 and vice versa. Column 1 shows all significant keywords ($p < 0.01$) when the 1990-2000 corpus was compared with 2000-2010; column 2 shows the same information for 2000-2010. Of note are the different categories of keywords more prevalent in one time period than another. Two categories of keywords in each period were not included in this table: 'Political practice' and 'Names of MWPCa'. All keywords are listed in Appendix 3 and all were significant when $p < 0.01$.

In sum, there were three benefits of CKWIC as a method in analysing the illness narratives of MWPCa in the UK print media in 1990-2000 and 2000-2010. My research question asks how the UK print media have been a force for change regarding how PCa has been addressed and experienced by MWPCa since the emergence of PCaOrgs in the UK in the mid-1990s. My first analytic step in answering this question was to investigate changes in how the media have represented the illness experience of MWPCa. This resulted in two large data sets—39 illness narratives in 1990-2000 with 41,487 words and 101 illness narratives in 2000-2010 with 108,107 words. The first

benefit therefore was the suitability of CKWIC for analysing large quantities of qualitative data where the research concern is regarding differences between datasets (Seale et al., 2006). The second benefit was that CKWIC was useful in impartially identifying those words more statistically salient, or *key*, in one corpus—here of media illness narratives of MWPCa—with another and vice versa. In this way, it attended to the criticism that sensitising concepts disrupt an inductive approach to the data (Glaser, 1992) where patterns of analysis are presumed to emerge out of the data (Patton, 1980). Third, it allowed an ‘inductive–deductive interplay’ (McGhee et al., 2007) between what I was sensitised to as potentially salient in my data through the literature review in Chapter 2 and what was inductively revealed in the data. In sum, the cumulative benefit was that CKWIC analysis gave me a quantitative ‘aerial view’ (Seale and Charteris-Black, 2008: 456) of patterns not seen from the ground which then enabled a more detailed qualitative analysis of these patterns in their narrative context using sensitising concepts from Chapter 2 (Table 3.13).

3.4.2.2 Data analysis: narratives of PCaA and MWPCa

Though Kelly and Dickinson describe genres as ‘devices for structuring and giving meaning to stories’ (1997: 266), they also suggest that genres have an ‘undesirable impression of categorization’ (p. 266). While I agree that genres may be a form of categorisation I view this as less undesirable than do Kelly and Dickinson. Similarly, Frank (2010: 119) argues that though ‘putting stories in boxes’ is risky, typologies of narratives are advantageous in that they recognise:

the uniqueness of each individual *story*, while at the same time understanding how individuals do not make up stories by themselves. Each story is singular; none is a mere *instance*. Yet, stories depend on other stories: on recognizable plots, character types, conventional tropes, genre-specific cues that build suspense, and all the other narrative resources that story tellers utilize (...) all storytellers work with these types as resources for telling and expectations for hearing. Experience is understood as residing as much outside persons as inside them; it is borrowed even as it is felt. (Frank, 2010: 119, emphasis in original)

Frank shows that it is through the categorisation of a variety of narrative elements that we can examine ‘how individuals do not make up stories by themselves’ but work with these narrative elements and their co-authoring audience in making up their own story. Many of these narrative elements are included as a selection of sensitising concepts in Table 3.13. These sensitising concepts became apparent as useful ideas to

think with and ask questions about and discover relationships between in the course of reviewing the literature and thinking about the emerging data.

Table 3.13 Selected Sensitising Concepts

Sensitising Concept	Brief Description
Narrative concepts	
Contingent narratives	Concerned with temporal unfolding of illness from onset, managing its effects and the relationship between those ill and those they interact with. Normalisation: Achieved either in maintaining one's pre-illness identity or incorporating illness into a changed identity—likely to not disclose illness in former and to disclose illness in latter Coping: Practically managing interactional issues of disclosing illness to family and friends—performative in allowing a preferred presentation of self; relieving others of interactional burden Strategic management of illness: Pacing of work and home activities and access to social support
Moral narratives	Justify self in the altered relations of body, self and society—usually pursuing a virtuous presentation of self; may attribute culpability to self or external other
Core narratives	People draw upon specific available language e.g. clichés, symbolic repertoires which constrain or allow what can be said.
Genres	Particular language resources which allow/constrain what is said: epic or heroic; tragic; comic or ironic; romantic; and didactic. People not necessarily consistent in using and may shift from tragic to ironic or heroic to comic as they see fit depending on context, intention of speaker, and response of audience
Emplotment	Communicators anticipate audience's response and work together to produce a meaningful story
Co-authorship	Narratives are constructed in relationship with various people and organisations implying a dialogue with other voices
Framing concepts	
Frames	Highlight, or diagnose, some aspect of social life as problematic and/or unjust in need of change; propose a solution, or make a prognosis, for the diagnosed problem specifying what needs to be done; make diagnostic attributions of blame by identifying a culpable adversarial 'they' of individual, collective or structural agents responsible for the problem; and make prognostic attributions by identifying a 'they' who will bring change by engaging in corrective action to resolve the problem.
Frame resonance	Speakers 'fit' their talk with their audience's beliefs, worldviews and experiences. Challenging actors can peer into histories of other challenging groups and borrow their language when there is silence in the arena where they are fighting their own struggle.

Frame transformation	Redefines events or biographies already meaningful from one viewpoint to another and often adopting an injustice frame and shift in blame
Frame amplification	The idealisation or embellishment of existing values and beliefs, for example, around family and fairness
Framing hazards	E.g. counterframing undermines other's frame; dialectic tension when an initial frame legitimates an action at one point but then transforms belief so that such action is later no longer legitimate; framing errors when action is based on erroneous beliefs
Dissonance /radicalism	A story which is too familiar is no story at all (Polletta, 2006) and novel/radical/dissonant elements are also needed (Ferree, 2003)
Emotions	Injustice as 'moral indignation' or a 'sense of outrage' is 'leaven' for social change when people/organisations can see many of own problems in terms set forth by others. Interest as the subjective evaluation of an event's novel-complexity (for example, its unexpectedness, surprise, or mysteriousness) and its familiarity or comprehensibility
Literary and concepts	
Repetition	Repetition gives talk the characteristic of familiarity which makes talk sound right or 'fit'. Stories, or narratives, resonate through a combination of familiarity, pleasurable surprise and emotional identification. Pre-patterning of talk
Heteroglossia and dialogical	Stories are dialogical in that there is always an implied dialogue in any utterance and potentially many voices or 'heteroglossia'.

The concepts in Table 3.13 interrelate at several points, examples of which are:

- Core narratives as instrumental in moral and contingent narratives—people draw on core ways of speaking to tell moral and contingent stories
- Heteroglossia, dialogism and co-authorship, repetition, and resonance in their recognition of the voices of others within stories
- Frame transformation, injustice, and moral narratives when storytellers seek to shift blame from self to another or from one object to another
- The novel-complex component of 'interest' and radicalism as unexpected and unpredictable elements in stories
- The familiar component of 'interest' and resonance, or repetition, as predictable elements in stories

Line-by-line coding of the kind advocated by Charmaz (2006), though it allows familiarity with content of the data, only somewhat hints at its form and breaks the data into too small segments than compared with what is usually advocated for narrative analysis (Bury, 2001; Riessman, 2008; Frank, 2010; Bury and Monaghan, 2013a). The constant comparison between codes and categories that line-by-line

coding entails is though, perhaps surprisingly, similar to how Frank (2010) identifies forms of narratives in his constant comparing, and re-sorting and renaming of forms until the type emerges:

Types become identifiable as they are named, and a typology compels or collapses depending on the descriptive force of its names. Names can describe the stories (for example, “diagnosis stories”), or they can borrow some phrase that reoccurs in that type of story, or names can be descriptively evocative, like my types of restitution, chaos or quest. Some names are immediate and obvious fits; some clusters of types seem resistant to naming. The process of naming a type proceeds iteratively with changing understandings of which stories fit that type. Stories that do not fit within proposed types require decisions whether to expand a type that has already taken shape and may have a name, or to create a new type (...) resorting and renaming bring the typology into being. No rule says when to stop; eventually, the analyst and enough others recognise the types as expressing something significant about the stories they describe. (Frank, 2010: 120-121)

The narrative elements as sensitising concepts in Table 3.13 and the ways of categorising such elements as advocated by Frank (2010) were used in my analysis of each of the empirical data sets. They were also useful in examining deviant, or negative, cases—where ““things go differently”” (Peräkylä, 2011) from an expected analytic pattern. Deviant cases at times provided additional support for my interpretation by showing how the participant also orientated to the pattern I expected; sometimes it led to my abandoning a particular interpretation; or at times I found particular contingencies of an individual case (see Peräkylä, 2004; Seale, 2012).

I interviewed all the PCaA and the MWPCa (2010) participants and transcribed all of the audio recordings¹. Transcribing the recordings took approximately five hours per one hour of recording, a process which served to begin to familiarise me with the data. This familiarisation continued as I reread each transcription before I imported all transcriptions into NVIVO 9 software. Though CKWIC analysis proved very useful in identifying patterns of changes in the representation of illness narratives of MWPCa in the print media, it was not conducive to analysing the MWPCa and PCaA interviews. This was because there was no comparative element in the PCaA interviews for CKWIC to be of benefit and my eventual analytic enquiry into changes in how MWPCa disclosed their PCa to various audiences was not one easily accommodated by CKWIC analysis.

¹ See note 1 in §3.4.1.2.4

3.4.2.2.1 Analysing the narratives of PCaA from 2010

On further close reading of the PCaA interviews I began to identify how PCa was presented as a 'problem' (Gamson et al., 1992; Snow and Benford, 1992) and identified three potential 'problem' stories around PCa: PCa as a neglected condition; a lack of information around PCa; and potential misinformation around PCa. Attracting funds for PCa research was described as "very very difficult" (PC-MP/2), and the early diagnosis of PCa was described as one of "several kinds of key issues (...) we needed to tackle" (PC-PC/1). I then used a thesaurus to identify words which indicated a 'problem' such as: issue, concern, question, matter, difficult, trouble, dilemma, predicament, quandary, complex and danger and used the query facility of NVIVO to search the data for these words. Examining these words in their narrative context allowed me to identify a nuanced story of injustice around PCa as not only neglected but also with inequalities in other ways such as the differential delivery of services or treatment by postcode lottery and access to information on screening. In addition it allowed me to see evidence of temporal and contentious elements to the 'neglect' story.

My queries in the PCaA interviews continued for contexts around particular phrases: cause/movement/issue; signs and symptoms; power; care; support; PSA, screening and testing; breast cancer; evidence; treatment; injustice; fundraising; humour; decision making; responsibility and blame; and family words. I then examined each of these queries in their narrative context to see which were relevant for my thesis and continually added to my categories as necessary. My coding was continually modified to ensure an adequate 'fit' with the data, while also accounting for 'deviant cases' or 'negative instances' (Seale, 2012). It was also an iterative process between the developing analysis, new data and emerging literature.

3.4.2.2.2 Analysing the narratives of MWPCa from 2000 and 2010

There was a lot of 'dialogic' talk by participants in both time periods—MWPCa repeating, or reconstructing familiar voices from past conversations with others around all sorts of issues related to their PCa. Inspired by Rapley's (2008) work on how decision-making is never just an individual cognitive activity, or even a dyadic activity between doctor and patient, but rather distributed over a range of settings, people and technologies, I examined how these men distributed their voice over a variety of

settings and people. Men's talk around issues, for example of disclosing their condition, testing, masculinity, awareness or treatment, was categorised as 'voicing'— 'voicing disclosure of PCa', 'voicing treatment choices', 'voicing masculinity' and so on. These 'voicing' categories were organised into coding frameworks using NVIVO (v9) software. The idea of 'voicing' emphasises how the 'private' voice of MWPCa integrates with other voices. These other voices were 'collective', for example, that offered by the media or accepted as a 'common sense' way of thinking. Or, they were another 'private' voice, that offered by a medical professional, a partner, child, or friend. When people reconstruct the voices of others they provide evidence not only of what they have actively heard from past conversations, and which is resonant, or 'rings true', with their experience, but also how they want those words to be heard in the present conversation (Bakhtin 1981; Volosinov 1986; Tannen 2007).

The data from the MWPCa interviews was analysed after the analysis of the media and PCaA data and the findings from the analysis of the media and PCaA data then prompted my analytic enquiry for Chapter 6 MWPCa data. A finding from the media analysis demonstrated that PCa as a "taboo disease that no one dares talk about" was more explicitly and frequently articulated in the media illness narratives of MWPCa in 1990-2000 than those in 2000-2010 (§4.4). A finding from the analysis of the PCaA data demonstrated that though towards the end of the 1990s "prostate cancer was just beginning to come out of the shadows of neglect" and that when men "would have their illness, they would not talk about it, they would die quietly", this was less the case towards 2010. In addition, my thesis focuses on changing narratives of PCa over time. Though I draw on ideas from several narrative and literary scholars, I use as a basis Bury's (2001) three non-mutually exclusive narrative forms: contingent, moral and core narratives (§2.4.3). Though all three are useful, contingent narratives of coping in particular address the practical management of interactional issues of disclosing illness to family and friends. Given these findings and my research enquiry, I was prompted to investigate whether there were differences in how MWPCa disclosed their illness over time to various audiences. I thus chose to focus on 'voicing disclosure of PCa' to various audiences over other substantive types of 'voicing'.

Chapter 4 Changing narratives of MWPCa: the UK national print media 1990-2010

4.1 Introduction

Print media is among the most relied on of sources of information regarding disease, illness, death and medicine for people in general (Clarke, 2004), and men with prostate cancer (MWPCa) in particular (Halpin et al., 2009). It is also considered, along with health social movements (HSM), to contribute to the social diagnosis of a disease (Brown et al., 2011). Although PCa is the research ‘flagship of men’s cancer’ (Wenger and Oliffe, 2013) there are relatively few studies of print media representation of PCa (Halpin et al. 2009). As yet, no study has compared how this representation may have changed since the emergence of PCaOrgs into the UK in the mid-1990s. This chapter begins to address this deficit by drawing on the conceptual frameworks of narrative and framing theory described in Chapter 2 and a comparative keyword in context (CKWIC) analysis described in Chapter 3 to analyse changes in how the illness narratives of MWPCa have been represented in the UK print media. These analytic frameworks allowed me to ask key practical questions: which words were significantly more frequently used by journalists when writing about MWPCa in 1990-2000 than in 2000-2010 and vice versa; and what insights did this give into how the UK national print media represented the illness experience of MWPCa since the emergence of PCaOrgs in the UK in the mid-1990s.

4.2 An ‘aerial view’ of the illness narratives of MWPCa in the UK print media

Sampling of the UK print media through Nexis UK, an on-line database of newspaper articles, resulted in 140 articles predominantly about the illness narrative of MWPCa (§3.4.1.1). Table 4.1 (reproduced from Table 3.7) shows the distribution of these articles across six newspapers and time.

Table 4.1 Sampled articles predominantly containing illness narratives of MWPCa

	Newspaper	01/06/1990-31/05/2000	01/06/2000-31/05/2010	Total
1.	Times & Sunday Times	9	16	25
2.	Independent & Independent on Sunday	1	8	9
3.	Guardian and Observer	5 ^{1*}	13	18
4.	Daily Mail & Mail on Sunday	19 ¹	47	66
5.	Mirror & Sunday Mirror	5 ¹	16	21
6.	People	0 ¹	1	1
	Total	39	101	140
¹ not fully uploaded 01/06/1990-31/05/1995 but fully uploaded 01/06/1995-31/05/2000				
*only one article from 1990-1995 (in the Guardian) contained the illness narrative of a MWPC				

Table 4.1 indicates that since the emergence of PCaOrgs into the UK in the mid-1990s—the Prostate Cancer Research Foundation in 1993 and The Prostate Cancer Charity¹ in 1996—there has been greater attention to the illness experience of MWPCa in the UK national print media, with 39 illness narratives in 1990-2000 and 101 in 2000-2010. Though there was only one article predominantly about the illness experience of a MWPCa during 1990-1995—in the time period approximately just prior to the emergence of PCaOrgs into the UK—rows 3-6 show that some newspapers were not fully uploaded to the Nexis database in this period.

The CKWIC analysis (§3.4.2.1) was useful in giving an inductive ‘aerial view’ (Seale and Charteris-Black, 2008: 456) of changes in how the UK print media represented the illness experience of PCa over time. It first identified words which were statistically more frequent when the print media illness narratives of MWPCa in 1990-2000 were compared with those in 2000-2010 and vice versa. These ‘keywords’ (Stubbs, 1996; Baker, 2006; O’Halloran, 2010) allowed patterns of analysis to emerge inductively from the data (Patton, 1980; Glaser, 1992) and these patterns were organised into keyword themes (Table 4.2). These keywords and themes then served as inductive “points of departure” (Charmaz, 2006: 17) for further deductive analysis; affording then an analytic “inductive-deductive interplay” (McGhee et al., 2007: 335). This was by examining the keywords in their concordances—which showed the keyword in its brief context—and by allowing the narrative and framing concepts described in Chapter 2 to sensitise me to which analytic paths to pursue (Charmaz, 2006).

¹Now Prostate Cancer UK

Table 4.2 Keywords and themes in a CKWIC analysis of illness narratives of MWPCa in UK print media 1990-2000 and 2000-2010

	Keywords and themes across time (p<0.01) ¹		Aerial view of PCa stories
	1990-2000	2000-2010	
1.	<p>Raising money for PCa: (GBP, million, spent, Mail*, raise*, Mail's*)</p> <p>No keywords</p> <p>No keywords</p> <p>Treatment side-effects: (sexuality, risks, greater)</p>	<p>No keywords</p> <p>Treatment types and procedures: (brachytherapy, procedure, robot, SPES, anaesthetic, keyhole, treatment, drug, trial, seeds, monitor, needles*, operations, work*, inoperable*, herbal, join, LRP, receive, robotic)</p> <p>Treatment policy and insurance: (Guildford, cover, PCT, policy)</p> <p>Treatment side-effects: (love, nerves, depression, again*, Zoladex, testicles, wear, Casodex)</p>	Stories of injustice
2.	<p>Being reluctant to talk: (taboo, quiet)</p> <p>Raising awareness: (Mail*, idea, raise*, Mail's*)</p> <p>Knowing about the prostate and prostate cancer prostatic, studying, shaped, BPH, tumour, surrounds, analysed, doughnut, slower, upper, enlarge, killer, develops, disease, capsule, hyperplasia, cancer</p>	<p>Being reluctant to talk: (reasons)</p> <p>Raising awareness: (radio, launch*, diary)</p> <p>No keywords</p>	Stories of taboo
3.	<p>Risks <u>Age risk:</u> (escalate, occur, age, young) <u>Genetic risk:</u> (genetic, history, link, gene) <u>Nutrition risk:</u> (vegetables, fruit, zinc, fats, oil, tofu, exposure, eat, vitamin, diet, meat, chemicals)</p> <p>Symptoms urine, symptoms, water, frequently, stream, passing, signs, enlargement</p>	<p>No keywords</p> <p>No keywords</p>	Stories of problematic waterworks and age
4.	<p>Tests and diagnosis: (examination, transrectal, medical, identifies, biopsy, rectal, reveal, digital, ultrasound, remains)</p>	<p>Tests and diagnosis; (again*, score, needles* inoperable*, PSA*)</p>	Stories of tests & diagnosis
<p>¹See Table 3.11 for a summary of the 138 and 118 keywords (p<0.01) identified in 1990-2000 and 2000-2010 respectively. All keywords are shown in Appendix 3. Five categories of keywords are not included for analysis (Political practice, Names of MWPC, Actants and expressivity, Lifestyle, and Other) (§ 3.4.2.1.1 & §3.4.2.1.2)</p> <p>*indicates a 'split' keyword (Seale et al., 2006: 2582) when its contextual examination shows that it should be associated with two or more themes (§3.4.2.1.2)</p>			

There are four rows and three columns in Table 4.2. Each row shows those words used statistically more frequently by journalists when writing about the illness experience of MWPCa in 1990-2000 (column 1) than in 2000-2010 (column 2) and vice versa. The

keyword themes in each row point towards differences in how journalists narrated the illness experience of PCa across time (column 3).

4.3 Shifting stories of injustice around PCa

The keyword themes in row 1 in Table 4.2—‘*Raising money for PCa*’ and the three themes around ‘*Treatment*’—provided an inductive analytic launch pad (Charmaz, 2006) for further exploration of narratives around PCa which seemed to suggest a shift from stories of injustice around the funding neglect of PCa in 1990-2000 to other injustices around treatment in 2000-2010.

4.3.1 The story of ‘neglect’ of PCa 1990-2000

There were six keywords associated with ‘*Raising money for PCa*’ in the 1990-2000 corpus (GBP [Great British Pounds], million, spent, Mail, raise and Mail’s) and none in 2000-2010 (Table 4.2). The raw and relative frequencies of these words in each time period are summarised in Table 4.3:

Table 4.3 ‘Raising Money for PCa’ Keywords 1990-2000

‘Raising money for PCA’					
Key word	1990-2000 Raw Freq.	1990-2000 Freq./100,000	2000-2010 Raw Freq.	2000-2010 Freq./100,000	P
GBP ¹ (GBP/POUNDS/\$/£)	33 (61)	79.5 (147)	15 (71)	13.9 (65.7)	p<0.001
MILLION	22	53.0	6	5.6	p<0.001
SPENT	22	53.0	17	15.7	p<0.001
MAIL*	18	43.4	13	12.0	p<0.001
RAISE*	16	38.6	13	12.0	p<0.01
MAIL'S*	5	12.1	1	0.9	p<0.01

¹Nexis UK variously represents the British monetary symbol as ‘E’/‘GBP’/‘pounds’. Row 1 also shows the raw and relative frequencies for the combined *GBP/pounds/£/\$* (\$ as the US monetary symbol)
 *‘split’ keyword (Seale et al., 2006: 2582) where contextual examination of the keyword in its concordance shows it is associated with two or more meanings.

There are six columns in Table 4.3 and in each of the subsequent summary keyword tables in this chapter. The first (Keyword) lists each keyword contributing to the category. The second and fourth columns (1990-2000 Raw Freq.) and (2000-2010 Raw Freq.) give the raw frequencies of the keywords in the two time periods. As the corpora differ in size, it was often more useful to consider the frequency per 100,000 words rather than raw frequencies. The third and fifth columns, (1990-2000

Freq/100,000) and (2000-2010 Freq/100,000) give the raw frequency as a ratio per 100,000 words. Though the software also indicated a keyness value, this is not included in the table as what is important to note is that as the list descends the log-likelihood statistic, as measured by the probability (p) value given in the sixth column, increases as keyness decreases. The greater the keyness, the greater the salience or 'proportional statistical frequency' (O'Halloran, 2010: 215) of the keyword. All keywords were statistically significant when $p < 0.01$. As an example, row 1 in Table 4.3 shows that *GBP* occurred 33 times in 1990-2000 and 15 times in 2000-2010 corresponding to 79.5 and 13.9 words per 100,000 words respectively.

Figure 4.1 shows the *GBP* concordance, and lists all instances of *GBP* in its context; as expected this keyword was associated with money in every occurrence:

Figure 4.1. 'GBP' keyword concordance 1990-2000

N Concordance
 1 lived for the company and built it into a GBP 350 million empire. He was
 2 year before he died.' His Trust, valued at GBP 3.5 million, paid out GBP 1 million
 3 worried because each scan costs GBP 400. It looks as though I've got
 4 spent on finding a cure is derisory - GBP 47,000 last year, compared to
 5 spent on finding a cure is derisory - GBP 47,000 last year, compared with
 6 spent on finding a cure is derisory -GBP 47,000 last year. That is why the
 7 Manchester M60 3JD I am donating GBP to the Daily Mail Prostate Cancer
 8 . HERE'S HOW TO DONATE For every GBP raised by Mail readers the
 9 . HERE'S HOW TO DONATE For every GBP raised by Mail readers the
 10 charity received a cheque - for exactly GBP 47,000. I hope the money will help
 11 get there.' The Daily Mail launched its GBP 1million fundraising campaign - in
 12 out that the Government spent just GBP 47,000 a year on research into
 13 insurance. The blood test costs only GBP 15, and it is appalling that it is not
 14 spent on finding a cure is derisory - only GBP 47,000 last year, compared to
 15 8,000 men in the UK a year but only GBP 47,000 was spent researching it in
 16 of cancer prevention and cure. Yet only GBP 47,000 a year goes on prostate
 17 , valued at GBP 3.5 million, paid out GBP 1 million a year ago to the
 18 - 10,000 die every year - yet a pitiful GBP 47,000 was spent last year
 19 Mail has launched an appeal to raise GBP 1 million to rectify this scandalous
 20 Mail has launched an appeal to raise GBP 1 million to rectify this scandalous
 21 Mail has launched an appeal to raise GBP 1 million to rectify this scandalous
 22 Mail has launched an appeal to raise GBP 1 million. Sidney Swan was
 23 Mail has launched an appeal to raise GBP 1 million. Here, 58-year-old
 24 I vowed that, when I was better, I'd raise GBP 47,000 for prostate research and
 25 UK. I had one mission: to raise GBP 47,000. Through my job in
 26 the disease. At the same time, GBP 18 million was spent on Aids,
 27 GBP 47,000 last year, compared to GBP 18 million spent on Aids. The
 28 - GBP 47,000 last year, compared to GBP 18million spent on Aids, which
 29 by generous Mail readers - up to GBP 500,000 another pound will be
 30 Charitable Trust will match it up to GBP 500,000. The money raised will go
 31 Charitable Trust will match it up to GBP 500,000. The money raised will go
 32 by generous Mail readers - up to GBP 500,000 - another pound will be
 33 - GBP 47,000 last year, compared with GBP 18 million spent on Aids, which

The most frequent collocate—the word company that *GBP* kept (Stubbs 1996: 173) (§3.4.2.1.3)—one place left of *GBP* was *raise*. *Raise* was also a 'Raising money for PCa' 1990-2000 keyword and examining all its instances in the *GBP* concordance and its

remaining instances in the *raise* concordance (Appendix 14: 'Raising money for PCa') showed that it was almost exclusively used in the context of raising money, for example regarding the launch of a Daily Mail appeal to raise one million pounds. Figure 4.1 shows other semantic equivalents of the Daily Mail raising money through earlier donations or announcements of the launch of this appeal. *Mail/Mail's* were also mostly used in the context of the Daily Mail either launching an appeal or/and campaign to raise funds or/and awareness. The keyword *spent* was predominantly used in the context of money and the keyword *million* occurred in an almost exclusive context of money; many of the instances of these keywords are also seen in Figure 4.1. Overall, the *GBP* concordance in Figure 4.1 and other relevant concordances (Appendix 14: 'Raising money for PCa') indicated concern with raising money for PCa either through the Daily Mail campaign or through other fundraising action. Thus, the CKWIC analysis gave an 'aerial view' (Seale and Charteris-Black, 2008: 456) of a narrative around PCa which was statistically more frequent in 1990-2000 than 2000-2010—PCa was an illness for which money needed to be raised. What narrative or framing devices were used in this story?

The figure "47,000" was repeated often in Figure 4.1 as the "derisory" or "pitiful" amount of money spent "last year" and in terms suggesting it was very limited—"just", "but only" and "yet only". Such repetition indicated a 'Derisory £47,000 PCa Spend' 'boilerplate' (Cotter, 2010: 171) (underlined in Extract 4.1). Although a boilerplate is 'seemingly throwaway material (...) repetitious, unattributed (...) and is potentially expendable as text (...) its role in framing a news story may also end up influencing public debate' (p. 171):

Extract 4.1

I am one victim, but I've raised more cash on my own for prostate cancer than the Government did all of last year

PROSTATE cancer has become the disease no one wants to talk about. Every hour a British man dies from it, yet the amount spent on finding a cure is derisory - GBP 47,000 last year, compared with GBP 18 million spent on Aids, which kills 400 a year. That is why the Daily Mail has launched an appeal to raise GBP 1 million. Here, 58-year-old businessman Ted Clucas, from Jersey, tells VICTORIA FLETCHER of his struggle to end the secrecy surrounding prostate cancer after he was told he needed surgery within hours of being diagnosed.

The 'Derisory £47,000 PCa Spend' boilerplate was one of two boilerplates evident in the data and which, to varying extents, were often (as in Extract 4.1) included as context for the illness narrative of a MWPCa. This boilerplate is included at the start of the very long illness narrative of Ted Clucas, a 58 year old businessman diagnosed with PCa. The first part of Ted's narrative (shown in Appendix 15: Daily Mail, 10/11/1999) may be considered to have a contingent form (Bury, 2001; Bury and Monaghan, 2013a), as it focused on the temporal unfolding of his illness from its onset and the relationship between Ted and his family and others he interacted with. The latter part of Ted's long narrative is shown here (Extract 4.2), as the CKWIC analysis demonstrated that some of the words within it were used significantly more frequently by journalists when writing about the illness experience of MWPCa in 1990-2000 than in 2000-2010. Ted's narrative ends, after Extract 4.2, with another boilerplate (shown in Extract 4.17)

Extract 4.2

The next few days were a whirlwind, but in that time I decided to learn all I could about the disease. All I kept thinking was: Why had my GP not known all of this? How had he missed the telling signs? And why was there so little information available to men, if so many suffer from prostate cancer? My shock soon turned to anger when I found out that the Government spent just GBP 47,000 a year on research into prostate cancer. No wonder I'd never heard about it; no wonder my GP wasn't knowledgeable about it. No one was taking it seriously, and at that moment I vowed that, when I was better, I'd raise GBP 47,000 for prostate research and education, to prove to the Government that just one man was capable of equalling their pitiful donation. After the operation, my recovery was quite quick - I knew I had to beat the disease. I had radiotherapy until February and then started to get fit. I'd decided to do a half marathon in July to raise money for the Prostate Research Campaign UK. I had one mission: to raise GBP 47,000. Through my job in international financial services, I know some wealthy clients, and with a bit of persuasion I knew I could reach my goal. I finished the race, and last week the charity received a cheque - for exactly GBP 47,000. I hope the money will help research into the disease. But more than that, I hope that it will be used to educate GPs and encourage the public to get themselves checked. Next year I am going to raise even more for research. We all have to beat this disease. (Daily Mail, 10/11/1999)

Ted's narrative in Extract 4.2 demonstrates aspects of framing theory specific to social movement framing (§2.3.1): presenting aspects of life as problematic and/or unjust and in need of change; attributing blame to culpable actants; proposing a solution to the injustice; and identifying actants who/which will engage in corrective action (Gamson et al., 1992; Snow and Benford, 1992). Ted transformed his diagnosis of PCa

from a tragic personal shock to an unjust event (Snow and Benford, 1986) with several actants identified as culpable: his GP's lack of knowledge about PCa; the general lack of information available to men; and ultimately the "pitiful" funding of PCa by the UK government. Ted proposed his own action as that which would address the lack of information available to men and GPs. His rationale of "I knew I had to beat the disease", ended with a collective plea for action—"We all have to beat this disease". "We" indicated not just "the [male] public" given that males are the only "public" who can "get themselves checked" but also potential others: the female public who might 'nag and drag' the male public to get checked; the "no one was taking it seriously" societal public; the unknowledgeable medical public of "GPs"; the PCa organisational public such as the "Prostate Research Campaign UK"; and the pitifully donating "Government".

Ted's identification as a 'victim' in the title of his narrative (Extract 4.1) seemed somewhat surprising given that this term implies that one has succumbed to the disease when instead it is survivorship which is often understood as key to activism (Kedrowski and Sarow, 2007). Smith (2005) argues that when a tragic genre is used it demonstrates an 'amplified awareness of suffering (p.25) and a 'futile struggle against the fates' (p.26); things which do not sustain activism. Conversely, a romantic genre—where a hero triumphs over adversity—inspires activism as it carries a hope that a wrong, or a wrongdoing antagonist, can be subject to successful resolution or negotiation. This shift from Ted as a tragic 'victim' to one who triumphs over adversity does though fit with Bury's (2001) observation that narrators are not necessarily consistent in using the narrative genres, or pre-patterned ways of talking and making sense, available for narrators and their audience (Tannen, 2007).

In addition to Figure 4.1 demonstrating the Daily Mail's launch of an appeal, other 'Raising money for PCa' concordance displays (Appendix 14) also show how individual MWPCa, or those associated with them, took action to raise money:

Extract 4.3

But prostate cancer is the "Cinderella" of cancers. Even when they have been diagnosed, men wait twice as long for surgery as breast cancer sufferers. And while pounds 16 million a year goes into breast cancer research, a mere pounds 1 million is spent on finding a cure for this killer disease. Roger Kirby, Doug and Andrew are running the London Marathon to raise money for the Prostate

Research Campaign. To sponsor them, send a cheque to: Prostate Research Campaign (The Mirror, 06/04/2000)

The metaphor “Cinderella” draws attention to PCa as a neglected disease when compared to waiting times for treatment for breast cancer. Blame for this was attributed to the disparity of research funding between these diseases. This suggested a gender-based neglect story and prompted further investigation of the *GBP* concordance (Figure 4.1) along such comparative lines. In addition to ‘raise’, another frequent *GBP* collocate in Figure 4.1 was ‘to’ and while most of its instances have already been highlighted, a further two compared the funding of PCa unfavourably with the disease of AIDS (see also “with” in line 33). This comparative aspect was also explicitly shown in other concordance displays (see the ‘Pounds/\$/£’ 1990-2000 concordance in Appendix 14: ‘Raising money for PCa’) and extended to breast cancer and heart disease. Other emotive words in Figure 4.1 were “appalling” and “scandalous” which helped to tell a story of neglect of PCa in relation to other illnesses.

The unjust neglect of PCa and also of “men’s lives and deaths” more generally, was also told alongside familiar hegemonic discourse regarding men’s reluctance to seek help on health issues (Gough 2006). “Suffering in silence” and “hoping it won’t happen” is understood as risky behaviour through the “Russian roulette” metaphor:

Extract 4.4

Suffering in silence or hoping it won't happen is like playing Russian roulette. There's also an issue of fairness here. Vast sums are spent on other forms of cancer prevention and cure. Yet only GBP 47,000 a year goes on prostate research. Does that mean men's lives and deaths don't matter? Is society saying: 'Men don't complain so we can ignore their illnesses?' (Daily Mail, 04/11/1999)

In contrast to the silence of men, Extract 4.4 shows that “society” was given a voice which spoke about the ease of neglecting the illnesses of uncomplaining silent men. This focused attention on the potential lack of value that society placed on the lives and deaths of men. This was also demonstrated by examining the keyword *million* in 1990-2000 which occurred not only in an almost exclusive context of money (many seen in Figure 4.1) but also again with an unfavourable comparison made between the relatively small amount of money spent on PCa and that spent on AIDS, heart disease and breast cancer in both the UK and America. Additionally, *million* was also used to

quantify how many men may have PCa, with this also in the context of an unfavourable and emotive comparison between British and European death rates:

Extract 4.5

At 10,000 deaths a year, Britain has Europe's second-highest mortality rate from prostate cancer. The figure has doubled in the past 20 years and some experts predict that it will reach 'epidemic proportions' over the next few decades. An estimated 2 million men in Britain over 50 probably have the disease, though only a small percentage will die from it. (Daily Mail, 14/12/1996)

Extract 4.5 shows a tentative attempt to describe PCa as an “epidemic”. It is tentative because of the particular phrases used around it, suggesting it was *like* or *almost* an epidemic; “epidemic proportions” (Extract 4.5), “an epidemic in waiting” (Guardian, 26/11/1996), and on “the verge of an epidemic” (Extract 4.6):

Extract 4.6

1 One of the main aims of the Institute of Cancer Research Everyman appeal,
2 which Richard Bentine is spearheading, is to raise \$6 million to build and equip
3 Britain's first dedicated male cancer research centre, which will be headed by
4 the ICR's Professor Colin Cooper. 'One man in ten can expect to get prostate
5 cancer in his lifetime yet research into male cancers has been minimal,'
6 Professor Cooper says. 'We spend \$16 million a year on breast cancer, for
7 example, \$40 million on heart disease and \$15 million on Aids, but only \$1
8 million on prostate cancer. '(sic) I think it's been so neglected because it's seen
9 as a disease of old men. But men as young as 40 can die of it and many older
10 men could live for an extra ten, even 20 years, if they were cured. '(sic) We are
11 on the verge of an epidemic. Within the next 20 years the incidence could be
12 as high as one in four, partly due to an ageing population. '(sic) But we're not
13 very good at treating it yet. Lack of research funds means that 70 pc of patients
14 will die of it. And the risks of side-effects are high. The Americans say better a
15 live husband than a dead lover, but it's a high price. It is an awful disease and
16 because we don't know the cause we cannot prevent it.' (Daily Mail,
17 12/05/1999)

There were three instances of “epidemic” in 1990-2000 and none in 2000-2010. Although it was excluded as a keyword as only those of five or more instances were sought (§3.4.2.1.1), articulating PCa as an epidemic resonated with the idea of neglect above and thus to a qualitative notion of keyness (Williams 1976; Seale et al., 2006). It is important as it potentially constituted PCa as a major health problem requiring government action. That two ‘epidemic’ phrases were in quotation marks drew

attention to the use of this word in other contexts. 'Epidemic' may have been a familiar term to journalists since breast cancer as an 'epidemic', with unacceptable rates of incidence in the young and old, was used in public claimsmaking around breast cancer in the USA in the 1980s (Kolker, 2004). Extract 4.6 also demonstrates (lines 6-8) how a 'dollar' version of the 'Derisory £47,000 PCa Spend' boilerplate was used as context for the neglect of PCa. Notable also (lines 8-9) was an indication of an ageist element to the gender-based neglect story—PCa has "been so neglected because it's seen as a disease of old men". This perhaps familiar notion though was placed alongside what might be considered as rather more novel information: PCa was a disease that "men as young as 40 can die of" (line 9). The above example ends with the implication that the lack of medical knowledge around PCa was a consequence of institutional neglect.

Though there were no '*Raising money for PCa*' keywords in 2000-2010, examining the GBP and pounds/\$/£ concordances in 2000-2010 (Appendix 14: '*Raising money for PCa*') showed differences in how these words were used in each time period. The most common use of GBP in 2000-2010 was regarding insurance—all of which were from the same article and concerned with problems caused for insurers paying out on huge numbers of policies resulting from increasing numbers of MWPCa being detected early and cured. The next most common use of GBP in 2000-2010 was around costs or affordability of treatment. Only three instances of GBP in 2000-2010 referred to the previous Daily Mail campaign to raise money and one to the "only GBP 47,000" spent in 1999. Similarly, the most frequent context for pounds/£/\$ in 2000-2010 was regarding the costs of treatment. The next most frequent articulation was around funding or raising money, followed by unfavourable comparisons between spending on PCa and other spending, and lastly the low cost of the PSA test.

In sum, many of the '*Raising money for PCa*' keywords in 1990-2000 were in the context of an appeal by the Daily Mail to raise £1million to "rectify [the] scandalous situation" of the "derisory" £47,000 of funding that PCa received compared to other illnesses including AIDS, breast cancer and heart disease. This, and other emotive language in the context of these keywords such as "appalling" and PCa being described as 'the "Cinderella" of cancers, suggested that PCa was problematised as a neglected disease. This neglect was mostly gender-based although there were also ageist elements. Blame for this neglect was attributed to various actants, including men

themselves who were stereotypically presented as “suffering in silence”. Other attributions of blame were towards a society that placed little value on the lives and deaths of its men, the medical profession and government. There was also evidence that PCa was tentatively framed as an ‘epidemic’ in 1990-2000 while not at all in 2000-2010. In contrast to 1990-2000, examination of GBP in 2000-2010 showed less concern with the funding neglect of PCa than with insurance and costs of treatment.

4.3.2 Stories of injustice about treatment in 2000-2010

Row 1, column 2 in Table 4.2 shows three categories of keywords around treatment in 2000-2010: ‘Treatment types and procedures’ (*brachytherapy, procedure, robot, SPES, anaesthetic, keyhole, treatment, drug, trial, seeds, monitor, needles, operations, work, inoperable, herbal, join, LRP, receive and robotic*); ‘Treatment side-effects’ (*again, Zoladex, nerves, depression, testicles, wear and Casodex*); and ‘Treatment policy and insurance’ (*Guildford, cover, PCT and policy*). Of note is the mere three ‘treatment’ keywords in 1990-2000 (row 1, column 1): ‘Treatment side-effects’ (*sexuality, risks and greater*). The raw and relative frequencies of these keywords in each time period are summarised in Table 4.4 and Table 4.5. With the sole exception of the keyword *treatment*, journalists made no or minimal use of 2000-2010 keywords in 1990-2000.

