

Prostate cancer: Exploring the reasons for timing of presentation and diagnosis



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Executive Summary

Prostate cancer is the most common malignancy in men, and the third highest cancer mortality in men. The observed increase in incidence alongside the reduction in men presenting with advanced disease is likely to be due in part to improved early detection rates associated with the introduction of the PSA test.

This study was undertaken to determine the pattern of timing of presentation with a diagnosis of prostate cancer in Glasgow.

A postal survey was distributed to all men in Greater Glasgow who were diagnosed with prostate cancer in 2008/9 (N=458). The survey was returned by 320 men; a response rate of 70%. A stratified sub-sample of survey respondents were interviewed (N=30); when possible, men's partners were included in these interviews. Quantitative data were analysed with descriptive and inferential statistics (chi-square and Spearman's). Qualitative data were analysed thematically, informed by psychosocial theories of delay.

The sample

- The total patient population had an average age of 69. Thirty-six percent of men were classified as having a high-risk prostate cancer.
- The total patient population for 2008/9 included more men from affluent areas, indicating that men from deprived background were diagnosed less frequently.
- Age was associated with clinical risk, with older men more likely to receive a high-risk diagnosis.
- Deprivation was not associated with higher clinical risk.

Symptom experience

- Eighty-three percent of men experienced one or more symptoms prior to their diagnosis; symptoms tended to be urinary. The remaining 17% experienced no symptoms.
- Eighty-five percent of men reporting symptoms had experienced them for over four weeks, with 41% experiencing symptoms for over a year. Men who explained their symptoms as part of normal ageing were significantly more likely to have experienced those symptoms for over 12 months before seeking help.
- There was no statistically significant relationship between the length of time men experienced symptoms before diagnosis and clinical risk.
- Men who had blood in their urine or semen, and those experiencing pain when urinating, did not attribute their symptoms to normal ageing.
- Men considered symptoms as both troublesome (57%) and worrying (49.8%). Men who appraised their symptom(s) as serious (24.5%) were significantly more likely to seek help more quickly.

- Men who had a history of urinary tract infections presented later than men without such a medical history. Men with benign prostatic hyperplasia explained their symptoms with reference to this co-morbid condition.

Routes to gaining a diagnosis

- The most common route to diagnosis for respondents was presenting to a healthcare professional with symptoms (48.3%).
- Men who gained their diagnosis following a visit to a Well Man clinic were more likely to receive *low* risk diagnosis.
- Forty men (13%) approached their GP and requested a PSA test. These men who requested a test were statistically significantly more likely to be from the least deprived backgrounds. They were also more likely to have low clinical risk disease, and to be asymptomatic.
- Men who requested a PSA test were significantly more likely to have a friend who had prostate cancer, and slightly more likely to have a family history of prostate cancer. Post-diagnosis, many men encouraged their friends/relatives to be tested.
- Family and friends were important in prompting men to visit their GP with symptoms, with 27% of men citing this as the reason they attended primary care. Twenty-nine percent were at the GP anyway and spoke about symptoms when they were there.
- Often when men reported that once they had presented at the GP, tests and referrals happened at an appropriate pace indicating little scheduling delay within the health service.

Knowledge of prostate cancer

- The majority of men experienced symptoms, yet despite the frequency of symptoms few men sought information on them. Men explained symptoms with reference to normal ageing.
- Men gain knowledge of the disease from informal channels such as family or friends.
- Forty-nine percent of respondents knew someone with prostate cancer, while 11% reported a family history of prostate cancer.

Perceptions of risk

- Most respondents reported that prior to their diagnosis they largely considered themselves to be at low risk of prostate cancer. Men in the older age categories were no more likely to perceive themselves as at high risk of prostate cancer than younger men.
- A minority of men did consider themselves to be at high risk of prostate cancer, but only low/moderate risk of other cancers.

- Age and family history were not integrated into men's perceptions of their overall risk of developing prostate cancer.

Recommendations

The findings indicate that knowledge of prostate cancer is low. Men are often prompted to seek tests from primary care following conversations with friends and family. Thus, health promotion messages could be tailored and targeted using relationships to drive communication and information about clinical risk factors.

Given the high prevalence of co-morbid conditions in men in the high risk age group, there is an opportunity to explore how this may provide a direct route to targeted health promotion.