Table 4.4 Treatment Keywords 2000-2010

Treatment types and procedures					
2000-2010 Keyword	1990-2000 Raw Freq.	1990-2000 Freq/100,000	2000-2010 Raw Freq.	2000-2010 Freq/100,000	P
BRACHYTHERAPY	0	0.0	60	55.5	6.40463E-12
PROCEDURE	1	2.4	52	48.1	2.68906E-07
ROBOT	0	0.0	26	24.1	3.9456E-05
SPES	0	0.0	23	21.3	0.00011
ANAESTHETIC	0	0.0	18	16.7	0.00063
KEYHOLE	0	0.0	17	15.7	0.00089
TREATMENT	81	195.2	313	290.0	0.00101
DRUG	6	14.5	51	47.2	0.00143
TRIAL	4	9.6	38	35.2	0.00348
SEEDS	3	7.2	33	30.5	0.00358
MONITOR	0	0.0	13	12.0	0.00365
NEEDLES*	0	0.0	13	12.0	0.00365
OPERATIONS	0	0.0	13	12.0	0.00365
WORK*	17	41.0	89	82.3	0.00444
INOPERABLE*	0	0.0	12	11.1	0.00523
HERBAL	0	0.0	11	10.1	0.00750
JOIN	0	0.0	11	10.1	0.00750
LRP	0	0.0	11	10.1	0.00750
RECEIVE	0	0.0	11	10.1	0.00750
ROBOTIC	0	0.0	11	10.1	0.00750

Treatment policy and insurance					
2000-2010 Keyword	1990-2000 Raw Freq.	1990-2000 Freq/100,000	2000-2010 Raw Freq.	2000-2010 Freq 100,000 words	P
GUILDFORD	0	0.0	15	13.9	0.00180
COVER	0	0.0	12	11.1	0.00523
PCT	0	0.0	11	10.1	0.00750
POLICY*	1	2.4	19	17.6	0.00828
Treatment side-effects					
2000-2010 Keyword	1990-2000 Raw Freq.	1990-2000 Freq/100,000	2000-2010 Raw Freq.	2000-2010 Freq/100,000	P
AGAIN*	6	14.5	52	48.1	0.00113
ZOLADEX	0	0.0	15	13.9	0.00180
NERVES	1	2.4	22	20.3	0.00330
DEPRESSION	0	0.0	13	12.0	0.00365
TESTICLES	0	0.0	11	10.1	0.00750
WEAR	0	0.0	11	10.1	0.00750
CASODEX	0	0.0	11	10.1	0.00750

*split keyword

Table 4.5 Treatment Keywords 1990-2010

Treatment: side-effects Keywords 1990-2000					
1990-2000 Keyword	1990-2000 Raw Freq.	1990-2000 Freq/100,000	2000-2010 Raw Freq.	2000-2010 Freq/100,000	P
SEXUALITY	5	12.1	0	0.0	0.00034
RISKS	10	24.1	7	6.5	0.00745
GREATER	9	21.7	6	5.6	0.00917

The 'Treatment types and procedures' keywords mostly represented new forms of treatments available in 2000-2010. *Brachytherapy* treats PCa with radiation from inside the prostate either through radioactive *seeds* or high dose radioactive material inserted by *needles* into the prostate. *LRP*, or laparoscopic radical prostatectomy, through *keyhole operations* and use of a *monitor*, removes the entire prostate. Medical professionals may also *monitor* PCa after treatment or the health of the prostate gland by regular PSA testing. *Join* is used mostly in the context of the *procedure* of a radical prostatectomy. A newer type of *keyhole* radical prostatectomy is a *robot* or *robotic* prostatectomy where the surgeon uses a machine to assist in removing the prostate. *Herbal* treatments included the Pfeiffer Protocol and (PC-) *SPES*, the latter previously available over the counter in the USA from 1996 but withdrawn in 2002 by the US Food and Drug Regulation Agency as samples contained warfarin. *Anaesthetic* was associated with various surgical treatments including prostatectomy, *brachytherapy* and cryotherapy. Though *procedure* was used predominantly regarding treatment procedures it also referred to appeal procedures for men unhappy with funding decisions around treatment. *Trial* was predominantly used in the context of trials of drugs or treatment with other instances referring mostly to various judicial trials. Figure 4.2 shows the 2000-2010 *brachytherapy* concordance:

Figure 4.2. 'Brachytherapy' concordance 2000-2010

N Concordance

1 home and searched the internet where he found out about brachytherapy. The treatment is widely used in America
2 have to fight for treatment once his clinicians have advised brachytherapy. What we need now is honesty in the
3 chemotherapy, radiotherapy, hormone therapy, and brachytherapy in implanting radioactive pellets to kill
4 is frozen; radiotherapy, which uses radiation X-rays; and brachytherapy, using radioactive seeds implanted in the
5 for him - a relatively modern procedure known as brachytherapy. This involves planting around 100
6 my PCT would need to approve the funding because brachytherapy is a more expensive procedure than slicing
7 is one of a growing number of men being treated by brachytherapy. Instead of radiation being applied by an
8 of daily doses of radiation; or something called brachytherapy, a procedure in which radioactive material
9 the cancerous cells. There is internal radiotherapy called brachytherapy, a relatively new treatment in which pellets
10 into the prostate. After consulting widely, Burton chose brachytherapy, which is suitable for men who have early
11 were malignant cells, and Professor Langley said he felt brachytherapy would be right for me. 'I had assumed
12 teased various facts out of my local trust. First, they figure brachytherapy costs approximately Pounds 1,300 more
13 1 per cent of men suffer incontinence problems following brachytherapy compared with 10 to 15 per cent after
14 of his prostate so he would be eligible as a 'guinea pig' for brachytherapy a treatment involving the implanting of
15 at the University Hospital of Wales, in Cardiff, to Leeds for brachytherapy - a form of radiation treatment. He said the
16 me. I asked my urologist if I would have been suitable for brachytherapy, a form of treatment that involves implanting
17 . Meanwhile, I understand that four new applications for brachytherapy funding for local men have been submitted
18 , one of many thousands of frightened men fighting for brachytherapy funding. So while she begins a slow
19 prostate so that he would be eligible as a guinea pig for brachytherapy in a treatment now being offered in Scotland
20 seeking legal advice. But without the means to pay for brachytherapy privately - it costs pounds 12,000 - Mr
21 , 54, is not an exceptional case to receive NHS funding for brachytherapy treatment in England. The
22 told me there was no need to panic. So I said I'd opt for brachytherapy when my work commitments had finished a
23 NHS services for Welsh patients, said it would now fund brachytherapy in England for 56 prostate cancer patients
24 to The Observer that it had a blanket ban on funding brachytherapy, and said that it had always looked at it on
25 grounds but simply because they were no longer funding brachytherapy. I am stunned. So what exactly, I ask, am I
26 National Institute for Health and Clinical Excellence gave brachytherapy its approval in 2005. The funding for it,
27 it was originally Wales alone which refused to give brachytherapy, it is now hearing of cases in Nottingham
28 it will pay for some men with prostate cancer to have brachytherapy in England. Mr Powell, a contracts manager
29 Wales had stopped paying for any patients to have brachytherapy in England. Last week the government body
30 have the courtesy to write to me about why I couldn't have brachytherapy. They told me later that they never deal
31 ensures their most effective distribution. Patients having brachytherapy are treated as day cases, despite
32 such as radiotherapy, radioactive seed implants (brachytherapy), high-intensity focused ultrasound (HIFU)
33 , or surgery which can lead to incontinence or impotence. "Brachytherapy has a lot to commend it," Steel says.
34 was going to New York a few days later to qualify in brachytherapy. If I waited for his return he would carry it
35 for cancer, and that Langley himself is an expert in brachytherapy it was surprising, to say the least.' What
36 . Why, then, am I having to fight tooth and nail for it? Brachytherapy is a treatment first developed 20 years ago,
37 . He saw a radiation oncologist privately. She mentioned brachytherapy, a specialised form of internal radiotherapy.
38 me that Guildford & Waverley PCT had rejected my brachytherapy funding. He reiterated that I could now
39 is still where we want it to be and we set a date for my brachytherapy, October 18. The seeds have to be ordered
40 sessions and is very weak. I start on stage one of my brachytherapy. While I'm under a general anaesthetic, the
41 Langley who performed the biopsy. He tells me I need brachytherapy - an alternative to surgery where radioactive
42 PCT which initially said it would not pay for a course of brachytherapy. The treatment, which involves planting tiny
43 may be external beam radiotherapy and a higher dose of brachytherapy. The National Institute for Health and
44 work within a week. There are now eight centres offering brachytherapy in the UK and another six will soon open.
45 , according to Health Commission Wales' draft policy on brachytherapy, I meet all the clinical criteria for this
46 brachytherapy in the UK and another six will soon open. Brachytherapy is recommended only if the cancer is at an
47 radical surgery, conformal external beam radiotherapy or brachytherapy, the insertion of tiny radioactive seeds into
48 , there is no cure. All treatments, whether radiotherapy or brachytherapy - when little radioactive seeds are put in the
49 chemotherapy; radiotherapy; hormone therapy; or brachytherapy, which involves having radioactive pellets
50 He was given the option of surgery to remove the prostate, brachytherapy -- a form of radiotherapy where radioactive
51 had a policy of not funding the treatment. Given that brachytherapy costs just £ 2,000 more than the radical
52 X-rays. In his opinion, the radiation that was a part of the brachytherapy had not only zapped my prostate, it had
53 that if he paid £ 11,000 and went private he could have the brachytherapy tomorrow. 'It's a two-tier service we have
54 was quite knocked back when he was unable to have the brachytherapy treatment," she says. "But we've been very
55 . "Two consultants have told me that I should have this brachytherapy treatment but someone pushing a pen
56 , I meet all the clinical criteria for this treatment. Brachytherapy involves the insertion of radioactive iodine
57 slightly by the prospect of a revolutionary new treatment. Brachytherapy, suitable for early stage prostate cancer,
58 all the cancer would be eradicated. The other option was brachytherapy, which involved having radioactive pellets
59 unacceptable that any man with prostate cancer for whom brachytherapy treatment is recommended, should be
60 give external radiation as data shows combining this with brachytherapy is more successful than using seeds alone.

The most significant *brachytherapy* collocates in Figure 4.2 was 'radioactive', describing the type of treatment that is *brachytherapy*. Its next most significant collocate was 'funding': *brachytherapy* was a treatment that "many thousands of men [were] fighting for" (line 18), the funding for which was likely to be "rejected" (line 38) because of "a blanket ban on funding" (line 24). Looking through Figure 4.2 revealed almost half of the concordance lines were in a context suggesting that funding for PCa was problematic. Though Bill Elliot and his wife Val were diagnosed with PCa and breast cancer respectively within an hour of each other, the stories they had to tell were very different (See Appendix 15: The Observer, 09/07/2006 for full narrative):

Extract 4.7

1 For [Val's] husband, the story is different. Still working as The Observer's golfing
2 correspondent, [Bill] has been turned down on cost grounds for the treatment
3 which his consultant, Professor Stephen Langley, recommended for him - a
4 relatively modern procedure known as brachytherapy. This involves planting
5 around 100 radioactive seeds, about the size of rice grains, within the prostate
6 gland in order to kill off the cancer through radiation. The alternative is to have
7 a radical prostatectomy, the surgical removal of the prostate which has a
8 higher risk of two major side effects - impotence and incontinence. 'I had been
9 having tests for the last three years, just to make sure there was no risk,' Bill
10 said. 'I'd been having the usual warning signs, such as getting up a lot in the
11 night to have a pee. Although my PSA [prostate-specific antigen] count was
12 relatively low, I had a biopsy which showed that there were malignant cells,
13 and Professor Langley said he felt brachytherapy would be right for me. 'I had
14 assumed everything would be fine, until the professor received a letter from
15 the Primary Care Trust, saying they had turned down the request for the
16 procedure. Given that Guildford is the major centre of excellence for cancer,
17 and that Langley himself is an expert in brachytherapy it was surprising, to say
18 the least. What angers Bill so much is that the PCT has refused to explain its
19 decision for the rationing. 'They didn't even have the courtesy to write to me
20 about why I couldn't have brachytherapy. They told me later that they never
21 deal directly with patients. Why not? Is that because they want to remain
22 unaccountable?' The Prostate Cancer Charity is worried that covert rationing of
23 treatment is starting to spread. Although it was originally Wales alone which
24 refused to give brachytherapy, it is now hearing of cases in Nottingham and
25 Bath. The charity's chief executive, John Neate, said: 'It is a disgrace and
26 completely unacceptable that any man with prostate cancer for whom
27 brachytherapy treatment is recommended, should be denied access to it.
28 (Observer, 09/07/2006)

There are several notable narrative elements in Extract 4.7. Lines 8-14 demonstrate Bill's pursuit of a virtuous self in a moral narrative (Bury, 2001) in endeavouring to lessen his perceived risk of PCa by having regular [PSA] tests; paying attention to what

he perceived to be symptoms of PCa; having a biopsy even though his PSA count was low; and trusting his consultant on treatment advice. In addition to this justification of his actions, his implicit blaming of the “unaccountable” (line 22) PCT for putting him at higher risk of impotence and incontinence also fits the form of a moral narrative (Bury, 2001). The metaphor “starting to spread” (line 23) bears similarities to that of “epidemic” used by journalists writing about PCa in 1990-2000. Here it refers to the “covert rationing of treatment” (lines 22-23), originally in Wales but now spreading to other PCTs. The idea that MWPCa should not be “denied access to” (line 27) treatment which has been recommended to them was common throughout the *brachytherapy* concordance. That this was a “disgrace and completely unacceptable” (lines 25-26) was also similar to the ‘derisory’ and ‘scandalous’ words used by journalists to tell a story of neglect around PCa in 1990-2000. This then suggests that the story of neglect told by journalists when writing about the illness experience of MWPCa in 1990-2000 shifted to other tales of injustice around treatment in 2000-2010. In addition to some of the narrative elements shown in Extract 4.7, Extract 4.8 shows that a MWPCa was given a family-based identity:

Extract 4.8

A grandfather has been refused funding for a new prostate cancer treatment for a second time - just a week after other patients were told they could have it. A special panel has ruled that David Powell, 54, is not an exceptional case to receive NHS funding for brachytherapy treatment in England. The grandfather-of-four has accused Health Commission Wales of infringing his human rights by denying him the treatment and is now seeking legal advice. But without the means to pay for brachytherapy privately - it costs pounds 12,000 - Mr Powell could have to undergo a different form of treatment with more side effects - or even surgery. (Mirror, 19/06/2006)

The family-based identity of ‘grandfather-of-four’ attributed to David Powell, a MWPCa, bears similarities to the identities of wives and mothers given to breast cancer sufferers in the US in the 1980s (Kolker, 2004). This helped to move breast cancer from that which not only threatened women but also American families with the result that ‘the pool of victims impacted by the disease expanded significantly to include the entire family’ (Kolker 2004: 831)—something also potentially the case for MWPCa.

Bill’s narrative in Extract 4.7 (line 8) demonstrates that at least one reason why men fought for brachytherapy was to lessen their risks of incontinence and impotence.

This concern was also demonstrated in the analysis of the ‘*Treatment side-effects*’ keywords. The exclusive context of all instances of the keyword *nerves* relating to side-effects was concerned with the risk of damage from keyhole robot or laparoscopic radical prostatectomy to the nerves responsible for continence and sexual function:

Extract 4.9

Mr Gillatt said the prostate was in a tricky location and he would try not to damage the nerves surrounding it which govern sexual function. But at that stage, whether or not I'd ever perform sexually again seemed irrelevant. I went in for my prostatectomy on May 3. I was the youngest man on the ward by 15 years (Daily Mail, 24/09/2002)

The relevant instances of *wear* showed that it predominantly referred to concerns around incontinence and impotence: “I was also left incontinent and had to wear pads for three years” (Daily Mail, 01/11/2005) and “That removed most of the cancer, but it damaged my ability to stay sexually aroused. I prayed it was just a temporary effect, that it would eventually wear off and everything would be normal” (Daily Mail, 06/11/2001). Though *love* was mainly used in a context of family love and support and Lloyd Webber’s production ‘Love Never Dies’, it was also used around ‘making love’ or one’s love-life. Although *Zoladex* and *Casodex*, trade names for Goserelin and Bicalutamide respectively, are types of hormone therapy acting on testosterone levels, their concordance (Figure 4.3) shows they were used in relation to their side-effects:

Figure 4.3. ‘Zoladex/Casodex’ concordance 2000-2010

N Concordance
 1 the prostate gland. His doctors prescribed radiotherapy and Zoladex (the brand name for the drug Goserelin) which inhibits
 2 or problems with attention and memory as side effects. But Zoladex works by reducing testosterone in the body to levels
 3 Breakfast chef in the early Eighties, was given a drug called Zoladex, which inhibits the production of the hormone
 4 Nigel would try radiotherapy plus a hormonal drug called Casodex, which reduces the production of testosterone but
 5 a suspected high incidence of cases of depression concerning Zoladex have been reported to the Medicines and Healthcare
 6 to me. Scans showed I was clear of cancer and he confirmed Casodex was probably to blame. The best treatment for such
 7 taken seriously, but in a written response his urologist denied Zoladex produces depression. And although a suspected high
 8 if the disease is caught early. The treatment was the drug Casodex and two months' radiotherapy. Casodex blocks the
 9 oncologist Robert Laing puts me on the hormone drug Casodex. This is an anti-androgen that blocks the effects of
 10 treatment would reduce my libido and give me hot flushes.' Zoladex was administered to Glynn by two injections. A few
 11 playground.. leuteinising hormone in the brain's pituitary gland. Zoladex stops the production of leuteinising h o r m o n e and
 12 . This was followed by another six- month course of Zoladex injections. Graham finished his treatment in November
 13 are treated by hormones alone. He was put on a course of Casodex, which prevents testosterone getting to the tumour
 14 almost immediately. First there was a 30-day course of Casodex, a pill which blocks the action of testosterone and
 15 at Ashford Hospital, Middlesex, and had monthly injections of Zoladex, a hormone therapy, to reduce the size of the tumour.
 16 to play an important role - and then I started an injection of Zoladex, which stops the production of testosterone and was
 17 being given a plan to tackle this thing.' Graham was started on Zoladex, a hormone which stops the body producing
 18 survival.' Before Nigel started radiotherapy, he was put on Casodex for two months. 'It had a dramatic effect. My PSA
 19 , once the wound has healed. Even if John has to go back on Casodex, his breasts will not regrow; the mastectomy should
 20 was the drug Casodex and two months' radiotherapy. Casodex blocks the male hormone testosterone, which feeds
 21 take the first treatment offered to me.' Nigel says that taking Casodex has allowed him to get on with his life, but admits
 22 be delayed and I will need to take drugs to try to reduce it. The Casodex drug makes me feel as though I am jetlagged. It
 23 drug began to wear off, so last November he was switched to Zoladex, which is administered by six-monthly injection. This
 24 , Maxton was prescribed a hormone-injection treatment - Zoladex - for three months. Prostate cancer feeds off the
 25 first consultant I saw believed it was cancer and wanted to use Zoladex, a drug that blocks production of testosterone (which
 26 about castration causing symptoms of depression and, with Zoladex being a chemical form of this, I felt sure there was a

The predominant story around *Zoladex/Casodex* (Figure 4.3) was regarding the mostly debilitating side-effects. These included depression, impotence, lack of libido, lack of confidence, tiredness, breast enlargement, pain and tenderness, hot flushes, and weight gain. Many of these were experienced by Glynn Christian, a celebrity chef with PCa who, because of hormonal treatment for PCa, became “like a menopausal woman” (Daily Mail, 24/02/2009):

Extract 4.10

WHEN TV chef Glynn Christian began to suffer from debilitating depression and co-ordination difficulties, his doctors could provide no explanation. Unable to work, drive or shop, he faced a frustrating battle to discover the cause of his symptoms. Only after five years of suffering did he work out what was wrong -- the depression was a side effect of [Zoladex] treatment he had received for prostate cancer. (...) 'I had read about castration causing symptoms of depression and, with Zoladex being a chemical form of this, I felt sure there was a connection. I told my doctors, but they sent me to a psychiatrist.' This treatment failed to help Glynn. He stopped working and lived on his savings and credit card. Eventually, his psychiatrist agreed that it might be worth finding out if the hormone treatment was partly responsible. She referred him to an endocrinologist, who recommended hormone replacement therapy. As soon as he started this, Glynn's libido returned, his depression eased and his memory improved (...) I really do feel I should have been warned (Daily Mail, 24/02/2009)

Though Glynn began his narrative with a tragic genre of suffering regarding the debilitating side-effects of Zoladex, he proceeded to tell about his triumph over the adversity, not only of PCa but also of its side effects. His felt injustice was that he ought to have been warned of these unwanted side-effects—perhaps he would not had chosen Zoladex as treatment. The desire to avoid impotence and incontinence was demonstrated even in the one article which described how Casodex preserved one man's sex life. After treatment with Casodex and radiotherapy, Nigel said:

Extract 4.11

'Although I'm divorced with two grownup sons, I wasn't prepared to trade in my sex life just yet. Men who have surgical or chemical castration are more likely to survive longer, but you have to weigh up quality-of-life issues. (...) One of the things that tipped me away from castration was an article in the British Medical Journal, where patients were surveyed and said they would prefer quality-of-life over increased survival. (...) I still hope to meet someone again. Impotence is not something most men could cope with. I know from my experience as a surgeon that patients want to find out about their treatment, and to have a say in what is decided. I'm so glad I didn't take the first

treatment offered to me.' Nigel says that taking Casodex has allowed him to get on with his life, but admits there are some side effects. 'It leaves you incredibly tired, and causes male breast enlargement. But I'm still prepared to live with these side-effects rather than have my sex life taken away,' he says (Daily Mail, 30/11/2004)

Unlike Glynn, Nigel's narrative did not start by drawing upon a tragic genre for his own suffering and moving to a romantic one of overcoming adversity. Nigel did though indicate competing versions of tragic genres—potential early death versus living with impotence—and corresponding competing romantic genres—longer survival versus a good quality, though potentially short, life. His choice of romantic optimistic genre, like Bill's (Extract 4.7) and Glynn's (Extract 4.10), was that which allowed him to overcome the threat to his valued sex life. Mens' narratives also demonstrated triumph over the threat of incontinence and impotence in other ways. The predominant context of *testicles* was regarding hormone treatment for PCa with most referring to side-effects:

Extract 4.12

My testicles also appeared to be shrinking, and I didn't have to shave every day. But it wasn't all bad, I joked, there were definite pluses to getting in touch with the kinder, more feminine me (Daily Mail, 20/12/2005).

Extract 4.12 shows how a MWPCa used a comic genre (Bury, 2001) to mock both himself (Kelly and Dickinson, 1997) and hegemonic masculinity (Courtenay, 2009) in a way which potentially created social distance from the suffering of these side-effects (Kelly and Dickinson, 1997: 270). Hilton (Extract 4.13) drew upon a variety of pre-patterned ways of talking (Tannen, 2007), or narrative genres (Bury, 2001), to tell his story of PCa:

Extract 4.13

1 "I was booked in for the treatment at the Royal Marsden in Surrey when they
2 asked me if I would like to go on their active surveillance programme. The
3 cancer was very small and they said that if at any time it showed signs of
4 growing or spreading they would operate". Now Hilton has a PSA test every
5 three or four months and a biopsy every two years. So far there is no sign that
6 the cancer is growing - so he has escaped potentially damaging treatment. "I
7 reckon I am going to die with the cancer, not of it. There are men who have
8 been treated because of the [PSA] test and are impotent and incontinent. It is a
9 fact that the cure is worse than the disease". He is appalled by the damage that
10 has been done by over-treatment. "If you were given the option of living with

11 cancer or having your sex life removed and being given a nappy to wear, which
12 would you choose?" Many men would be appalled by the idea of living with a
13 cancer inside them, but he is unworried by it. "I feel like a fraud. I go to the
14 Royal Marsden for my check-ups and there are people undergoing
15 chemotherapy who have lost their hair and have yellow, waxy skin, and I think I
16 shouldn't be saying I have the same disease as these people". His experience
17 illustrates the unique feature of prostate cancer: it is curable but may not need
18 treatment. In many men it is slow-growing - so slow that they can live with it
19 and die of something else. (The Independent, 20/09/2004)

There are several notable elements in Hilton's narrative. He used emotive words similar to those used by journalists writing in 1990-2000 to describe the injustice of neglect of PCa: this time though it was regarding injustice around the *appalling* damage of overtreatment (lines 9-10). This tragic genre of unjust suffering (Smith, 2005) was though also juxtaposed with another ostensibly tragic genre: the "appalling" (line 12) idea of living with a cancer inside you. Dying *with* PCa and not *of* it (line 7, 18-19) is known in at least the academic literature (Neal and Donovan, 1998); likewise for the idea that the cure of PCa with its risks of incontinence and impotence may be worse than the disease (lines 9-12) (Parker, 2004). Finally, Hilton contrasted what he saw as his fraudulent identity as a person with cancer with those who were really sick, at least as a result of their treatment for the same disease he had.

Of the 'Treatment side-effects' keywords in 1990-2000, sexuality was used mostly in the context of regaining potency: "At first my check-ups were every three months, but now it's every six. My PSA level is below normal and my sexuality has returned" (Daily Mail, 12/05/1998). The predominant context of *greater* was regarding treatment, and most of these referred to recovery from side-effects such as the 'greater chances of regaining potency'. Likewise, the almost exclusive context of *risks* in 1990-2000 was regarding the risks of incontinence and impotence from a prostatectomy. Thus, the keywords around 'Treatment side-effects' in 1990-2000—though much fewer than in 2000-2010—also indicated men's concern around impotence and incontinence.

Of the 'Treatment policy and insurance' keywords in 2000-2010 all but one instance of *cover* referred to insurance and this was almost exclusively used alongside *policy*. The predominant context of *policy* was insurance *cover* for illness. This was followed by a treatment policy context, many of which were regarding problematic funding of brachytherapy and cryotherapy, one regarding a policy of 'watchful waiting'

and one regarding the lack of a national screening policy for PCa. In all but one instance *PCT* referred to a MWPCa battling for funding for brachytherapy in a series of articles in *The Observer* (for an example see Extract 4.7), with the remaining instance referring to the refusal of Bolton PCT to fund cryotherapy.

In sum, keywords around treatment for PCa were more evident in 2000-2010 than in 1990-2000. These mostly represented new forms of treatments and procedures available in 2000-2010 such as brachytherapy, Zoladex and Casodex hormone treatment, laparoscopic or robotic radical prostatectomy, herbal remedies and trials for new drugs. The “disgraceful” and “unacceptable” injustice around funding for brachytherapy and attention to NICE and PCT policies were of concern in 2000-2010. In addition, and in contrast to 1990-2000 where journalistic concern was mainly for the risks of impotence and incontinence post-prostatectomy, concern in 2000-2010 also centred on the “debilitating” and feminising side-effects of hormone treatment. There was also attention to the problems caused for insurance companies given the increasing numbers of MWPCa being diagnosed early and cured. Thus, the ‘aerial view’ from the CKWIC analysis showed a narrative around PCa which was statistically more frequent in 2000-2010 than 1990-2000—PCa was an illness for which there was injustice around funding for treatment and concern over debilitating side-effects. So far then, the CKWIC analysis has indicated a shift from the injustice around the funding neglect of PCa in 1990-2000 to injustice around treatment in 2000-2010.

4.4 A story of ‘taboo’ around PCa

Row 2, column 1 in Table 4.2 shows three categories of ‘Awareness’ keywords: ‘*Being reluctant to talk*’ (*taboo, quiet*); ‘*Raising awareness*’ (*Mail, raise, Mail’s*); and ‘*Knowing about the prostate and prostate cancer*’ (*studying, prostatic, shaped, BPH [benign prostatic hyperplasia], tumour, surrounds, analysed, doughnut, slower, upper, enlarge, killer, develops, disease, capsule, hyperplasia, cancer, idea*). There were four ‘Awareness’ keywords in 2000-2010: ‘*Being reluctant to talk*’ (*reasons*) and ‘*Raising awareness*’ (*radio, launch, and diary*). The raw and relative frequencies of these keywords are summarised in Table 4.6 and Table 4.7:

Table 4.6 Awareness Keywords 1990-2000

'Being reluctant to talk'					
1990-2000 Key word	1990-2000 Raw Freq.	1990-2000 Freq/100,000	2000-2010 Raw Freq.	2000-2010 Freq/100,000	P
TABOO	6	14.5	0	0.0	8.76E-05
QUIET	8	19.3	2	1.9	0.00059
'Raising awareness'					
1990-2000 Key word	1990-2000 Raw Freq.	1990-2000 Freq/100,000	2000-2010 Raw Freq.	2000-2010 Freq/100,000	P
MAIL*	18	43.4	13	12.0	0.00042
RAISE*	16	38.6	13	12.0	0.00196
MAIL'S*	5	12.1	1	0.9	0.00451
'Knowing about the prostate and prostate cancer'					
1990-2000 Key word	1990-2000 Raw Freq.	1990-2000 Freq/100,000	2000-2010 Raw Freq.	2000-2010 Freq/100,000	P
STUDYING	9	21.2	0	0.0	1.55E-06
PROSTATIC	14	33.7	3	2.8	2.71E-06
SHAPED	11	26.5	1	0.9	2.76E-06
BPH	12	28.9	2	1.8	5.68E-06
TUMOUR	44	106.1	47	43.5	3.13E-05
SURROUNDS	9	21.2	1	0.9	3.31E-05
ANALYSED	5	12.1	0	0.0	0.00034
DOUGHNUT	5	12.1	0	0.0	0.00034
SLOWER	5	12.1	0	0.0	0.00034
UPPER	9	21.2	3	2.8	0.00068
ENLARGE	7	16.9	2	1.8	0.00182
KILLER	16	38.6	13	12.0	0.00196
DEVELOPS	8	19.3	3	2.8	0.00197
DISEASE	95	229.0	165	152.6	0.00204
CAPSULE	5	12.1	1	0.9	0.00451
HYPERPLASIA	7	16.9	3	2.8	0.00557
CANCER	567	1366.7	1288	1191.4	0.00678
IDEA	16	38.6	15	13.9	0.00511
*‘split’ keyword					

Table 4.7 Awareness Keywords 2000-2010

'Being reluctant to talk'					
2000-2010 Keyword	1990-2000 Raw Freq.	1990-2000 Freq/100,000	2000-2010 Raw Freq.	2000-2010 Freq/100,000	P
REASONS	0	0.0	14	13.0	0.00256
'Raising awareness'					
2000-2010 Keyword	1990-2000 Raw Freq.	1990-2000 Freq/100,000	2000-2010 Raw Freq.	2000-2010 Freq/100,000	P
RADIO	0	0.0	16	14.8	0.00126
LAUNCH*	0	0.0	15	13.9	0.00180
DIARY	0	0.0	11	10.2	0.007
*‘split’ keyword					

The combined *taboo* and *quiet* concordance (Figure 4.4) demonstrates that all instances of *taboo* and most of *quiet* were in a context indicating that keeping one’s experience of PCa “quiet” and PCa as a condition which “no one dares talk about” (line

14) was more common in 1990-2000 than 2000-2010. There were no instances of *taboo* and only two of *quiet* in 2000-2010:

Figure 4.4. 'Taboo' and 'quiet' concordance 1990-2000

N Concordance

1 , and that made me feel more positive. But a quiet moment in the house would always bring
2 my cancer. My initial impulse was to keep it as quiet as possible. I felt that it was no one's
3 of death cross my mind. I kept the condition quiet from everyone else, including my three
4 and said: 'You'd better come into my office, it's quiet in there.' We exchanged glances and
5 checked out. And it could save their life. I kept quiet about my cancer for almost a year before
6 his money on the one condition that they kept quiet about the name of their benefactor. The
7 treatment and, right, gives the lowdown on the quiet killer IF ANYONE can bring glamour to the
8 the panto season. At the time I kept it very quiet and didn't want the Press or the showbiz
9 . For too long prostate cancer has been a taboo. It has been ignored by politicians and
10 prostate cancer is that for many it remains a taboo subject. Medical sociologist Clare
11 then will we stop making prostate cancer a taboo subject. HOW TO SPOT THE DANGER
12 in its most treatable form, still carries a heavy taboo among American voters, and with no
13 isolating silence of his own fears, or break the taboo and talk. Boldy, he chose the latter.
14 MONEY AND AWARENESS FOR THE TABOO DISEASE THAT NO ONE DARES

The Oxford English Dictionary defines taboo as 'a social or religious custom prohibiting or forbidding discussion of a particular practice (...) or thing'. As such, articulating PCa as a taboo suggests that blame for men's reluctance to talk was attributed to a society which prohibits them from doing so and which the society has an obligation to address. There was knowledge around PCa, but such was this knowledge that it both constructed "isolating silence" (line 13 Figure 4.4,) for men and also the illness as taboo for society:

Extract 4.14

For too long prostate cancer has been a taboo. It has been ignored by politicians and greeted by too many people with giggles, embarrassment or a shocked silence. Too many men are reluctant to admit there could be anything wrong and don't bother going to the doctor for checks. It's also a disease every woman who loves a man must address. Indeed, the scale of this 'forgotten disease' was revealed yesterday as Government figures showed a huge rise in cases during the past decade. The only good news was a slight fall in death rates due to early diagnosis. This message reinforces the Mail's campaign to raise money for the Prostate Cancer Charity, Britain's only group dedicated to raising public awareness and encouraging research. (Daily Mail, 03/11/1999)

Extract 4.15

It's always struck me how different men are to women. For men, it's all about upholding this tough, macho image, regardless of the consequences. But women are far more aware of potential problems. With the Mail promoting the issues, maybe the Government and medical profession will follow suit. Only then will we stop making prostate cancer a taboo subject. (Daily Mail, 11/11/1999)

Men's culpability in making PCa a taboo subject was demonstrated in their drawing upon hegemonic masculinity discourse (Courtenay, 2009) in their seeking to uphold a macho image and reluctance to seek help on health issues. Other actants though were also identified as both responsible for the construction of PCa as a taboo and as agents in its solution. These included "politicians"; the "too many people"; the "every woman who loves a man"; the "Government"; "the Mail's campaign"; "the Prostate Cancer Charity"; the "medical profession"; and the "we" who made PCa a taboo subject. As raising *money* was articulated as a solution to the problem of the funding neglect of PCa, so raising *awareness* was articulated as a solution to the problem of prostate cancer as a taboo.

There was one '*Being reluctant to talk*' keyword in 2000-2010. In most instances *reasons* is used by George Carman, a celebrity MWPC, who announced his retirement:

Extract 4.16

saying he needed treatment for a "little local difficulty" but did not expand on the description until yesterday. "On reflection, I feel it important to say, to dispel rumour, and for other reasons, that in fact I have suffered from prostate cancer for over three years". (Times; Guardian; and Daily Mail all 04/09/2000)

A further two instances of *reasons* indicated that the *reasons* why PCa did not have a high profile was at least because men found it difficult to talk about PCa: "it's difficult for men to deal with strong emotions. This is one of the reasons why prostate cancer has not had a high profile, because men have found it difficult to talk" (Independent on Sunday, 10/09/2005). One instance of *score* also indicated this difficulty in talking: "Ladies easily discuss breast cancer, but you don't see a gathering of men in a pub talking about their prostates. They are talking about the latest page three girls or the cricket score because they think that any problem "down there," as they'd put it, is a nonmacho situation (Daily Mail, 27/07/2002). This use of *reasons* and *sport* somewhat

indicated that PCa and its treatment was that which men might prefer to keep quiet about.

Mail*, raise* and Mail's*, split keywords discussed earlier, were also categorised as 'awareness' due to their meaning around '*Raising awareness*'. There were three such keywords (*radio launch**, and *diary*) in 2000-2010. *Radio* was used in seven of its 14 relevant instances to describe how this medium was used to inform others both about new treatments for the disease and of the necessity to get checked out. Though *launch* was a split keyword and used mainly to describe launching a show or a book in the context of employment of MWPCa, it was also used regarding the launch of awareness campaigns. *Diary*, in most of its instances, referred to Andy Ripley, a celebrity sportsman with PCa, who wrote a diary about his battle against PCa which was later published by The Prostate Cancer Charity in line with Ripley's wishes to "get one more man to go and get checked out" (Independent on Sunday, 25/11/2007).

Most instances of the keyword *idea* in 1990-2000 were around men having "no" or "little" idea regarding the prostate or PCa. Apart from *idea*, many of the '*Knowing about the prostate and prostate cancer*' keywords were likely keywords because of their use in the boilerplate (Cotter, 2010): 'Your guide to the prostate' (Extract 4.17):

Extract 4.17

*WHAT is the prostate? A doughnut-shaped gland the size of a walnut that surrounds the upper part of the urethra - the tube that carries urine from the bladder to the penis. When cells in the gland grow, a tumour develops. Cancer cells then spread to other parts of the body. * WHEN does it occur? With age, it is normal for the prostate to enlarge. This condition is Benign Prostatic Hyperplasia (BPH) and can occur in men as young as 30. BPH can be easily treated. * WHAT is prostate cancer? There are two types - an aggressive form and a slower one. Pathologists determine the type by studying the cells. * WHAT are the symptoms? You need to urinate frequently. The urine stream is poor. You have lower back pain. There is blood in your urine. * HOW is it diagnosed? There are four types of test. Digital Rectal Examination: A doctor feels the prostate and identifies an enlargement. Prostate Specific Antigen (PSA) test: A blood test that measures levels of a protein called PSA. Transrectal ultrasound: A probe is placed in the rectum and pictures are taken of the prostate. Biopsy: A sample of prostate tissue can be analysed to see how aggressive the cancer is. * WILL you get it? The odds escalate with age: 70 pc of men in their 70s will have it, rising to 80 pc in their 80s. *WHAT are survival rates? Within five years of being diagnosed, the survival rate in Britain is less than 50 pc. (for example, Daily Mail, 10/11/1999)

BPH, surrounds, doughnut, studying, analysed, slower, upper, enlarge, develops and *hyperplasia* are used in this boilerplate either exclusively or almost so; *tumour, disease, prostatic, and shaped* less so. *Develops* was used almost exclusively with *tumour*, and *tumour* principally around the presence or aggressiveness of the tumour or what was happening to the tumour post-treatment. *Killer* did not appear in any boilerplate and was used almost three times as often in 1990-2000 as 2000-2010. All 1990-2000 instances referred to the ‘killer disease’ of PCa and five also referred to it as a silent or quiet killer or that which was ignored or neglected. This boilerplate (Extract 4.17) was used in seven Daily Mail articles over two weeks in November 1999 during the launch of its campaign to raise money and awareness. Like the boilerplate in Extract 4.1, it was often inserted before or after the narrative of a MWPCa and articulated biomedical information about PCa in a way to construct men’s awareness of this condition and so fulfil the awareness aims of the Daily Mail’s campaign.

In sum, PCa as a “taboo” disease that “no one dares talk about” and about which men kept quiet was more explicitly and frequently articulated in 1990-2000 than 2000-2010. PCa was allowed to be a taboo by society in that “it has been ignored by politicians and greeted by too many people with giggles, embarrassment or a shocked silence.” Though there were no instances of ‘taboo’ in 2000-2010, the limited use of the keyword *reasons* by journalists in 2000-2010 indicated that PCa remained somewhat difficult to talk about. In 1990-2000, raising awareness was proposed as a solution to PCa as a taboo with particular actants identified both as culpable for this problem and also as those who must act to change it including “every woman who loves a man” and the “we [who] will stop making prostate cancer a taboo subject”. Additionally, MWPCa in 1990-2000 were more frequently described as having ‘no idea’ about the prostate and PCa than in 2000-2010. Increasing awareness of PCa was still of concern in 2000-2010, with awareness-raising media such as radio and diaries used to inform men and urge them to get themselves checked.

4.5 Stories of symptoms and risks

Row 3, Table 4.2 shows two categories of keywords more frequent in 1990-2000 than in 2000-2010: ‘Risks’ (including age, nutrition and genetic risk); and ‘Symptoms’—there were no such keywords in 2000-2010. These keywords are summarised in Table 4.8:

Table 4.8 ‘Symptoms’ and ‘Risk’ Keywords 1990-2000

‘Symptoms’					
1990-2000 Key word	1990-2000 Raw Freq.	1990-2000 Freq/100,000	2000-2010 Raw Freq.	2000-2010 Freq/100,000	P
URINE	47	113.3	43	39.8	1.01E-06
SYMPTOMS	67	161.5	93	86.0	0.00013
WATER	14	33.7	8	7.4	0.00046
FREQUENTLY	11	26.5	7	6.5	0.00318
STREAM	10	24.1	6	5.6	0.00380
PASSING	13	31.3	10	9.3	0.00387
SIGNS	18	43.4	19	17.6	0.00711
ENLARGEMENT	10	24.1	7	6.5	0.00745
‘Age risk’					
ESCALATE	6	14.5	0	0.0	8.76E-05
OCCUR	13	31.3	7	6.5	0.00053
AGE	46	110.1	63	58.3	0.00121
YOUNG	22	53.0	23	21.3	0.00269
‘Genetic risk’					
GENETIC	9	21.2	2	1.9	0.00019
HISTORY	14	33.7	9	8.3	0.00093
LINK	6	14.5	2	1.9	0.00555
GENE	7	16.9	3	2.3	0.00557
‘Nutrition risk’					
VEGETABLES	8	19.3	0	0.0	5.91E-06
FRUIT	7	16.9	0	0.0	2.26E-05
ZINC	7	16.9	0	0.0	2.26E-05
FATS	5	12.1	0	0.0	0.00034
OIL	5	12.1	0	0.0	0.00034
TOFU	5	12.1	0	0.0	0.00034
EXPOSURE	5	12.1	0	0.0	0.00034
EAT	15	36.2	9	8.3	0.00039
VITAMIN	9	21.2	3	2.8	0.00068
DIET	14	33.7	10	9.3	0.00174
MEAT	9	21.2	5	4.6	0.00447
CHEMICALS	6	14.5	2	1.9	0.00555

Many of the ‘Symptoms’ keywords were used in the ‘Your guide to the prostate’ boilerplate (Extract 4.17) (21 instances of *urine*; seven each of *symptoms*, *frequently* and *stream*; five of *enlargement*; and four of *signs*). *Urine* was almost three times relatively more frequent in 1990-2000 than in 2000-2010. Overall, 36/47 raw instances of *urine* in 1990-2000 were in the context of symptoms of PCa; referring either to blood in urine or to lower urinary tract symptoms (LUTS). The remaining instances referred to urine tests or to some aspect of the prostate or organs around it. In addition, the almost exclusive use of the keywords *water* and *passing* were regarding some or other LUTS:

Extract 4.18

THE only clue that anything was wrong was that I noticed I was getting up once or twice during the night to pass water, which had never happened before. At first, I didn't take it seriously, because there was no pain and it wasn't difficult to urinate. I thought it was a minor bladder problem and put it to the back of my mind. But it didn't get any better, so I went to see my doctor. He told me he wanted to check my prostate and examined me. Although he could find nothing wrong, he referred me to a specialist for a PSA (Prostate Specific Antigen) reading. (Daily Mail, 03/11/1999)

Extract 4.19

After he had performed the [flu] inoculation, he said, matter-of-factly: 'How's the old water works?' 'Fine,' I lied, my hand on the door handle. 'Perhaps we'd better have a look anyway.' (Daily Mail, 12/01/1999)

Similarly, the exclusive use of *stream* and the almost exclusive use of *frequency* in 1990-2000 refer to LUTS. All instances of *enlargement* in 1990-2000 referred to prostate enlargement in the context of PCa. Five of these were in the 'Your guide to the prostate' boilerplate (Extract 4.17) and the remaining five were regarding the difficulty in distinguishing between malignant and benign prostate enlargement:

Extract 4.20

The symptoms of the benign enlargement of the prostate which is an inevitable part of ageing are well known; but these same symptoms, usually to a lesser extent, also cause suspicion of cancer of the prostate. (The Times, 09/10/1997)

All but two instances of *enlargement* in 2000-2010 also referred to this difficulty; with the remaining two instances instead referring to breast *enlargement* as a side-effect of Casodex. The keyword *signs* was used over twice as frequently in 1990-2000, predominantly as a semantic equivalent of symptoms. *Symptoms* was used by journalists almost twice as frequently in 1990-2000 than 2000-2010 and Figure 4.5 shows its 1990-2000 concordance:

Figure 4.5. 'Symptoms' concordance 1990-2000

N Concordance

1 attacks around one in ten men, mostly aged over 65. Symptoms include: difficulty with or delays in urinating;
 2 one close relative with prostate cancer at a young age Symptoms: (most of these symptoms are more likely
 3 at you is not unbearable." Know the enemy: site and symptoms: EACH YEAR 10,000 men die of prostate
 4 prostate cancer in men who have not developed any symptoms. But we still don't know whether offering
 5 other people with prostate cancer, I didn't display any symptoms,' he said. 'They discovered it only through
 6 And my advice is always, if you are worried or have any symptoms such as difficulty passing water, don't
 7 men. A simple blood test can detect it before it causes symptoms, but this is generally carried out only if
 8 prostate is an insidious disease; by the time it causes symptoms, which disturb the patient, there is a 50 per
 9 Michael Bentine discovered it. 'He'd had all the classic symptoms, but his GP here hadn't diagnosed anything.
 10 . Alternatively, they can wait and see if they develop symptoms and then opt for treatment at that stage.'
 11 . He was unusually unlucky because he had very few symptoms, and that his cancer was the 'tiger' kind
 12 was one of a tiny minority who only experience very few symptoms. He did go to the bathroom once a night,
 13 , do not have regular PSA blood tests should watch for symptoms that could foretell the need for urgent
 14 experiencing problems in my early forties. The initial symptoms were obvious - I had a frequent need to go to
 15 Dr Thomas Stuttard reports on prostate cancer: its symptoms, advances in treatment, and their success
 16 one in my case. For people with mild or moderate symptoms, there is only mild or moderate relief. Third,
 17 doctor. So I left it dangerously late before getting my symptoms checked out in the summer of 1997. I was in
 18 . How right she was. I went to my GP and explained my symptoms. Going to the lavatory was becoming really
 19 with the flow of urine. As soon as I had described my symptoms my GP sent me immediately to a specialist
 20 factors persuaded me against the operation. First, my symptoms were only moderate. I do not mind getting up
 21 worrying thing in my case is that I had absolutely no symptoms. A lot of men who get prostate cancer find
 22 blood was found in his urine; apart from this he had no symptoms and the bleeding would not have been
 23 banker Andrew, 63, from Kensington, London, had no symptoms. And his cancer, too, was detected at a
 24 to admit that I had a problem. Also, I had absolutely no symptoms at all, apart from impotence. 'When a
 25 in my left groin, but I couldn't feel anything. I'd had no symptoms but my daughter had wanted me to have the
 26 wives play in detecting the cancer is crucial. I had no symptoms, but I know that men often find themselves
 27 to 1983, is still astonished at the fact that he had no symptoms of the killer disease which claims more than
 28 the cancer in my prostate gland, but there were no symptoms to alert me. Now I'm paying a heavy price for
 29 for their book, Prostate Problems: The Facts. . Often no symptoms until the disease is advanced Problems with
 30 he would never have to worry about - he simply had no symptoms. Yet this insidious disease, which kills 11,
 31 , I'm not feeling very invincible. "I gather the normal symptoms are peeing too much - or getting up in the
 32 aches and pains in the bones and joints are the obvious symptoms. By this time treatment options have
 33 prostate cancer? If ever I have friends who complain of symptoms I tell them: 'For goodness sake get it
 34 . Neither my friend George nor I had much in the way of symptoms. Rectal examinations reveal only 40 per cent
 35 and my sexuality has returned. And I've had no other symptoms. I feel lucky. I'd recommend all men of my
 36 aspect of this cancer is that there are no real outward symptoms. I felt fine but I had no idea what was going
 37 is that he looked so well and there weren't any outward symptoms," she says. "Prostate cancer is a very slow
 38 inevitable part of ageing are well known; but these same symptoms, usually to a lesser extent, also cause
 39 had screened him earlier, because he was showing symptoms for three months before he finally got a
 40 screened for prostate cancer unless you have specific symptoms of the disease. This is because most
 41 putting on too much weight. He had none of the tell-tale symptoms of prostate cancer, including a frequent urge
 42 is also not without politically inconvenient long-term symptoms, though they may take longer to become
 43 nothing until there is evidence of spread. Thereafter the symptoms can be dealt with as they arise. The Institute
 44 was Dementia Care because dementia was one of the symptoms developed by his wife Elsie. She had
 45 : 25 per cent in one study. So if you suffer from the symptoms (less powerful flow, more frequent urination,
 46 have expected to live for another 15 or 20 years. The symptoms of the benign enlargement of the prostate
 47 and make them go to the doctor.' WHAT ARE THE SYMPTOMS? THE prostate is a male sex gland about
 48 Richard Bentine says: 'I want people to know about the symptoms, to know that there is a test which costs
 49 until the spread of the disease had made the symptoms unmistakable. Once the cancer has
 50 likely to get, including prostate. I asked her what the symptoms were. She listed about five, such as having
 51 by the year 2018. Very few men are aware of the symptoms, which can include impotency, difficulty in
 52 as 30. BPH can be easily treated. * WHAT are the symptoms? You need to urinate frequently. The urine
 53 the type by studying the cells. * WHAT ARE THE SYMPTOMS? You need to urinate frequently. The urine
 54 as 30. BPH can be easily treated. * WHAT are the symptoms? You need to urinate frequently. The urine
 55 the type by studying the cells. * WHAT ARE THE SYMPTOMS? You need to urinate frequently. The urine
 56 the type by studying the cells. * WHAT are the symptoms? You need to urinate frequently. The urine
 57 the type by studying the cells. * WHAT ARE THE SYMPTOMS? You need to urinate frequently. The urine
 58 the type by studying the cells. * WHAT are the symptoms? You need to urinate frequently. The urine
 59 cancer at a young age Symptoms: (most of these symptoms are more likely to be due to benign disease)
 60 on the way to the loo. Patients who wait for these symptoms before they have a PSA test (see left) may
 61 Research says it is vital that a man with any of these symptoms sees a doctor as soon as possible. Leaflets
 62 is advanced Problems with passing urine (similar to symptoms from a non- cancerous enlargement of the
 63 of cancer of the prostate. When discussing urinary tract symptoms doctors always ask their patients three
 64 it because he felt so fit and had no urinary tract symptoms. Only when the diagnosis had been
 65 was growing silently inside me. If I had waited until symptoms developed it could have been too late. I
 66 , the enlarged prostate often causes abnormal urinary symptoms, which men are embarrassed about and
 67 been diagnosed early, because I had none of the usual symptoms of prostate trouble - I didn't keep getting up

The most frequent collocate one place left of *symptoms* is 'the', followed by 'no' and then 'my'. Lines 52-58 of Figure 4.5 show that seven of 'the' form part of the 'Your guide to the prostate' boilerplate (Extract 4.17) and indicate that the "need to urinate frequently" is a symptom of PCa. Another 27 lines in Figure 4.5 also indicate that problematic urination was a symptom of PCa. Examining the collocate 'no' (lines 21-30) shows that though men knew that problematic urination was a symptom, they did not experience it themselves: "I had no symptoms, but I know that men often find themselves getting up three times a night to pass water" (Daily Mail, 16/11/1999). Further examination of Figure 4.5 reveals 24 lines indicating this pattern:

Extract 4.21

When discussing urinary tract symptoms doctors always ask their patients three salient questions. Do you get up at night to pass water? Is your urinary flow slow? Are you in any way bothered by bladder function? Further questions often reveal that the patient may have intermittent urination, that their flow is very slow and they can't dawdle on the way to the loo. Patients who wait for these symptoms before they have a PSA test (see left) may be waiting too long. Neither my friend George nor I had much in the way of symptoms. (The Times, 09/10/1997)

In contrast, examining 'my' in Figure 4.5 (lines 17-20) indicates that some MWPCa did have such symptoms. Further examination shows a total of eight lines indicating this pattern. Also, thirty lines in Figure 4.5 are in the context of a PSA test, most of which indicate the usefulness of the PSA test in finding PCa when there were no symptoms:

Extract 4.22

Dr Tim Key, epidemiologist at the Imperial Cancer Research Fund, explains: 'We know that the PSA blood test can help to detect prostate cancer in men who have not developed any symptoms'. (Guardian, 23/09/1997)

The predominant use of the 'nutrition risk' keywords (*vegetables, fruit, zinc, exposure, fats, oil, tofu, eat, vitamin, diet, meat* and *chemicals*) was in one Daily Mail article. The predominant use of 'genetic risk' keywords (*genetic, gene, history* and *link*) was around inherited risk of PCa. The 'age risk' keywords were *age, young, occur* and *escalate*. *Escalate* was used exclusively, and *occur* almost so, in the 'Your guide to the prostate' boilerplate (Extract 4.17). In contrast, only approximately one quarter of the instances of the keywords *age* and *young* were used in this boilerplate. Figure 4.6 shows the concordance for the 1990-2000 keyword *age*:

Figure 4.6. 'Age' concordance 1990-2000

N Concordance

1 family history, the cancer often strikes earlier than the average age of 70, and tends to be more aggressive, so the sooner
2 ranged from 30 to 70 per cent). The figures are complicated by age. The mean age for a prostate operation is 70. Many men at
3 prostate cancer, as it is extremely rare in someone of Conlan's age. He started to suffer bowel and bladder problems and had
4 , we can start targeting them for screening at a much earlier age.' In cases where there is a family history, the cancer often
5 , Major Ferguson remains more active than most men half his age. He rides his daughter Alice's equestrian through the
6 chances of getting prostate cancer,' Key says. 'Increasing age, having one or more family members who contracted it at a
7 to 70 per cent). The figures are complicated by age. The mean age for a prostate operation is 70. Many men at this age may
8 by his particular growth. The mayor, at 55, is still in middle age. Even the most conservative doctor would agree that he
9 ." Prostate cancer is common among men in mid to late middle age. Recent celebrity sufferers include former James Bond star
10 me realise how important it is for men, as we move into middle age, to take an interest in their health. "This cancer was
11 I'm optimistic. Above all, the one thing I would urge all men in middle-age to do is don't be complacent, don't ignore the
12 one and he's just 47," the patient replied. Advised that middle age was no protection, his brother was tested and found to
13 fact, they were down to a level considered safe for a man of my age. However, I'd never say I'm free of prostate cancer. I have a
14 to worry about because this was quite normal in a man of my age. It was at this point that alarm bells went off. I told him
15 brought home to me is how important it is for people of my age to have regular check-ups. It was discovered as a result of
16 no other symptoms. I feel lucky. I'd recommend all men of my age to have a check-up. The man who dared to speak out
17 prostate removed and made a full recovery. I urge all men of my age to make sure the same does not happen to them. Already
18 at the posters about prostate cancer and the wide range of age of the other men who were also waiting. That was the
19 trouble. Cancer is usually a disease of late middle or old age. As well as cancer of the prostate running in families, it
20 . But like so many others, I thought it was a disease of old age. Initially, the doctors thought might have a urinary infection
21 of the 14,000 men diagnosed each year are post-retirement age, one in ten is under 65, and 5 pc of deaths occur among
22 father and his brother died from prostate cancer, at the same age and on the same day. Even now, when I think about that
23 and they are unaware of its existence until, around the age of 50, it starts to enlarge. By pressing on the bladder, the
24 prostate examination is recommended for all men over the age of 50, or over 40 for those with a family history of the
25 upper lip. He was first diagnosed with prostate cancer at the age of 65 and I have the impression that treatment was not
26 surgery and my father, too, died of prostatic disease at the age of 80. There is a genetic link in cancer of the prostate. The
27 like this, it's clear you have to react swiftly. Since the age of 40, I've been having a check-up at least once a year.
28 has to be tailored to the individual and take into account their age, their general health and the importance to them of
29 not contemplate performing the operation in men around this age. In my favour, I was reasonably fit. I played golf a couple of
30 The mean age for a prostate operation is 70. Many men at this age may want to stop sexual activity. I'm 56 and do not wish to.
31 so sad that it wasn't detected sooner. So it doesn't matter what age you are, doctors and specialists need to be constantly
32 the cancer is. * WILL YOU GET IT? The odds escalate with age: 70 pc of men in their 70s will have it, rising to 80 pc in
33 can be analysed. * WILL YOU GET IT? The odds escalate with age: 70 pc of men in their 70s will have it. 7 WAYS TO SAVE
34 the cancer is. * WILL you get it? The odds escalate with age: 70 pc of men in their 70s will have it, rising to 80 pc in
35 get it? The odds of developing prostate cancer escalate with age: 70pc of men in their 70s will have it, 80 pc in their 80s. *
36 get it? The odds of developing prostate cancer escalate with age: 70pc of men in their 70s will have it, 80 pc in their 80s. *
37 the cancer is. * WILL you get it? The odds escalate with age: 70pc of men in their 70s will have it, rising to 80pc in their
38 also living longer, and the disease grows more common with age. Despite its high incidence, surveys show that men remain
39 gland grow, a tumour develops. * WHEN does it occur? With age, it is normal for the prostate to enlarge. This condition is
40 spread to other parts of the body. * WHEN does it occur? With age, it is normal for the prostate to enlarge. This condition is
41 gland grow, a tumour develops. * WHEN does it occur? With age, it is normal for the prostate to enlarge. This condition is
42 . Cancer cells then spread. * WHEN does it occur? With age, it is normal for the prostate to enlarge. This condition is
43 to other parts of the body. * WHEN DOES IT OCCUR? With age, it is normal for the prostate to enlarge. This condition is
44 to other parts of the body. * WHEN DOES IT OCCUR? With age, it is normal for the prostate to enlarge. This condition is
45 one or more family members who contracted it at a young age, and the population you come from. Black Americans have
46 cancer, or one close relative with prostate cancer at a young age Symptoms: (most of these symptoms are more likely to be

Age occurred almost twice as often in 1990-2000 as 2000-2010. The most frequent collocate one place left of *age* was “with” and these were used almost exclusively in the ‘Your guide to the prostate’ boilerplate (Extract 4.17): “with age” the risks of benign changes in the prostate or PCa *escalate*. Another frequent collocate left of *age* was ‘middle’ (lines 8-12) and this indicated that PCa was that which men should consider as they “move into middle-age”. Overall, almost half of the concordance lines in Figure 4.6 refer to younger men. These often contained either an imperative to act in relation to PCa or were regarding the risk of impotence and incontinence to younger men from side-effects of treatment for PCa:

Extract 4.23

Daunted by the risks of becoming incontinent or impotent, I returned to Brendan Devlin, an old friend who is director of the medical-audit unit of the Royal College, and his colleagues who conducted the prostate survey. "Don't have it [a radical prostatectomy]," was their unanimous verdict. (...) The figures are complicated by *age*. The mean *age* for a prostate operation is 70. Many men at this *age* may want to stop sexual activity. I'm 56 and do not wish to. (Guardian, 03/11/1995)

The keyword *young* occurred over twice as often in 1990-2000 as in 2000-2010. It was used six times in the ‘Your guide to the prostate’ boilerplate (Extract 4.17) referring to BPH occurring “in men as young as 30”. Its remaining 16 instances showed that it was almost exclusively used regarding the risks and concerns to younger men though three are in the exceptional circumstance of a 19 year old man who died of PCa. In three instances MWPCa are placed in a familial setting with grown-up children:

Extract 4.24

Young people like me aren't meant to suffer. GRAHAM BREEZE, 46, was diagnosed with prostate cancer a year ago, and recently underwent surgery to remove his prostate gland. Graham is an editor at the North Wales Newspaper Group and is married to Yolande. They have two sons, Paul, 23, and Neil, 20, and live in Welshpool, Wales. (...) I thought it was something that affected only elderly men. Men in their 40s don't expect this to happen to them (...) The next stage was an appointment to discuss treatment options. The main two were radiotherapy or surgery to remove the prostate gland. There are two main possible side-effects of the surgery, incontinence and impotence. Being so young, both of those possibilities were terrifying. (Daily Mail, 03/11/1999)

Examining ‘age risk’ in 2000-2010 showed that although *age* and *young* were relatively less frequently articulated than in 1990-2000 there were some qualitative similarities.

While the predominant context of *age* in 2000-2010 was also of the risk to younger men, in contrast to 1990-2000, this was more often in the context of *much* younger men to include those in their thirties. This was often in the context of relative knowledge that while PCa was “just an old man’s disease” and “half of all cases involve the over-75 age group”, PCa “hit me at 37 and now I’m living on borrowed time” (Daily Mail, 17/05/2005) and “a significant and growing number of men in their thirties and forties are developing malignant tumours” (Daily Mail, 29/04/2002). Similarly, the predominant context of *young* in 2000-2010 is regarding ‘young’ men either already diagnosed with PCa or who ought to be made aware of it. As in 1990-2000, men are also positioned in a familial context with older children and grandchildren but also more frequently as “young family men” and having young children/daughter/kids themselves.

In sum, language around symptoms was significantly more frequent in 1990-2000 than 2000-2010. Urinary symptoms were those most frequently articulated in 1990-2000 and these were predominantly frequent/nocturnal/intermittent urination followed by blood in urine. MWPCa in both 1990-2000 and 2000-2010 were more frequently articulated as having no symptoms rather than experiencing symptoms. There was concern in both 1990-2000 and 2000-2010 regarding the difficulty in distinguishing benign from malignant enlargement of the prostate as each cause the same symptoms. While language around ‘age risk’ was used relatively approximately twice as frequently in 1990-2000 as in 2000-2010, there were qualitative similarities across time. In 1990-2000, the most common, though not predominant, context of *age*, and predominant context of *young*, was around the risks of PCa to younger men. In 1990-2000 men were sometimes positioned in a familial context with brothers or fathers with PCa or with a wife, older children and grandchildren. In 2000-2010 the risk of PCa was in much younger men to include those in their thirties and with young children themselves.

4.6 Stories of Tests & Diagnosis

Table 4.2 shows ten ‘*Tests & diagnosis*’ keywords in 1990-2000 and five in 2000-2010 and the raw and relative frequencies of these words are shown in Table 4.9 and Table 4.10:

Table 4.9 Tests & diagnosis Keywords 1990-2000

‘Tests and diagnosis’					
1990-2000 Key word	1990-2000 Raw Freq.	1990-2000 Freq/100,000	2000-2010 Raw Freq.	2000-2010 Freq/100,000	P
EXAMINATION	26	62.7	20	19.0	4.39E-05
TRANSRECTAL	6	14.5	0	0.0	8.76E-05
MEDICAL	50	120.5	69	63.8	0.00084
IDENTIFIES	6	14.5	1	0.9	0.00133
BIOPSY	46	110.9	64	59.2	0.00154
RECTAL	15	36.2	12	11.1	0.00246
REVEAL	7	16.9	3	2.8	0.00557
DIGITAL	7	16.9	3	2.8	0.00557
ULTRASOUND	15	36.2	14	13.0	0.00653
REMAINS	10	24.1	7	6.5	0.00745

Table 4.10 Tests & Diagnosis Keywords 2000-2010

‘Tests and Diagnosis’					
2000-2010 Keyword	1990-2000 Raw Freq.	1990-2000 Freq/100,000	2000-2010 Raw Freq.	2000-2010 Freq/100,000	P
AGAIN*	6	14.5	52	48.1	0.00113
SCORE	0	0.0	14	13.0	0.00256
NEEDLES*	0	0.0	13	12.0	0.00365
INOPERABLE*	0	0.0	12	11.1	0.00523
PSA*	63	151.9	240	222	0.00535
*‘split’ keyword					

All but *medical* and *reveal* of the ‘Tests & diagnosis’ keywords in 1990-2000 were to some extent used in the “Your guide to the prostate” boilerplate (Extract 4.17) with *transrectal*, *identifies* and *digital* almost exclusively so. *Ultrasound* was used 5/15 times in this boilerplate and the remainder referred to further diagnostic tests. Five instances of *reveal* were in the context of what *examinations reveal* and four of *remains* indicated controversy around the lack of specificity of the PSA test. Though the predominant use of *medical* was synonymous with *examination* as in “my cancer was discovered during a routine medical” (Daily Mail, 16/11/1999), most instances of *examination* referred to a *digital rectal examination* (DRE).

Of the ‘Tests & diagnosis’ keywords in 2000-2010 (*again**; *score*; *needles**, *inoperable** and *PSA**), all but *score* were ‘split’ between this category and ‘Treatment’. *Inoperable*, *needles* and *score* were not used at all in 1990-2000. Six instances of *needles* were in a biopsy context with the remainder regarding technical aspects of treatment, mostly around brachytherapy. Half of the instances of *inoperable* were in a PCa diagnosis context with the remainder referring to initially

diagnosed *inoperable* PCa which later responded dramatically to experimental treatment.

Score was predominantly used in the context of the Gleason and PSA *score*. The Gleason score, a measure of malignancy of prostate tumours using needle core biopsies, is often used in combination with PSA to predict pathological stage and clinical outcome of prostate cancer (Osunkoya 2012). Though the immediate context of *score* was the diagnosis of PCa, almost all concordance lines associated with 'Gleason' and 'PSA' also indicated treatment options for MWPCa.

Extract 4.25

Luckily, my Gleason score (which grades the tumour on a scale of two to ten: two to six being termed non aggressive; seven moderately aggressive; and eight to ten aggressive and, therefore, likely to spread faster) was a six. HOWEVER, I was relatively young to have prostate cancer, since the average age for diagnosis is 75. So even though mine was a slow-growing one, the doctors felt it was better to take the prostate out in a radical prostatectomy (removal of the entire prostate gland) rather than simply monitor the disease. (Daily Mail, 12/09/2006)

The predominant use of *again* was in a treatment context followed by diagnosis and often either indicated the use of PSA tests in the diagnosis of PCa or to check whether the cancer had returned *again* after treatment.

Analysis of the keyword *PSA* indicates two main but contrasting stories. First, *PSA* was a reliable indicator for PCa and associated both with a basis for further testing for PCa and also with the success or failure of treatment: if *PSA* was raised then treatment was begun; *PSA* lowering after treatment; and *PSA* rising post-treatment:

Extract 4.26

I had no symptoms, but my PSA continued to rise and, about a year later, a biopsy confirmed it was cancer. The cancer was treated with radiotherapy. Although this was originally successful, my PSA levels started to creep up again. In July last year, it was confirmed that my cancer had returned. Amazingly, I still had no symptoms. I felt fine but I needed more treatment. (Daily Mail, 28/09/2004)

Secondly, *PSA* was also described as an unreliable indicator for PCa, and may also be in a 'grateful' context:

Extract 4.27

Not all men in the UK are offered the PSA test routinely because it's not always completely reliable as an indicator of cancer, according to Cancer BACUP. But in my case, I believe it saved my life. The normal PSA upper limit for my age at the time, which was 53, should have been 3.5, so my first result of 5.3 was high enough to be a warning. (Daily Mail, 12/09/2006)

In sum, words around tests and diagnosis for PCa were more plentiful and used more frequently in 1990-2000 than in 2000-2010. Journalists used the phrase 'digital rectal examination' (DRE) more frequently in 1990-2000 than in 2000-2010 when talking about tests and diagnosis of PCa. The 1990-2000 keywords were used almost exclusively in the context of the tests needed for diagnosis. In contrast, the 2000-2010 words are mostly regarding the treatment men might receive because of their diagnosis. PCa was more frequently described as an inoperable disease in 2000-2010 than in 1990-2000 and *score* is used regarding Gleason and PSA readings to predict pathological stage of this disease. Although *PSA* appeared in the 'Your guide to the prostate' boilerplate (Extract 4.17) in 1990-2000, it was significantly more frequent in 2000-2010 and thus a keyword.

4.7 Discussion

The analysis in this chapter begins to address the gap in the literature examining how UK print media representation of PCa may have changed since the emergence of PCaOrgs into the UK in the mid-1990s. PCaOrgs may be considered to be a form of health social movement (HSM); HSMs are generally considered to be a force for change in society in the way health issues are addressed (Crossley and Crossley, 2001; Brown et al., 2004; Kedrowski and Sarow, 2007). Actors around social movements are argued to be actively engaged in the production or transformation of meaning for their various audiences (Snow and Benford, 1992) which includes print media. Though framing theory has often been used to understand the meaning-making of social movement actors, Smith (2005) suggests that framing has only 'nuisance value' (p.9) and 'permits only guerrilla warfare' (p.9) in understanding such meaning. Instead, the 'heavy artillery' (p. 9) afforded by narrative structures has more explanatory value. The analysis in this chapter has used an inductive-deductive interplay (McGhee et al., 2007) with CKWIC analysis and narrative and framing concepts to compare two

datasets of illness narratives of MWPCa in the UK print media: 39 narratives in 1990-2000 and 101 narratives in 2000-2010. This analytic approach allowed me to determine first, which words were significantly more frequently used by journalists when writing about MWPCa in 1990-2000 than in 2000-2010 and vice versa and second, what insights this gave into how the UK national print media represented the illness experience of MWPCa since the emergence of PCaOrgs in the UK in the mid-1990s.

My findings suggest that there have been changes in the representation of the illness experience of MWPCa since the emergence of PCaOrgs into the UK in the mid-1990s. They show that the UK print media told stories of injustice around PCa. This may though be unsurprising—at least to social movement theorists though not perhaps to those interested in the substantive topic of PCa. Injustice, as a ‘hot’ emotion (Gamson 1992: 7), has been used as ‘leaven’ (Turner, 1969: 399) for social change by all social movements in each main historical era (Turner, 1969; Snow, 2004). Journalists writing for the UK print media, as an audience for the meaning-making activities of PCaOrgs, may then also be expected to include injustice when writing about the illness experience of MWPCa. What may be surprising is that the substantive focus of this injustice changed over time—from PCa as “neglected” and “taboo” in 1990-2000 to injustices around treatment in 2000-2010.

When journalists wrote about the illness experience of MWPCa in 1990-2000 they used certain words more frequently than in 2000-2010 to tell a story of PCa as a neglected ‘Cinderella’ disease when compared with breast cancer, AIDS and heart disease. Many of these words were in the context of an appeal by the Daily Mail to raise £1million to “rectify [the] scandalous situation” of the “derisory” £47,000 of funding that PCa received compared to other illnesses. Other emotive words included ‘appalling’ and ‘epidemic’. This neglect was mostly said to be gender-based although there were ageist elements mentioned. Blame for this neglect was distributed across: men themselves as those stereotypically “suffering in silence”; a society which placed little value on the lives and deaths of men; the medical profession; and government.

Why though was the neglect story picked up by journalists in the 1990s? One answer is that in a ‘world of narrative, [where] very little is ever new’ (Frank, 2010: 123), journalists were able to draw upon a pre-patterned (Tannen, 2007) way of talking, or genre (Bury, 2001), already familiar to their audiences. The ‘neglect’ story

was likely already familiar to journalists and their audiences through its successful use in several other social movements (see Kolker, 2004). Familiarity for media audiences was also provided by the repetition of a 'Derisory £47,000 PCa Spend' (Extract 4.1) 'boilerplate' (Cotter, 2010: 171), often included as context for the illness narrative of MWPCa. A boilerplate, argues Cotter, may end up influencing public debate through repetition; this boilerplate repeated the figure "47,000" as the "derisory" or "pitiful" amount of money spent by the UK government on PCa "last year", in terms suggesting it was very limited—"just", "but only" and "yet only". This boilerplate formed part of the Daily Mail's campaign to raise money and awareness for PCa; the potential efficacy of which was demonstrated in the publication of the NHS Prostate Cancer Programme in 2000, and subsequent Prostate Cancer Risk Management Programme (PCRMP) in July 2001.

Stories of the neglect of PCa seemed no longer to be told when journalists were writing about the illness experience of MWPCa in 2000-2010. Instead, journalists wrote about the "disgraceful" and "unacceptable" injustice around funding for new treatments such as brachytherapy, the risks of impotence and incontinence post-prostatectomy and the "debilitating" and feminising side-effects of hormone treatment. But why the switch from one type of injustice to another? Seale (2002) argues that journalists "'twitch" the plot from time to time in order to retain audiences' interest' (p. 36).

PCa as a "taboo" disease that "no one dares talk about" and about which men kept quiet was more explicitly and frequently written about by journalists in 1990-2000 than in 2000-2010. PCa was allowed to be a taboo by society in that "it has been ignored by politicians and greeted by too many people with giggles, embarrassment or a shocked silence." Though there were no instances of 'taboo' in 2000-2010, PCa remained, at least somewhat, difficult to talk about. In 1990-2000, raising awareness was proposed as a solution to PCa as a taboo with particular actants identified both as culpable for this problem and also as those who must act to change it, including "every woman who loves a man" and the "we [who] will stop making prostate cancer a taboo subject".

My findings also show that words around symptoms were used significantly more frequently by journalists in 1990-2000 than 2000-2010 when writing about the illness experience of MWPCa. Lower urinary tract symptoms (LUTS) — frequent,

nocturnal or intermittent urination—followed by blood in the urine were those urinary symptoms most frequently articulated. Particular phrases included “difficulty passing water” and having problems with “the old waterworks”. MWPCa in both 1990-2000 and 2000-2010 were more frequently articulated as having no symptoms rather than experiencing symptoms. That this language was less used by journalists in 2000-2010 than in 1990-2000 may be due to evidence indicating that LUTS are not indicative of PCa (Collin et al., 2008). Such a way of talking may be perceived as less valid, as for example, less validated by extant evidence by journalists in 2000-2010 than in 1990-2000. Validity though is not necessarily a requirement of successful storytelling as viability, or resonance with existing cultural ideas, is more important. Kolker (2004) shows that despite its lack of validity, the ‘epidemic’ frame around breast cancer in the early 1990s was viable.

This is controversial ground for the potential medicalisation of old age with the ‘natural processes of aging’ (Armstrong, 2014: 15), such as physical changes in men’s bodies which result in benign enlargement of the prostate normatively revised (Turner, 1969) or ‘reinvigorated and incorporated into a model of pathological disease’ (Armstrong, 2014: 16). Here, there is a redefining of symptoms ‘that are already meaningful from the standpoint of some primary framework [urinating problems experienced by large numbers of men as they age], in terms of another framework [the pathological disease of PCa]’ (Snow et al., 1986: 474). This also shows the compounding and intricate interaction between disease and illness (Timmermans and Hass, 2008). Armstrong (2014) argues that the diagnostic labels of any period, as here in the transformation of symptoms for benign prostate problems to PCa, may not in reality reflect an underlying biological reality but rather reflect a medical perception contaminated by contemporary world views. That autopsy studies show very young men with PCa (Powell et al., 2010) suggests potential for an underlying biological reality of PCa. Given also that PCa is being looked for harder than ever before (Welch et al., 2012), as more men are persuaded themselves or by other audiences—partners, families, friends, or GPs—that LUTS should be further investigated, this underlying biological reality may increasingly be found. Many of these men are likely to be glad that their cancer has been found “early” and to avail of treatments.

While language around ‘age risk’ was used approximately twice as frequently in 1990-2000 as in 2000-2010, there were qualitative similarities across time. In 1990-

2000, the most common, though not predominant, context of *age*, and predominant context of *young*, was around the risks of PCa to younger men. In 1990-2000 men were sometimes positioned in a familial context with brothers or fathers with PCa or with a wife, older children and grandchildren. Likewise, although relatively less frequently articulated than in 1990-2000, the predominant context of 'age risk' keywords in 2000-2010 is also of the risk to younger men. However, in contrast to 1990-2000, this is more often in the context of *much* younger men, where "a significant and growing number of men in their thirties and forties are developing malignant tumours". As in 1990-2000, men are also positioned in a familial context with older children and grandchildren but also more frequently as "young family men" and having young children/daughters/kids themselves. Thus, there are two aspects of PCa that are made salient here and relevant to the framing of MWPCa in UK print media: 1) that younger men are increasingly being diagnosed with PCa; and 2) that 'family' is likely to be of concern to these men.

As men get older they are more likely to be diagnosed with PCa although this may change as more and more younger men are diagnosed with PCa (Cancer Research UK, 2013c). In addition, the autopsy studies referred to above show a surprisingly high level of premalignant and malignant disease is found in the prostates of men aged in their 20s, 30s and 40s (Soos et al., 2005; Powell et al., 2010). Framing ever younger men at risk of PCa may thus make this framing both valid and viable (Kolker 2004). As with the discussion around symptoms above, this is simultaneously interesting, controversial and consequential in several ways in understanding how the social life around PCa matters for at least its morbidity and vice versa (Timmermans and Hass, 2008). It may be that much of the diagnosed cancer in younger men may be 'destined merely to be an incidental histological event' (Parker, 2004: 101). Naming these pre-malignant and malignant conditions as PCa, and diagnosing men as such, especially with pre-malignant or 'early' PCa (Aronowitz 2009; Faulkner 2012) substantially increases the risk of detecting non-clinically relevant PCAs and moves many more men onto a risk/disease spectrum (Aronowitz 2009) of PCa.

This has consequences for both the overdiagnosis of PCa, that is 'the diagnosis of men who would not have clinical symptoms during their lifetime' (Schroder et al., 2009: 1327) and its overtreatment (Wolters et al., 2012). In turn, this has corresponding consequences for morbidity around PCa in that these men may be more

likely to adopt decision-making styles typically used for more advanced states as is currently potentially the case for women with breast cancer (Aronowitz, 2009; Henderson, 2013; Wise, 2013). In addition, it has consequences for the public face of PCa, which may become healthier as those with a poor prognosis become relatively fewer (Aronowitz 2009). Moving many more younger men onto the risk/disease spectrum of PCa also has consequences for creating a larger and more mobilised disease/at risk population, giving a greater audience for disease advocates. This, in turn, has consequences for the success of health social movements or grassroots survivor organisations (Kedrowski and Sarow 2007).

Chapter 5 Changing narratives of prostate cancer advocates

5.1 Introduction

In the UK, in the past twenty years the public visibility of PCa has increased as prostate cancer organisations (PCaOrgs), as a potential health social movement (HSM), have emerged to promote awareness of the condition and lobby for funding of services and research. Actors in HSMs are argued to be actively involved in the production and transformation of particular aspects of reality and ways of understanding the world (Benford and Snow, 2000). As yet there are no studies of how PCaOrgs in the UK may produce or transform aspects of PCa. My aim in this chapter is to address this deficit through an analysis of narratives of advocates around PCaOrgs collected through research interviews in 2010. Drawing on the conceptual framework informed by a combination of narrative, framing and literary concepts (Bakhtin, 1986; Bury, 2001; Smith, 2005; Polletta, 2006; Riessman, 2008, Tannen, 2007; Frank, 2010;) described earlier, I ask: 1) how have advocates around PCa sought to produce or transform meanings around PCa and 2) what narrative forms or elements have they used in doing so. I present my findings in two sections: 1) using the neglect story of prostate cancer and 2) losing the neglect story of prostate cancer and finding other pockets of injustice.

5.2 Using the neglect story of prostate cancer

In answer to my opening question, 'So tell me how you became associated with prostate cancer and the organisations associated with it?', a chief executive of a PCaOrg began to tell the story of his recruitment to the post and how his own personal lack of awareness of the prostate gland or PCa gave him an indication of the challenge the organisation faced in raising awareness:

Extract 5.1

Participant: The charity was set up in [year] and really from the outset, it had a dual objective to increase research investment, but also to raise public awareness of the disease and to provide support and information to men affected by it.

Interviewer: And how have you managed to do that?

Participant: (...) so there's been a radical transformation in our income and our resources and the extent to which we've been able to influence the external world and the agenda [since 2002]. I think it's fair to say that back in 2002, prostate cancer was just beginning to come out of the shadows of neglect. There had been a fairly major, or a very major, media campaign run by the Daily Mail, I think in 1999, which had really been a seminal point in the growing up of the charity. They were raising money for, I think, a research unit at Hammersmith Hospital, and pretty much around that time, in 2000, the government published its prostate cancer programme. So there was general stirring of realisation in government and NHS circles and in the media that this was a neglected disease and something needed to be done about it. So there were lots of levers for change that started to appear around the end of the 1990s into the beginning of the 2000s. (PCa-ORG/3/1)

Telling the story about PCa as a “neglected disease” hidden in the “shadows” and about which “something needed to be done” was a story which effected action in the late 1990s shortly after the emergence of the first PCa organisations into the UK. This action was achieved not only through the Daily Mail campaign in 1999 to raise money (§4.3.1) but also by the “general stirring of realisation”, which led to the publication of the NHS Prostate Cancer Programme (NHS, 2000), to which this participant refers, and the subsequent Prostate Cancer Risk Management Programme (PCRMP) (Burford et al., 2010) in July 2001. Why did the neglect story effect such action back in the late 1990s? The answer, I suggest, in a ‘world of narrative, [where] very little is ever new’ (Frank, 2010: 123), partly lies in the extent to which actors around PCaOrgs were able to draw upon a pre-patterned (Tannen, 2007) way of talking, or genre (see for example Bury, 2001), already familiar to audiences. However, a story which is ‘entirely predictable (...) [is] no story at all (Polletta, 2006: 10) and thus the success of the ‘neglect’ story in effecting action, I suggest, also lies in the extent to which this appropriated language was inflected with new meaning (Steinberg, 1999).

The ‘neglect’ story had already been successfully used in the early 1990s when public claimsmaking by breast cancer movement activists defined breast cancer not as a problem of access to screening and treatment but one of gender-based neglect

(Kolker, 2004). A sense of injustice, such as that engendered by ideas of 'neglect', has been used as 'leaven' (Turner, 1969: 399) for social change by all social movements in each main historical era. Advocates around PCa were able to use the 'tried and true method' (Steinberg, 1999: 752) of seeing 'their own problems in the terms set forth by [breast cancer] activists' (Turner, 1969: 399). This is one beneficial consequence of social movement 'spillover' (Meyer and Whittier, 1994) where new movement actors align their messages with what they know is already familiar, or *resonant*, to their potential audiences. Resonant language 'fits' or 'rings true' in some way with audiences' already existing beliefs, values, ideologies or experiences (Williams, 2004: 105). Viewing the language of 'neglect' as culturally resonant begins to explain why the 'neglect' story from the breast cancer movement could be used to influence the illness sufferers and other attentive audiences around PCa. The difficulty in, or aversion to, constructing explicitly oppositional discourse (Steinberg, 1999) is seen in the concern of a public consultant around PCa to avoid "the tendency to kind of revert to the kind of oppositionist, 'we're outsiders, everything's terrible' approach, which is very easy, and is very understandable as well" (PCa-PC/1) for the "condition and cause" (PCa-PC/1) of PCa.

The appropriated story of neglect was then a mechanism which offered hope from history to successfully articulate the problems facing both MWPCa and those concerned with treating them. The following medical professional was involved in very early attempts to publically articulate these problems and find solutions for them. He begins this section of narrative in an ostensibly tragic genre, with an 'amplified awareness of suffering' (Smith, 2005: 25), to articulate the hopelessness around a forgotten disease which had no institutional interest and the shame and fatalistic behaviour of its sufferers when nobody knew "what to do in those days":

Extract 5.2

Interviewer: Okay, and the campaigning issue then, what was it, can you remember?

Participant: That this was a disease that was forgotten about and not talked about, where management and treatment was not optimal, where there was no research, where, because there was no central interest and no cancer charity interest, where there was no information source for the patients, there was nothing, so you couldn't find out about the disease if you were a patient and how you should be treated

Interviewer: so the campaigning was then to?

Participant: To increase public awareness of the disease and to provide proper academic research, to lobby central government, to make men not ashamed about talking about what they had

Interviewer: Do you think that they've been successful in that or?

Participant: Oh yeah, it's knockout, it's been really brilliant

Interviewer: In that men are not ashamed?

Participant: Well whether it's just to do with societal aspects in the way that men are now as compared with how they were in the 1980s and 90s, yeah, I mean it's true society has changed, but the men (didn't sort of) stand up in the way that the women stood

Interviewer: They didn't?

Participant: No, they would have their illness, they would not talk about it, they would die quietly, and unlike breast cancer, where there was tremendous fuss and noise, where women were talking about mutilating surgery, where women got lots of money into research, there was nothing, you couldn't, didn't know what to do in those days.

Interviewer: Yeah, yeah, so, was there anything that, in those early days, made a particular impact, was particularly successful in...

Participant: The Daily Mail campaign was amazing

(PCa-MP/2)

The tragic genre of suffering was, however, not consistently adhered to even in this short section of narrative. Peering into the actions and history (Steinberg, 1999) of the breast cancer movement to tell a neglect story of PCa effected "brilliant" and "amazing" action. Such successful action implies the hope of triumph over adversity and thus this narrative also shows elements of a romantic genre (Smith, 2005). This though is in line with Bury's (2001) observation that speakers may move from one genre to another as they see fit. Though the borrowing of language around breast cancer activism was "'half the battle'" (Berbrier, 1998: 432) in successfully narrating PCa as a neglected disease, it was still only 'half the story' (Ferree, 2003: 306). A story is not a story unless it contains elements of unpredictability (Polletta, 2006) or 'radical' non-resonant language (Ferree, 2003); it is not an 'interesting' story unless it contains elements of novelty (Silvia, 2008). So how then were novel, unpredictable or radical aspects included in the story of neglect of PCa?