Acknowledgements

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1 Background

Prostate cancer (PCa) is now the most common malignancy in men, and the third highest cancer mortality in men in Scotland (ISD Scotland, 2010). In 2007, 2507 men were diagnosed with PCa in Scotland, accounting for 19.1% of all cancers (ISD Scotland, 2009). These data is comparable with European data, where PCa accounts for 20.3% of cancer diagnoses (Ferlay et al., 2007) and the USA (Surveillance Epidemiology and End Results (SEER), 2010). In the UK, PCa incidence has increased greatly over the last 20 years, however, mortality rates have remained relatively stable (Cancer Research UK, 2010).

Prostate cancer predominantly affects older men (aged ≥ 70 years). The median age at diagnosis is 68 years; overall, two-thirds of prostate cancer-related deaths occur in men aged ≥ 75 years (Droz et al., 2010).

Eisenberger reports that the number of men presenting with advanced disease has shrunk significantly in recent years: “The distribution of stages at the time of initial diagnosis has dramatically shifted and this can be illustrated by a 75% reduction in the proportion of cases presenting initially with metastatic prostate cancer from 1984–1987 to 2004–2007” (Eisenberger, 2008 pg 406). The observed increase in incidence alongside the reduction in men presenting with advanced disease (or “stage migration”) is likely to be due in part to improved early detection rates associated with the introduction of the PSA test as well as greater awareness of the disease (Bostwick et al., 2004).

Deprivation may influence the likelihood of individuals being diagnosed with PCa, and be related to the stage of disease at the time of diagnosis. Recent evidence suggests that men from low socioeconomic backgrounds are significantly more likely to present with advanced prostate cancer (Greenlee and Howe, 2009), and other cancer types (Macdonald et al., 2006; Macleod et al., 2009; Scott et al., 2008) and have lower survival rates in prostate cancer (Jeffreys et al., 2009) than men from affluent backgrounds.

However, PCa is conceptualised as a “disease of affluence” due to higher incidence rates among more affluent populations, and evidence from England suggests men from affluent areas are offered more radical treatment (Fairley et al., 2009). Survival rates of men from higher socio-economic backgrounds are shown to be higher than those from disadvantaged backgrounds, even when adjusting for stage at diagnosis (Kogevinas et al., 1997).

UK screening programmes have been introduced for some cancers (e.g. breast, cervical and bowel), to aid in early detection. Similar programmes have been trialled for prostate cancer, but evidence on its overall effectiveness in reducing mortality is not considered sufficiently compelling to warrant such a service. Since prostate cancer may be asymptomatic at diagnosis, and with no national screening in place, diagnosis and patterns of incidence may be opportunistic; this explains some of the variance in incidence statistics and stage of disease at diagnosis across Scottish health boards. Djulbegovic’s (2010) meta-analysis of screening studies suggests that areas with higher levels of PSA testing diagnose greater numbers of men. Greater Glasgow and Clyde is an area characterised by lower levels of PSA testing and lower incidence rates (Brewster et al., 2000).

1.1 The local context

Greater Glasgow and Clyde (GGC) health board has a population of 1,199,026 (General Register Office for Scotland, 2010), with oncology services delivered through secondary and tertiary care.

Approximately 500 men are diagnosed with prostate cancer annually in GGC (ISD Scotland, 2010). This is equivalent to a rate of 78.3 per 100,000 (EASR) which is lower than the rate for Scotland as a whole (85.1) (ISD Scotland, 2010). Reasons for this are unclear and warrant further investigation. One possible explanation relates to lower rates of PSA testing in deprived areas.

A local unpublished audit in Glasgow (Leung, 2009) revealed that between 30 and 40% of men diagnosed with prostate cancer had disease that was so advanced they were likely to die from it (rather than any-cause mortality) compared with only 10% in other parts of the UK (Foster, 2009).

Significant inequalities in health outcomes for Glasgow have been reported, identifying, in a phenomenon known as “The Glasgow effect”. The Glasgow effect is characterised by poorer health outcomes, even when adjusting for deprivation, than other cities with equivalent deprivation:

Premature deaths in Glasgow are more than 30% higher, with all deaths around 15% higher than in the other cities. This ‘excess’ mortality is seen across virtually the whole population: all ages (except the very young), both males and females, in deprived and non-deprived neighbourhoods. (Walsh et al., 2010 p8).