One answer is that actors around PCa were able to inject this neglect story with elements of the “story about men versus women” (PCa-MP/6) and in this way transform it to articulate their own specific sense of injustice and moral authority (Steinberg, 1999: 751). In some ways though, this gender-based inflection was also resonant—and thus not novel—as it was used by breast cancer activists in the US a decade earlier (Kolker, 2004). In other ways it was novel in that men, rather than being the usual perpetrators of discrimination, were now the ones being discriminated against. The medical professional quoted below began his story of how he became involved with PCa and its organisations by contrasting at length the lack of historical struggles of men against discrimination with the several and varied such struggles of women. He particularly observed how women’s health issues were successfully “bolted on” to existing institutional mechanisms for dealing with these struggles:

Extract 5.3

It was a mixture of [discrimination, isolation and abuse] and demand for better health care and things like screening for breast cancer and so on, which drove the women’s health movement. This mix with feminism and political agitation for better rights for women, a lot of it working with trade unions to a very large extent, deeply committed to all these kind of things, and then bolted on to whatever the issue was to do with health. So what you found is, with the women’s health movement it didn’t really matter which one you looked at, there was always an element of, the political side which was very strong, along with the health messages that they were putting across. So it did tend to attract women in political spheres and the media and entertainment and so on, they tended to come out of the woodwork very quickly to support it, not just in the health sense but also the political objectives which they were trying to achieve. Men’s health came from a completely different animal, men didn’t need to worry about discrimination and isolation cos they were the ones who were doing the discrimination in the first place. So the discrimination against women was a male attribute, so men didn’t have to worry about fighting the political battle cos that was already won, or lost whichever way you look at it, so the animal came very much from simply the needs of men for health, and it and it came around two areas really. One was the men themselves and the (amount of) insight they had and their use of services, and the other one was the political side, which was the delivery of the services within the health service itself, and what happened was that the early workers did a bit of digging and found things like for instance that there was only something like forty thousand pounds a year spent on prostate cancer research. When you compared that to breast cancer research it was like countless millions and millions into breast cancer research, and their argument was that this was actually (inequality based), and of course they were quite right, it was. (PCa-MP/4)

Notably then for this participant, women were able to ‘piggyback’ (Kedrowski and Sarow, 2007: 153) their health issues onto other issues of discrimination in a way which men, at least up to that point, were not. Such ‘piggybacking’ is similar to social movement spillover (Meyer and Whittier, 1994) where at least one consequence of spillover is the creation of sympathetic allies for the cause of concern; for women in the above account these included at least trade unions, the media and the entertainment industry. All of these allies though were lacking for those advocating around PCa. Not lacking though was the culturally resonant story of neglect which could be appropriated to ‘articulate identities, grievances, and goals where there [were] gaps and silence in the discursive field in which they [were] fighting their own struggle’ (Steinberg, 1999: 752). The discovery by the early advocates around PCa of the huge discrepancy in funding for breast cancer and PCa served as a supporting and motivating element in this story; a narrative element also used in media illness narratives of MWPCa in the late 1990s (§4.3.1), the approximate time to which this participant referred.

Kolker (2004) notes how breast cancer activists constructed themselves as part of ‘an angry disenfranchised group that would not stay silent in the face of governmental neglect’ (2004: 839). What is evident in the following narrative by a medical professional is that rather than being ‘angry’, ‘disenfranchised’ and a ‘group’ who ‘would not stay silent’ and who made a “tremendous fuss and noise” (Extract 5.2), men are instead described as “passive” and not making “a fuss” in a society where “no-one made a fuss” about men suffering and dying from PCa. Such hegemonic discourse regarding men’s passive behaviour (Connell and Messerschmidt, 2005; Courtenay, 2009) is intrinsically familiar and therefore, ostensibly, not novel. Nonetheless, when used in striking contrast to the language describing the behaviour of women, it potentially works to inject novel, unpredictable or radical language into the neglect story:

Extract 5.4

It became my job to try and attract funds for the treatment of people with prostate cancer and for research into that area, and it was very very difficult to do so, because prostate cancer was not a fashionable illness, and breast cancer, by contrast was. So the women’s movements in the sixties had been great, and radicalising lesbians had taken a banner and taken breast cancer as a campaign issue and the women’s liberation movement did wonderful things for breast

cancer, but here was prostate cancer, and men got the disease and they suffered and they died and they didn't make a fuss. No-one made a fuss. It just was remarkable. Men were very passive in dealing with prostate cancer (...) so I got rather frustrated about the fact that I'd write for grants to the cancer charities for research money and get no, get nothing, and it seemed that there was no central government interest also in prostate cancer in the way that there was an interest in breast cancer, so (...) I set up a charity to try and bring to the public's attention the fact that prostate cancer was a, a significant illness, to lobby the government for change in the way that they view prostate cancer and to provide information for prostate cancer patients cos there was absolutely nothing there, and as a token of that the amount of central government money coming to prostate cancer in 1996 (...) was forty-eight thousand pounds, which compared with about five million that went to breast cancer. So derisory figure for breast cancer but negligible amount of money for prostate. (PCa-MP/2)

This medical professional described his frustration at the "absolutely nothing there" with regard to research funding and information particularly detailing the "negligible" "forty-eight thousand pounds" so prominently featured in media illness narratives in the late 1990s (§4.3.1). This moved him to "set up a charity" to change the way the public and government viewed PCa. That this helped to produce a change is seen with "fuss" beginning to be made within the Department of Health:

Extract 5.5

The Department of Health made, I think made a big effort to listen to the story about men versus women, I think there was a change about ten years ago when, there was quite a lot of fuss in the Houses of Parliament about the amount of money spent on prostate cancer research compared to breast cancer research. The Department of Health responded to that by setting up these advisory groups [the Prostate Cancer Risk Management Programme and Prostate Cancer Reference Group, Scientific Reference Group], and they've worked quite hard together with the charities. So on the Prostate Cancer Advisory Group, there's someone from the charities on that group as well. So they've worked quite hard to listen, and to try and come out with a sort of national cancer strategy, because when they did the national audit they discovered that prostate cancer was not being well managed in the UK in terms of a lot of variability in waiting times and surgical availability, surgical skills and when they talked to men they got rather sad reports really, of men not feeling they were being managed very well, having to wait a long time, not being told very sympathetically what the diagnosis is. So I think they've listened to that and as a response to that, we produced a document which was, advice on the PSA test that went out to thirty-six thousand GPs, probably seven years ago now, and we rewrote that document last year, and it went out to the same number of GPs last year. (PCa-MP/6)

The “men versus women”, or gender-based, ‘neglect’ story of PCa thus resonated in the Houses of Parliament at the end of the 1990s, with action effected with lasting consequences. So far then, this analysis has indicated that a gender-based ‘neglect’ story worked as a story, at least because it combined the familiar and unpredictable (Polletta, 2006; Silvia, 2008)—the ‘half battle’ (Berbrier, 1998) and the ‘half story’ (Ferree, 2003). Why did this combination of resonance and dissonance work so successfully? The answer, I suggest, paradoxically lies in considering how the neglect story became an unacceptable story, at least to some audiences.

5.3 Losing the neglect story of prostate cancer and finding other “pockets of injustice”

While the data mostly showed the success of the ‘neglect’ story in effecting action in a historical context, there were examples which were used in a contemporaneous context and these were important to consider as deviant cases (Seale, 1999; Silverman, 2004, 2005). Just as “prostate cancer is a condition whose time has come” (PCa-PC/1), there was also evidence of temporal and contentious elements to the success of the ‘neglect’ story in that, at least to some but not all audiences, it was one whose time had come and gone. These temporal and contentious elements centred on sustaining, constructing, or opposing a variety of ‘interests’: 1) sustaining media interest; 2) sustaining the interest of “the man in the street”; 3) constructing the interest of the “family”; and 4) opposing “vested” interests.

5.3.1 Sustaining media interest

Of first note in the accounts below is that the neglect story of PCa, in a contemporary context, is no longer a “universally true story”. This is noteworthy as it indicates that it is the “heavy artillery” (Smith, 2005: 9) of ‘injustice’ that is perhaps a better explanation for compelling stories around PCa than the “scattered sniping” (p. 9) of ‘neglect’. Losing “the legacy of neglect” and finding other “pockets of injustice”, such as inequalities in PSA testing and screening, was necessary in order to provide an ‘entertaining disruption of expectations’ (Seale, 2002: 36) for the media audience of those advocating around PCa; entertainment which the media could subsequently transfer to its own audience:

Extract 5.6

I think what has changed is the angle that the media is interested in, whereas ten years ago, and certainly maybe twenty years ago, it was possible to talk generally about the hidden nature of prostate cancer, long neglected, and it was a kind of universally true story. The media angle was this terrible hidden story. Now the media feels that it is no longer a hidden cancer and I think increasingly that's becoming more true. So although they are still very interested in prostate cancer as an issue, it's not about the hidden nature of the disease. It's not about the legacy of neglect. It's much more now about research stories. It's about inequalities. It's about PSA testing and screening and that kind of stuff, so I think the issues have changed from the media perspective, what really interests them and what they're going to run with. (PCa-ORG/3/1)

Extract 5.7

The media is not stupid and they start to question that kind of thing, [not understanding where the cause is at] and to sustain their interest you have to refresh the cause, so we should know where the pockets of injustice are, we should know what, if and when it has increased we should admit to that, but show the media there's still a long, long way to go, so we had this campaign last year which was talking about prostate cancer being the hidden cancer, and it I think it worked (across) marketing materials because they just wanted to give a more simple message to the man in the street but it really didn't work for the media, there was a big backlash around it, so I had like four national journalists saying, "but it's not hidden any more, why are you saying that", so and I spoke to our chief exec about that and just said "you know just be aware that the cause has moved on you can't keep giving out the same old message that it's the hidden disease or no one talks about prostate cancer, I don't believe that any more", (...) the other challenge, is really understanding exactly where the cause is at and keeping it fresh for journalists. (PCa-ORG/3/2)

These narrative segments indicate a dialectic tension confronting social movement actors: an initial story ceases to be successful in effecting action as it transforms the original beliefs that prompted the action, so that similar stories are no longer efficacious. Narrating PCa as a neglected disease resulted in the successful Daily Mail campaign in 1999 (§4.3.1) and the publishing of the PCRMP in 2002. This subsequently changed the belief, at least to some audiences, that PCa was a neglected disease. Rather than resulting in comparable collective action, contemporary use of the neglect frame invoked the response, reported in the voice of "four national journalists": "but it's not hidden any more, why are you saying that" (Extract 5.7) which, in turn, invoked the response from this participant to the chief executive "I don't believe that any more" (Extract 5.7). The need to "show the media there's still a long, long way to go"

(Extract 5.7) indicates the realisation of a continual need to ‘twitch’ (Seale, 2002: 36) the PCa plot to retain the interest of the media. PCa as a neglected illness was no longer an acceptable story to tell or hear. Was this though true for all audiences?

5.3.2 Sustaining the interest of the “man in the street”

Another aspect of this dialectic tension is seen when “the same old message that it’s the hidden disease or no one talks about prostate cancer” (Extract 5.7) was no longer believed as a viable frame for one audience, that of the media, but did *still* serve as “a more simple message to the man in the street” (Extract 5.7). This indicates evidence of a problem associated with the concept of frame resonance (Ferree, 2003) where actors in the same movement have reasons for framing issues differently—essentially, in this example, entering an intra-organisational framing contest. Here, the short-term strategic effectiveness of the “simple” message to the “man in the street” by the marketing department differs from those concerned with strategically refreshing the media’s interest. Though seemingly incongruous, good stories are argued to be ‘good’ because they are indeed open to different interpretations as particular audiences collaborate with the storyteller in their interpretation (Polletta, 2006). The gender-based ‘neglect’ story of PCa was also told by a participant, himself diagnosed with PCa several years earlier, who was active in setting up a leading grassroots PCa patient’s support network:

Extract 5.8

I’m still a member [of support network] and I still go to meetings when I can, one of my wife’s comments is that there’s too much prostate cancer around particularly when I’m cured, which brings me, I suppose it touches on my motivation because I still feel really quite angry that prostate cancer patients, well actually men in general, get a very raw deal, in comparison with women, I know this is a politically, generally regarded as an unacceptable view, but if you look at the lobbying and the amount of money that is put into women’s cancer when compared with, let’s add testicular cancer in as well for instance, with the male cancers, it’s about, it’s nearly ten times as much, ten times as much attention, ten times as much money. (PCa-ORG/1)

Here again, like the participants from Extract 5.6 and Extract 5.7, is the observation that the ‘neglect’ story is not universally true but rather one which is politically and generally unacceptable. It still did though work as a motivating factor for this

participant. Why was this? One answer is that an unpopular political belief may itself be enough of a novel injection into a resonant story to make it interesting (Silvia, 2008). Another answer is that this participant may be the “man in the street” (Extract 5.7) to whom the ‘neglect’ story still resonates.

5.3.3 Constructing the interest of the “family”

Another contemporary use of the ‘neglect’ story is used in a context which seeks the ‘family’ as audience. Part of the point being made by in Extract 5.9 is that although men with PCa and women with breast cancer share the experience of being diagnosed with cancer, their reactions to it are ‘shaped by their history, personal experiences, and the gendered nature of these diseases’ (Kedrowski and Sarow, 2007: 19):

Extract 5.9

If I contrast the women’s health movement and particularly breast cancer, and men, I think that one of the great things about the breast cancer movement has been that women are amazingly good at networking and that sort of collective action. Their ability to apply political pressure to the system is quite remarkable. I think men, by contrast, don’t network in the same sort of way generally and so trying to replicate the same kind of movement for men as we have for women I think is actually not what we’ve been about. It’s much more about saying that what we have to do with men is to take a more holistic, family based approach. So we need to be thinking about the impact of prostate cancer on sons and daughters and partners and how can we get sons and daughters and partners involved in some of the things we do, to show support for prostate cancer. So very often it will be about showing support for dad or whatever and our emphasis has been much more looking at the impact of prostate cancer on significant others and on building family involvement as the means by which we can generate this movement for change. Women, by contrast, are actually quite capable of - just on a women only basis - building their networks. When it comes to messaging, it’s partly hard edge messaging around the signs and symptoms to look out for, what are the preventative things you might be able to do, do you know what the gland does, and so on. So factual stuff, for sure, but it’s also about getting across the message that this has been a neglected disease, this is about precious men in your life, what can you do as a family member to help dad or whoever it is to take the right steps to make him aware of the options and the choices. (PCa-ORG/3/1)

The appropriation of the ideological ‘family’ frame resonates with a prior use of this frame in the United States where, in addition to the public construction of breast cancer sufferers as victims of gender-based neglect, family-based identities of wives and mothers were added to breast cancer sufferers (Kolker, 2004). This resulted in the

portrayal of breast cancer as not only as a threat to women but also to American families meaning that ‘the pool of victims impacted by the disease expanded significantly to include the entire family’ (Kolker, 2004: 831). What was of note in the narrative above was how the inclusion of ‘family’ not only increased ‘the pool of victims’ (p. 831) by “looking at the impact of prostate cancer on significant others” but also, in contrast to its use around breast cancer, included increasing family activism for change. A likely tension here though is that casting women and families as guardians of and campaigners for men’s health may perpetuate an alternative story—men’s lack of agency and passivity around their health.

5.3.4 Opposing “vested” interests

The final example of the contemporaneous use of the neglect story of PCa is particularly notable as it is used in an adversarial way which attempts to undermine other “vested” interests (Gamson and Modigliani, 1989; Benford, 1997):

Extract 5.10

Those with a, what might or might not be a vested interest will continue to try and stimulate the idea that there is some sort of, there is a benefit to be gained, by detecting more prostate cancers and they will use all the influence that they have to make that argument and the influence will be in terms of putting forward patient’s stories. It will be the politics of big P saying “this is, men’s health is being neglected, women’s health is being very prominent and this is a scandal”, and they will try and influence the people who make policy. And the people who make policy will be influenced to some extent by these appeals to them, but will be grounded by the fact that resource is limited, particularly now, and will be unwilling to embark on costly new initiatives, unless there is good evidence. On the one hand there is very good evidence that these new initiatives will produce benefit, which is not the case at the moment, or, the political impulse produced by those other things becomes so strong that they become less able to resist it. So there’ll be a tension, between the forces which are trying to push through a particular way of looking at things, and the forces of, that want to make sure, partly for good reasons, that things don’t change. And I guess (it’s overall is a good reason) they don’t, that we as a society should not waste our money doing things which we can’t show we’ve got a benefit. (PCa-MP/1)

Lakoff’s (2010) argument that ‘negating a frame just activates the frame, as when Nixon said, “I am not a crook” and everyone thought of him as crook [sic]’ (p. 72) suggests that repeating a particular story strengthens it. This indicates then that the repetition of the speech of the “vested interest” of big P politics—“men’s health is

being neglected, women's health is being very prominent and this is a scandal"—strengthens the gender-based 'neglect' story. I propose though that this appropriation is essentially ironic (see Bloomaart, 2005: 199-201) and instead serves to undermine and discredit the 'neglect' story. Thus, when this participant takes these gender-based neglect words which have existed 'in other people's mouths, in other people's contexts, serving other people's intentions' (Bakhtin, 1981: 294), he instead inflects them with his own meaning (Steinberg, 1999: 751), and makes them serve his own intention in his own context. Such an accomplishment is the crux of 'constructed dialogue' (Tannen, 2007) which is a discursive strategy used by a speaker not only to recontextualise words into a current discourse but also to augment their own credibility while diminishing the credibility of their opponents.

This medical professional highlights the virtues of his own position relative to 'society', namely "that we as a society should not waste our money doing things which we can't show we've got a benefit". His 'benefit' of choice is not the "benefit to be gained by detecting more prostate cancers" of the potential vested interests in their use of "patient's stories" as a 'trump card' (Russell and Greenhalgh, 2012: 50) in "influenc[ing] the people who make policy". Those "people who make policy" will at least include the UK National Screening Committee (NSC) who so far have not been sufficiently influenced to introduce a screening policy given that the 'harms from prostate cancer screening using PSA are currently likely to outweigh the benefits' (Mackie, 2010: 13). While currently there is no known benefit of screening for PCa by PSA testing, DRE or any other method (Andriole et al., 2009) there is widespread agreement that national screening programmes have been introduced due to such "vested" interest advocacy rather than clinical or epidemiological evidence (Brown et al., 2004; Jutel, 2009; Armstrong and Eborall, 2012; Faulkner, 2012; Welch et al., 2012).

5.3.5 Finding other "pockets of injustice"

Extract 5.6 and Extract 5.7 show the necessity of shifting the "terrible hidden story (...) [of] the legacy of neglect" (Extract 5.6) to other "pockets of injustice" (Extract 5.7) to keep the cause of PCa "fresh for journalists" (Extract 5.7). I asked PCa-ORG/3/1 what he meant by "inequalities" and these are also elaborated on by PCa-PC/1:

Extract 5.11

Oh, so either regional inequalities, postcode lottery type differences, different mortality rates by primary care trust areas, for example, differential provision of clinical nurse specialists in different parts of the country and then socio-economic differences around awareness in particular. We know almost without exception, that when you measure awareness of some aspect or another of prostate cancer, you know that awareness would drop off by social gradient, so whatever problem you have at an overall population level gets amplified once you start to look at people in less fortunate social backgrounds. (PCa-ORG/3/1)

Extract 5.12

Our role now is much more about uncovering data which can then be used to create a discussion about prostate cancer, so for example last year we were involved in uncovering some data on variations in mortality rates for prostate cancer so doing that by PCTs so you know, looking at what was the () variation in mortality, now in of itself that tells you nothing but what it does do is give you an opportunity to introduce that story to the media and then get them thinking about “well what are the inequalities in prostate cancer, why do they exist, what are the variations in access to treatment” etcetera etcetera. (...) I think the care and support aspects are absolutely critical. We have many hundreds of thousands of men who live with and beyond their prostate cancer, many of whom don’t necessarily have the right support to meet their needs and we need to do more about that. I think there are issues around equality and prostate cancer, in terms of the way that different men are treated, I mean you’ve got a couple of big equality issues. One, the (roles of older) men and we know there are issues around “ageism”, in inverted commas, in the NHS. We also have men of African descent are three times more likely to develop prostate cancer than white men, there are therefore issues around how we provide advice, what form of advice we provide, how we make sure services are culturally sensitive. There are issues around deprivation and making sure we get access, so that all men get access to the right services, I’m still struck by, I forget what the statistic is, but it’s something like, the prostate, the PSA testing rate is something like nine times as high in Hampshire as it is in Northern Ireland, now I’m not sure what the right rate is, but what I know is that is a clear function there of affluence and information, and you know, there are those sorts of issues which we really need to know and work very very hard to address. (PCa-PC/1)

There are several ‘pockets of injustice’ storylines evident in the above narratives. First are ‘postcode’ inequalities around mortality rates and support with the latter specifically regarding the provision of clinical nurse specialists. Narrating PCa around mortality rates is potentially relevant in the framing of PCa as an aggressive ‘tiger’ which one may die *of* rather than *with*, rather than as an indolent ‘pussycat’ PCa that one is likely to die *with* rather than *of* (Neal and Donovan, 1998).

A second 'pocket of injustice' is regarding socio-economic inequalities in awareness measured by "some aspect or another of prostate cancer" (Extract 5.11). The differences in awareness levels in the informed 'affluent' man and the uninformed man of "less fortunate social background" (Extract 5.11) leads to "what we have in the UK is a situation where the informed, just get themselves screened, and the uninformed, don't" (PCa-MP/3). However, this supposedly "clear function" (Extract 5.12) between "affluence and information" is instead rather murky:

Extract 5.13

Part of the reason why we're seeing so much more about prostate cancer now is that affluent men are living longer, so therefore they're living long enough to develop prostate cancer, and the most vocal people in society when it comes to health issues are the affluent, the dispossessed and the poor have very little voice in health (...) the men whose votes don't count are the guys in Glasgow whose life expectancy is only fifty-four years, those men won't develop prostate cancer, to them prostate cancer is not an issue, never will be probably (...) the issues now are very much to do with delivery of services and men's use of services, but because it's the affluent who are pushing this, it's very much based upon early diagnosis, screening programmes. (PCa-MP/4)

While the "dispossessed and the poor (...) to [whom] prostate cancer is not an issue" (Extract 5.13) may be understood as those who are uninformed and who don't get themselves screened (PCa-MP/3); being uninformed they cannot then be 'misinformed'. The potential paradox here is that the affluent and ostensibly informed men who "just get themselves screened" (PCa-MP/3) may instead be 'misinformed':

Extract 5.14

They've gone to see their doctor about a few symptoms that other men in the population wouldn't bother about, or they've seen an advert suggesting that they should have their PSA done, or they've seen a telly programme that's worried them about prostate cancer, so and what, potentially would happen if you, if every man was screened, is that you would throw up a lot of small harmless prostate cancers, which would then, probably put a proportion of those people into forms of treatment which were destructive. (...) One of the things that you need to realise is that, most of the symptoms of prostate cancer, are symptoms which are present, to some degree, in all men over a certain age, so if it so happened that prostate cancer was associated with baldness or greying of the hair, then alerting people to the fact that if they've got baldness or greying of the hair, they might have prostate cancer, isn't going to help very many people. And the same applies to passing your water slightly more frequently, or getting up at night, or your sexual function deteriorating. Almost everybody, when they get over a certain age, these are symptoms that

are a common experience, and are associated, mostly with benign disease and the distinction between the symptoms produced by benign disease and the symptoms produced by malignant disease, is, is nothing, there is no difference. So the bladder symptoms you get with prostate cancer are precisely exactly the same as the symptoms you get with benign disease of the prostate, and it's only if you've got life-threatening metastatic prostate disease that you get other, additional symptoms specific to the cancer, and then it's too late. So, because it's very difficult to distinguish from, what is, if you like, normal aging, you end up by having posters like I've noticed they've got at [a London Tube Station], saying, "are you getting up a couple of times a night, if so, go and see your GP". So, the person would go and see their GP, they'll have a PSA done, probably, they'll be found to have a, a slightly raised PSA, they will or will not have a biopsy, that will or will not be positive, and they'll end up at the end of it, having to make decisions about themselves which will be extraordinarily difficult, and will raise all sorts of anxieties and unhappiness, and yet they started off from a position which was probably barely distinguishable from the rest of the population of their age. (PCa-MP/1)

Although as men get older they are more likely to be diagnosed with PCa, the rates of incidence of PCa for the most elderly are declining; for those aged 85+ from the mid-1990s and for those aged 75-84 from the early 2000s (Cancer Research UK, 2013c). One explanation for this is as more and more men are diagnosed younger there are increasingly fewer men who have not been diagnosed by the time they reach their 70s. In his revisionist account of chronic illness, Armstrong (2014) suggests that 'natural processes of ageing' (p. 15) are pathologised into new diagnoses of chronic illness. These natural processes of ageing most certainly include the physical changes in men's bodies such as benign enlargement of the prostate and lower urinary tract symptoms (LUTS) to which the medical professional in Extract 5.14 refers. LUTS are present in more than 50% of men aged over 60 and nearly 100% of men aged 90 (Weight, 2013)—statistics likely to be similar for the "baldness or greying of the hair" (Extract 5.14) in men of this age. The resulting diagnoses from the pathologisation of these natural processes, Armstrong (2014) argues, are not 'uncontaminated by contemporary world views or theoretical frameworks' (p. 16)—which at least include information on the likes of posters at London tube stations with the seemingly simple suggestion to go to the GP who will likely offer a PSA test, a point also made by the public consultant below:

Extract 5.15

Life expectancy is extending, the more that goes on, the more men get old enough to "achieve", in inverted commas, a diagnosis of prostate cancer

because prostate cancer is so typically a disease of older men, so you have this problem that in terms of the demographics, you're adding, more men, to the pool of men who could get prostate cancer, by virtue of getting older, so how is that built into how you understand the perception of prostate cancer, if you keep saying "it's not just old men that get prostate cancer" and concentrating on the men in their fifties and sixties, perhaps by suggesting to them in a very simple fashion that the PSA test for example is something they should know about, because I think once you give people the idea that there is some sort of intervention that might work, is that they take a qualitative understanding of that, which is "oh it's an intervention that might work." (PCa-PC/2)

Also notable in Extract 5.14 is that the pathologisation of these natural ageing processes may increase the chance of detecting non-clinically relevant PCas and induce overtreatment (Wolters et al., 2012). Men diagnosed with "small harmless prostate cancers", this participant suggests, may end up making "extraordinarily difficult" decisions around treatment—a situation not unlike the 'semantic slippage' (Aronowitz, 2009: 435) in naming certain diseases as 'cancer' rather than an underlying risk state and which results in those diagnosed adopting decision-making styles typically used in more advanced cancer states. Making seeming simple suggestions to men about what they should do about their LUTS may then be seen by some, though not all, as misinformation. This may then be a, likely contested, type of injustice around PCa

Aronowitz (2009) also argues that, especially regarding chronic diseases, new screening and diagnostic technologies and disease definitions lead to 'the recruitment of larger numbers into chronic disease diagnoses' (p. 417). What this leads to is a 'larger and highly mobilised disease/risk population, resulting in an expanded market for interventions and greater clout for disease advocates' (Aronowitz, 2009: 417-8):

Extract 5.16

[MWPCa] are advocating for themselves, in general compared to the rest, other cancers, they're a healthy bunch of men, they normally aren't smokers, because otherwise they would have got their stroke or their heart attack in their fifties or sixties and not lived to have got their prostate cancer (...) they tend to be men of an age where they've either made it in their career or they're comfortable financially, or they're sorted in some shape or form, they're unlikely to be you know, thirty-five years old, living on benefits and wondering where the next ten pounds is coming from, in general they're sorted out in some shape or form, they're living on a pension, or they're, after a successful career, so they're better able to advocate for themselves, I think, you know, they're in a better position to stand up and say, you know, "I've got prostate cancer, and here's what it means, and here's the treatment I want." (PCa-MP/5)

Affluent and self-advocating MWPCa may form part of the “many hundreds of thousands of men who live with and beyond their prostate cancer” (Extract 5.12) in the context of what is in effect, after treatment, a chronic illness (Doyle-Lundred 2007; Oliffe and Thorne 2007; Oliffe, 2009). An increased mobilisation of a PCa population and greater clout for disease advocates (Aronowitz, 2009) more fully meets the seven characteristics of a successful grassroots survivors’ organisation (Kedrowski and Sarow, 2007: 52-60). These: 1) form around long term health hazards; 2) adopt and use the organisational structures and practices of existing activist organisations; 3) offer their own experiences as evidence; 4) depend on an empowered and educated activist support base; 5) depend on the media and courts for keeping issues alive and in the public’s agenda; 6) depend on women as activist leaders; and 7) need financial and promotional support from business and industry to ensure long term viability.

Whether MWPCa are misinformed or uninformed, they may still need someone to fight their corner as victims of prior neglect and in present need of protection and caring. Extract 5.4 shows that unlike the women’s movement or the breast cancer movement there was no equivalent of “radicalising lesbians” for prostate cancer, made explicit by another participant:

Extract 5.17

People didn’t feel that there was anyone fighting the good fight for prostate cancer, now, frankly it doesn’t really matter who does that as long as someone does it and someone does it effectively. (PCa-PC/1)

This is not to say that there were no voices around PCa; there were a number of PCaOrgs at this time but instead of fighting the good and effective fight, they “fought like cats and dogs, and (...) very often undermined each other’s cause by contradicting each other, saying different things, the most obvious, but not the only example, being around the PSA test” (PCa-PC/1). That there is disagreement over aspects of potential reality of PCa is not surprising as the very existence of social movements around health suggests differences around the meaning of some aspect of reality and a struggle between actors to invest this with their preferred meaning (Benford and Snow, 2000).

5.3.6 Age inequalities

The “(equality) issues around ‘ageism’” envisioned by the participant in Extract 5.12 was also reflected on by others:

Extract 5.18

Old men are seen to be, almost a nuisance, and that’s where the expression “dirty old men” probably comes from, you don’t hear of “dirty old women”, you know, “dirty old man”, and it’s and it’s this sort of ageist approach to the whole damn thing, age and modern society, (), older men are not seen as being, as relevant for health care either for prevention, promotion. (PCa-MP/4)

Extract 5.19

the huge problem, I don’t think the prostate cancer brotherhood understands, is that the average age from, of death from prostate cancer is significantly higher, than all the other cancers, that doesn’t mean, you don’t approach it, it does mean, to my mind, that you approach it in a different way, you are trying to solve a different problem, and I’m not sure they see that, because you will come across phases like, “it’s not just a disease of older men” (...) just because you know that’s what makes people pay attention, but in my, inside my heart I’m screaming “even if it was just disease of older men why do you then think that that’s good enough to let a man die of cancer? Because he’s older?” Is that all old people do? (PCa-PC/2)

Narrating PCa as “not just a disease of older men” to make “people pay attention” or to capture their ‘interest’ thus has the potential to ignore the needs of older men and not help in addressing the lack of attention to potentially common idioms such as “dirty old men”:

5.4 Discussion

This analysis shows how advocates around PCa have sought to produce or transform meanings around PCa and the narrative forms or elements they have used in doing so. What is of initial relevance is that a story of ‘neglect’, already successfully used in the early 1990s by breast cancer movement activists in the US (Kolker, 2004), was used in the late 1990s by actors around PCa in the UK. Critically, however, the neglect story became no longer acceptable as a story to be told and heard, at least to the media producing audience.

The success of the neglect' story of PCa was due to the combination of novelty and familiarity—necessary elements in making a story a story (Polletta, 2006) and which created 'interest' (Silvia, 2008) around PCa in the years following the advent of PCaOrgs into the UK. Borrowing this neglect story in the late 1990s was a discursive strategy which made this frame 'sound right' (Tannen, 2007: 62) and 'fit' or resonate with audiences' previous experiences. The 'silence in the discursive field in which [advocates around PCa] were fighting' (Steinberg, 1999: 752) meant they lacked a prior familiar history to draw upon to cope with their novel status as victims. This combination of novelty and lack of familiarity and comprehensibility led to uncertainty and confusion (Silvia, 2008) and the situation where one "didn't know what to do in those days". There was, however, a 'spilled-over' familiarity from women's activism around breast cancer in the gender-based neglect frame and it was this borrowed familiar story alongside the novelty of men as victims which juxtaposed the resonance and dissonance necessary to stir realisation and create interest. The broadening of blameworthy agents of injustice from government to society may constitute a basis for a necessary 'normative revision' (Turner, 1969: 391) in how a person, or group of people, comes to look at a problem. The problem is no longer that men suffering and dying from PCa is a result merely of their own passivity but rather that they are also neglected by both society and central government; the former not making "a fuss" and the latter giving worse than a "derisory" amount of money to PCa. Thus, in summary, the neglect story was familiar and novel in several ways:

1. It was familiar as it had previously been used by breast cancer activists in 1990s
2. It was novel as men rather than women were neglected—this particular novelty also was familiar as it was gender-based like its use in the breast cancer context
3. It was familiar as it articulated hegemonic discourses about men's passive health behaviour
4. It was novel as it contrasted the silence of men with the noise of women
5. It was novel as it broadened the attribution of blame from government to all society

There was a need for media producers to "twitch" the plot from time to time in order to retain audiences' *interest*' (Seale 2002: 36, emphasis added). A strong 'twitch' takes the form of a 'reversal, in which polarities previously set up may suddenly be reversed,

so that evil and good swap places to provide an entertaining disruption of expectations' (p. 36). The same may be said here about how advocates around PCa 'twitch' the plot for their media producing audience. While there are some interesting, and very relevant, instances of a contemporary use of the neglect story, there is also a shift from the injustice around the "legacy of neglect" to "other pockets of injustice" in contemporary messaging around PCa. These include 'postcode' inequalities around mortality rates and support, socio-economic inequalities in awareness, and age inequalities. There are few studies around socio-economic deprivation and risk for PCa (for one exception see McVey et al. 2010). The findings above are evidence that there is disagreement over how MWPCa may be socio-economically framed: as affluent and self-advocating survivors; as uninformed; or as misinformed. What is more, successful frames may combine contradictory ideas to meet the different strategic needs of the frame-makers (Polletta and Ho 2006).

What is important in this study is that there are increasing numbers of men being diagnosed with PCa and correspondingly 'recruited' onto the PCa disease spectrum (Aronowitz, 2009). If these men are indeed "a healthy bunch of men (...) [who have] made it in their career (...) [and are] better able to advocate for themselves (...) they're in a better position to stand up and say, you know, "I've got prostate cancer, and here's what it means, and here's the treatment I want"" (PCa-MP/5) then this will 'result in an expanded market for interventions and greater clout for disease advocates' (Aronowitz, 2009: 417-8). It also makes this a constituency which more fully meets the seven characteristics of a successful grassroots survivors' organisation (Kedrowski and Sarow, 2007). Likewise, those men who are uninformed and victims of prior neglect need someone to fight the "good fight for prostate cancer", as do those who are 'misinformed'.

Chapter 6 Changing narratives of disclosure by MWPCa

6.1 Introduction

My aim in this chapter is to explore the changing disclosure behaviour of MWPCa by analysing research interviews with MWPCa carried out in 2000 and 2010. Though the term ‘disclosure’ has been used to describe how cancer patients may openly discuss their diagnosis and thoughts and feelings about the disease (Hilton et al., 2009), it is used in the main here to refer to the initial telling of a PCa diagnosis from a man with this condition to his family and others (Gray et al., 2000). It may also refer to situations when men discuss being involved in disclosure conversations with other MWPCa. It is thus not here considered as the announcement of diagnosis of PCa from a medical professional (see Mróz et al., 2013).

I focus on disclosure for three reasons. First, my research question in this thesis asks how PCaOrgs and the UK print media have been a force for change in the UK regarding how this condition has been addressed and experienced by MWPCa. A finding from Chapter 4 demonstrates that PCa as a “taboo disease that no one dares talk about” (Figure 4.4) was more explicitly and frequently articulated in the media illness narratives of MWPCa in 1990-2000 than those in 2000-2010 (§4.4). A finding from Chapter 5 demonstrates that though towards the end of the 1990s “prostate cancer was just beginning to come out of the shadows of neglect” (Extract 5.1) and that when men “would have their illness, they would not talk about it, they would die quietly” (Extract 5.2), this was less the case towards 2010. Though these findings were not known when the MWPCa were interviewed in 2000 and 2010—and thus disclosure was not an *a priori* research enquiry—men in both periods were asked about how they told others about their illness. Secondly and relatedly, this thesis focuses on changing narratives of PCa over time. Though I draw on ideas from several narrative and literary scholars, I use as a basis Bury’s (2001) three non-mutually exclusive narrative forms: contingent, moral and core narratives (§2.4.3). Though all three are useful, contingent narratives of coping in particular address the practical management of interactional

issues of disclosing illness to family and friends. Finally, there are few studies which consider how MWPCa disclose their illness. These reasons provide validity for my focus here on how MWPCa disclose their illness to a variety of audiences.

I specifically ask: 1) are there differences in how MWPCa disclose their illness over time and to various audiences; and 2) what narrative forms and elements do MWPCa draw upon when disclosing their illness to various audiences. I present my findings in four sections: disclosing to 'partners'; disclosing to 'children and wider family'; disclosing to 'friends and others'; and disclosing to 'colleagues'. I suggest that many of the same narrative forms and elements occur across these audience types. While one might expect less interactional difficulty for MWPCa in disclosing their illness when a tragic genre of 'taboo' may be less available to draw upon, my study suggests that with some audiences this is often not the case. I close this chapter by briefly discussing the reasons for this increase in interactional difficulty in more detail and some potential consequences of it.

6.2 Disclosing to partners

In large part, men interviewed in both 2000 and 2010 told how they made a prompt disclosure of diagnosis of PCa to their partners and how they received welcome support: "my wife's been a wonder with me all the time and she's been my right arm all the way through it" (Taylor 2000). Men mainly disclosed in the expectation of hearing worry from their 'partners' and either pre-empted this or responded to it by indicating an anticipated or desired good treatment and recovery. In wondering how to disclose, Harry (2000) implicitly anticipated the worry of his family and sought to counter this worry with reassurances of his recovery:

Extract 6.1

I think the impact of the diagnosis mainly was as I said coming home, I could recall nothing whatsoever about the journey; how do I explain it to my wife and my family in particular because there was a large family involved and I suppose as much as anything I wanted to offer those people the reassurance, even at that time perhaps silly, of there was life thereafter. (Harry, 2000)

Sometimes the diagnosis, in both time periods, was made with an accompanying partner. Ernie, one of the oldest participants and from South Asia, unusually received his diagnosis in the company of both his wife and children. Ernie reconstructed a

conversation with his wife and children and described his expectation of “worry” and “shock” from his wife and children in their mutual knowledge of the death of his father from PCa some years previously:

Extract 6.2

Ah yes my whole family, my son was with me, my wife, my two daughters yes (...). Aw probably it was a big shock for them like you know so, but I told them “it’s nothing to worry about”, well I was the brave one, I said nothing to worry my wife but “my father died of it so I got it and these days this modern equipment and the technology so high, the success rate so high so I’ll be, alright”. (Ernie, 2010)

Ernie’s narrative demonstrates how he transformed this worry with an anticipation of his likely “alright” recovery given the high success rate associated with modern treatment. Likewise, Neil (2010) described how his wife, on hearing “the word ‘cancer’”, and thinking of it as fatal, “was anxious that I get the treatment quickly, get rid of the cancer and just start the recovery process”. One man reported his prompt disclosure to his partner with an explicit moral imperative as “the *right* thing to do” (Fred, 2010) (emphasis added). Fred wanted to model his disclosure on his wife’s disclosure of her breast cancer to him some years previously; he was sorry though that it “brought back some of those early stages for her” (Fred, 2010). Keith (2010) reconstructed his disclosure conversation with his wife while simultaneously reconstructing his consultant’s confidence in his treatment and recovery:

Extract 6.3

Well, I, yeah well obviously I discussed it with [wife] that evening, and I said to her “well, I’ve to go to the scan, but the consultant is confident that if I have my prostate removed, that will sort the problem out”, and you know, that’s the way it was, and at the same time, we, well probably when I say we, but the way that I was going to deal with it, was that nobody else apart from [wife] and I would know about it until, until we had to tell them. (Keith, 2010)

Contingent narratives of coping are made possible through core narratives—culturally available genres or ways of talking ‘which allow or constrain what is said and how it is expressed’ (Bury, 2001: 278). The above narrative extracts demonstrate that upon the disclosure of illness to their partners, MWPCa expected to hear worry and concern regarding potential poor outcomes and suffering and fitting with a ‘tragic’ genre (Smith, 2005). Genres though, argues Bury (2001), are always open to negotiation,

always “at risk” (p. 279) in the everyday interactions people face, especially, suggests Bury, with their families. Likewise, in his analysis of a news delivery sequence, Maynard (2003) suggests that rather than thinking of a certain type of news delivery, for example disclosing PCa, as inherently bad, participants in such a disclosure event ‘must *interactively* establish the valence of the news and just how good or bad it is’ (2003: 89, emphasis in original). Similarly, Maynard (2003) proposes, that participants in an interaction may each choose to respond to an ‘intended valence’ (2003: 116) in a way which assesses it ‘positively or negatively, usually but not always in accord with displayed anticipations’ (p. 106.). Though MWPCa anticipated the tragic genre of worry from their ‘partners’, the above extracts demonstrate that these men did not respond in accord with this displayed anticipation.

Instead, MWPCa disclosed their illness to their ‘partners’ with an ‘intended [positive] valence’ (Maynard, 2003: 116) which included an anticipated treatment and recovery. In this way then, they countered the tragic genre and instead advanced a romantic narrative genre. A romantic genre—not inevitably about love—indicates that a ‘change for the better is in the air’ (Smith, 2005: 26). The above narratives demonstrate the triumph of a good treatment and recovery over the adversity of illness. They also demonstrate the ‘co-authored’ (Williams, 1984: 181) nature of these disclosures in that they are bounded by and constructed in negotiation with this audience. This co-authorship though also includes those not present in the immediate interaction such as when Keith (2010) in Extract 6.3 reconstructed the voice of his consultant in his disclosure to his wife. Frank (2010: 10; see also Hyden, 1997) suggests that stories work to emplot so that a particular future is not only plausible but compelling. All of the above stories work to ‘emplot’ a compelling romantic genre using an anticipated recovery to counter the expected or explicit tragic genre of worry from this audience.

That genres are open to negotiation (Bury, 2001) was also seen in a reverse way in Calvin’s (2000) narrative (Extract 6.4). Calvin’s heightened awareness of potential death indicated an “amplified awareness of suffering” (Smith, 2005: 25) typical of a tragic genre. He reconstructed in detail his wife’s countering of his displayed genre:

Extract 6.4

Suddenly it's like somebody saying you know you're going to die and you'd never thought of dying. And I was disturbed by it, rather quiet I suppose, pensive, worried. And we're walking back to where we had parked the car, passing a café and my wife said "Well let's go into the café, let's talk about it." So we went into the café and we sat down and we had a cup of coffee and she says, well I think I said "Where are we going from here?" to her or something like that and she says "Well what are you worried about?" I said "Well you know it's a disaster, I'll have to give up work, I'll have to do this, I'll have to do that." And she says "Well why, you know, you're here today, you're in perfectly good health, you're going to be here tomorrow aren't you?" I said "Well yes," "And you'll be here the next day." She said "Well there's three days, what are you worried about you know we could be knocked over by a bus going for our car or something you know so why is this suddenly the big disaster. Because it's not happening tomorrow, it's not happening next week, the next month, okay it's not very good but you know let's be positive about it. (...) And suddenly I thought 'well yes I am here today, there is a tomorrow, there is a day after that' and that was very encouraging. And she has been tremendously positive and supportive right the way through. But having said that, at times it has got to her. There have been tearful moments because she doesn't want to lose me; I wouldn't want to lose her so moments have become a little bit difficult. (Calvin, 2000)

Calvin's wife negotiated with him in his choice of genre in his disclosure narrative to advance instead the 'fundamentally optimistic' (Smith, 2005: 26) romantic genre; this included anticipating a good, albeit perhaps temporary, recovery. This negotiation is understood as a 'genre war' (Smith, 2005: 28) where interactants compete over how to interpret aspects of reality. In addition to genres being "'at risk'" (Bury, 2001: 279) in everyday interactions, Bury suggests that people are not consistent in their choice of genre and may move between, say, romantic and tragic as they see fit. Though Calvin indicated his glad acceptance of his wife's proffered romantic genre at that point of time, it is evident that this genre was also "'at risk'" (p. 279) in difficult "tearful moments" since.

There were though assorted deviances in that some disclosures were delayed or the anticipated worry was not in the end effectuated. Three men in 2010 spoke about how they intentionally delayed disclosure to their partners. Don delayed disclosing to his wife until compelled to do so when she saw him feverish after his biopsy:

Extract 6.5

I was referred to the hospital, around about [date], and throughout this time I was subject to MRI scans, ultrasounds, numerous blood tests and the biopsy,

and up until the biopsy I'd not told my wife or a living soul, a word of my circumstance. I drove myself to hospital each time, drove home again, and drove home, a little discomfort after the biopsy, and got in my house and found that I was feverish, I was shivering, shaking. My wife was out, and I got a blanket, and sat in the lounge trying to shake the fever off knowing she would come into the house shortly, but she came, found me, shivering, with a fever, which didn't last more than two hours after the biopsy, it was just a reaction. And I told her then, and being firm with her, I says 'look this is not a matter of your sympathy for me, it's a matter for me dealing with, so don't start blubbing, just do the things that I ask of you and just trust me to deal with this'. But if I could have gone the whole, nine yards, without telling, I would have done, and that way, the worry's contained, the anxiety's all mine, and I don't share it and people don't have to worry about me, which is a, part of, I prefer, but again it's a character thing, I'm pretty much a secretive person, and would object to somebody else keeping me in the dark, how about that for hypocrisy? (....) I went for a year and only told my wife. I went from diagnosis, prognosis, referral, prognosis, diagnosis, right up to treatment and then, four months after treatment and getting what please God is a cure. So I went for sixteen months and never told a soul, except my wife, and she, credit to her, she never blurted it out to anybody either. (Don, 2010)

Don's narrative is exceptional in its seemingly ostentatious display of hegemonic masculinity (Courtenay, 2009). Maynard (2003) suggests though that a 'stoic response [is] an interactional and not just psychological phenomenon. Deliverers [of news] (...) sometimes intentionally, often inadvertently encourage stoicism on the part of their recipients' (p. 121). Don's forbidding of his wife to either "start blubbing" or to 'blurt' out his diagnosis of PCa would seem to be an intentional imperative, rather than encouragement for a corresponding stoicism on the part of his wife. As such, stoicism, though advanced by Don and described by him as "a character thing", may well also be a co-authored feature of this narrative demonstrated in his reconstruction of his wife's collaboration with him. Don's disclosure though delayed, and thus not prompt like the others described above, still indicated an expected hearing of worry and concern from his wife. To this extent, Don's narrative also drew on the romantic genre but one perhaps less open to negotiation (Bury, 2001).

Two other men in 2010 intentionally temporarily delayed disclosing to their wives due to particular circumstances. Joe talked about how he made a "terrible mistake" in disclosing his PCa to a friend just before they went off together on a cycling holiday before he told his wife: "so I just said, "I'll not tell her, she'll only be worrying about it, and I'm going to go anyway" (Joe, 2010). Hugh, who worked overseas,

planned in detail how he would tell his wife when he returned home three weeks after his diagnosis:

Extract 6.6

I says “oh right, can you come in a wee second”, ((laughs)). I knew the moment I told her to sit down for a second she went on guard immediately, suspicion was too strong a word but she knew something was coming that was out of the ordinary. So, I had practised what I thought I would say, to lead into it, but there isn’t any way of, being kind with the word cancer, at the end of the day, I thought I’m actually just going to get her more and more upset if I beat around the bush, and I could see that she was beginning, “what, what’s coming?” So, the only way to deal with that was, I just said, very very simply, “I’ve got cancer”. And you know, she reacted the same way I did, immediate shock. She was actually very good. She’s been tremendous throughout all of this. We’d a bad day that day, so we did, but you learn, you cope, she’s been brilliant. (Hugh, 2010)

Hugh and Joe’s narratives of disclosure indicate that they expected to hear worry from their wives. In Joe’s case his decision not to proceed with any negotiation with this tragic genre resulted in regret. In Hugh’s case, though his negotiation of genre began some weeks before his disclosure as he practiced what he might say to his wife, this was then re-negotiated in the immediate interactional setting of his disclosure.

Another type of deviant disclosure was when Charlie (2010) told how his expectation of shock and concern from his wife and children did not happen:

Extract 6.7

Interviewer: And then what about telling others, your wife was with you whenever you heard?

Charlie: I don’t know whether what you see in soap operas and the like is the real world, where somebody near to you goes into a state of shock when they receive this information, at no stage, did either my wife or my daughters show shock and horror, maybe it was that in a previous illness, I should have succumbed to the problem and I survived and whether they keep this in the back of their minds, that things aren’t desperate, I don’t know, but I wouldn’t say that there was, there was shock or panic, maybe they disguised it well. (Charlie, 2010)

Charlie’s disclosure narrative made explicit his knowledge of the culturally available genre available through “soap operas and the like”: family members go “into a state of shock” when they hear a disclosure of illness from their husband/father. His attempt to explain this missing tragic genre—“maybe they disguised it well” or maybe it

resulted from their background knowledge of his good recovery from a previous illness—demonstrated his surprise that this expected genre was not advanced. His narrative may though still be understood to correspond to the examples above as it still shows a negotiation between a tragic and romantic genre. In this case it was the implicit romantic genre by his wife and daughters of an expected good treatment and recovery that worked to counter the ‘soap opera’ tragic genre that Charlie expected.

The final deviant example was Graham’s (2010) brief summary (the only reference in his interview of disclosing to his wife) which was in the context of his receiving his diagnosis from his consultant:

Extract 6.8

‘well Graham, you’ve got cancer’, (...) he said the good news was that I think it was only two out of the ten samples contained cancer, the other eight were clear, so it was quite possible that we’d got it in its very early stages which he said was a very, was very good news, so he spent I think the rest of the twenty-five or thirty minutes, very quickly going over a whole list of options, as to where we go from here, and sent me home to think about it, for three or four weeks to arrange another, to go back and talk about what we decided to do, so, it was quite a shock and I remember phoning my wife and telling her that that’s what had come out of it. (Graham, 2010)

Graham’s summary disclosure to his wife from his diagnosis conversation with his consultant, though prompt, ostensibly suggests that he did not anticipate a tragic genre of worry on her part. What is evident however is that the ‘bad’ news given by the consultant of “well Graham, you’ve got cancer” is combined with the consultant’s “very good news” that his PCa was caught “in the very early stages” with “a whole list of [treatment] options”. It is thus reasonable to infer that Graham’s brief reported statement of disclosure to his wife was a reconstruction of his diagnosis conversation with his consultant and that this drew upon a romantic genre of an anticipated triumph over the adversarial illness.

In sum, MWPCa interviewed in 2000 and 2010 disclosed to their ‘partners’ in very similar ways. Though there were deviant examples, men in both periods made prompt disclosures and received a welcome supportive response. All the narratives, even deviant cases, demonstrated the negotiation between a tragic and romantic genre. In the main, these narratives commenced with an at least anticipated tragic genre and were subsequently countered by a romantic genre. In one instance, though

a tragic genre was anticipated it was not—somewhat surprisingly to the MWPCa—voiced in the disclosure interaction. All narratives were co-authored with this audience.

6.3 Disclosing to ‘children and wider family’

Seemingly similar to disclosing to ‘partners’ was that when MWPCa disclosed to ‘children and wider family’ they expected to hear worry and receive support. What was different to disclosing to ‘children and wider family’ though was concern by the MWPCa over the additional anxiety their disclosure caused this audience. Also, unlike that received from ‘partners’, the support from ‘children and wider family’ at times seemed to be unwelcome, for example in the “excessive” support received by Barry (2000). One potential consequence of this was, unlike the prompt disclosure to ‘partners’, disclosures to ‘children and wider family’ were sometimes delayed. That Don (2010) “went for a year and only told his wife” was also the case for other men in each time period who initially told only their wives and ‘kept it quiet’ from others. Taylor (2000) delayed telling his mother until almost the time of his operation as he “did not want to worry [her] because my father had died only nine months before, so I was a bit concerned”. This expectation by MWPCa of hearing worry demonstrated that these men anticipated that their ‘children and wider family’ would draw upon a tragic genre of suffering upon hearing their disclosure of illness.

Also ostensibly similar to disclosures to ‘partners’ was how MWPCa sought to counter this tragic genre with an optimistic romantic genre based on a hoped for good treatment and recovery. Mark’s (2000) family “just said ‘get on with it’ you know, I think they were relieved at least there was something wrong and that I was taking a very positive attitude about it”. Finlay and Graham, though speaking ten years apart, told of the relief felt by their respective families when they could present an at least attainable treatment and recovery:

Extract 6.9

I kept it to myself. I told my daughters, [youngest daughter] is a nurse, my youngest daughter she's another very positive person “Oh you'll be alright dad”, [oldest daughter] had a little weep (...) I think, I think my attitude rubbed off on the family, they took it that I was happy, that something was happening, something was getting done. My personality went back to itself again, I got

back my bubbly self and said “Well I'm going in for an op, that's it and they're going to fix me” ((laughs)) so I think that rubbed off on everyone, including [wife]. (Finlay, 2000)

Extract 6.10

I think even in terms of family, my own parents were still alive; I was able to talk to them about it quite openly. It's slightly worrying because they get very anxious and so you know that you're putting an additional anxiety on people when you tell them that you have cancer, and, but then on the other hand they want, I mean, they want to support you and go through it with you, so but that they were quite relieved when it was all solved in the end. But no, I can't think, you know, certainly within immediate family, even to some extent, my sister, siblings, I wasn't, I didn't go broadcasting it, but certainly the people that I'd been in any sort of reasonably close relationship with I felt I had to let them know, and that this was something we were going to have to confront. (Graham, 2010)

That Finlay's positive attitude “rubbed off on everyone” is indicative of how welcome a positive disclosure is in enabling a convenient ‘wrapping up’ (Wilkinson and Kitzinger, 2000: 803) of the conversational burden involved in disclosing illness. Though his eldest daughter “had a little weep”, all others accepted his displayed valence in their work to establish just how good or bad this disclosure news was (Maynard 2003) and did not renegotiate a tragic genre (Bury, 2001). Notable also in Finlay's narrative was his work to maintain his pre-illness “bubbly self” identity—fitting with a contingent narrative of normalisation (Bury, 2001).

Keith's (2010) disclosure to his children, delayed until “a very short time before [he] went into hospital”, again reconstructed his consultant's words that a radical prostatectomy “will sort the problem out”:

Extract 6.11

we just arranged for all the family to be here, when I say all the family I mean our children, and we had them here, and I told them, the problem, and I said “but listen, this, this should be okay, the consultant has told me, ‘removal of the prostate [sic] will sort the problem out’”, and that's the positive way that I looked at it, and you know needless to say, I suppose they were shocked, because they had no suspicions whatsoever, and I suppose they all felt sorry for me, as such, but we all remained very positive about the thing. (Keith, 2010)

Fred (2010), who modelled his disclosure of his PCa on his wife's disclosure of her breast cancer to him, knew that his children also had knowledge of their mother's previous successful treatment. He delayed his disclosure to his children until he was

able to tell about an optimistic treatment and recovery outcome. Notable in Fred's narrative (like Finlay's in 2000, see Extract 6.9) was his work to maintain his pre-illness identity—again fitting with a contingent narrative of normalisation (Bury, 2001). Of interest, though not explored further here, is that Fred (2010) and Finlay (2000) were MWPCa matched along age at diagnosis/age at interview and socio-economic variables (Table 3.9). Of further note is that when his son told him concerns about his own genetic risk of cancer, Fred also negotiated with this tragic genre to posit a more hopeful outcome:

Extract 6.12

We didn't actually speak to the children about it, until I'd, I'd been diagnosed and sort of the treatment was being lined up (...) but when I was able to say to them "well, you know I also have to have treatment but it's not spread and it's going to be fairly straightforward and it's probably not going to make, you know, a huge difference to how I am", then, they, they sort of took it in their stride (...) my oldest son did ask that about whether because both my partner and I had had cancer whether he would, that meant he was more likely to have cancer, later in his life, and, I think we sort of, we reassured him that quite a lot of causes of cancer were environmental, and although there was a genetic factor, the other thing to say was that treatment was advancing so fast. (Fred, 2010)

Though temporarily delaying disclosure to 'children and wider family' was a feature of men's disclosure narratives, some men significantly prolonged the delay and in some cases chose not to disclose at all. Such lengthy delays were done in both time periods to avoid worrying elderly parents, vulnerable adult children, and young children. Nathan (2000) limited disclosing his illness to his wife and kept quiet about his PCa to his children until he "couldn't really keep it a secret any more":

Extract 6.13

I think that it's been very traumatic [for my family], I did keep it back from the children for a long time when they came to visit, actually they came to visit me in [American city] and they stayed in this [accommodation] and there's a big sign that said 'American Cancer Society' so I think the cat was more or less out of the bag. We went to a kind of, there was a kind of a prayer meeting that we went to and somebody mentioned prostate cancer and then they became aware of it. (Nathan, 2000)

Lawrence (2000) said that he did not tell his 88 year-old mother as it was "a worry that I would not put on her shoulders, I mean I've had it now for nearly four years, she

doesn't know and I just want to leave it that way, I think it's better that way". Both Robert and Don in 2010 also made lengthy delays in telling their children:

Extract 6.14

I think, it was obvious I went in for the operation but I said, or we just said it was a man's problem, you know, didn't say it was cancer, and I remember I was I took her out for lunch and told her some time afterwards (...) She was pleased I didn't tell her ((brief laugh)), cos I was able to tell her "I'm on the mend", you know, "that's it", you know, I didn't say I was cured, but "I'm on the mend and it's been done, nothing to worry about". (Robert, 2010)

Extract 6.15

I never told a soul except my wife, until I'd been to the specialist on [date], when he'd comforted me by telling me "it's under control and you're looking at a cure", it was at that stage I could tell everybody but while I was still threatened with prostate cancer I didn't want my daughter to know, I didn't want her to be terrified, so she was kept in the dark throughout that year's treatment. (Don, 2010)

Although Don did not mention that his daughter was particularly vulnerable, Robert's daughter was pregnant and bipolar. Both Don and Robert, though tentative in Robert's case, drew upon a romantic genre of cure and recovery in their disclosures.

Thus, the above narratives demonstrate the negotiation between tragic and romantic genres in disclosing to 'children and wider family'. MWPCa sought to counter an implicit or explicit tragic genre in at least two ways: delaying their disclosure temporarily, significantly or permanently; and by indicating an optimistic treatment and recovery. However, as with disclosures to 'partners', there were deviances to the negotiation from the tragic genre to a romantic one. In contrast to an expectation of worry, two men in 2010 spoke of the lack of worry from their mothers:

Extract 6.16

My mother, ((laughs)) she said, "oh that's what my old boss died off", I said, "oh thank you mother, that's very reassuring", ((laughs)) she doesn't believe I've got it really (...) She imagines that I'm you know, I'm going to be cured, if I've got it, it's not that serious and I'm going to be cured any minute (...) I just laugh and say, "oh, if only" ((laughs)). (Quinn, 2010)

Extract 6.17

When I told my mother she was, she used to be a nurse, so she knew that it was recoverable, so she, I was surprised how well she took it, she wasn't, she didn't seem too worried. (Neil, 2010)

In different ways, both mothers drew upon a romantic genre of an optimistic treatment and recovery—both Quinn and Neil though expressed their surprise at the lack of worry showed. Quinn told how he expected reassurance rather than disbelief that he had PCa. His “oh, if only” demonstrates his work to renegotiate the optimistic “it’s not that serious and [he’s] going to be cured any minute” romantic genre choice of his mother into a tragic one. Though not made explicit, one reason for this renegotiation might be to obtain the sympathy he originally expected.

In sum, men interviewed in 2000 and 2010 disclosed similarly to ‘children and wider family’. Like disclosures to ‘partners’, men anticipated a tragic genre of worry of this audience but sought to transform it with an optimistic treatment and recovery. What was different in disclosing to this audience than to ‘partners’ was that men often achieved this by delaying their disclosure—temporarily, significantly or permanently. Some men in 2010 though, like Charlie (2010) in his disclosure to his wife and daughters (Extract 6.7), did not receive the response of worry, or tragic genre, they expected but rather an optimistic expectation of a good treatment and recovery akin to a romantic genre. In one case this prompted further work by the MWPCa to renegotiate a tragic genre.

6.4 Disclosing to ‘friends and others’

Unlike disclosures to ‘partners’ and ‘children and wider family’, MWPCa in 2000 and 2010 did not talk about their expectation of worry from ‘friends and others’. Similar numbers of men in 2000 and 2010 talked about receiving support from this audience. This support though was often alongside interactional difficulty as when Lawrence (2000) talked of how “when people know that you’ve got a cancer, there’s always an awkwardness when they meet you for the first time having heard it”. This “awkwardness” appeared to result from an uncertainty of which genre should be drawn upon in a disclosure conversation—for both the speaker and the hearer:

Extract 6.18

Interviewer: Anybody you’ve chosen not to tell?

Calvin: (...) No we didn't have any, any particular person we didn't tell. I haven't, I haven't gone up to people, sort of tapped them on the shoulder saying “Hey guess what I've got?” I haven't been in that sort of vein but when it

has cropped up in conversation, yes, I don't see any point in going around and saying what's happened unless it crops up, unless you're asked and then there's no hesitation. But the support from people has been very, very good. The only, the only thing I find is that some people find it a little bit difficult in reacting to you. You can be very positive about it and maybe they're not too sure what to say. It's like in some ways I suppose when there's a bereavement, you know the person who's left very well and you find it a very difficult subject to broach because you don't know the attitude of the person. You sometimes find the strange attitude in that direction and again you find that some people say "How are you?" you know wondering how your cancer is, and it's almost you know "You do look well", and it's almost the sort of big surprise as to "Oh you're still with us!" (Calvin, 2000)

Calvin's comparison between "bereavement" and his disclosure of PCa serves well to shed some narrative light on this "awkwardness". It suggests that talking about bereavement may be interactionally difficult, perhaps because one does not know whether the person bereaved will draw upon, for example, a tragic genre where death is "a futile struggle against the fates" (Smith, 2005: 26), or a romantic genre believing that some type of "change for the better is in the air" (p. 26). Until you "know the attitude of the person", it is difficult to know what to say—or which genre to draw upon. Likewise, when describing how 'friends and others' reacted to his PCa, Calvin seemed to recognise the work they were doing to establish just how good or bad his news was (Maynard, 2003)—moving between a romantic genre of "You do look well" and a tragic expectation of death. This expectation of death reflected in the surprised "Oh, you're still with us!" and others not being "too sure what to say" was also indicated in 2010 when Alan told how people "just said 'I'm very sorry to hear', shook hands with me and all, and said, 'sorry to hear, hope you're alright in the future and the best of luck'". This combination of 'shaking hands', often done with bereaved relatives, and wishing Alan the best for the future presents a paradox; cancer as a 'living-dying' experience' (Muzzin et al., 1994: 1201).

Though this paradox is well described in the literature, it is further complicated in this data. Quinn and Charlie, both interviewed in 2010, demonstrated the intricacies of genre negotiation when they disclosed their PCa:

Extract 6.19

They don't quite know how to approach the subject, you say, "oh I've got prostate cancer", people say "oh well that's quite curable now isn't it, you just need an operation", which is what I used to think, and you say, "well yes, in a

lot of cases yes, but some, where it's, where it's spread, it's a bit more of a problem, and it can be un-, you know, it can be incurable." (Quinn, 2010)

Extract 6.20

Interviewer: So what about others, did you tell anybody else that you had prostate cancer?

Charlie: I, have a very very wide social circle, and whilst many of them knew, they never conveyed to me neither sympathy or wanted to discuss the matter in fact one person with a medical background who I mentioned it to, and she didn't know, she said, "well, they can treat these things can't they", and I thought well, "how's that for sympathy" but then perhaps I wasn't looking for sympathy, ((laughs)) I don't want to paint it as a matter of fact experience but there was nothing really that stuck out as, in fact, to be honest with you, I was surprised that the general, the general reaction to it was as subdued as it was.

Interviewer: Right, why were you surprised?

Charlie: Because here again, you, you turn on the television and you hear stories about, "oh and he heroically fought this" and all the rest of it, and there was great rejoicing all round that you've come out of it, somehow I never went in to that type of feeling, or mode, nobody's ever said to me, "oh well done, because you've fought it, and you've won", I don't know whether I've won or not, it's just, just one of those things perhaps they also know that my previous illness was more critical, and that, then there was considerable concern, but the fact that I came through it, maybe has conditioned their way of thinking, I don't know, but then I will never go up to anybody and say, well, "what do you think about me being, having cancer", it would seem a silly question to ask anyway, and I'm not so sure they would know how to reply ((laughs)). (Charlie, 2010)

Upon disclosure by Quinn and Charlie of their PCa, their audience advanced a surprising and unexpected, to Charlie and Quinn at least, romantic genre of an optimistic recovery where "you just need an operation" (Quinn) and "well, they can treat these things can't they" (Charlie). A disclosure of PCa did not then, for their audience, necessitate a tragic genre of suffering and potential death. This genre was though "at risk" (Bury, 2001: 279) in the disclosure interaction in different ways by these men. Though Quinn drew his audience's attention to the appropriateness of a romantic genre in some circumstances, he also told them how, for his own case, a tragic genre might be better deployed. Though Charlie did not explicitly renegotiate the romantic genre with his audience, his narrative demonstrates his work to explain to himself the discrepancy between the romantic genre he received and the tragic genre and sympathy he expected.

In contrast to the experience of Quinn and Charlie in 2010, more men in 2000 than in 2010 told how cancer discredited men as those near death and to be pitied (though see Keith [2010] in Extract 6.21). Eddie (2000) said it used to be “that if anyone got cancer it was a sort of goodnight nurse situation, but now I think we're having much more success with cures”. David (2000) said that while “people didn't like to ask”, he “didn't mind telling people about it at all” and when playing bowls one day “it came up and I happened to tell somebody and he couldn't believe it ((laughs)) “You can't be, you look normal”, “well of course I look normal””. Harry (2000) said that “the main reaction to [his disclosure] was “Poor Harry” and that isn't me unfortunately. I think I met it square on”. This discrediting and pity continued even after men recovered:

Extract 6.21

When you mention the word cancer, it, it conjures up in people's minds, you know, a certain thing, and so many people when they hear the word cancer, just think, you know, in terminal terms, so a lot of people just, I think, felt very sorry for me (...) people still sort of think “well you know that fella has had cancer, you know, is he alright”, type thing, ((brief laugh)) but that's, that's just the way it is. (Keith, 2010)

Extract 6.22

You mention cancer, people don't react very well to it they just clam up and don't talk about. I think prostate cancer is probably even more sensitive because it's that area which is personal, private and it's the area that you don't generally talk about. So having been diagnosed with prostate cancer I found it very difficult initially to talk about it. (...) It's not a matter of not admitting you've got cancer, it's knowing the reaction when you tell people. And a certain, if you've got cancer, a certain number of people, probably a high percentage, will write you off, that's not because you're not going to recover but when you recover they say “Oh well yeah well he had cancer”. Now it's not a final diagnosis in today's society because it's very curable and most cancer cases are cured, and it's long term cure. But it's still difficult when you've been one of the people who's seen other people say “Oh I've got cancer”, and you always think the worst. It's not very easy to then become one of the victims and to face it the same as you would if you'd be one of the people who were just viewing from afar. It's a very difficult subject to talk about, I find it easier now to talk about it than I did initially, and I don't have the same embarrassment, (...) But it is still one of those subjects that people find, is taboo, you don't speak about it. (Karl, 2000)

Though such discrediting was not necessarily heard as ‘death’, it was still resisted as a tragic genre and was then “at risk” (Bury, 2001: 279) in the disclosure negotiation.

MWPCa sought to counter the tragic genre with a romantic one of a hopeful overcoming of adversity (Smith, 2005). Karl was the only man, interviewed in either 2000 or 2010, to speak about PCa explicitly as a taboo; this idea however is implicit in the talk of men in both periods, some making repeated reference. Oliver (2000) told how men found it difficult to talk about anything to do with the prostate and Don (2010) how he and his golfing pals paid little attention to the disclosure of PCa by four other golf friends:

Extract 6.23

They won't talk about it because they're frightened that it's going to knock their macho image. (...) in America especially men are really keen on this big macho thing about being manly and the fact that, going back over the years, way, way back, right into Morecambe and Wise and that, you know, prostate has always been a subject for joke and humour, you know, men running off to the toilet and things like that. (Oliver, 2000)

Extract 6.24

No it was a kind of an intimacy thing that people only make a quick reference to, and probably a couple of jokes would be floated to the prejudice of the sufferer, but there was never no discussion other than just a loose talk in terms of, "oh I must get a PSA" (Don, 2010)

These narratives indicate the use of a comic genre (Bury, 2001) as that which involves mocking of the self or others (Kelly and Dickinson, 1997). Kelly and Dickinson (1997) argue that humour is a narrative device—used by a narrator—to lessen the suffering, create social distance from it and provide a practical cue for the listener to do likewise (p. 270). In Don's example it appears that it was the listeners who created social distance from the narrator and one reason for this might be to ease their own discomfort upon hearing of others' PCa. Men across time also talked explicitly, often with several references, either about other's embarrassment (Barry, 2000, Oscar 2010, Quinn, 2010) or their own (Karl, 2000). Barry's neighbour also had PCa and Barry compared his neighbour's embarrassment and his own such lack saying "I think there's a lot of embarrassment, he's a tremendously fit person too and so, but I didn't feel the embarrassment, I don't know why but I didn't" (Barry, 2010). He went on to grapple with what 'embarrassment' might mean and also referred to humour:

Extract 6.25

Barry: I don't know what this embarrassment is really. I remember a guy talking to me who'd lost a testicle on something and he was deeply embarrassed about even mentioning that to anybody on earth you see. But over a cup of tea we were talking about and the sort of relief you know came out of him, so I think, you know, why not, yeah. It's as if it's caught up with the macho thing, probably, I don't know.

Interviewer: Have you ever felt that it sort of offends your sense of masculinity to talk about health problems or

Barry: Not at this stage of life no. I think it might've done earlier on but I don't think so. But I think it could, for many men it could really yes, yeah and it becomes something of a joke perhaps I don't know. (Barry, 2000)

Oscar (2010) also elaborated on the nature of embarrassment—and also perhaps the nature of comic genre—when he described the response of men witnessing ‘The Great Drag Race’, an event aiming to “drag [prostate cancer] into the limelight” (Oscar, 2010). Oscar dressed up in women’s wigs and clothing and gave leaflets about PCa symptoms and treatment to men in various public places including a Millwall football match:

Extract 6.26

it became very obvious that guys who would not talk to another man about embarrassing things like visits to the loo late at night, frequency, anything in the nether regions, in normal everyday clothes, they were quite open, if I was in a dress and a wig, very strange but we actually got mobbed by people, wanting to tell us about their, their problems, and that, that’s an interesting thing, I’ll have to look into the psychology of that, but I suppose it’s, “well if you’ll go that far, I’ll talk to you about it” (Oscar, 2010)

Dressing in ‘drag’ then also potentially drew on a comic or an ironic genre where though the macho image was dramatically and visually mocked, it served to signal to those observing and talking to Oscar that the affront to their masculinity was not to be taken seriously (Kelly and Dickinson, 1997).

Similar numbers of men in each time period talked about either themselves or others ‘keeping it quiet’. Ralph (2000) had been “trying to keep it to myself” while Don (2010) went for “sixteen months and never told a soul” except his wife. One potential reason for this was men’s reluctance to talk about health issues in general:

Extract 6.27

Interviewer: And why do you think men aren't ((Graham laughs)) more open about it?

Graham: It's probably the macho thing, you know that certainly in our culture men, men don't cry, men don't display any weakness, men are never vulnerable, they're always the top dog, they're always in charge, in control and in command, and, men's issues in general, particularly health issues in general, I think men don't go there, as readily, it's probably, you know, it might be type casting to an extreme but I certainly, from a prostate [sic] cancer point of view, hadn't talked to anybody about it beforehand. (Graham: 2010)

Graham (2010) drew upon what is normally considered to be a discourse of hegemonic masculinity (Connell and Messerschmidt, 2005; Courtenay, 2009). It may be though that such a form of masculinity is a romantic genre where the actions of the hero overcome various adversities. Such a genre is though also likely to be 'at risk' to the extent that men draw upon this form of masculinity.

Hugh (2010) discussed how "prostate cancer and all that it entails is extremely sensitive and very close to the male psyche". He described being out socially with his brother and observing another man's attempt to tell others about his PCa and his knowledge about how such stories are usually received by other men:

Extract 6.28

The only person in that particular group that knew I had had prostate cancer was my brother, and [brother] was very funny, he was actually watching me, to see how I was reacting to this guy telling his story. Anyway, I just watched the behaviour. They [the audience] didn't want to hear (...) they interrupted or "so and so's over there" ((reconstructing what this audience was doing and saying)). The guy didn't, I don't think there was a single person in the group who heard the whole story. The guy got telling his story but the group kept changing and looking away, they weren't listening, they weren't listening, [they had a closed] mind-set, "it's not going to happen to me" ((reconstructing what may be the verbal or non-verbal indication of this audience)), not half. (...) And [brother] said, "Why didn't you say anything"? And I said, "Well I knew what was going to happen", I says, "I've seen it happen". (Hugh, 2010)

Though there was no indication by Hugh of the narrative elements of the other man's disclosure of PCa, he observed important aspects of the hearers' response. The men in this audience interrupted the speaker; they did not listen; they not only looked away but also looked around for validating distractions that would excuse them from the conversation; and they indicated (at least non-verbally) that they did not expect PCa to

happen to them. Though this cannot be explored more from my data, Hugh told how this was a familiar scenario. It may then be indicative, in addition to the use of humour discussed above, of how men might create social distance from the suffering associated with PCa.

There were seemingly ‘unsayable’ disclosures to ‘friends and others’ by MWPCa interviewed in each time period—by this I mean disclosures prefaced by one or more versions of ‘I’m not going to broadcast/promote/broach the fact that I’ve got prostate cancer’ and ‘you just can’t say ‘hello, I’ve got prostate cancer’’. Seemingly ‘sayable’ disclosures, such as when men in each period told how ‘there’s nobody that I wouldn’t tell’, were sometimes combined with what was ‘unsayable’ as when Joe (2010) asserted: “no, there’s nobody that I wouldn’t tell, but, I just don’t bring it up really in conversation”. Sometimes peripheral friends were not told as when Peter described how although he had told his close friends, “there have been other friends who I only see now and again, who I’ve simply not told”. PCa was “obviously a very personal thing” (e.g. Liam, 2010), potentially something “to hide” (e.g. Calvin, 2000 and Ivan, 2010), and that some people are going to be “embarrassed if you tell them, sort of straight out”:

Extract 6.29

I wouldn’t sort of broach the subject, I’m more than willing to tell people all about it, but I’ve found that some people are embarrassed if you tell them, sort of straight out, and say, “how’re you doing?”, you know, “oh hello, how are you?”, I say, and you say, “well I’ve got incurable cancer”, and you think well, it’s a bit of a, not a way to sort of start a conversation is it, ((laughs)) but my wife would tell them, you know, “well don’t you know he’s got such and such”, and then they’ll say “oh well that’s not too bad is it, it’s curable”, and she’ll say, “well not in his case”. (Quinn, 2010)

Though this embarrassment, awkwardness and ‘unsayableness’ in interaction was described in both time periods, what was demonstrated as different in 2010, as Extract 6.29 shows (see also Extract 6.19 and Extract 6.20), was that some men had to counter an unexpected romantic genre of recovery and cure with a tragic genre of PCa as an incurable condition. In Quinn’s case above, his wife was also involved in this negotiation.

In sum, unlike disclosures to ‘partners’ and ‘children and wider family’, MWPCa in 2000 and 2010 did not talk about their expectation of worry from ‘friends and others’

and there was no evidence of an imperative to disclose to 'friends and others'. Similar numbers of men in 2000 and 2010 talked about receiving support from this audience. This support though was often alongside interactional difficulty; difficulty more apparent to this audience than the audiences of 'partners' and 'children and wider family'. Though there were similarities across time, there were also nuanced differences. Similar numbers of men in each time period talked about either themselves or others 'keeping it quiet' because of fear of damage to their macho image or their own or other's embarrassment. More men in 2000 than in 2010 told how PCa discredited men as near death and to be pitied—these men sought to counter this tragic genre with a romantic genre of recovery. In contrast, more men in 2010 than in 2000 told how they had to counter an unexpected romantic genre of recovery and renegotiate a tragic genre of PCa as an incurable condition. Though the narrative elements mostly drawn upon in men's disclosures to 'friends and others' were that of tragic and romantic genres, there was also evidence of use of a comic/ironic genre.

6.5 Disclosing to 'colleagues'

Different across time in disclosures to 'colleagues', was that more men in 2000 than in 2010 spoke about receiving concern or support. Finlay (2000) was "virtually" told: "Well go home and come back when you're ready". Ralph's (2000) colleagues were advised to treat him "as normal":

Extract 6.30

Ralph: I also told them at work, they were very understanding at work. I worked in [particular part of organisation], they held a meeting unknown to me that they were, I was to be treated as normal because there's no doubt about it you mention cancer to people and some people think you're, ((laughs)) you know you've sort of got the plague or something. And though I worked amongst [particular staff] there was one or two, there was a few, more than one or two actually, who found it hard to talk to me about it. But they had a meeting, the Head of the Department called a meeting which I found out later, that they were to treat me as normal.

Interviewer: Why do you think people find it so difficult to talk to cancer patients?

Ralph: Fright, they don't actually understand the modern treatment and they think that's the end. (Ralph, 2000)

The first response then of Ralph's colleagues appeared to be to draw upon a tragic genre of an awareness of suffering and futile hope (Smith, 2005). Negotiation with this genre began though before Ralph's first interaction with his colleagues, through the meeting between the head of department and his colleagues, in the hope that he would be treated as normal. His colleagues still though tended to give what Ralph perceived as unnecessary support:

Extract 6.31

Sometimes I found it, I found it at work ((laughs)) you know [the support] wasn't necessary, "You sure you can do this?" you know "are you sure you can do that?" And there was nothing wrong me with me you know nothing wrong with me at all except this prostate cancer which is inside you and is giving you no pain while I'm working. (Ralph, 2000)

After receiving test results from his consultant three weeks after his diagnosis Finlay (2000) reconstructed a conversation with his work colleagues:

Extract 6.32

The only thing I heard [my consultant] saying, he was explaining all about the prostate cancer, but he said "It is contained". Now to me, it was just like saying you haven't got it and when I told them in work they were "Well you've still got cancer", I said "yeah but it's contained", it was like getting a, the only way I can explain it's like getting a second bite of the cherry, so I felt so relieved. (Finlay, 2000)

Finlay demonstrates how he drew on the romantic genre and the voice of his consultant to put forth the fundamentally optimistic romantic genre of a hoped for recovery. This was though immediately renegotiated in his conversation with his colleagues.

Only three men spoke of organising their workload—in a contingent narrative around the strategic management of illness (Bury, 2001); one man, Graham (2010) as an imperative in how he "*had* to let [the guys in work] know" (emphasis added) as he was going to be out of action for several months. Likewise, Harry (2000) wanted neither to 'promote' his PCa nor "frighten" anyone:

Extract 6.33

Interviewer: Was there anybody you chose not to tell about the cancer at that point?

Harry: No I'm not that kind of person, not that I want to involve other people to frighten other people but I believe personally that if you can talk freely about it, and talk to anyone within your family and your friends and even your work mates to say "well look this is the situation", I can look back on all those aspects of the way that I dealt with it in not being promoting it in any form but saying to people "well look I won't be into work for the next couple of weeks", or "I won't be refereeing this sort of game, or that sort of game". (Harry, 2000)

Men in 2010 discussed a variety of outcomes of disclosure to 'colleagues': having closer relationships; finding others relieved when they could disclose using a romantic optimistic genre; giving insights to others about PCa; and warning others. Fred (2010) said "my colleagues at work were very supportive, which was great, in fact it probably led to me having sort of closer relationships with some of them than I had before really". To the extent that men gave insights to or warned their colleagues about PCa, it may be that they drew on a didactic genre (Miller et al., 1997; Bury, 2001) used to convey moral or social standards. Joe's (2010) purpose in disclosing to his first set of colleagues "was more to tell the other men that were there, you know, 'don't ignore this guys, have a think about it'". Graham (2010) used his disclosure to warn those "in a certain age group" that "the sooner you confront it and get on with it, the better, you know, the more likely you are to be around long term". Graham (2010) told how being able to say "it's solved, [I'm] cured" enabled his colleagues to approach him for insights into prostate cancer in particular, and death in general:

Extract 6.34

Everybody's quite relieved when you can tell them that it's solved, that you're cured, and well I never had a conversation with anybody till I was able to say that, cos I think people maybe don't want to go there, to contemplate what might be a horrible end, but having come through the thing successfully, I can think immediately of at least two guys who I had a more in depth conversation with, about what it was that led me there, why I thought I had it, and what had happened and what the consequences of it were, so obviously some of these guys are thinking about it, and are maybe glad of the opportunity to speak to somebody or somebody will talk to them about it (...) so there's a few relationships like that which are probably different and deeper as a consequence of it, but the vast majority of people, just glad it's over, and get on with life as normal, that includes family. (Graham, 2010)

Although men did not often explicitly talk about delaying their disclosure to 'colleagues', some men told how they limited details of their disclosure and other men told how they both delayed and limited their disclosure to work colleagues. Nathan

(2000) again said that “the cat was out of the bag” when after telling a few people at work others also found out. Joe (2010) told his colleagues after one meeting when “they were all in one room at the same time, and there weren’t any of the women present”. While his colleagues appeared “slightly shocked, or taken aback, but appreciative more than anything” it was never “mentioned again”. When asked if he also told his colleagues about the treatment side effects in his disclosure Joe replied:

Extract 6.35

No, not really, no I mean, I just keep it pretty light hearted to be honest, I don’t go into the details, I mean if they really wanted to know I would tell them, the conversation’s just never been in that much depth, I mean these are people that I know professionally rather than as friends. (Joe, 2010)

At the time of his interview Joe had a different set of colleagues and said “I don’t actually know whether they know or not, I don’t have a problem with them knowing, but I don’t go out of my way to tell them about it”. Keith (2010) delayed telling his work colleagues until the last few days before treatment as they:

Extract 6.36

didn’t need to know all those details until they needed to know, and you know really ((brief laugh)) I suppose if I could have went into hospital and got this matter dealt with, without actually telling anybody, I might have actually done it that way ((brief laugh)). (Keith, 2010)

Two men chose to retire from work with one, Paul (2000), stressed from his work anyway, telling his managing director “immediately” before going on the “sick” until his due retirement; and Michael (2010), the only man to specifically talk about not telling his colleagues, said:

Extract 6.37

I didn’t really sort of tell people at work because I didn’t consider it was relevant to them anyway, and when I had the cancer confirmed at the end of the year I just said, “I’m not going back to work, I’m going to concentrate on getting this, getting through this” as such and I didn’t return to work at all. (Michael, 2010)

In sum, there were differences over time in how men disclosed to ‘colleagues’. When men disclosed in 2000 they mostly placed their disclosure in a context of receiving support or concern, organising the workload, and treatment and recovery. The

disclosures of men in 2010 instead led to closer relationships, finding others relieved when men could put their disclosure positively, giving insights and warnings to others.

6.6 Discussion

In this chapter I have explored changes and differences in how MWPCa interviewed in 2000 and 2010 disclose their condition to the audiences of ‘partners’, ‘children and wider family’, ‘friends and others’ and ‘colleagues’. In addition I have considered the extent to which Bury’s (2001) insights into narrative form can explain the practical management of interactional issues in disclosing PCa to such audiences. I asked: 1) are there differences in how MWPCa disclose their illness over time and to various audiences—especially given that changes in a tragic “taboo” genre suggest the potential for changes in interactional difficulty in disclosing PCa; and 2) what narrative forms and elements do MWPCa draw upon when disclosing their illness to these audiences. My analysis shows that though one might expect less interactional difficulty for MWPCa in disclosing their illness when a tragic genre of ‘taboo’ is ostensibly less available to draw upon, with some audiences this may not be the case. It also demonstrates that, with some exceptions, the same narrative forms and elements occur across these audience types.

MWPCa and their audiences across time demonstrated their use of narrative genre. There was no evidence to indicate that these genres were consciously drawn upon. This corresponds then to the suggestion by Bury (2001) and Frank (2000) that when people tell stories of illness they do so by unconsciously drawing on culturally available genres ‘which allow and constrain what is said and how it is expressed’ (Bury, 2001: 278). The genres drawn upon were mostly tragic and romantic genres. A tragic genre allows talk which suggests at least ‘a futile struggle against the fates’ (Smith, 2005: 26), ‘an amplified awareness of suffering’ (p. 25) and ‘the inevitable failure of heroic action’ (p. 26). A romantic genre—not necessarily about love—is instead ‘fundamentally optimistic (...) marked by the belief that actions can make a difference and that change for the better is in the air’ (p.26). The tragic genre most drawn upon in men’s disclosures of PCa was that of worry about potential suffering and death from PCa; the typically drawn upon romantic genre was that of an optimistic overcoming of the illness through treatment, recovery and cure. There was though also evidence of

comic/ironic (Kelly and Dickinson, 1997; Bury, 2001) and didactic genres (Miller et al., 1997; Bury, 2001). Comic/ironic genres were drawn upon when men, across time in their disclosures to 'friends and others', told how they or others drew upon some form of humour to widen or lessen social distance from the suffering associated with PCa. Didactic genres were used by men in 2010 to put forth a moral imperative to 'colleagues' in warning them to pay attention to their health to increase their likelihood of being around long-term (Graham, 2010).

When men were making their disclosures to the audiences of 'partners' and 'children and wider family' they expected these audiences to draw upon a tragic genre of anticipated suffering and death. Most often, men resisted this genre and instead put forth an optimistic outcome with treatment that would, for example, "sort the problem out" (Keith, 2010). There was also evidence of one man drawing upon a tragic genre only for this to be renegotiated by his 'partner' to a romantic one which he then accepted. On the whole though there was no difference across 2000 and 2010 in the expectation of the tragic genre and its countering with a romantic genre in men's disclosures to 'partners' and 'children and wider family'. There were though differences in the timeliness of the disclosure to these audiences and whether audiences did in actuality draw upon the tragic genre that the men expected them to. Though men, almost exclusively, made prompt disclosures to 'partners', they very often delayed—temporarily, significantly or permanently—to 'children and wider family', especially so if the family member was perceived as vulnerable; there was no difference across time. There were though differences across time regarding whether these audiences did in fact draw upon the tragic genre expected by the men. Instead of drawing upon a tragic genre, three men in 2010 talked about their surprise when their audience—the wife and children together for one man and the mothers of two other men—used a romantic genre of an optimistic good recovery. In one case this prompted further work by the man to renegotiate a tragic genre.

In contrast to 'partners' and 'children and wider family', MWPCa in 2000 and 2010 did not talk about their expectation of worry from 'friends and others' or 'colleagues' and there was little evidence of an imperative to disclose to these audiences. Similar numbers of men in 2000 and 2010 talked about receiving support from 'friends and others' though this was often alongside interactional difficulty; difficulty not evident in men's disclosures to 'partners' and 'children and wider family'. One consequence of

this “awkwardness” was that men found it “a very difficult subject to broach” (Calvin, 2000) and their audience found it hard to respond to. Though there were similarities across time, there were also nuanced differences in this “awkwardness”. Men, across time, similarly indicated that PCa was an illness about which they or others kept quiet because of fear of damage to their macho image or their own or others’ embarrassment. Those who were not embarrassed often contrasted their openness to talk with that of their knowledge of others’ embarrassment and reluctance to talk. More men in 2000 than in 2010 told how PCa discredited men as near death and to be pitied—these men sought to counter this tragic genre with a romantic genre of recovery. In contrast, more men in 2010 than in 2000 told how they had to counter an unexpected romantic genre of recovery and renegotiate a tragic genre involving PCa as an incurable condition.

My findings suggest that disclosing PCa to ‘friends and others’ was at least as interactionally difficult for men interviewed in 2010 as it was for those in 2000. This is the case despite indicatively optimistic evidence from Chapter 4 and Chapter 5: PCa as a “taboo disease that no one dares talk about” (Figure 4.4) was less frequently written about by journalists in 1990-2000 than in 2000-2010; and towards the end of the 1990s PCa came out of the “shadows of neglect” (Extract 5.1) where men “would not talk about [their illness] (...) [and] would die quietly” (Extract 5.2). These findings do though concur with Gray et al. (2000) when they note that ‘there is no evidence to suggest that concerns about stigmatization are unwarranted, despite recent, optimistic signs’ (p. 280). The ‘optimistic signs’ to which they refer was the ‘dramatic shift in public awareness of prostate cancer within the last decade’ (p. 274), in their Canada context, and where ‘prostate cancer has ceased to be hidden to public gaze’ (p. 274)—the same ostensibly optimistic situation in the UK at present.

My findings demonstrate that genres were continually “at risk” (Bury, 2001: 279) in men’s disclosure interactions with the various audiences—meaning that though a particular genre was drawn upon by one party in the disclosure interaction it was not necessarily accepted by another. That the genres were ‘at risk’ and negotiated throughout the disclosure interaction demonstrates the ‘co-authored’ (Williams, 1984: 181) nature of these disclosures. This negotiation was most often shown when a tragic genre of potential suffering and death was drawn upon by an audience and this was renegotiated to a romantic genre of a cure and recovery by the MWPCa. It was though

also demonstrated when an audience unexpectedly drew upon a romantic genre of cure and recovery and the MWPCa renegotiated into a tragic genre. Such negotiation (Bury, 2001) is also understood as a 'genre war' (Smith, 2005: 28) where interactants compete over how to interpret aspects of reality. Negotiation over aspects of reality is also common ground in the everyday business of actors around social movements (Benford and Snow, 2000) who strategically seek to make their messages 'fit' or resonate with their audiences' understandings of reality (Williams, 2004). Along similar lines, Maynard's (2003) work suggests that participants in a news event, such as a disclosure of PCa, not only interactively establish just how good or bad the news is, but also may not always respond in accord with the genre drawn upon.

As discussed above, my findings suggest that a romantic genre includes the triumph of the MWPCa over his illness through treatment, cure and recovery. My findings though also hint at the possibility that some aspects of hegemonic masculinity (Connell and Messerschmidt, 2005; Courtenay, 2009) may also be called upon as a romantic genre where the "hero is motivated by high ideals and overcomes a series of obstacles, challenges and enemies" (Smith, 2005: 26). One aspect of hegemonic masculinity is stoicism, defined by the Oxford English Dictionary as 'the endurance of pain or hardship without the display of feelings and without complaint'. In my data Don (2010) ostentatiously displayed stoicism in his forbidding of his wife to either "start blubbing" or to 'blurt' out his PCa to anybody (Extract 6.5). Maynard (2003) suggests though that a 'stoic response [is] an interactional and not just psychological phenomenon. Deliverers [of news] (...) sometimes intentionally, often inadvertently encourage stoicism on the part of their recipients' (2003: 121). Don's wife, at least in how he told his story to me, seemed to collaborate with him in his stoicism and did not seek to renegotiate another genre.

Though Don was unique in his blatant display of stoicism, my findings suggest that men across time used the romantic genre of a hopeful cure and recovery to transform the worry of the 'partner' and 'children and wider family' audiences over their potential suffering and death. At least in the stories told to me, there was no evidence that these audiences sought to renegotiate back to a tragic genre, thus suggesting an ostensible mutual collaboration with the optimistic romantic genre. Men's use of this romantic genre in transforming the worry of these audiences may then, though less blatant than Don's, be a display of stoicism with little change little over time.

I suggest that such a collaboration constitutes a performance of hegemonic masculinity (Connell and Messerschmidt, 2005; Courtenay, 2009) with all actors in the disclosure interaction collaborating in the construction of the MWPCa as having his illness under control with nothing to worry about. This finding is interesting because criticisms of the concept of hegemonic masculinity include its lack of attention to how masculinities change across the lifespan (Connell and Messerschmidt, 2005). While the plurality of masculinities available to a man may indeed change as he gets older, this finding shows that these men perform at least this aspect of hegemonic masculinity.

However, such stoicism in the transformation of worry about suffering and death to an optimistic hoped for cure and recovery may not be limited to hegemonic masculinity. Wilkinson and Kitzinger (2000) show how women with breast cancer are morally exhorted to 'think positive' to enable the disclosure and convenient 'wrapping up' (p. 803) of troubles telling and to relieve 'listeners of a potential conversational burden' (p. 805). Thus, the findings here that across time men use the romantic genre of a hopeful cure and recovery to transform the worry of various audiences over potential suffering and death may indeed be a feature of broader culture in a hegemonic imperative for men and women to draw upon a romantic genre for the convenient 'wrapping up' (p.803) of 'troubles' such as disclosure of illness.

My findings also have implications for the healthy public face of PCa (Aronowitz, 2009). PCa is being looked for harder than ever before (Welch et al., 2012) and as autopsy studies show PCa in the prostates of men as young as aged 20-29 (Powell et al., 2010), it may be that 'nearly every man may eventually develop [either clinically or non-clinically relevant] PCa' (Weight et al., 2013: 1022). Further, as the 'natural processes of ageing' (Armstrong, 2010: 15) are increasingly 'incorporated into a model of pathological disease' (p. 16) it may be that the massive discrepancy between UK/GB incidence and mortality rates of PCa (Figure 1.1) will widen. If so, the relative proportion of those with a poor prognosis of PCa will decrease and its public face will become healthier (Aronowitz, 2009) potentially resulting in a 'veneer of optimism' (p. 436) put onto the identity of the expanded group of MWPCa.

In describing how they disclosed their PCa to audiences of 'partners', 'children and wider family' and 'friends and others', some men in 2010 talked about their surprise that these audiences did not draw upon the tragic genre of likely suffering and death. Instead audiences drew on a romantic genre of cure and recovery such as "oh

well that's not too bad is it, it's curable" (Quinn, 2010 in Extract 6.29). One interpretation of such a response could be that these audiences were being supportive and encouraging to the man by allowing him to understand his illness through an optimistic recovery genre. However, examining the response of the men to this disruption of their normative expectation indicates another interpretation. The response to this could be a tentative acceptance of this romantic genre (Neil, 2010 in Extract 6.17); an introspective coming to terms with the genre discrepancy (Charlie, 2010 in Extract 6.20); or a renegotiation back to a tragic genre as in "well yes, in a lot of cases yes, but some, where it's, where it's spread, it's a bit more of a problem, and it can be un-, you know, it can be incurable" (Quinn, 2010, in Extract 6.19). The response of these men demonstrated instead the interactional implications of this for an increasingly healthy face of PCa.

Finally, and in conclusion, my findings also have something to say about the links which may be drawn between narratives expressed publically in the media and by PCaOrgs and those drawn upon in research interview. Philo (2008: 542) argues that 'patterns of belief and understanding can be traced to [elite media producers]'. This optimistically indicates that one might expect less interactional difficulty for MWPCa in disclosing their illness when a tragic genre of 'taboo' appears less publically available to draw upon. Critically though, this optimistic indication appeared in my study not to have the effect that it might predict as my findings imply that with some audiences this was often not the case. My findings thus do not confer with Philo's contention against the trend to seriously neglect media power in favour of the power of a reflective resisting audience.

Chapter 7 Discussion

7.1 Introduction

The concern of this thesis was to ask how PCaOrgs and the UK print media have been a force for change in the UK regarding how PCa has been addressed and experienced by men with this condition. To answer this question I investigated a variety of narratives: narratives about illness to explore how key individuals within PCaOrgs describe how they sought to address PCa; illness narratives of MWPCa in the UK national print media for changes in the representation of the illness experience of such men since the emergence of PCaOrgs in the UK in the mid-1990s; and illness narratives of MWPCa in research interviews in 2000 and 2010 to explore how they described their illness experience over this time. I proceed now to summarise my findings from Chapter 4, Chapter 5 and Chapter 6 and to discuss how they concur with or differ from those available in the existing literature. I show how my analysis demonstrates the recursive nature of social practices common to both individual actors and social structures across space and time (Giddens, 1984). Language practices around PCa are not brought into being by those concerned with PCa but rather are ‘continually recreated’ (p. 2) from already existing pre-patterned language (Tannen, 2007). I try and show how the concept of ‘interest’, composed of comprehensibility and novelty (Silvia, 2008)—or resonance and dissonance—can add to an understanding of this recursive recreation of language.

7.2 Summary of findings

1. Stories of injustice around PCa that come and go: from PCa as a ‘neglected’ disease in 1990-2000 to one where other ‘pockets of injustice’ are found in 2000-2010

1.1. Stories of the neglect of PCa in UK national print media 1990-2000 regarding its ‘derisory’ and ‘scandalous’ funding and ‘Cinderella’ status when compared with other diseases (Chapter 4)

- 1.2. Stories of the ‘disgraceful’ and ‘unacceptable’ funding for treatment for PCa and the ‘debilitating’ side effects in the UK national print media 2000-2010 (Chapter 4)
- 1.3. Historical stories of the neglect of PCa up to around 2000 narrated by advocates around PCaOrgs (Chapter 5)
- 1.4. Contemporary stories of neglect of PCa for some audiences narrated by advocates around PCaOrgs (Chapter 5)
- 1.5. Stories of other ‘pockets of injustice’ around PCa around 2010 narrated by advocates around PCaOrgs (Chapter 5)

The analysis of media illness narratives of MWPCa in Chapter 4 demonstrated that when journalists wrote about the illness experience of MWPCa in 1990-2000 they used certain words more frequently than in 2000-2010 to tell a story of PCa as a neglected ‘Cinderella’ disease when compared with breast cancer, AIDS and heart disease. Many of these words were in the context of an appeal by the Daily Mail to raise £1million to “rectify [the] scandalous situation” of the “derisory” £47,000 of funding that PCa received compared to other illnesses. Other emotive words included ‘appalling’ and ‘epidemic’. This neglect was mostly gender-based although there were ageist elements. Blame for this neglect was distributed across: men themselves as those stereotypically “suffering in silence”; a society which placed little value on the lives and deaths of men; the medical profession; and government. In contrast, when journalists were writing about the illness experience of MWPCa in 2000-2010 they used words more frequently which told about the “disgraceful” and “unacceptable” injustices around funding for brachytherapy, a treatment for PCa and the “debilitating” side-effects of hormone treatment and prostatectomy resulting in severe physical and financial costs for MWPC. Unlike in 1990-2000 where concern was only for the risks of impotence and incontinence post-prostatectomy, in 2000-2010 there was also a focus on the feminising side-effects of hormone drugs.

The analysis of the narratives about PCa by advocates around PCaOrgs in Chapter 5 shows how the story of gender-based ‘neglect’, already successfully used in the early 1990s by breast cancer movement activists in the US, was used in the late 1990s when actors around PCa in the UK did not know “what to do in those days” (Extract 5.2). Elements of the neglect story still continue to be told to contemporary audiences—

when opposing “vested” interests and when capturing the interest of the “man in the street” or the “family”. Critically, however, to at least the media audience, the efficacy of the neglect story came and went and it no longer worked as a story. Advocates around PCaOrgs then sought to shift the story of PCa from one of a “legacy of neglect” to “other pockets of injustice” in their contemporary messaging around PCa. Such ‘pockets’ include ‘postcode’ inequalities around mortality rates and support, socio-economic inequalities in awareness, and age inequalities.

2. Stories of ‘taboo’ around PCa in the UK national print media 1990-2000

The analysis of media illness narratives in Chapter 4 demonstrated that PCa as a “taboo” disease that “no one dares talk about” and about which men kept quiet was more explicitly and frequently articulated in the UK national print media in 1990-2000 than 2000-2010. Raising awareness was proposed as a solution to this problem with particular actants identified both as culpable for this problem and also as those who ought to address it including: “every woman who loves a man” and the “we [who] will stop making prostate cancer a taboo subject”. Though journalists did not use the word ‘taboo’ at all when writing about the illness experience of MWPCa in 2000-2010, PCa remained—though to a much lesser extent—an illness which men found difficult to talk about.

3. Stories of ‘problematic old waterworks’

The analysis of the media illness narratives in Chapter 4 demonstrated that words around symptoms were used significantly more frequently by journalists in 1990-2000 than 2000-2010 when writing about the illness experience of MWPCa. Urinary symptoms were those symptoms most frequently articulated and these were predominantly frequent/nocturnal/intermittent urination—lower urinary tract symptoms (LUTS)—followed by blood in the urine. Particular phrases included “difficulty passing water” and having problems with “the old waterworks”. MWPCa in both 1990-2000 and 2000-2010 were more frequently articulated as having no symptoms rather than experiencing symptoms—though men’s narratives showed their understanding that LUTS were symptoms of PCa. The PSA test was often spoken about when describing symptoms and described in both periods as helpful in detecting PCa in men with no symptoms.

4. Stories of young men as at risk from PCa

The analysis of the media illness narratives in Chapter 4 demonstrated how young men were more frequently articulated as being at risk of PCa in 1990-2000 than in 2000-2010. This included phrases like: “Young people like me aren't meant to suffer (...) I thought it was something that affected only elderly men. Men in their 40s don't expect this to happen to them” (Daily Mail, 03/11/1999, Extract 4.24). In addition, men in 1990-2000 were sometimes given a familial identity such as being a brother or a father; having a wife; or having older children or grandchildren. Although significantly less frequently articulated as ‘young’ in 2000-2010, there were qualitative similarities in each time period with men in 2000-2010 described as *much* younger: “[PCa] hit me at 37 and now I'm living on borrowed time” (Daily Mail, 17/05/2005). This, as in 1990-2000, was often in the context of PCa being “just an old man’s disease”. As in 1990-2000, men were also placed in a familial setting with having older children and grandchildren—though they were more likely to be described as “young family men” and as having ‘young children/daughter/kids’ themselves.

5. Stories of socio-economic inequalities in awareness: men as informed, misinformed, or uninformed

The analysis of the narratives about PCa by advocates around PCaOrgs in Chapter 5 showed how contending stories of men’s level of awareness ostensibly related to their socio-economic status; MWPCa may be “a healthy bunch of men (...) [who have] made it in their career (...) better able to advocate for themselves (...) [and] in a better position to stand up and say, you know, “I’ve got prostate cancer, and here’s what it means, and here’s the treatment I want”” (Extract 5.16); they may be uninformed and victims of prior neglect in need of someone to fight the “good fight for prostate cancer” (Extract 5.17); or they may be misinformed and persuaded that natural processes of ageing such as LUTS are symptoms of PCa.

Findings 1 and 2 above directed the analytic enquiry for Chapter 6: Given that PCa as a “taboo disease” was more frequently articulated in the media illness narratives of MWPCa in 1990-2000 than 2000-2010 (Chapter 4) and that PCa came “out of the

shadows of neglect” where men “would not talk about it (...) [but] die quietly”, towards the end of the 1990s (Chapter 5), were there differences in how MWPCa disclosed their illness over time to various audiences?

6. Stories of overcoming suffering and death with an optimistic cure and recovery

Men in 2000 and 2010 demonstrated a normative expectation that their various audiences would draw upon a ‘tragic’ genre of worry or concern about the likely suffering and dying of the MWPCa. Men though either pre-empted or responded to this by drawing upon a ‘romantic’ genre of an optimistic outcome for treatment and cure that would “sort the problem out”. Though there was some evidence of men themselves drawing upon a tragic genre in initial disclosures to ‘partners,’ this was countered by a romantic genre by their ‘partner’. In contrast to ‘partners’ and ‘children and wider family’, though MWPCa in 2000 and 2010 did not talk about their expectation of worry from ‘friends and others’ or ‘colleagues’, they still expected a tragic genre of suffering and potential death to be drawn upon. There was little evidence of an imperative to disclose to these audiences.

7. Stories of prompt and delayed disclosures

Though men almost exclusively, made prompt disclosures to ‘partners’, they very often delayed disclosing to ‘children and wider family’, especially if they perceived them as vulnerable. There was little explicit talk about delaying to other audiences.

8. Stories of unexpected drawing on a romantic genre

More men in 2000 than 2010 told how disclosing their PCa to ‘friends and others’ discredited them as near death and to be pitied and how they subsequently sought to counter this ‘tragic’ genre with a ‘romantic’ genre of recovery. However, in 2000-2010 some ‘partners’, ‘children and wider family’ and ‘friends and others’ surprisingly did not in fact draw upon the ‘tragic’ genre expected by the men and instead drew upon a ‘romantic’ genre of an optimistic good recovery. In some cases this prompted further work by the man to renegotiate a tragic genre involving PCa as an incurable condition.

9. Stories of interactional difficulty across time

Men across time talked about receiving support from ‘friends and others’ though this was often alongside interactional difficulty. This meant “awkwardness” in disclosing with men finding it “a very difficult subject to broach” (Calvin, 2000) and their audience finding it hard to respond to. Men, across time indicated that PCa was an illness about which they or others kept quiet because of fear of damage to their macho image or their own or other’s embarrassment.

7.3 Resonance and dissonance in the changing narratives of prostate cancer 1990-2010

The trouble with words is that you never know whose mouths they have been in. (Dennis Potter n.d.)

The stories around PCa conveyed in my findings show attention to both the content and form of narratives around PCa which were generated through sampling the UK national print media from 1990-2010 and interviews with advocates around PCaOrgs in 2010 and MWPCa in 2000 and 2010. My findings show that, akin to the words of the dramatist Denis Potter in the above epigraph, language around PCa was an ‘accumulation of prior texts’ (Tannen, 2007: 49, 103) involving taking, or ‘snatching’ (Steinberg, 1999: 772), words which existed ‘in other people’s mouths, in other people’s contexts, serving other people’s intentions’ (Bakhtin, 1981: 294), to make them serve intentions in a PCa context. The following discussion shows how my findings confer with or differ from those available in the existing literature. I propose that the PCa stories evident in my findings were not brought into being by those concerned with PCa but rather ‘continually recreated’ (Giddens, 1984: 2) from already existing pre-patterned language (Tannen, 2007).

A common feature of the content of narratives from the UK print media and advocates around PCa–Orgs was the importance of injustice and how the substantive focus of this injustice changed over time. My findings show that when writing about the illness experience of MWPCa in 1990-2000, journalists told how PCa was neglected in comparison with other diseases and how it was a ‘taboo’ disease which men and others found difficult to talk about. Likewise, my findings from the analysis of the narratives of PCa by advocates around PCaOrgs demonstrate how telling the story of PCa as a “neglected disease” hidden in the “shadows” and about which “something

needed to be done”, was one which effected action in the late 1990s, shortly after the emergence of the first PCaOrgs into the UK. This action was achieved not only through the Daily Mail campaign in 1999 to raise money but also by the “general stirring of realisation in government and NHS circles and in the media” (Extract 5.1), which led to the publication of the NHS Prostate Cancer Programme (NHS, 2000).

The drawing upon of a narrative of injustice by advocates around PCaOrgs is unsurprising given that injustice, as a ‘hot’ emotion (Gamson 1992: 7), has been used as ‘leaven’ (Turner, 1969: 399) for social change by all social movements in each main historical era (Turner, 1969; Snow, 2004). But why did the neglect story effect such action back in the late 1990s? One potential answer is that in a ‘world of narrative, [where] very little is ever new’ (Frank, 2010: 123), actors around PCaOrgs were able to draw upon a pre-patterned (Tannen, 2007) way of talking, or genre (see for example Bury, 2001), already familiar to their audiences, at least one of which included the UK print media.

The ‘neglect’ story in the form of a ‘gender equity frame’ was one of three interconnecting culturally relevant stories around ‘family’ and ‘fairness’ successfully used in the early 1990s, when breast cancer movement activists in the USA defined breast cancer not as a problem of access to screening and treatment but as one of gender-based institutional neglect (Kolker, 2004). This frame was easily mobilised by breast cancer activists not only because of its prior use in the women’s movement and women’s health movement but also because of the familiarity of the equity story to audiences through its use in other movements. Breast cancer as an ‘epidemic’, with unacceptable rates of incidence in the young and old, was the second frame used by breast cancer advocates in the US. Kolker (2004) shows that though the epidemic frame lacked validity, it was still viable as it ‘resonated strongly with both Congressional and public audiences’ (2004: 827) through its prior use by the US media in the 1980s. The analysis of media narratives (Chapter 4) also showed how PCa was tentatively framed as an ‘epidemic’ in the UK print media in 1990-2000 and not at all in 2000-2010. The analysis of the media narratives also demonstrated that stories of ‘problematic old waterworks’ were used more frequently in 1990-2000 than in 2000-2010. The sheer number of men who experience LUTS as they age means that they are present in 50% of men aged over 60 and nearly 100% of men aged 90 (Weight, 2013).

This decrease in frequency of LUTS mentions across time may be due to evidence that LUTS are not indicative of PCa (Collin et al., 2008), though as Kolker (2004) shows, a lack of validity does not necessarily lessen viability.

In addition to the public construction of breast cancer as an epidemic and as subject to governmental neglect, family-based identities of wives and mothers were added to breast cancer sufferers in the USA. This meant that breast cancer was not only a threat to women but also to American families and so ‘the pool of victims impacted by the disease expanded significantly to include the entire family’ (Kolker 2004: 831). Chapter 4 and Chapter 5 showed also how a ‘family’ story was used around PCa in the UK print media and by advocates around PCa; potentially then also increasing the pool of victims impacted by this illness.

Thus in the UK, advocates around PCaOrgs and journalists writing about the illness experience of MWPCa in print media were able to ‘peer into the actions and histor[y]’ (Steinberg 1999: 752) of breast cancer activism and ‘borrow’ its discourse in order ‘to articulate identities, grievances, and goals where there [were] gaps and silence in the [PCa] discursive field’ (p. 752). This ‘trafficking and transferring’ (p. 752) of the neglect story may be understood by first considering that the possibilities for changing ways of understanding are limited and that the messages of new social movements must make sense in terms of the existing ways of understanding (Lakoff 2010: 72). It demonstrates a useful consequence of social movement ‘spillover’ (Meyer and Whittier, 1994)—new movement actors align their messages with what they know is already familiar to, or *resonant* with, their potential audiences through the messages of some other social movement. Resonant language ‘fits’ or ‘rings true’ in some way with audiences’ already existing beliefs, values, ideologies or experiences (Williams, 2004: 105) and its achievement is considered to be “‘half the battle’” (Berbrier 1998: 432) in legitimising new ideas. Viewing the story of ‘neglect’ as culturally resonant begins to explain why the ‘neglect’ story from the breast cancer movement was used to influence the illness sufferers and other attentive audiences around PCa in the UK.

One of the audiences of PCaOrgs was the UK print media and notable in my findings was how the stories journalists told in 1990-2000 and 2000-2010 about the illness experience of MWPCa corresponded to those told by advocates around PCaOrgs. Kedrowski and Sarow (2007), in their study of PCa and breast cancer activism

in the USA, are concerned with what *interests* 'the masses' (p. 165) and also, by extension, with what *interests* the media as a means of access to these masses. For both the 'media' and the 'masses' to be *interested* in an event, they need to evaluate it as familiar and comprehensible (Silvia, 2008). The repetition of the gender-based neglect story from its prior use by breast cancer activists in the USA (Kolker, 2004) provided familiarity for the media. This was in the form of a media template where meaning could be (re)constructed over time, retrospectively making salient aspects of past problems to explain current events (Kitzinger, 2000). Such reconstruction of meaning from repeated texts is suggested as routine by Tannen (2007) and Bakhtin (1981)—repetition of prior texts then may then be instrumental for achieving resonance.

Though print media was an audience for the messages of PCaOrgs, print media had its own audiences to be concerned with. Familiarity for media audiences was also provided by the repetition of a 'Derisory £47,000 PCa Spend' (Extract 4.1) 'boilerplate' (Cotter, 2010: 171), which was, to varying extents, often included as context for the illness narrative of MWPCa by journalists writing in 1990-2000. This boilerplate repeated the figure "47,000" as the "derisory" or "pitiful" amount of money spent by the UK government on PCa "last year", in terms suggesting it was very limited—"just", "but only" and "yet only". Although a boilerplate is 'seemingly throwaway material (...) repetitious, unattributed (...) and is potentially expendable as text (...) its role in framing a news story may also end up influencing public debate' (p. 171). Such influence was seen in the "lot of fuss in the Houses of Parliament about the amount of money spent on prostate cancer research compared to breast cancer research" (Extract 5.5) when "the Department of Health made, I think made a big effort to listen to the story about men versus women" (Extract 5.5).

However, although resonance is considered to be "'half the battle'" (Berbrier 1998: 432) in legitimising new ideas, it is also considered to be 'only half the story' (Ferree, 2004: 306). A story, argues Polletta (2006), that is 'entirely predictable (...) [is] no story at all (p. 10). And so, I suggest, the success of the 'neglect' story in effecting action cannot be explained solely by its familiar elements. 'Interesting' stories also need to be 'new, unexpected, complex, hard to process, surprising, mysterious or obscure' (Silvia, 2008: 58). 'Interest' is thus composed of both comprehensibility (or familiarity) and novelty elements (Silvia, 2008)—elements which are also important for

other knowledge related emotions such as boredom and confusion. If an event is novel and comprehensible, it is interesting; if novel and incomprehensible, it is confusing; but if it is comprehensible and not novel, it is boring. The extent to which the 'neglect' story was successful in effecting action, I suggest, lay also in the extent to which this familiar language was inflected with novel elements (Steinberg, 1999) and whether it was considered interesting, confusing or boring.

There were several ways in which the familiar gender-based neglect story was combined with novel elements: it was familiar as it had previously been used by breast cancer activists in 1990s; it was novel as men rather than women were neglected—this particular novelty also was familiar as it was gender-based as with its use in the breast cancer context; it was familiar as it articulated hegemonic discourses about men's passive health behaviour; it was novel as it contrasted the silence of men with the noise of women; it was novel as it broadened the constituency of blameworthy agents from government to all society.

The requirement for the familiar to be combined with novelty—or resonance and dissonance—in the 'neglect' story of PCa indicates how media and social movement actors "'twitch" the [familiar] plot from time to time in order to retain audiences' *interest* (...) [and] provide an entertaining disruption of expectations' (Seale 2002: 36 emphasis added). However, and critically, though the gender-based 'neglect' story with a PCa 'twitch' worked because it combined familiarity with unpredictability (Polletta, 2006; Silvia, 2008)—the 'half battle' (Berbrier, 1998) and the 'half story' (Ferree, 2003)—over time it too became overly familiar and was no longer seen as a "universally true story" (Extract 5.6). Why was this? As the 'twitched' plot becomes the norm, Seale (2002) argues, there is a continuing—indeed chronic—need for twitching' (p. 36). This helps to explain the shift of stories from injustice around the funding and neglect of PCa in the media and advocates around PCa analysis to injustice around treatment from 2000.

Finally, the findings in Chapter 6 demonstrated the 'dialogic' nature of talk by participants in both time periods—MWPCa in some way repeating, or reconstructing, familiar voices from past conversations with others about all sorts of issues related to PCa. These voices were often of those present at the disclosure dialogue, for example, the MWPCa, their partners, children or other family member as in the voices of Finlay (2000) and his youngest daughter: "'Oh you'll be alright dad', (...) I got back my bubbly

self and said 'Well I'm going in for an op, that's it and they're going to fix me'". They also included the voices of others such as the consultant of the MWPCa: "'but listen, this, this should be okay, the consultant has told me, 'removal of the prostate [sic] will sort the problem out'" (Keith 2010). Bakhtin suggests that 'sooner or later what is heard and actively understood will find its response in the subsequent speech or behaviour of the listener' (1986: 69). While this may be so, the work of Bakhtin, and Tannen who argues that 'one cannot speak another's words and have them remain primarily the other's words' (2007: 104) (see also Steinberg, 1999), also suggest that these MWPCa may take the words which existed in others' mouths and make them serve their own intention in their own context.

This reconstruction of voices demonstrated how the 'private' voice of MWPCa may combine with other voices. These other voices may be 'collective' such as that offered by the media or accepted as 'common sense'. Or they may be another 'private' voice such as that offered by a medical professional, a partner, child, or friend. When people reconstruct the voices of others they provide evidence not only of what they have actively heard from past conversations, and which is resonant, or 'rings true', with their experience, but also how they want those words to be heard in the present conversation (Bakhtin 1981; Volosinov 1986; Tannen 2007).

Volosinov suggests that the reconstruction of voices constitutes an 'objective document' (1986: 117) of the reception and manipulation of another's speech by an individual speaker. Learning to decipher such a document provides information not on 'subjective psychological processes (...) but about steadfast social tendencies in an active reception of other speakers' speech' (p. 117). I did not attempt such a deciphering of the dialogic content of men's talk; I do though recognise its existence and propose its relevance in understanding how public narratives may combine with private narratives. To borrow the language of Medvedev and Bakhtin; men's experience of disclosing PCa is 'not within [them], but between [them]' (1978: 8) and society. Of note also are not only voices heard in men's dialogic reproduction of their experience, but also 'missing' voices of concern: "you turn on the television and you hear stories about, 'oh and he heroically fought this' and all the rest of it, and there was great rejoicing all round that you've come out of it (...) nobody's ever said to me, 'oh well done, because you've fought it, and you've won'" (Charlie, 2010). Though 'missing', these voices were still expected and orientated to.

7.4 Conclusion

In conclusion, how narratives of PCa were constructed depended on what other narratives were available to borrow and these included those around breast cancer in the early 1990s (Kolker, 2004). This corresponds to previous studies in the illness narrative literature indicating that when people tell stories of illness they unconsciously draw on familiar culturally available core narratives (Bury, 2001; Frank, 2000), or “genres of expression” (Bury and Monaghan, 2013a: 81), in the implicit expectation that their intended audience does likewise. Notably, and differing from what might be expected from this existing literature, my analysis shows that in addition to the familiarity aspects that genres provide, narratives need to include novel elements in order to work as a story (Polletta, 2006; Silvia, 2008). My study shows that what counted as novel in the different narratives reflected temporal interpretations of what counted as interesting. Rather than a single narrative of neglect, rather more complex and interrelated stories of injustice emerged from my study. Neglect, though sufficient as guerrilla warfare (Smith, 2005: p.9) to win the battle to effect action for PCa in the late 1990s, was not necessarily the artillery needed to win a war (p.9). What mattered was the bigger story of injustice and how this could be ‘twisted’ (Seale, 2002: 36) to suit the contemporary context and interests.

There is a strategic necessity by actors around PCaOrgs to construct PCa messages in language which ‘fits’, ‘rings true’ or resonates with existing cultural ideas. I propose that there has been a combination of resonance and dissonance in the language around PCa from 1990-2010 which resulted in an ‘entertaining disruption of expectations’ (Seale 2002: 36) to the various PCa audiences. This combined the familiar and the strange in a way which not only ‘sticks in the mind because it references the expected but also because it makes some new connection through and beyond those categories’ (Bell 2011: 40-41). This, I suggest, demonstrates the recursiveness and self-reproducing discourses inherent in human social practices (Giddens, 1984).

Chapter 8 Conclusion

8.1 Introduction

This thesis addresses the distinct lack of UK studies of print media representation of PCa, of health social movement (HSM) activity around PCa, the interaction between the two, and how any of this may impact on the experience of MWPCa. In this thesis I have asked how PCaOrgs and the UK print media have been a force for change in the UK regarding how PCa has been addressed and experienced by MWPCa. I have investigated: 1) how key individuals within PCaOrgs described how they sought to address the condition of PCa; 2) changes in how MWPCa described their illness experience in research interviews over this time; and 3) changes in how the UK national print media has represented the illness experience of MWPCa from the emergence of PCaOrgs into the UK in the mid-1990s. In this final chapter I discuss the limitations of the study, propose some potential avenues for future research and indicate potential implications for MWPCa and for PCaOrgs and for professional sociology.

8.2 Limitations

My study has a number of limitations. Sampling of the public representation of PCa was limited as I did not sample NHS or government health policy documents regarding PCa or web or hard document representations from PCaOrgs. This limitation was justified by the need to avoid data overload (§3.2). Sampling of the UK print media was also limited. Only those newspapers fully uploaded to Nexis in 1990-1995 (§3.4.1.1.1) were sampled as searching hard copy indices of the media was too time-consuming (Brown et al., 2001). The impact of the potential loss of data is described in §3.4.1.1.2. Additionally, the media sample was limited in that only those articles which were predominantly illness narratives of MWPCa were included (§3.4.1.1.3). However, many of the excluded articles may have been ‘peripheral’ articles of little consequence for the research enquiry (see Halpin et al. 2007). Sampling of the media was also limited in that there was no mention of ‘Movember’ despite the first ‘Movember’ article occurring in November 2006. Movember, a global campaign launched in the UK

in 2007, asks men to grow moustaches in November to raise money and awareness for PCa, testicular cancer and mental health (Movember, 2013). However, sampling the media articles in line with the start of the 'Movember' campaign would have been detrimental to the research design given the advent of PCaOrgs to UK in the mid-1990s and my access to the www.healthtalk.org interviews with MWPCa in 2000. These limitations noted; the sampling was both pragmatically and comparatively efficacious for the overall research design.

Another potential limitation was my explicit research enquiry into how PCaOrgs and the UK print media have been a force for *change* as, consequentially, this ignored potentially interesting *unchanging* things in the data. For example, the overt focus of CKWIC analysis on *differences* in the frequency of particular words over time neglected the way *similarly* frequent words might also be interesting and relevant in the qualitative interpretation (Seale et al., 2006; Seale et al., 2007) of my data. This limitation prompts the question as to whether the media articles could have been usefully analysed differently. Clarke (1999; 2004) and Halpin et al. (2009) (§2.2.2.1) conduct a 'manifest' and 'latent' analysis of PCa in various print media. They suggest that such analysis combine a quantitative counting of themes and a qualitative interpretative thematic analysis. Though their analysis produces interesting findings which correspond to some of mine, their research enquiry was not to compare differences between datasets (§3.4.2.1). Seale et al. (2006) use both CKWIC and conventional thematic analysis on the same data to evaluate whether the results of the former are consistent with the latter. They conclude that CKWIC is effective in revealing similar differences in the data to a conventional analysis while allowing a more inductive analysis and economical way of identifying salient aspects of the data without *a priori* conceptual bias. That my findings show some correspondence with those of Clarke (1999; 2004) and Halpin et al. (2009) and also across Chapter 4 and Chapter 5 indicates the ability of this method to identify important aspects of changes in narratives around PCa. That it shows nuanced differences across time shows the benefit of this method over a conventional thematic analysis for the particular purpose of comparing data across time.

A final limitation is that the MWPCa participants in my research represent those who chose to speak publically about their illness. Their experiences as described here may not therefore represent the experiences of those not willing to speak publically.

8.3 Suggestions for future research and articles

My findings in Chapter 6 suggest the opportunity to produce a paper based on the article 'Thinking differently about thinking positive: a discursive approach to cancer patients' talk' (Wilkinson and Kitzinger, 2000). These authors refute the idea that the 'thinking positive' talk of women with breast cancer is concerned with reporting their actual cognitions. Rather, they persuasively demonstrate that when such talk is used, it is instead as an 'idiom (...) that is, it is a common place saying which summarises a taken-for-granted piece of cultural knowledge' (2000: 802). They argue that: 1) thinking positive is 'interactionally occasioned', (2000: 809) enabling the disclosure and convenient 'wrapping up' (2000: 803) of troubles telling and relieving the 'listeners of a potential conversational burden' (2000: 805); and 2) women with breast cancer are morally exhorted to think positive. The interest of a corresponding paper would be to compare the use of the commonplace idiom of 'thinking positive' with the negotiation between a 'tragic' genre of futile suffering and death and a 'romantic' genre of triumph over adversity. It would also allow examination of the extent to which stoicism, as an aspect of hegemonic masculinity, is merely illustrative of a more general culture of stoicism.

Along similar lines is the attention of the organisational and patient safety literature to the difficulties people have in speaking out about particular concerns to peers. This literature could be used to further explore how men speak out to other men about PCa.

The global campaign Movember is suggested to mislead men (McCartney, 2012). Empirical enquiry into whether this is so might be to compare narratives of Movember in the UK print media and its website (launched 15 September 2013) with men's narratives of Movember. Sampling men of different ages would also allow enquiry into the plurality of masculinities at least with regard to age. Such a research enquiry is also intriguing from a dialogical perspective. I was introduced to the idea of dialogic talk through the concept of resonance and then onwards into the literary theories of Bakhtin (1981), Volosinov (1986) and Tannen (2007). There is though a growing literature on dialogism (see for example Madill and Sullivan, 2010; Märtsin et al., 2011; Sullivan, 2011) which I did not explore within this thesis. It is clear from my findings that many participants orientated to the voices of others and often reproduced them

in some way. This may constitute an ‘objective document’ (Volosinov, 1986: 117) of the reception and manipulation of another’s speech by an individual speaker—also demonstrating how the speaker would like those words heard in the current context. Paying attention to this would also allow examination of narrative forms in addition to content and why a particular story may be told in a particular way (Riessman, 1993: 2). Incidentally, of the three reader responses to McCartney’s (2012) article, two mentioned PCa as ‘a gender-equality issue’; a “Cinderella’ cancer’; and ‘a condition the NHS sinfully neglects’. This is interesting as this way of talking about PCa reflects my findings—stories of neglect may be used for some contemporary audiences. It is also interesting McCartney’s original article did not mention such ideas—it may also be a valid research enquiry to analyse reader commentary to see what the ‘real’ argument is about (O’Halloran, 2010).

Finally, despite PCa often having ‘a very indolent history’ (Parker, 2004: 102), there were 10,837 PCa deaths in the UK in 2012 (Cancer Research UK, 2013a). Deaths in men with non-lethal prostate tumours in the USA have been attributed in error to PCa. Though such error is thought to be less likely the case for the UK (Cancer Research UK, 2013a), literature around the social production of statistics—ethnostatistics—which includes at least the collection and measurement of data and how the produced statistics are used in the public domain, may serve to investigate this.

8.4 Implications

The methods I used to answer my research question involved collecting and analysing a variety of illness narratives. Although the sociological enquiry of illness narratives stretches back thirty years (Hyden, 1997; Mishler, 2005), it has been ‘stormy’ (Morse, 2001) for much of this time. The centre of this debate may reflect the tension between public and professional sociologies (Thomas, 2010; Bury and Monaghan 2013a): the former concerned with producing extra-academic knowledge for patient groups; the latter with producing academic knowledge for peers (Burawoy, 2004). Public and professional sociologies are though interfacing ‘ideal types, each of which is internally complex’ (Burawoy, 2004: 1609). Professional knowledge is instrumental for public knowledge in that an effective public sociology may depend upon a professional

sociology to provide relevant legitimacy, expertise, and analytic techniques (p. 1610). Correspondingly, the engagement of public sociologists in political and moral concerns makes the pursuit of methodological and theoretical coherence all the more worthy (Burawoy, 2004). This thesis has implications for both professional and public sociology.

The implications of my thesis for public sociology—for MWPCa and PCaOrgs—are as follows. When MWPCa talk about their illness they unconsciously draw on available and acceptable ways, or genres, of talking and understanding. These ways of talking may be sought, strategically or consciously, by actors around PCaOrgs in order to construct messages in language which ‘fits’ or resonates with MWPCa or other desired audiences. Though such resonant language has included ideas of injustice—the funding neglect of PCa and injustices around funding for treatment and suffering of treatment side-effects—types of injustice are subject to dialectic tension and contestation. By the former I mean that though some injustice stories may be successful in effecting action, this same success may transform the original belief so that similar stories of injustice may no longer be efficacious. By the latter I mean, audiences are not homogenous—the ‘man in the street’ audience is not the same as the media audience—and a story of injustice resonant with one audience may be contested by another. Critically though, for actors around PcaOrgs, using resonant language is not sufficient to sustain the interest of any audience. Those concerned with constructing messages around PCa must also use novel, unusual, unpredictable or complex language. The combination of resonant and novel—or dissonant—language will work to sustain the interest of audiences. Notable though is that novel language itself is subject to temporal constraints in that it too eventually becomes overly familiar and *new* novel language will then need to be continually sought.

One potential contested injustice may be around the likelihood of increasing numbers of men moving onto the disease spectrum of PCa through the transformation of natural processes of ageing such as incontinence and impotence (Armstrong, 2014). As more and more men are diagnosed with non-clinically relevant PCa, with no clinical symptoms expected during their lifetime (Schroder et al., 2009), the public face of PCa may become healthier as those with a poor prognosis become relatively fewer (Aronowitz, 2009). This expanded group of MWPCa may be “a healthy bunch of men (...) able to advocate for themselves” (Extract 5.16), result in an ‘expanded market for

interventions and greater clout for disease advocates' (Aronowitz, 2009: 417-8) and also more fully meet the seven characteristics of a successful grassroots survivors' organisation (Kedrowski and Sarow, 2007).

My findings show that the increasingly healthy face of PCa may lead to some interactional difficulties for at least those MWPCa with a poor prognosis but also perhaps for those with a good prognosis. The potential 'veneer of optimism' (Aronowitz, 2009: 436) onto the identity of the expanded group of MWPCa may lead audiences of MWPCa to view PCa as "not too bad" (Extract 6.29). Though this is ostensibly good news, it may have a number of unwanted effects. It may mean that those with a poor prognosis will have to work to convince others that their type of PCa is not curable and therefore deserving of interactional outcomes such as sympathy and so on. It may also mean that those with a good prognosis may not receive the sympathy they expect. Further, interactional difficulty can be expected when men disclose their PCa to some audiences as, despite optimistic signs that PCa is no longer a "taboo disease that no one dares talk about" and where men just "die quietly", men and others still find this an embarrassing illness to talk about.

The implications of this thesis for professional sociology concern elements of the 'storm in the academic teacup' (Morse, 2001: 587) around illness narratives and the idea of frame resonance as "half the battle" (Berbrier, 1998: 432) in constructing language which 'fits' with audiences' ways of understanding. The principal forces in the academic storm are the arguments of Atkinson (1997, reproduced in 2006) and Frank (2000, 2010). Atkinson suggests that narrative analysis of illness narratives tends to privilege the story-teller over the story-analysers and romanticise illness sufferers as heroes in contrast with villainous doctors (Atkinson, 1997, reproduced in 2006). Frank (2000) argues that focussing on narrative structures risks excluding what is most important to storytellers, for example, their moral accounts of a virtuous self. Frank (2010) though indicates that when illness sufferers offer such accounts they may, albeit unconsciously, draw on available and acceptable ways, or structures, of telling—and so indicating structures which a story analyst might seek.

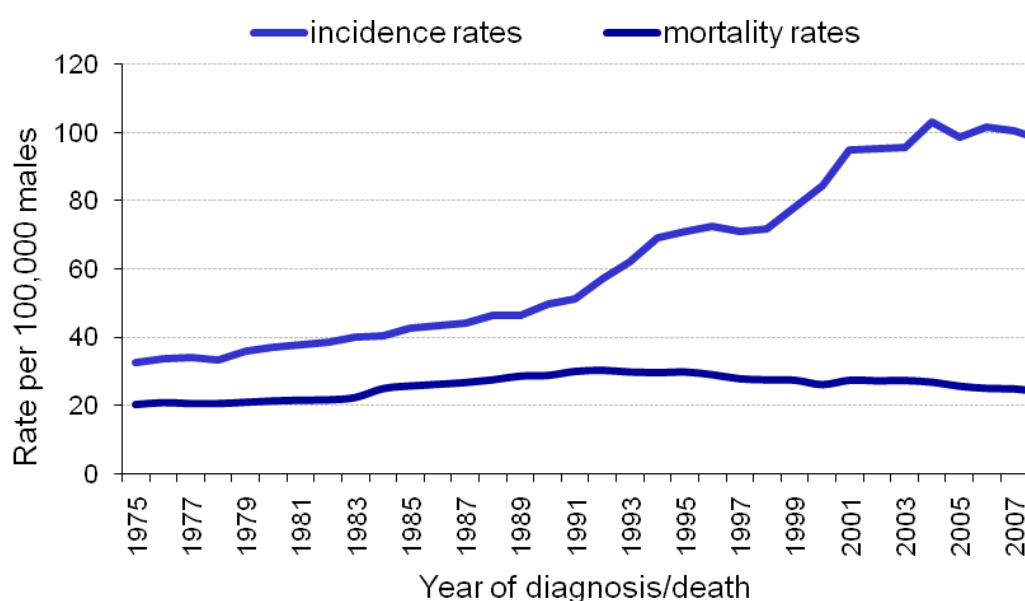
This thesis corresponds to previous studies in the illness narrative literature: when MWPCa, advocates around PCaOrgs and print media journalists tell stories of PCa, they draw on culturally available ways of talking—core narratives (Bury, 2001; Frank, 2000), genres (Bury, 2001), pre-patterned talk (Tannen, 2007), or words

previously existing in others' mouths and contexts (Bakhtin, 1981). They expect their intended audience to do likewise and their talk is also likely to be "recipient designed" (Frank, 2010: 90) or "co-authored" (Williams, 1984) in that it is tailored to fit the expected response of their audience (Frank, 2010; see also Riessman, 2008). Differing though from what might be expected from this literature and in the "world of narrative, [where] very little is ever new" (Frank, 2010: 123), my thesis demonstrates, akin to Polletta (2006), that a story which 'is so familiar as to be entirely predictable (...) [is] no story at all (p. 10). My thesis shows that the familiarity that genres provide is not enough to make a narrative work; novel and unpredictable elements are also needed. What counts as novel in narratives may also reflect temporal interpretations of what counts as 'interesting' (Silvia, 2008). I propose that those analysing illness narratives will need to examine not only familiar genres or ways of talking which people draw upon, but also novel and unpredictable language. Examining the combination of resonant and dissonant language will help to understand the recursiveness and self-reproducing inherent in human social and discursive practices (Giddens, 1984).

Appendices

Appendix 1. Prostate cancer incidence and mortality rates, GB 1975-2008

Figure 1. 1 Prostate Cancer, age-standardised (European) incidence and mortality rates, GB, 1975-2008



The following is a personal email communication from the CRUK Statistical Information team 23/05/2012:

“[The chart above] (Figure 1.5: Prostate Cancer (C61), European Age-standardised Incidence and Mortality Rates, Great Britain, 1975-2008) has now been superseded by charts showing the latest incidence and mortality data separately: Incidence Great Britain 1975-2009:

<http://info.cancerresearchuk.org/cancerstats/types/prostate/incidence/uk-prostate-cancer-incidence-statistics#trends> Figure 1.3 [and] Mortality UK 1971-2009:

<http://info.cancerresearchuk.org/cancerstats/types/prostate/mortality/#trends> Figure 2.2 (NB this will be updated to 2010 data within the next month or so). Unfortunately we are unable to make the graph you downloaded available on our website again, as those data are now out of date. However, we can confirm the chart you downloaded was available on our website in April 2011, and was replaced by the updated chart on May 4th 2012.”

I was also later advised that I could recreate the above chart by downloading the Excel files of the raw data through the above web pages (personal email CRUK Statistical Information team 24/05/2012).

Appendix 2. Original research proposal, abstract and plan of investigation

Original Proposed Title: The public face of prostate cancer in the UK

Abstract

This study will apply Health Social Movements (HSM) theory to UK Prostate Cancer awareness-raising activity. The purpose is to derive principles from past and current experience to guide future strategies for organisations involved in the UK prostate cancer HSM. This work comprises a) a comparative study of media, b) focus group work, and c) interviews with key people in the HSM. First there will be a comparative study, using linguistically-oriented keyword analysis, of changes over time in mass media (newspaper and internet) representations of prostate cancer, and in policy documents produced (a) by governmental and NHS sources and (b) prostate cancer awareness-raising organisations. Second, a focus group study will involve men with prostate cancer and intimate family members. This will assess the degree to which the collective identity 'offered' to men through media and policy discourse is incorporated into personal biographical experience (known as 'frame alignment' within the cultural framing approach to HSMs). Third will be a snowball sample of interviews with key people in relevant organisations, using resource mobilisation and 'political opportunities' perspectives within HSM theory to assess strategies pursued in the UK over the past 20 years.

Plan of investigation and methodology

(1) Investigation of changing public image

The aim of this will be to investigate the changing language associated with prostate cancer through a systematic study of relevant public documents. This will involve a random sample of national and local newspaper articles (taken from the Nexis database of all UK newspapers) about prostate cancer dating back 20 years, using qualitative and quantitative computer-assisted methods to assess changes over time. Another sample of relevant health policy documents concerning prostate cancer emanating firstly from NHS and governmental sources, and secondly from prostate cancer HSMs over this period, will be drawn up and subjected to similar analysis to detect changes in the language of prostate cancer over time. Particular attention will be paid to the spread and interchange of key terms (e.g.: 'expert patient'; 'living with prostate cancer') across mass media and the two categories of policy documents so that directions of influence can be assessed. Where found, the analysis will describe examples of frame bridging, amplification, extension and transformation (Snow et al., 1986).

The PhD student will be trained in the use of 'keyword' analysis, developed by the applicant and used on a number of documentary studies. This provides a reliable quantitative and qualitative overview of very large amounts of text, and is particularly useful for comparative studies (e.g.: comparisons over time or between different types of document).

(2) Impact on experience of prostate cancer

The experiences of men with prostate cancer and their intimate family members ('carers') will be investigated with the aim of assessing the extent to which their personal approaches to living with the illness, and the language they use to express this, is in harmony with the concerns and language of prostate cancer promoted in the mass media and in policy documents. This will help in assessing whether the prostate cancer social movement is currently successful in achieving one of the core tasks of any health social movement: to help individuals with a condition interpret their experience as being linked to the 'collective identity' provided by the public and policy 'discourse' the HSM promotes ('frame alignment').

Five focus groups containing men with prostate cancer and/or their 'carers' will be convened. A proportion of participants will be African or African-Caribbean to enable comparisons between these individuals and others, since it seems possible that ethnically-based cultural differences may influence the degree to which the collective identity 'offered' to these individuals is taken up. Participants will be recruited either through health services or through connections with prostate cancer charities so NHS ethical committee approval for this element of the study will be sought.

Focus group participants will be presented with examples of the public and policy language of prostate cancer and asked to discuss what these statements mean to them. Focus groups will be audio-recorded and transcribed and analysed using computer-assisted qualitative data analysis software, of which the lead applicant has extensive experience.

(3) Investigation of prostate cancer organisations

While the above two strands of investigation largely draw on the cultural 'framing' of prostate cancer and the impact that has on personal experience, the third element of the project will focus on understanding resource mobilisation and exploitation of political opportunities by the prostate cancer HSM over the past two decades. This will be done largely by means of an interview study with up to 20 leading proponents of prostate cancer awareness, as well as those associated with such individuals, such as influential medical and research scientists and policy makers with responsibility for cancer services and research. University ethical committee approval for this aspect of the study will be needed.

The sample of interviewees will be formed on a 'snowball' basis by first contacting and interviewing leading figures within prostate cancer organisations such as the Prostate Cancer Charity itself. Interviews will focus on the personal biography of the individual concerned as this relates to activities associated with prostate cancer, reflections on the history and future prospects of the prostate cancer awareness movement, and an account of key contacts made by the individual in pursuit of awareness raising activities. Where relevant these contacts will themselves be approached for similar interviews.

Interviews will be audio-recorded and transcribed and analysed using computer-assisted qualitative data analysis software, of which the lead applicant has extensive experience.

Appendix 3. Identified keywords in analysis of media narratives

Identified keywords 1990-2010

There are 8 columns in the tables below. The first of these (N) simply lists the keywords in numerical order and the second (Keyword) lists each keyword. The third (Freq.) gives the frequencies of each keyword as it appeared in the examined corpus and the fourth (%) gives this frequency as a percentage of the whole corpus. As the two corpora are different sizes it is useful to consider the % column rather than the raw frequency. Columns 5 and 6 (RC. Freq.) and (RC. %) show the same figures for the reference corpus. Column 7 gives the keyness value of each word and the eighth column gives the p value. The keyness values gradually decrease as the list descends and the p value correspondingly increases as the keyness becomes less significant. The first table shows the 138 positive keywords ($p < 0.01$) when the 1990-2000 corpus is compared with reference to 2000-2010. The second shows the 118 positive keywords ($p < 0.01$) when the 2000-2010 corpus is compared with reference to 1990-2000.

Keywords 1990-2000

N	Key word	Freq.	%	RC. Freq.	RC. %	Keyness	P
1	KORDA	35	0.083157122	0		89.77902222	4.60975E-15
2	GIULIANI	45	0.106916294	5		86.17584229	5.63225E-15
3	SENATE	23	0.054646108	0		58.99290085	5.12436E-14
4	CLINTON	17	0.0403906	0		43.60169601	9.03745E-13
5	REPUBLICAN	15	0.035638765	0		38.47156906	8.94767E-12
6	GBP	33	0.078405283	15	0.013682136	34.76482773	7.95644E-10
7	MAYOR	18	0.042766519	2		34.46268463	1.42032E-09
8	MILLION	22	0.052270189	6		31.22846222	2.00131E-08
9	MARGARET	12	0.028511012	0		30.77663803	2.60255E-08
10	MRS	16	0.038014684	2		29.77790451	4.55235E-08
11	MICHAEL	24	0.057022024	9		28.73115921	8.02303E-08
12	GEOFFREY	11	0.026135094	0		28.21172905	1.05819E-07
13	BRUCE	17	0.0403906	4		25.7498188	3.85739E-07
14	SENATOR	10	0.023759177	0		25.6468544	4.07039E-07
15	BENTINE	10	0.023759177	0		25.6468544	4.07039E-07
16	URINE	47	0.111668132	43	0.039222125	23.90206909	1.0107E-06
17	STUDYING	9	0.021383259	0		23.08201408	1.54944E-06
18	HILLARY	9	0.021383259	0		23.08201408	1.54944E-06
19	HUGHES	9	0.021383259	0		23.08201408	1.54944E-06
20	PROSTATIC	14	0.033262849	3		22.01153564	2.70724E-06
21	CHARLES	11	0.026135094	1		21.97735023	2.75595E-06
22	SHAPED	11	0.026135094	1		21.97735023	2.75595E-06
23	BPH	12	0.028511012	2		20.59273148	5.67822E-06
24	DOUG	8	0.019007342	0		20.5172081	5.90683E-06
25	VEGETABLES	8	0.019007342	0		20.5172081	5.90683E-06
26	YORK	25	0.059397943	16	0.014594279	19.66991997	9.20096E-06
27	CLIFF	10	0.023759177	1		19.59455872	9.57122E-06
28	IT	633	1.50395596	1341	1.223183036	18.13307571	2.05963E-05
29	MFI	7	0.016631424	0		17.95243835	2.26465E-05
30	SOUTHON	7	0.016631424	0		17.95243835	2.26465E-05

31	ONSLow	7	0.016631424	0		17.95243835	2.26465E-05
32	FRUIT	7	0.016631424	0		17.95243835	2.26465E-05
33	ZINC	7	0.016631424	0		17.95243835	2.26465E-05
34	TUMOUR	44	0.104540378	47	0.042870693	17.33822823	3.12801E-05
35	GIULIANI'S	9	0.021383259	1		17.2300663	3.31125E-05
36	SURROUNDS	9	0.021383259	1		17.2300663	3.31125E-05
37	EXAMINATION	26	0.061773859	20	0.018242849	16.69498634	4.38939E-05
38	RACE	17	0.0403906	9		15.9066124	6.65429E-05
39	MAGDA	6	0.014255506	0		15.38770103	8.75534E-05
40	MYRA	6	0.014255506	0		15.38770103	8.75534E-05
41	TRANSRECTAL	6	0.014255506	0		15.38770103	8.75534E-05
42	ELECTION	6	0.014255506	0		15.38770103	8.75534E-05
43	LAZIO	6	0.014255506	0		15.38770103	8.75534E-05
44	CLINTON'S	6	0.014255506	0		15.38770103	8.75534E-05
45	VOTERS	6	0.014255506	0		15.38770103	8.75534E-05
46	TABOO	6	0.014255506	0		15.38770103	8.75534E-05
47	DOLE	6	0.014255506	0		15.38770103	8.75534E-05
48	ESCALATE	6	0.014255506	0		15.38770103	8.75534E-05
49	TERENCE	6	0.014255506	0		15.38770103	8.75534E-05
50	SYMPTOMS	67	0.159186482	93	0.084829248	14.70995808	0.000125379
51	SPENT	22	0.052270189	17	0.015506421	14.04780388	0.000178219
52	GENETIC	9	0.021383259	2		13.95037842	0.000187697
53	MILKEN	9	0.021383259	2		13.95037842	0.000187697
54	FERGUSON	20	0.047518354	15	0.013682136	13.23761082	0.000274385
55	ROWE	5	0.011879588	0		12.82299805	0.000342382
56	CHARMED	5	0.011879588	0		12.82299805	0.000342382
57	FATS	5	0.011879588	0		12.82299805	0.000342382
58	EXPOSURE	5	0.011879588	0		12.82299805	0.000342382
59	DOUGHNUT	5	0.011879588	0		12.82299805	0.000342382
60	OIL	5	0.011879588	0		12.82299805	0.000342382
61	GEOFFREY'S	5	0.011879588	0		12.82299805	0.000342382
62	GOON	5	0.011879588	0		12.82299805	0.000342382
63	CONLAN	5	0.011879588	0		12.82299805	0.000342382
64	SEXUALITY	5	0.011879588	0		12.82299805	0.000342382
65	ANALYSED	5	0.011879588	0		12.82299805	0.000342382
66	SLOWER	5	0.011879588	0		12.82299805	0.000342382
67	TOFU	5	0.011879588	0		12.82299805	0.000342382
68	EVEN	63	0.14968282	90	0.082092822	12.74950981	0.0003561
69	RUDOLPH	7	0.016631424	1		12.57385349	0.000391178
70	SHADOWS	7	0.016631424	1		12.57385349	0.000391178
71	CANDIDATE	7	0.016631424	1		12.57385349	0.000391178
72	SISTER	7	0.016631424	1		12.57385349	0.000391178
73	EAT	15	0.035638765	9		12.56341171	0.00039337
74	MAIL	18	0.042766519	13	0.011857851	12.4467783	0.000418711
75	WATER	14	0.033262849	8		12.26266956	0.000462107
76	OCCUR	13	0.030886929	7		11.991436	0.000534453
77	QUIET	8	0.019007342	2		11.80861568	0.00058957
78	FAMILY	48	0.114044048	64	0.058377117	11.72367001	0.000617098
79	I'D	50	0.118795887	68	0.062025685	11.59757996	0.000660374
80	UPPER	9	0.021383259	3		11.53512192	0.000682933
81	VITAMIN	9	0.021383259	3		11.53512192	0.000682933
82	ALMOST	27	0.064149775	28	0.025539989	11.2135849	0.000812004
83	MEDICAL	50	0.118795887	69	0.062937826	11.15092564	0.000839895
84	HISTORY	14	0.033262849	9		10.964468	0.000928753

85	AGE	46	0.109292217	63	0.057464972	10.47111893	0.00121255
86	IDENTIFIES	6	0.014255506	1		10.29582405	0.001333313
87	BIOLOGY	6	0.014255506	1		10.29582405	0.001333313
88	BIOPSY	46	0.109292217	64	0.058377117	10.03087902	0.001539373
89	DIET	14	0.033262849	10		9.801968575	0.001743249
90	HARRY	10	0.023759177	5		9.799973488	0.001745141
91	ENLARGE	7	0.016631424	2		9.717207909	0.001825503
92	DUCHESS	9	0.021383259	4		9.632606506	0.001911529
93	KILLER	16	0.038014684	13	0.011857851	9.59043026	0.001955938
94	RAISE	16	0.038014684	13	0.011857851	9.59043026	0.001955938
95	DEVELOPS	8	0.019007342	3		9.57544136	0.001971971
96	DISEASE	95	0.22571218	165	0.150503501	9.511831284	0.00204151
97	RECTAL	15	0.035638765	12	0.010945709	9.171572685	0.00245803
98	AS	271	0.643873692	564	0.514448345	9.01608181	0.002676142
99	YOUNG	22	0.052270189	23	0.020979276	9.007304192	0.002689025
100	FREQUENTLY	11	0.026135094	7		8.702689171	0.003177407
101	ONLY	78	0.185321584	133	0.121314943	8.466990471	0.00361649
102	FIGURE	10	0.023759177	6		8.375099182	0.003803965
103	STREAM	10	0.023759177	6		8.375099182	0.003803965
104	PASSING	13	0.030886929	10		8.346051216	0.003865262
105	MEAT	9	0.021383259	5		8.081440926	0.004472084
106	PATHOLOGISTS	5	0.011879588	1		8.066028595	0.004510283
107	JOKE	5	0.011879588	1		8.066028595	0.004510283
108	CHARITABLE	5	0.011879588	1		8.066028595	0.004510283
109	CONTEST	5	0.011879588	1		8.066028595	0.004510283
110	MAIL'S	5	0.011879588	1		8.066028595	0.004510283
111	YORK'S	5	0.011879588	1		8.066028595	0.004510283
112	CAPSULE	5	0.011879588	1		8.066028595	0.004510283
113	ALL	148	0.351635814	289	0.263609171	7.879816055	0.004998954
114	SOCIETY	8	0.019007342	4		7.839799404	0.005110825
115	IDEA	16	0.038014684	15	0.013682136	7.838580132	0.005114273
116	HAPPEN	16	0.038014684	15	0.013682136	7.838580132	0.005114273
117	JOHNSON	6	0.014255506	2		7.689846516	0.005553232
118	POWERFUL	6	0.014255506	2		7.689846516	0.005553232
119	LINK	6	0.014255506	2		7.689846516	0.005553232
120	CHEMICALS	6	0.014255506	2		7.689846516	0.005553232
121	POLICE	7	0.016631424	3		7.684381485	0.005570074
122	FORTUNATELY	7	0.016631424	3		7.684381485	0.005570074
123	GENE	7	0.016631424	3		7.684381485	0.005570074
124	HYPERPLASIA	7	0.016631424	3		7.684381485	0.005570074
125	REVEAL	7	0.016631424	3		7.684381485	0.005570074
126	DIGITAL	7	0.016631424	3		7.684381485	0.005570074
127	MEN	179	0.425289273	362	0.330195576	7.468176842	0.006279909
128	ULTRASOUND	15	0.035638765	14	0.012769994	7.398842812	0.006526582
129	CANCER	567	1.347145319	1288	1.174839497	7.331418037	0.006775955
130	SIGNS	18	0.042766519	19	0.017330706	7.244087219	0.007113484
131	REMAINS	10	0.023759177	7		7.160042286	0.007454541
132	ENLARGEMENT	10	0.023759177	7		7.160042286	0.007454541
133	RISKS	10	0.023759177	7		7.160042286	0.007454541
134	RUN	16	0.038014684	16	0.014594279	7.069717407	0.007839759
135	INSTITUTE	16	0.038014684	16	0.014594279	7.069717407	0.007839759
136	SOON	20	0.047518354	23	0.020979276	6.837277412	0.008927478
137	BRIAN	9	0.021383259	6		6.790011883	0.009166927
138	GREATER	9	0.021383259	6		6.790011883	0.009166927

Keywords 2000-2010

N	Key word	Freq.	%	RC. Freq.	RC. %	Keyness	P
1	BRACHYTHERAPY	60	0.054728545	0		38.99879456	6.40463E-12
2	MAX	56	0.051079977	0		36.3983078	5.7993E-11
3	SAID	380	0.346614122	74	0.175817907	33.09715652	5.84198E-09
4	MEGRAHI	50	0.045607124	0		32.49772644	9.00851E-09
5	RIPLEY	50	0.045607124	0		32.49772644	9.00851E-09
6	STEEL	46	0.041958552	0		29.89744377	4.26266E-08
7	PROCEDURE	52	0.047431406	1		26.44014931	2.68906E-07
8	DAVID	48	0.043782838	1		23.99838257	9.61242E-07
9	UK	104	0.094862811	12	0.028511012	21.20781898	4.11788E-06
10	SHE	198	0.180604205	36	0.085533038	20.09279442	7.37449E-06
11	ENGLAND	41	0.037397839	1		19.75985527	8.77785E-06
12	ELLIOTT	28	0.025539989	0		18.19716835	1.99146E-05
13	ANDY	26	0.023715703	0		16.89723969	3.9456E-05
14	ROBOT	26	0.023715703	0		16.89723969	3.9456E-05
15	POWELL	25	0.022803562	0		16.24728203	5.55864E-05
16	VAL	25	0.022803562	0		16.24728203	5.55864E-05
17	YES	25	0.022803562	0		16.24728203	5.55864E-05
18	BOB	53	0.04834355	4		15.73698235	7.27842E-05
19	DAVE	24	0.021891419	0		15.59733009	7.83622E-05
20	KID	24	0.021891419	0		15.59733009	7.83622E-05
21	RUGBY	33	0.030100701	1		14.98816013	0.000108185
22	GROUNDS	23	0.020979276	0		14.94738293	0.000110548
23	SPESS	23	0.020979276	0		14.94738293	0.000110548
24	LOVE	61	0.05564069	6	0.014255506	14.63071632	0.000130763
25	COURT	22	0.020067133	0		14.29744148	0.000156074
26	RELEASE	31	0.028276416	1		13.81133175	0.000202111
27	MAUREEN	21	0.019154992	0		13.64750385	0.000220531
28	JACKIE	20	0.018242849	0		12.9975729	0.000311892
29	SCOTTISH	36	0.032837126	2		12.85463905	0.000336641
30	CARMAN	19	0.017330706	0		12.34764576	0.00044154
31	MARTIN	19	0.017330706	0		12.34764576	0.00044154
32	PARLIAMENT	19	0.017330706	0		12.34764576	0.00044154
33	UNIVERSITY	28	0.025539989	1		12.06162453	0.000514701
34	ANAESTHETIC	18	0.016418563	0		11.69772434	0.000625763
35	DE	18	0.016418563	0		11.69772434	0.000625763
36	DICK	18	0.016418563	0		11.69772434	0.000625763
37	STUFF	18	0.016418563	0		11.69772434	0.000625763
38	COMPASSIONATE	17	0.015506421	0		11.04780769	0.000887918
39	GAME	17	0.015506421	0		11.04780769	0.000887918
40	KEYHOLE	17	0.015506421	0		11.04780769	0.000887918
41	LOCKERBIE	17	0.015506421	0		11.04780769	0.000887918
42	TREATMENT	313	0.285500586	81	0.192449331	10.80762482	0.001010826
43	AGAIN	52	0.047431406	6	0.014255506	10.60055923	0.001130532
44	GLYNN	16	0.014594279	0		10.39789581	0.001261587
45	LIBYAN	16	0.014594279	0		10.39789581	0.001261587
46	MACASKILL	16	0.014594279	0		10.39789581	0.001261587
47	MEGRAHI'S	16	0.014594279	0		10.39789581	0.001261587
48	PRESIDING	16	0.014594279	0		10.39789581	0.001261587
49	RADIO	16	0.014594279	0		10.39789581	0.001261587

50	DRUG	51	0.046519265	6	0.014255506	10.17096138	0.001426696
51	HE	1506	1.373686552	492	1.168951511	10.04950142	0.001523889
52	GUILDFORD	15	0.013682136	0		9.747989655	0.001795186
53	JAIL	15	0.013682136	0		9.747989655	0.001795186
54	LAUNCH	15	0.013682136	0		9.747989655	0.001795186
55	MONKHOUSE	15	0.013682136	0		9.747989655	0.001795186
56	PARK	15	0.013682136	0		9.747989655	0.001795186
57	ZOLADEX	15	0.013682136	0		9.747989655	0.001795186
58	NOVEMBER	23	0.020979276	1		9.197760582	0.002423111
59	RETURN	23	0.020979276	1		9.197760582	0.002423111
60	TV	23	0.020979276	1		9.197760582	0.002423111
61	ALLOWED	14	0.012769994	0		9.098088264	0.002558765
62	GRAHAM'S	14	0.012769994	0		9.098088264	0.002558765
63	REASONS	14	0.012769994	0		9.098088264	0.002558765
64	SCORE	14	0.012769994	0		9.098088264	0.002558765
65	TESTICULAR	14	0.012769994	0		9.098088264	0.002558765
66	NERVES	22	0.020067133	1		8.63481617	0.003297982
67	NURSE	22	0.020067133	1		8.63481617	0.003297982
68	YOU'RE	28	0.025539989	2		8.629724503	0.003307213
69	AROUND	87	0.079356395	16	0.038014684	8.609138489	0.003344802
70	TRIAL	38	0.034661412	4		8.536099434	0.003481707
71	SEEDS	33	0.030100701	3		8.487279892	0.003576378
72	CAROLINE	13	0.011857851	0		8.448191643	0.003654063
73	CHARITY'S	13	0.011857851	0		8.448191643	0.003654063
74	DEPRESSION	13	0.011857851	0		8.448191643	0.003654063
75	FINAL	13	0.011857851	0		8.448191643	0.003654063
76	MONITOR	13	0.011857851	0		8.448191643	0.003654063
77	NEEDLES	13	0.011857851	0		8.448191643	0.003654063
78	OPERATIONS	13	0.011857851	0		8.448191643	0.003654063
79	RIPLEY'S	13	0.011857851	0		8.448191643	0.003654063
80	WOOD	13	0.011857851	0		8.448191643	0.003654063
81	WORK	89	0.081180677	17	0.0403906	8.093930244	0.004441372
82	LIZ	21	0.019154992	1		8.075832367	0.004485947
83	MANCHESTER	21	0.019154992	1		8.075832367	0.004485947
84	LATER	117	0.106720664	25	0.059397943	7.987145901	0.004711059
85	BONO	12	0.010945709	0		7.798300743	0.005229536
86	CLUB	12	0.010945709	0		7.798300743	0.005229536
87	COVER	12	0.010945709	0		7.798300743	0.005229536
88	INOPERABLE	12	0.010945709	0		7.798300743	0.005229536
89	KEN	12	0.010945709	0		7.798300743	0.005229536
90	MCKEOWN	12	0.010945709	0		7.798300743	0.005229536
91	RELEASED	12	0.010945709	0		7.798300743	0.005229536
92	PSA	240	0.218914181	63	0.14968282	7.757273197	0.005349664
93	ON	701	0.639411867	218	0.517950058	7.694582462	0.005538679
94	EITHER	26	0.023715703	2		7.615805626	0.005785888
95	PROFESSOR	49	0.044694979	7	0.016631424	7.597306728	0.005845553
96	AL	31	0.028276416	3		7.545934677	0.006014558
97	CASODEX	11	0.010033567	0		7.148414135	0.007503028
98	DIARY	11	0.010033567	0		7.148414135	0.007503028
99	DOC	11	0.010033567	0		7.148414135	0.007503028
100	ERIC	11	0.010033567	0		7.148414135	0.007503028
101	FLIGHT	11	0.010033567	0		7.148414135	0.007503028
102	HERBAL	11	0.010033567	0		7.148414135	0.007503028
103	JOIN	11	0.010033567	0		7.148414135	0.007503028

104	LRP	11	0.010033567	0		7.148414135	0.007503028
105	MAXTON	11	0.010033567	0		7.148414135	0.007503028
106	NIGEL	11	0.010033567	0		7.148414135	0.007503028
107	PCT	11	0.010033567	0		7.148414135	0.007503028
108	RECEIVE	11	0.010033567	0		7.148414135	0.007503028
109	ROAD	11	0.010033567	0		7.148414135	0.007503028
110	ROBOTIC	11	0.010033567	0		7.148414135	0.007503028
111	TEA	11	0.010033567	0		7.148414135	0.007503028
112	TESTICLES	11	0.010033567	0		7.148414135	0.007503028
113	WEAR	11	0.010033567	0		7.148414135	0.007503028
114	EMOTIONAL	19	0.017330706	1		6.971316338	0.008282652
115	POLICY	19	0.017330706	1		6.971316338	0.008282652
116	ROWING	19	0.017330706	1		6.971316338	0.008282652
117	OVER	185	0.168746352	47	0.111668132	6.919641018	0.008525406
118	HIS	984	0.897548139	321	0.762669563	6.64923048	0.009919863

Appendix 4. Ethical approvals

1. Queen Mary University of London ethical approval

6th April 2010
c/o Professor Clive Seale
Room 203 - Centre for Health Sciences
Queen Mary's School of Medicine and Dentistry
Abernethy Building
2 Newark Street
London E1 2AT

To Whom It May Concern:

Re: QMREC2010/27 – The Changing Public Face of Prostate Cancer in the UK

The above study was approved by The Queen Mary Research Ethics Committee Sub-Board C on the 31st March 2010.

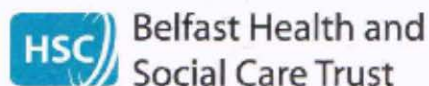
This approval is valid for a period of two years, (if the study is not started before this date then the applicant will have to reapply to the Committee).

Yours faithfully

A handwritten signature in black ink, appearing to read 'E. Hall', is written over a faint horizontal line. The signature is cursive and somewhat stylized.

Ms Elizabeth Hall – QMREC Chair.

2. Belfast Health and Social Care Trust ethical approval



19 November 2010

Ms Sue Ziebland
Reader in Qualitative Health Research
University of Oxford
Rosemary Rue Building
Old Road Campus
Roosevelt Drive
Headington
Oxford
OX3 7LF

Dear Ms Ziebland

Study Title: Narratives of Health and Illness for www.healthtalkonline.org (formerly DIPEX) and www.youthhealthtalk.org

HSC Trust Ref: 10142SZ-SP (Please quote this number in all future correspondence)

REC Ref: 09/H0505/66

I am pleased to advise that Belfast HSC Trust has given final Research Governance Permission for the above project to commence. Permission is granted for the duration of the project to 30/04/2024.

Permission is granted subject to the attached conditions and I would ask you to please ensure that all members of the research team are familiar with these. Failure to abide by these conditions will invalidate permission and may result in the cessation of the research.

I wish you every success with your project.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Ian Young', is written over the typed name.

Professor Ian Young
R&D Director

Cc Anne Montgomery ✓

Research Office, 2nd Floor King Edward Building, Royal Hospitals, Grosvenor Road, Belfast, BT12 6BA

V1.0

Date: 08/02/2010

Conditions of Permission

Research Governance permission is issued provided the researcher(s) involved adhere to and abide by the conditions below.

1. The researcher(s) must adhere strictly to the research protocol.
2. There must be no changes to the research protocol or approved study documentation without the prior consent of the Trust, the Research Ethics Committee and, where applicable, the MHRA.
3. There must be no changes in research staff without prior consent of the Trust.
4. The Research Office should be informed if the Chief Investigator or Principal Investigator (CI/PI) is unable to continue to fulfil his/her duties as CI/PI for any reason such as long term absence, change in employment etc.
5. There must be no increase in the resources required without prior consent of the Trust
6. Researcher(s) must report all untoward incidents and serious adverse events to the Trust.
7. Any concerns in relation to the research protocol must be reported to the Trust.
8. Researcher(s) must report all untoward incidents and serious adverse events to the Trust.
9. Any concerns in relation to the research protocol must be reported to the Trust.
10. Researcher(s) must adhere to good research practice principles in line with the ICH Good Clinical Practice (GCP) guidelines.
11. Researcher(s) must adhere to the Trust's Research & Development Standard Operating Procedures (available from the Research Office on request).
12. On request, researcher(s) must make their research project available to Trust appointed monitors.
13. The lead researcher must make an annual report to the Research Office for the duration of the project.
14. The lead researcher should inform the Research office on completion or termination of the project. Completion reports must be sent to the Research Office, Research Ethics Committee and, if applicable, MHRA.

Research Office, 2nd Floor King Edward Building, Royal Hospitals, Grosvenor Road, Belfast, BT12 6BA

3. Department of Primary Health Care: Health Experiences Research Group ethical approval



Department of Primary Health Care
Health Experiences Research Group

Old Road Campus, Roosevelt Drive, Headington, Oxford OX3 7LF, UK
Tel: +44 (0)1865 289328, Fax: +44 (0)1865 289287, E-mail: Francie.smee@dphpc.ox.ac.uk

To whom it may concern

5 March 2010

The interviews with men with prostate cancer that Anne Montgomery will carry out on behalf of The Health Experiences Research Group/Healthtalkonline for her PhD thesis are covered by:

Narratives of Health and Illness for www.healthtalkonline.org (formerly DIPEx) and www.youthhealthtalk.org. REC ref number: 09/H0505/66.

Yours faithfully

A handwritten signature in cursive script, appearing to read 'Francie Smee'.

Francie Smee
Administrator

Appendix 5. Information for participants in PCaA interviews

Information for participants

Please read the following information carefully before you decide to take part. This will tell you why the research is being done and what you will be asked to do. Please ask if there is anything that is not clear or if you would like more information. It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. You are still free to withdraw at any time and without giving a reason.

The Changing Public Face of Prostate Cancer in the UK

My name is Anne Montgomery. I am a PhD student at the Centre for Health Sciences at St Barts and The London School of Medicine and Dentistry with Professor Clive Seale and Dr Moira Kelly as my supervisors. The purpose of this research is to provide men with prostate cancer and those who care for them and campaign on their behalf, with up-to-date information about what the experience of prostate cancer is like.

You have been asked to take part on the basis of your significant activities in raising awareness and funding for prostate cancer and in planning policies for its prevention, treatment and cure, within the UK.

You should only agree to take part if you would like to, it is entirely up to you. If you choose not to take part there will not be any disadvantages for you. If you choose to take part the location and time of the interview will take place at your convenience. The length of interviews will be negotiated with you and will depend on what you have to say and how much time you feel able to devote.

Interviews will, in the first instance, involve asking you to tell the story of your personal involvement with prostate cancer and the organisation(s) associated with it that are relevant to your biography. I may ask you further questions on themes relevant to the research agenda e.g. how you have used 'resources' (e.g. your membership base or your contacts with opinion leaders and other key actors in this arena) in response to opportunities that have arisen to promote awareness of prostate cancer and/or how you have influenced policies for preventing, treating or curing prostate cancer.

The report from this research will be published as a PhD thesis, a report to the funding organisation, and in academic publishing outlets such as academic journals. A potential risk from your participation in this research is that you may say something in the interview which, if published, would damage either your own or somebody else's reputation. Additionally, during your interview you may describe some activities that are highly publicly visible and thus anonymity will not always be easy to ensure and will therefore be negotiated with you on an individual basis.

Your interview will be audio recorded and transcribed so that a written version of the interview is produced. At this point, in order to avert the potential risks detailed

above, I will send you a copy of the interview transcript and ask you to highlight any passages that cause you any concern and you would prefer not to be published. In addition, you may require me to make changes to particular passages in order that they may be written in a way that preserves your anonymity. Therefore, this gives you the opportunity to check, amend and veto anything you say in the interview which you would prefer not to be included in reports arising from the study. The recordings and transcripts will be kept in a secure location in my office and only I and my two supervisors will listen to your original recording or see your transcript unless you agree to the transcripts being deposited in the Qualidata archive so that other researchers may analyse them.

I would like to deposit your interview transcript (after you have approved it and after the study has finished) with ESRC Qualidata for potential secondary analysis by future researchers. If you would prefer this not to happen, you can either indicate this on the consent form or contact me at any point by email or letter after the interview and your transcript will be excluded from this deposition.

If you require further information before deciding to take part in this research or after you have already done so, or if you wish to withdraw from the study for any reason then please contact me using the details below:

Anne Montgomery
Centre for Health Sciences
St Barts and The London School of Medicine and Dentistry
2 Newark Street
London E1 2AT

Email: xxxx
Mobile: xxxx
Office: xxxx

Appendix 6. Supplementary questions for PCaA interviews

QMREC2010/27: The Changing Public Face of Prostate Cancer

Supplementary Information: Potential Interview Prompts

After the participant has told his/her story, the following prompts are indicative of what may be asked if the participant has not already covered them in their narrative:

- Tell me about the different strategies that you/your organisation have/has used to raise awareness of prostate cancer over the last 20 years.
- Have you/how have you sought to influence the media?
- Have you/how have you sought to influence government policy?
- Have you/how have you sought to make men aware of the risks of prostate cancer?
- Have you/how have you sought to make the general public aware of the risks of prostate cancer?
- Have you/how have you identified potential ally (or antagonist) organisations in your strategy to increase awareness of prostate cancer?
- Have you/how have you identified any elite decision makers that will aid/hinder your aim to increase awareness of prostate cancer?
- Is there any model of successful influence by another health related organisation, either in the UK or internationally, that you particularly like and would like to duplicate?
- In what way has your membership base changed over this time?
- What do you think of (...)?
 - (e.g. PSA screening/complementary therapies/xyz treatment/nutritional guidance or other relevant theme)
- Does your organisation have a specific policy positions on (...)?
 - (e.g. PSA screening/complimentary therapies/xyz treatment/nutritional guidance or other relevant theme)
- What would you say are the key values of your organisation?
- How have these values changed over the last twenty years?
- What are your views about the nature/cause/seriousness of prostate cancer?
- Is there anything else that you would like to say about how you/your organisation has raised awareness of prostate cancer?

Appendix 7. Consents

1. Consent for prostate cancer advocate participants

Thank you for considering taking part in this research. Please complete this form after you have read the Information Sheet. If you have any questions arising from the Information Sheet, please feel free to contact me before you decide whether to take part. You may keep a copy of this Consent Form and Information Sheet to refer to at any time.

Title of Study: The Changing Public Face of Prostate Cancer in the UK
Queen Mary Research Ethics Committee Reference: QMREC2010/27

I understand that if I decide at any time during or after the interview that I no longer wish to participate in this research, I can notify the researcher and be withdrawn from it immediately.

I consent to the processing of my personal information for the purposes of this research study as described in the information sheet. I understand that such information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998.

I consent to the depositing of my interview transcript (after I have approved it and after the study has finished) with ESRC Qualidata for potential secondary analysis by future researchers.

Participant's Statement:

I _____ agree that the research project named above has been explained to me to my satisfaction and I agree to take part in the study. I have read both the notes written above and the Information Sheet about the project, and understand what the research study involves.

Signed:

Date:

Investigator's Statement:

I _____ confirm that I have carefully explained the nature, demands and any foreseeable risks of the research to the participant

2.Consent for men with prostate cancer participants

Database reference number: _____

Series title: _____

CONSENT FORM

Title of Project: Healthtalkonline – personal experiences of health & illness

Name of Researcher: _____

Please initial
box

I confirm that I have read and understand the information sheet dated _____ (version _____) for the above study, have had the opportunity to ask questions and have had these answered satisfactorily.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reasons, without my medical care or legal rights being affected.

I understand that relevant data collected during the study may be looked at by individuals from the University of Oxford, for the purpose of audit and monitoring, and where it is relevant to my taking part in this research. I give permission for these individuals to have access to the records of my participation in this research.

I agree to take part in the above study.

Name of Participant (block capitals) Date Signature

Researcher Date Signature

Version 10 November 2009

Appendix 8. Transcription and quote notation

Transcription Notation	Description
<u>Word</u>	Underlining: speaker's emphasis or stress
()	Empty parentheses: unclear talk
(words)	Text in parenthesis: the best possible hearing of talk
((laughs))	Double parenthesis indicates participants non-verbal behaviour
Quote Notation	Description
(...)	3 full stops in parentheses: small quantity of excluded talk
(....)	4 full stops in parentheses: quantity of excluding talk exceeding one sentence

Appendix 9. Letters and information

1. Letter accompanying transcript to prostate cancer advocate participants

August 2011

Dear

The Changing Public Face of Prostate Cancer in the UK: Research Interview Transcript

I would like to thank you again for agreeing to be interviewed earlier this year for my research. Please find attached the transcription of your interview.

I would like to invite you to view this transcription so that you have the opportunity to check, amend or veto anything you said in the interview which you would prefer not to be included in reports arising from the research. Please do then take this opportunity to read through the transcription and correct anything you think I have transcribed wrongly; make changes to particular passages in order that they may be written in a way that preserves your anonymity; or highlight any passages that you would prefer not to be published. Please try not to be alarmed by the verbatim nature of the transcription. It is normal for false starts, repeated words and words like “ehm” and “er” to occur in normal conversation but we are not used to seeing these in print.

If you do not make any changes to your transcription then you do not need to take any action. If you do make changes or would like to veto any passage, then please return the transcription to me with the relevant changes made and vetoed passages highlighted. I expect that the analysis and writing up of my research and therefore potential publications will occur from October 2011 and so I would be grateful if you would inform me of any changes or veto to your transcription by this time.

Once again, thank you for your valuable contribution to my research.

Yours truly

Anne Montgomery

2. Sample access letter to specialist nurse gatekeepers to men with prostate cancer

May 2010

Dear

My name is Anne Montgomery and I am a PhD student in the Centre for Health Sciences at Barts and the London School of Medicine and Dentistry. I am writing to invite the Urology Centre at Barts Hospital to be a Participant Identification Centre (PIC) in a research study called **The Changing Public Face of Prostate Cancer**.

This research is funded by The Prostate Cancer Charity and is being carried out in collaboration with the Health Experiences Research Group at Oxford University. The aim of this study is to provide men with prostate cancer, and those who care for them and campaign on their behalf, with up-to-date information about what the experience of prostate cancer is like.

The study will include a maximum variation sample of approx 50 participants from Belfast and London. Qualitative semi-structured audio or video taped interviews will be conducted with men who have experience of prostate cancer. Using a narrative approach, an oral history of the men's experience of prostate cancer will be collected with supplementary questions prompting reflection on areas of interest identified through literature review and ongoing analysis.

Some of the interviews will also contribute to the www.healthtalkonline.org website, run by the Health Experiences Research Group, which can be used by people to find out what other people in the same situation have experienced. The website is also a valuable resource to let doctors and nurses know what patients experience.

The study has been approved by the Berkshire Research Ethics Committee (09/H0505/66) under 'Narratives of health and illness for www.healthtalkonline.org (formerly DIPEX) and www.youthtalkonline.org'. This study requires that your centre acts only as a PIC; as such management permission for this study is not required although the R&D office should be notified. You are invited to hand out information packs (sample enclosed) about the study and patients who are interested in participating in the study return a reply slip directly to me. All subsequent contact, including the interview itself, is conducted away from the clinical setting. I, as researcher, do not have access to any patient data at any point in the study.

I would be grateful if you would let me know the best time to contact you in order for you to let me know if you wish to be involved in this study.

If you have any queries about the research please telephone me on xxxx (email: a.t.montgomery@qmul.ac.uk) or Sue Ziebland, of the HTO research team, on xxxx.

Yours sincerely
Anne Montgomery

3. Sample introductory letter to men with prostate cancer participants

May 2010

Dear sir,

My name is Anne Montgomery and I am a PhD student in the Centre for Health Sciences at Barts and the London School of Medicine and Dentistry. I am writing to invite you to take part in a research study called **The Changing Public Face of Prostate Cancer**. You are being invited to take part because of your experience of prostate cancer.

This research is funded by The Prostate Cancer Charity and is being carried out in collaboration with the Health Experiences Research Group at Oxford University. The aim of this study is to provide other men with prostate cancer, and those who care for them and campaign on their behalf, with up-to-date information about what the experience of prostate cancer is like.

Some of the interviews will also contribute to the www.healthtalkonline.org website, run by the Health Experiences Research Group, which can be used by people to find out what other people in the same situation have experienced. The website is also a valuable resource to let doctors and nurses know what patients experience. You do not have to be video recorded; your interview could appear on the website simply as an audio or written version.

I enclose a copy of an information sheet which describes this study. I would be very grateful if you would take the time to read this and consider whether you would like to take part in the study. You are, of course, free to decide not to take part in this research and your decision would have no effect on your usual medical care. If you do decide to take part you would be free to withdraw at any time.

If you have any queries about the research please telephone me on xxxx or Sue Ziebland, of the HTO research team, on xxxx. When you have read the information sheet please complete the attached slip and send it to me in the enclosed reply paid envelope. Many thanks for your time in reading this.

Yours sincerely

Anne Montgomery

Appendix 10. MWPCa interviews in 2010 available on www.healthtalk.org

The collaboration with HERG at Oxford University responsible for www.healthtalk.org led to 12 of my 20 interviews with MWPCa in 2010 being made accessible online at www.healthtalk.org. Here, qualitative research into personal stories of health and illness enables the general public, patients, families, carers and healthcare professionals to benefit from the experiences of others. Brief and fuller 'more about me' summaries of the experience of these MWPCa and between 1-6 video/audio clips and corresponding transcripts are accessible through the following web-pages:

http://www.healthtalkonline.org/Cancer/Prostate_Cancer/People/Interview/3061/Catagory/133

http://www.healthtalkonline.org/Cancer/Prostate_Cancer/People/Interview/3062/Catagory/134

http://www.healthtalkonline.org/Cancer/Prostate_Cancer/People/Interview/3063/Catagory/135

http://www.healthtalkonline.org/Cancer/Prostate_Cancer/People/Interview/3064/Catagory/132

http://www.healthtalkonline.org/Cancer/Prostate_Cancer/People/Interview/3065/Catagory/133

http://www.healthtalkonline.org/Cancer/Prostate_Cancer/People/Interview/3066/Catagory/136

http://www.healthtalkonline.org/Cancer/Prostate_Cancer/People/Interview/3067/Catagory/133

http://www.healthtalkonline.org/Cancer/Prostate_Cancer/People/Interview/3068/Catagory/134

http://www.healthtalkonline.org/Cancer/Prostate_Cancer/People/Interview/3069/Catagory/134

http://www.healthtalkonline.org/Cancer/Prostate_Cancer/People/Interview/3070/Catagory/132

http://www.healthtalkonline.org/Cancer/Prostate_Cancer/People/Interview/3071/Catagory/133

http://www.healthtalkonline.org/Cancer/Prostate_Cancer/People/Interview/3072/Catagory/132

Appendix 11. Reply slip for men with prostate cancer participants

Reply Slip for Module: Prostate Cancer 2010-2011

Yes, I am happy for a researcher to contact me about this project.

Name:

(Block Capitals)

Address:.....

.....

..... Post Code:

Telephone number: Day: Evening:

Best time to contact me:

Age:

Date or year of diagnosis:

Occupation:

(if retired please state and give last occupation)

Ethnic Background.....

(It is important for us to include perspectives from a range of ethnic groups in our research).

Please return to:

Anne Montgomery

(Address given)

Email: xxxx

Tel: xxxx

Appendix 12. Recruitment through 'Prostate Cancer Voices'

The following recruitment message was included in 3 issues of the 'Prostate Cancer Voices' bulletin between June-August 2011 (both email and print) and on the website <http://prostatecanceruk.org/get-involved/volunteer/get-involved-now>.

External Opportunity: Participate in a research study 'The Changing Public Face of Prostate Cancer'

PhD researcher Anne Montgomery is looking for men with experience of prostate cancer, and who live in the London¹ area, to take part in a research study which is funded by The Prostate Cancer Charity. The aim of the study is to provide other men with prostate cancer, and those who care for them and campaign on their behalf, with up-to-date information about what the experience of prostate cancer is like.

Anne is located at the Centre for Primary Care and Public Health at Barts and The London School of Medicine and Dentistry at Whitechapel and is collaborating with the Health Experiences Research Group at Oxford University. Some of the interviews will contribute to the www.healthtalkonline.org website, run by the Health Experiences Research Group, which can be used by people to find out what other people in the same situation have experienced.

How do I get involved?

For more information about the research study and to request an information pack, please reply to this email or contact Anne directly, on xxxx or by emailing xxxx.

If you have any questions about anything contained within this bulletin, please contact us by replying to this email or by calling Philippa on xxxx.

¹ Later amended to also include Belfast

Appendix 13. Guiding script for gatekeepers

The following is a short guiding script that I offered to the gatekeeping nurses at Barts and The London and Belfast City Hospitals which they could choose to ignore or use if helpful to them in distributing the PIPs to MWPCa.

This envelope contains information about research funded by The Prostate Cancer Charity. Its aim is to provide other men with prostate cancer and those who care for them and campaign on their behalf with up-to-date information about what the experience of prostate cancer is like. Please take this away and read it and consider whether you would like to take part in the study. You are free to decide not to take part and your decision will not affect your usual medical care. If you do decide that you would like to take part in the research then use the reply slip inside to contact the researcher directly. You can withdraw from the research at any time.

Appendix 14. Selected CKWIC concordance displays

'Raising money for PCa' keywords

'GBP' keyword concordance 1990-2000

N Concordance

1 lived for the company and built it into a GBP 350 million empire. He was
2 year before he died.' His Trust, valued at GBP 3.5 million, paid out GBP 1 million
3 worried because each scan costs GBP 400. It looks as though I've got
4 spent on finding a cure is derisory - GBP 47,000 last year, compared to
5 spent on finding a cure is derisory - GBP 47,000 last year, compared with
6 spent on finding a cure is derisory -GBP 47,000 last year. That is why the
7 Manchester M60 3JD I am donating GBP to the Daily Mail Prostate Cancer
8 . HERE'S HOW TO DONATE For every GBP raised by Mail readers the
9 . HERE'S HOW TO DONATE For every GBP raised by Mail readers the
10 charity received a cheque - for exactly GBP 47,000. I hope the money will help
11 get there.' The Daily Mail launched its GBP 1million fundraising campaign - in
12 out that the Government spent just GBP 47,000 a year on research into
13 insurance. The blood test costs only GBP 15, and it is appalling that it is not
14 spent on finding a cure is derisory - only GBP 47,000 last year, compared to
15 8,000 men in the UK a year but only GBP 47,000 was spent researching it in
16 of cancer prevention and cure. Yet only GBP 47,000 a year goes on prostate
17 , valued at GBP 3.5 million, paid out GBP 1 million a year ago to the
18 - 10,000 die every year - yet a pitiful GBP 47,000 was spent last year
19 Mail has launched an appeal to raise GBP 1 million to rectify this scandalous
20 Mail has launched an appeal to raise GBP 1 million to rectify this scandalous
21 Mail has launched an appeal to raise GBP 1 million to rectify this scandalous
22 Mail has launched an appeal to raise GBP 1 million. Sidney Swan was
23 Mail has launched an appeal to raise GBP 1 million. Here, 58-year-old
24 I vowed that, when I was better, I'd raise GBP 47,000 for prostate research and
25 UK. I had one mission: to raise GBP 47,000. Through my job in
26 the disease. At the same time, GBP 18 million was spent on Aids,
27 GBP 47,000 last year, compared to GBP 18 million spent on Aids. The
28 - GBP 47,000 last year, compared to GBP 18million spent on Aids, which
29 by generous Mail readers - up to GBP 500,000 another pound will be
30 Charitable Trust will match it up to GBP 500,000. The money raised will go
31 Charitable Trust will match it up to GBP 500,000. The money raised will go
32 by generous Mail readers - up to GBP 500,000 - another pound will be
33 - GBP 47,000 last year, compared with GBP 18 million spent on Aids, which

Partial 'raise*' keyword concordance 1990-2000

N Concordance

1 cut the number of deaths from the cancer and raise the profile of a condition many men are
3 , which Richard Bentine is spearheading, is to raise \$6 million to build and equip Britain's first
4 themselves checked. Next year I am going to raise even more for research. We all have to
11 fit. I'd decided to do a half marathon in July to raise money for the Prostate Research
12 This message reinforces the Mail's campaign to raise money for the Prostate Cancer Charity,
13 and Andrew are running the London Marathon to raise money for the Prostate Research Campaign
14 THE MAIL'S CRUSADING CAMPAIGN TO RAISE MUCH NEEDED MONEY AND
15 forces with the Prostate Cancer Charity to raise public awareness as well as funds. THE
16 the opportunity - which I regard as a duty - to raise these matters on behalf of other sufferers

'Pounds/\$*/£*' keyword concordance 1990-2000

N Concordance

1 boom of the 1980s. In 1987 he made \$ 550m (Pounds 335m). The dream then turned to disaster
2 cancer.as his son ,I want all men to know a £12 test can save lives; good health WHEN the
3 funding is needed for research. 'At present about \$1million a year is spent on research, compared
4 \$15 million to breast cancer research as against \$400,000 to studying the prostate. Korda is
5 , for example, \$40 million on heart disease and \$15 million on Aids, but only \$1 million on
6 , compared to \$16m on breast cancer and \$40m on heart disease. 'We also need to start
7 published on February 6, 1997 by Little, Brown, pounds 18.99 Prostate Research Campaign UK,
8 by Michael Korda is published by Little Brown \$18.99. Prostate cancer: The facts and the future
9 go to his charity, which has already distributed \$ 53m to more than 365 projects worldwide.
10 lamentably under-resourced: cancer charities give \$15 million to breast cancer research as against
11 \$16 million a year on breast cancer, for example, \$40 million on heart disease and \$15 million on
12 takeover boom of the 1980s. In 1987 he made \$ 550m (Pounds 335m). The dream then turned
13 a year goes into breast cancer research, a mere pounds 1 million is spent on finding a cure for this
14 and cures of prostate cancer. Thousands of pounds have already been donated after just a
15 Charity - on November 2. Already thousands of pounds have been donated by readers to help pay
16 and cures of prostate cancer. Thousands of pounds have already been donated after just a
17 , to know that there is a test which costs only \$12 and that they can insist on having it. If your
18 heart disease and \$15 million on Aids, but only \$1 million on prostate cancer. 'I think it's been so
19 HA6 1HP. Send large sae for free leaflets, or pounds 5.95 for their book, Prostate Problems:
20 from cancer." Chris's sons Matthew and Ben paid pounds 250 for his medical. The results showed
21 Richard Bentine is spearheading, is to raise \$6 million to build and equip Britain's first
22 Trust is giving the Institute of Cancer Research \$ 300,000 over the next three years to investigate
23 minimal,' Professor Cooper says. 'We spend \$16 million a year on breast cancer, for example,
24 . He served just under two, and paid more than \$ 1 billion in fines and to settle lawsuits. Just six
25 got the all-clear." Matthew has raised more than pounds 1,000 for prostate cancer research by
26 a year is spent on research, compared to \$16m on breast cancer and \$40m on heart
27 for surgery as breast cancer sufferers. And while pounds 16 million a year goes into breast cancer
28 Forbes magazine recently estimated to be worth \$ 700m - set up CaPCURE, the Association for

'GBP' keyword concordance 2000-2010

N Concordance

1 overdose. The 46-year- old was found on a bed in a GBP 1a-night room in a Thai guesthouse. Monkhouse's
2 to have a vacuum pump cylinder, which cost about GBP 200 - it's not available on the NHS - and came in
3 a four-night hospital stay, it will cost approximately GBP 8,000. Bob's royal return; After cancer fight, the
4 expert on the illness. With the couple worth around GBP 75 million, it helped to ensure the best medical
5 raised awareness of the disease and readers donated GBP 1million for research. I'm back on line; Sir David
6 in 1988 and forming SelecTV, which he sold in 1996 for GBP 46 million. The straight-talking Londoner, who fell
7 Prostate In The Sun by Ken Robson, send a cheque for GBP 7.99 (includes P&P) to Stoll Publishing, 5 Ganton
8 down to zero. RADICAL prostatectomy costs the NHS GBP 5,500. Privately, including a four-night hospital
9 bladder cancer. He had two policies, providing a total of GBP 170,000 cover. While Permanent Insurance paid
10 10,000 men die of it annually in Britain as a whole, only GBP 47,000 was spent on researching it in 1999. And,
11 . A campaign by Daily Mail readers last year raised GBP 1million in just four months to help fund research
12 cover remains for any future claims. With Skandia, the GBP 10,000 benefit, or 20 per cent of the sum assured,
13 to be launched this week. The insurer will pay out up to GBP 10,000 to policyholders diagnosed with
14 non-invasive cancer as standard. It is also offering up to GBP 10,000 benefit to sufferers of a noninvasive breast
15 . Its Elixia plan launched in April last year pays up to GBP 25,000, or 25 per cent of the policyholder's cover

'Pounds/\$*/£*'keyword concordance 2000-2010

N Concordance

1 baby with a hole in the heart. Cost to **cure, £x**; 2. A 30-year-old woman with breast cancer.
2 woman with breast cancer. Cost to **cure, £x**; 3. A 70-year-old man with prostate cancer.
3 man with prostate cancer. Cost to **cure, £x**; but you only have £2x to hand out. Whom do
4 by the Pounds 16 DIY test for prostate cancer A **Pounds 16** DIY test could be an accurate
5 Grace Hospital, London, which has just bought a **Pounds 1million** da Vinci robot. Despite the
6 Pounds 5,000. Privately it costs **about Pounds 12,000**. CANCER TURNED ME INTO A
7 Thursday to Saturday. Tickets cost pounds 4 **and pounds 6** and are available by calling 029 2030
8 , they figure brachytherapy costs **approximately Pounds 1,300** more than radical surgery but they
9 prostatectomy costs the NHS **approximately Pounds 5,000**. Privately it costs about Pounds 12,
10 a permanent cure. * THE operation costs **around Pounds 3,000** to have done privately. The
11 in Cardiff from Thursday to Saturday. Tickets **cost pounds 4** and pounds 6 and are available by
12 to pay for brachytherapy privately - it **costs pounds 12,000** - Mr Powell could have to undergo
13 medicine industry is now worth an **estimated pounds 4.2bn** - and that has direct financial
14 cervical cancer. Last year, the Government **gave pounds 1million** towards combating the disease.
15 ,000. Last year, it was a barely more **impressive pounds 200,000**. Even now, as Carman noted,
16 signed for Manchester United for a transfer fee **of Pounds 115,000**, where I played with George
17 but the operation is available privately at a cost **of Pounds 15,000** at the Princess Grace Hospital,
18 of his generation, he regularly featured in lists **of pounds 1m** a year QCs, although his earnings
19 scientific studies that drive these men to shell **out pounds 300** for a month's supply. It is the stories
20 a year on breast cancer research, yet just **over Pounds 9** million goes in to finding a cure for
21 our efforts, we're almost on target to **raise Pounds 200,000** for the Prostate Cancer Charity,
22 ,000. Then last September the Daily Mail **raised pounds 1m** with its "Dying of Embarrassment"
23 female breast cancer. The Government **spends Pounds 72million** a year on breast cancer
24 I might never have known.' Prostate Disorder **Test Pounds 14.99** plus p&p from www.homehec. co.
25 of its Christmas charity and raised more **than pounds 100,000**. Then last September the Daily
26 defender" in addition to earnings of more **than Pounds 1million** a year. He now plans to use his
27 ago to highlight the disease and raised more **than Pounds 1million** for research. Last month,
28 with 60 to 70 per cent. You cannot pay **the Pounds 1,300** difference because it might
29 or visit www.icr.ac.uk/everyman. Saved by **the Pounds 16** DIY test for prostate cancer A Pounds
30 . But the contribution is tiny compared to **the pounds 18million** spent on Aids which claims 400
31 prostate cancer, bringing government funding **to pounds 4.2m** by 2004. He also promised that by
32 prostate cancer, bringing government funding **to pounds 4.2m** by 2004. He said: "Prostate cancer
33 spending on research into the disease **totalled pounds 47,000**. Last year, it was a barely more
34 of his two sons and bitter family rifts. Bob, **worth pounds 15** million, learned he had cancer after
35 Campaign UK, which last year raised **about £800,000**, slightly less than the other significant
36 paid for life-saving op A man who had to **pay £8,000** for surgery to rid him of prostate cancer is
37 accounts, he decided to prove his point by **buying £70,000** worth of shares in the company. He
38 is a simple blood test -- it costs the NHS **around £7** -- to measure levels of prostate specific
39 played no part in considerations.' **THE £7 TEST THAT COULD HAVE SAVED MY**
40 by the NHS," he said. "I must have paid **over £500,000** in taxes and NHS contributions. I
41 , that's enough for a tiny project. Now it's **about £4m, which** is still a drop in the ocean. Every
42 for prostate cancer research.' He says it **again: '£47,000**. That's crap, that's enough for a tiny
43 ago after a radical prostatectomy and **raised £47,000**. 'Why that amount? Because that was
44 cancer research centre in Sutton, Surrey. **The £3.2million** centre funded by the Institute's
45 cancer. Cost to cure, £x; but you only **have £2x** to hand out. Whom do you throw overboard?
46 Blanc's Le Manoir aux Quat' Saisons, **at £2,000** each. Not that Max shares his skills with
47 Five Star Scanner Appeal, which aims to **raise £1million** to buy an MRI scanner for the New
48 prelude to his biggest success yet. However, **the \$100m (£ 50m)** study into the safety and
49 specialist Karol Sikora and two others **received £100 an** hour to consider how long they believed
50 side effects in about 70% of cases. It costs **about £ 550** a month, dropping to £ 200 for the
51 to his biggest success yet. However, **the \$100m (£ 50m)** study into the safety and effectiveness of
52 than the surgical alternative, which **costs £ 3,500**. But Elliott still doesn't know what will
53 cases. It costs about £ 550 a month, dropping **to £ 200** for the maintenance dose. Unable to afford
54 treatment. Given that brachytherapy costs **just £ 2,000** more than the radical prostatectomy, and
55 will change our lives.' Bill knows that if he **paid £ 11,000** and went private he could have the
56 seeds into the prostate gland to kill the cancer, **is £ 1,500** more expensive than the surgical

'Treatment' (procedures, side-effects, policy & insurance) keywords

'Risks' 1990-2000

N Concordance

1 , but I had no means of measuring the **countervailing risks**. That required a reporter's notebook. Even then,
2 infection. Others might undergo surgery, with its **high risks** of incontinence and impotence, when their
3 meat and dairy produce, seem to enjoy the **lowest risks**. Lowering fat can enhance the immune system
4 invasive than radical prostatectomy but there are **still risks** of incontinence and impotence. And
5 . My GP found it extremely difficult to track down **the risks**, even on the Internet. He's asked me to provide
6 risks of having the operation seemed to outweigh **the risks** of not having one in my case. For people with
7 means that 70 pc of patients will die of it. And **the risks** of side-effects are high. The Americans say
8 - did conclude I needed an operation. Daunted by **the risks** of becoming incontinent or impotent, I returned
9 four glasses of wine) to go to the loo. Second, **the risks** of having the operation seemed to outweigh the
10 tests. I learned from my GP and consultant of **the risks** of not having an operation: the possibility of

'PCT' concordance 2000-2010

N Concordance

1 with it. 'I'm so angry about it,' she said. 'I've worked for a **PCT** for the past seven years, and we've always been huge
2 test. Kevin Snee, chief executive of the trust, said: "**Bolton PCT** has a policy for the fair and effective use of NHS
3 for a man in my physical state. There's just one problem; **my PCT** would need to approve the funding because
4 of this decision having been taken. Last week, when **the PCT** became aware that The Observer was looking into Bill's
5 , to say the least.' What angers Bill so much is that **the PCT** has refused to explain its decision for the rationing.
6 as I walked through a sultry city my mobile rang. It was **the PCT**. It had agreed my funding. I asked about the other local
7 come to terms with their diagnosis.' After many calls to **the PCT**, the answers that Bill has received are even more
8 they have other cost pressures. The Guildford and **Waverley PCT** denied to The Observer that it had a blanket ban on
9 Professor Langley informing me that Guildford & **Waverley PCT** had rejected my brachytherapy funding. He reiterated
10 . But, reassures the professor, even if Guildford & **Waverley PCT** says no, then I can appeal and, usually, appeals get
11 spent two months battling with the Guildford and **Waverley PCT** which initially said it would not pay for a course of

'Policy' concordance 2000-2010

N Concordance

1 lives with his girlfriend Maxine Dilloway-Thompson, took out a **policy** five years ago, and within a year was diagnosed with
2 Snee, chief executive of the trust, said: "Bolton PCT has a **policy** for the fair and effective use of NHS resources, which
3 told that they were not clinical, that the trust simply had a **policy** of not funding the treatment. Given that brachytherapy
4 cancer. But buyers are advised to check the terms of **any policy** and be aware that in some cases complex medical
5 of policies. Over the past year, insurers have **changed policy** definitions to cut the cover for prostate cancer that is
6 of string. 'But, according to Health Commission Wales' **draft policy** on brachytherapy, I meet all the clinical criteria for this
7 Parliament to inflict a defeat on the government on its **fishing policy**. Sir David will continue his hectic schedule until his
8 Seen as an internal critic of much of President Bush's **foreign policy**, it is widely expected that General Powell will not
9 cancer that are not lifethreatening under a new critical **illness policy** to be launched this week. The insurer will pay out up to
10 suing the hospital. I discovered that my household **insurance policy** had a clause covering any legal charges attached to a
11 grateful that he decided to take out a critical illness **insurance policy**. He was diagnosed with potentially fatal prostate cancer.
12 was very lucky,' he said. 'A friend who does my life **insurance policy** rang to make plans for a routine medical and they found
13 The Great, written for the History Channel by his son Peter. '**Policy** gave me a new life after a death sentence' Cancer
14 is to fight Government failure to introduce a national **screening policy** for prostate cancer, in the way women are screened for
15 Sussex, did not even miss a day's work. With the **substantial policy** payout, David has bought an impressive 36ft Dutch-built
16 for 56 prostate cancer patients from Wales. Despite **the policy** u-turn, Mr Powell was told that his only chance of
17 , which aims to ensure equity for all Bolton residents. **This policy** does not normally allow for the funding of treatments
18 eye both on the size of the prostate and the PSA levels. **This policy** has spared many men from unnecessary and
19 to prevent further hefty premium rises in a sector **where policy** costs are already escalating. But David's insurer,

Appendix 15. Selected media illness narratives

Daily Mail, 10/11/1999

Context for Extract 4.1, Extract 4.2 and Extract 4.17

Extract 4.1

I am one victim, but I've raised more cash on my own for prostate cancer than the Government did all of last year

PROSTATE cancer has become the disease no one wants to talk about. Every hour a British man dies from it, yet the amount spent on finding a cure is derisory - GBP 47,000 last year, compared with GBP 18 million spent on Aids, which kills 400 a year. That is why the Daily Mail has launched an appeal to raise GBP 1 million. Here, 58-year-old businessman Ted Clucas, from Jersey, tells VICTORIA FLETCHER of his struggle to end the secrecy surrounding prostate cancer after he was told he needed surgery within hours of being diagnosed.

[Narrative segment not included in analysis]

DISBELIEF - that was all I felt when I was told I had cancer. Total disbelief. I had been visiting my GP for two years saying I was in pain. Each time he sent me away with antibiotics and told me it was just an infection. But it got worse and worse, until I had to get a second opinion. In September last year I went to to see a specialist in London. After some preliminary tests, I was told it could be prostate cancer and would need a biopsy the next day. I remember stumbling outside into the pouring rain and just walking the streets. I had no idea what to do, who to talk to. I knew nothing about the illness. All I'd heard were horror stories about what the operation does to your body and your lifestyle. What would I do if it was cancer? I called my wife Jill, and said it looked serious. She was shattered. She didn't cry or ask why it had to happen to me - she was the strong shoulder I needed. She's a tough cookie, and although I felt confused and numb, her calm attitude helped me focus on the tests I would face over the next few days. I wandered back to my hotel room and just sat quietly, thinking. The biopsy would not be pleasant, and I worried about what it might reveal. Surely prostate cancer couldn't happen to me? The next day, Jill arrived and called my son John, 29, who lives in London. I needed him more than ever, to cart me from test to test and sit with me while I waited for diagnosis. Eventually the results came and, even though I thought I'd prepared myself for the worst, when I was told I had prostate cancer, it came as a shock. I never thought it could be so serious, especially after the attitude of my GP. In fact, the specialist said it was so bad, I'd need to say within two hours whether I wanted surgery. Both in shock and exhausted, the only thing my wife and I could think to do was visit an old friend, Mike, who lived in London and had prostate cancer. HE'D BEEN diagnosed too late, and seeing him drove it home to me that if I didn't act, I could end up like him. Mike told me to jump at the chance that he'd never had - to wait would be too risky. Sadly, he died at Christmas, aged just 55.

[Extract 4.2]

The next few days were a whirlwind, but in that time I decided to learn all I could about the disease. All I kept thinking was: Why had my GP not known all of this? How

had he missed the telling signs? And why was there so little information available to men, if so many suffer from prostate cancer? My shock soon turned to anger when I found out that the Government spent just GBP 47,000 a year on research into prostate cancer. No wonder I'd never heard about it; no wonder my GP wasn't knowledgeable about it. No one was taking it seriously, and at that moment I vowed that, when I was better, I'd raise GBP 47,000 for prostate research and education, to prove to the Government that just one man was capable of equalling their pitiful donation. After the operation, my recovery was quite quick - I knew I had to beat the disease. I had radiotherapy until February and then started to get fit. I'd decided to do a half marathon in July to raise money for the Prostate Research Campaign UK. I had one mission: to raise GBP 47,000. Through my job in international financial services, I know some wealthy clients, and with a bit of persuasion I knew I could reach my goal. I finished the race, and last week the charity received a cheque - for exactly GBP 47,000. I hope the money will help research into the disease. But more than that, I hope that it will be used to educate GPs and encourage the public to get themselves checked. Next year I am going to raise even more for research. We all have to beat this disease.

[Extract 4.3]

HOW TO SPOT THE DANGER SIGNS

* **WHAT** is the prostate? A doughnut-shaped gland the size of a walnut that surrounds the upper part of the urethra - the tube that carries urine from the bladder to the penis. When cells in the gland grow, a tumour develops. Cancer cells then spread to other parts of the body. * **WHEN** does it occur? With age, it is normal for the prostate to enlarge. This condition is Benign Prostatic Hyperplasia (BPH) and can occur in men as young as 30. BPH can be easily treated. * **WHAT** is prostate cancer? There are two types - an aggressive form and a slower one. Pathologists determine the type by studying the cells. * **WHAT** are the symptoms? You need to urinate frequently. The urine stream is poor. You have lower back pain. There is blood in your urine. * **HOW** is it diagnosed? There are four types of test. Digital Rectal Examination: A doctor feels the prostate and identifies an enlargement. Prostate Specific Antigen (PSA) test: A blood test that measures levels of a protein called PSA. Transrectal ultrasound: A probe is placed in the rectum and pictures are taken of the prostate. Biopsy: A sample of prostate tissue can be analysed to see how aggressive the cancer is. * **WILL** you get it? The odds escalate with age: 70 pc of men in their 70s will have it, rising to 80 pc in their 80s. * **WHAT** are survival rates? Within five years of being diagnosed, the survival rate in Britain is less than 50 pc.

The Observer, 09/07/2006

Context for Extract 4.7

[Narrative segment not included in analysis]

Special Report: Both have cancer. But why can't one get the best care? Observer sports writer Bill Elliott was diagnosed with prostate cancer in April. Within an hour, his wife Val was told she had breast cancer. Now they have had to come to terms with the stark fact that her treatment has 10 times as much funding as his. Health Editor Jo Revill examines the human cost of NHS inequalities. Receiving a diagnosis of cancer is difficult for any man to come to terms with; when the news comes on the very day that your wife discovers she has breast cancer, it is a doubly hard blow. Bill and Val Elliott received their respective diagnoses within an hour of each other on Thursday,

27 April. Both had undergone initial biopsies but didn't know quite what to expect. Their grown-up sons, Simon and James, had insisted on accompanying them to the clinics in Surrey that day. 'I was seen first in Frimley at around 12.10pm, and then Val went over to the breast clinic in Guildford where she was given the news 55 minutes later. We met up at an Italian restaurant and consumed several bottles of red wine,' recalled Bill. 'It was pretty hard for the boys and for us, well, it was simply mind-numbing.' Walking along a deserted beach in Norfolk last week, the couple spoke of the remarkable twist their lives had taken. They came for a short holiday to stay at a friend's cottage before Val begins her radiotherapy treatment, when in fact they were due to be spending this summer taking it easy as Val retired last month after years of demanding work as a child protection expert. But when it comes to adjusting to their diagnoses, the hardest part of all has been hitting the biggest brick wall within the National Health Service - the stark fact that different cancers are given very different funding priorities. The truth is that some cancers are more equal than others, and campaigners know that a more vociferous and passionate group is likely to have more success at persuading governments, and the NHS, to fund their treatment than one that is less vocal. Breast cancer currently enjoys 10 times more funding than prostate cancer. It has benefited from very glamorous campaigns, such as Ralph Lauren's initiative, Fashion Targets Breast Cancer, supported by models such as Kate Moss, Naomi Campbell and Giselle. Pictures of men in underpants highlighting prostate cancer do not have quite the same appeal as sexy women in white T-shirts. Val, who turned 60 last month, was diagnosed after noticing a small dimple to the side of her left breast. She has already undergone a lumpectomy to remove the small tumour inside, and she has had to have some lymph glands removed to protect her from the risk of it spreading. Her oncologist has put her on Arimidex, an expensive but highly successful drug given after surgery, which will give her the best possible chances of survival as it lowers the amount of the oestrogen hormone in the body. This week she will begin a course of radiotherapy to kill any surviving malignant cells.

[Extract 4.7]

For her husband, the story is different. Still working as The Observer's golfing correspondent, he has been turned down on cost grounds for the treatment which his consultant, Professor Stephen Langley, recommended for him - a relatively modern procedure known as brachytherapy. This involves planting around 100 radioactive seeds, about the size of rice grains, within the prostate gland in order to kill off the cancer through radiation. The alternative is to have a radical prostatectomy, the surgical removal of the prostate which has a higher risk of two major side effects - impotence and incontinence. 'I had been having [prostate] tests for the last three years, just to make sure there was no risk,' Bill said. 'I'd been having the usual warning signs, such as getting up a lot in the night to have a pee. Although my PSA [prostate-specific antigen] count was relatively low, I had a biopsy which showed that there were malignant cells, and Professor Langley said he felt brachytherapy would be right for me. 'I had assumed everything would be fine, until the professor received a letter from the Primary Care Trust, saying they had turned down the request for the procedure. Given that Guildford is the major centre of excellence for cancer, and that Langley himself is an expert in brachytherapy it was surprising, to say the least.' What angers Bill so much is that the PCT has refused to explain its decision for the rationing. 'They didn't even have the courtesy to write to me about why I couldn't have brachytherapy. They told me later that they never deal directly with patients. Why

not? Is that because they want to remain unaccountable?' The Prostate Cancer Charity is worried that covert rationing of treatment is starting to spread. Although it was originally Wales alone which refused to give brachytherapy, it is now hearing of cases in Nottingham and Bath. The charity's chief executive, John Neate, said: 'It is a disgrace and completely unacceptable that any man with prostate cancer for whom brachytherapy treatment is recommended, should be denied access to it.'

[Narrative segment not included in analysis]

'It is not an untested, experimental treatment - it's now recognised by a large body of research and can help men whose cancer has not spread. What it means is that patients can have a few short visits to the hospital, and post-treatment recovery time is minimised to a few days. 'And frankly, no one should have to battle with the bureaucracy and financial aspects of their treatment when they need all their energy to come to terms with their diagnosis.' After many calls to the PCT, the answers that Bill has received are even more surprising. He asked one official what the clinical reasons were for turning him down for treatment and was told that they were not clinical, that the trust simply had a policy of not funding the treatment. Given that brachytherapy costs just £2,000 more than the radical prostatectomy, and carries fewer side effects, he found this irrational. His home in Rowledge, near Farnham, is just 10 miles from the Guildford cancer centre. None of the doctors to whom the Elliotts have spoken, including their own GP, was aware of this decision having been taken. Last week, when the PCT became aware that The Observer was looking into Bill's experience, the trust told Bill that it would start to look at the treatment on a 'case-by-case basis'. Bill had a conversation with Nicola Chandler, the PCT's associate director of recovery and reform, who told him that part of the problem was that doctors kept 'raising patients' expectations' by suggesting treatments that were not necessarily available. Bill's case will come up for consideration before a specially-convened panel within the next fortnight. There is no cancer specialist among this group. Instead, a GP and public health doctor provide the clinical input. Bill asked Chandler if he could attend the meeting so that he could explain the situation from the patient's perspective, but was told that this would be impossible as it would be a 'virtual meeting'. He still doesn't know what that means. As for Val, she has to stand by and watch her husband live with all the uncertainty and fear that his dilemma brings with it. 'I'm so angry about it,' she said. 'I've worked for a PCT for the past seven years, and we've always been huge supporters of the NHS. I'll defend it to the death, because it is a system that works, and I've always felt that it doesn't discriminate between the haves and the have-nots, but suddenly you find yourself dealing with a lottery. You also find yourself trying to get some sense out of administrators who are unaccountable and who will make decisions that will change our lives.' Bill knows that if he paid £ 11,000 and went private he could have the brachytherapy tomorrow. 'It's a two-tier service we have now,' he remarked. 'In an area like Guildford, there are probably quite a few middle-class guys who would have savings and simply pay up. 'But what about all the other men I sit next to when I go to the clinic? Are they even told that their treatment has been denied to them? It seems to me that men don't kick up a fuss about healthcare because they are scared of talking about illness. But it shouldn't be up to us to kick up a fuss, should it? This is a treatment which the government's own experts have said should be available. Why, then, am I having to fight tooth and nail for it?' Brachytherapy is a treatment first developed 20 years ago, but which has been slow to come to the NHS. Radioactive seeds of iodine-125 are

inserted within the prostate gland, where they slowly release their radiation over a period of three months. By delivering localised radiation, doctors avoid damaging nearby organs such as the rectum or the bladder, and thus reduce the potential side effects such as incontinence which can come with surgery. The treatment is most suitable for men whose tumours are not large, and where the cancer is thought unlikely to have spread. For those whose disease may have spread, the alternatives after surgery may be external beam radiotherapy and a higher dose of brachytherapy. The National Institute for Health and Clinical Excellence gave brachytherapy its approval in 2005. The funding for it, however, is up to individual PCTs which commission care from hospitals. Many of them are facing large deficits, and are under pressure to curb hospital spending as they have other cost pressures. The Guildford and Waverley PCT denied to The Observer that it had a blanket ban on funding brachytherapy, and said that it had always looked at it on a case-by-case basis. 'Certainly we will investigate why this gentleman's treatment was turned down,' said a spokeswoman. She declined, however, to talk about his case in detail, saying that this would constitute a breach of patient confidentiality. As Bill and Val walk out over the sands near Cromer, their closeness is obvious. They retain a strong sense of humour, managing to laugh about the unique nature of their situation. 'We will come through this together, although the timing of it all is a bit bizarre,' said Bill. 'Our lives have been changed forever.'

Appendix 16. Conference presentations

September 2013: *Disclosing prostate cancer: juxtaposing the 'good', the 'bad', and the 'unsaid'*. MEDSOC, University of York, UK. Oral presentation

October 2012: *Prostate cancer interfaces: the changing media face of prostate cancer in the UK 1990-2010*. Interdisciplinary Linguistics Conference (ILINC) Queen's University, Belfast. Poster presentation.

September 2012: *Prostate cancer interfaces: resonance and dissonance in the strategic and dialogic framing of prostate cancer in the UK*. MEDSOC, University of Leicester, UK. Oral presentation.

June 2012: *The Changing Public Face of Prostate Cancer in the UK*. Inter-Varietal Applied Corpus Studies (IVACS), University of Leeds, UK. Oral presentation.

April 2012: *The Changing Public Face of Prostate Cancer in the UK*. British Sociological Association (BSA), University of Leeds, UK. Roundtable discussion.

April 2012: *Prostate cancer interfaces: resonance and dissonance in the strategic and dialogic framing of prostate cancer in the UK*. Blizard Institute Graduate Day, Queen Mary University of London, UK. Oral presentation.

July 2011: *The changing public face of prostate cancer*. Health and media symposium. Bath Spa University, UK. Oral presentation

June 2010: *The changing public face of prostate cancer*. Institute of Health Science Education. Queen Mary University of London, UK. Poster presentation

April 2010: *The changing public face of prostate cancer*. Institute of Health Science Education, Queen Mary University of London. Oral presentation

January 2010: *Andrew and Adrian: A Tale of Two Men*. Junk the Jargon competition. Queen Mary University of London, UK. Oral presentation

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