1.2 Timing of presentation and diagnosis of prostate cancer

A range of theories are evidenced in the literature exploring the timing of men being diagnosed with prostate cancer, linked with clinical risk and psychosocial variables, and are outlined in the sections below. Some of the most well rehearsed arguments revolve around gender theories regarding men being reluctant to access their GP services (Courtenay, 2000; O'Brien et al., 2005).

Research looking at typical delay periods in symptomatic men found that a significant number wait at least two months before presenting to a healthcare professional. A large-scale retrospective analysis of GP records in Scotland identified that the median time from first noticing symptoms to first presentation with a GP was 14 days for men with prostate cancer; 25% of the sample of 874 men waited more than two months before presenting (Baughan et al., 2009). Data from Japan with a smaller sample of 76 men identified the median interval as 22 days, with 25% of men waiting more than 90 days before presenting (Tokuda et al., 2009). A secondary analysis of a large-scale English dataset (Allgar and Neal, 2005) identified that those with prostate cancer had the longest total delays compared to five other cancer types (148.5 days) with the majority of the delay being defined as “patient and primary-care delay” (97.5 days).

Early detection of prostate cancer is associated with better survival outcomes (Nicholson and Harland, 2002). Thus, delay in presentation with symptoms may be a factor influencing the likelihood of presenting with advanced disease. The notion of delay is difficult to define and researchers have developed typologies of the stages of delay. Anderson et al. (1995) provide a model of delay which includes five dimensions, encapsulating much of the patient's journey from initial symptoms through to treatment:

1. *Appraisal delay*: related to symptom interpretation and understanding symptoms as related to something worrying. Cancer is likely to foster anxiety/distress, and consequently there may be a tendency toward not appraising symptoms as worrying, leading to not taking any action.
2. *Illness delay*: The time elapsed from the time the person concludes that the symptoms are worrying to seeking help. Thus, illness delay is associated with decision making.
3. *Behavioural delay*: The time that elapses between making a decision to seek medical attention and actually acting on that decision. Thus, behavioural delay is associated with delay in taking action.
4. *Scheduling delay*: The time elapsed between making an appointment and first receiving medical attention. This may include system delays (such as waiting lists) or patient-induced delays (for example if a patient does not fully describe symptoms to the healthcare professional).
5. *Treatment delay*: The time elapsed before treatment commences, associated with lags in commencing treatment. This is of less significance for the current study, due to the focus on the time prior to diagnosis.

Other studies have adopted similar typologies, but applied different terminology, for example, terms such as: patient-mediated and practitioner-mediated delay (Macleod et al., 2009) or patient, primary care, referral and secondary care delays (Allgar and Neal, 2005; Neal et al., 2008).

1.3 Reasons for delay

Despite a general consensus that earlier diagnosis is likely to result in a more positive outcome, further research is required to investigate the factors which influence a man's decision to seek or postpone healthcare when experiencing symptoms. Previous research has explored the triggers and barriers to presentation with cancer symptoms to a healthcare professional, and there is accumulating evidence regarding the reasons for delayed diagnosis (Corner et al., 2006; Ramirez et al., 1999; Scott et al., 2006), however, the specific reasons for late presentation in prostate cancer are still under-researched. Accounts of men's (or indeed partners') experiences of prostate cancer, their routes to diagnosis and reasons for late presentation are limited (Chapple and Ziebland, 2002) (Boehmer and Clark, 2001). There are significant gaps in knowledge regarding the reasons *why* men present late with PCa and *the experience* of men who presented late with prostate cancer. This lack of information means that the ability to provide statutory and voluntary services is severely compromised.

1.3.1 Risk perception, family heredity and social context

A man is two-and-a-half times more likely to develop prostate cancer if his brother or father have a history of the disease (Johns and Houlston, 2003; Steinberg et al., 1996). Having a relative with prostate cancer could mean that people have a greater awareness of the disease and therefore are more likely to present promptly in the event of having symptoms or heightened sensitivity to risk (Bratt et al., 2010). People who feel less at risk of cancer are less likely to report to a GP. Perceived risk is likely to be based on a knowledge of the risk factors of prostate cancer such as being male,

older, and having a family history of prostate cancer, as well as knowledge of the common symptoms of prostate cancer. Fitzpatrick et al. (2009) asked men with PCa and their partners to state how "at risk" they felt before diagnosis; 50% believed that they/their husband or partner were previously at low or very low risk of PCa before diagnosis.

In a qualitative synthesis Smith et al. (2005) identified that family members played an important role in sanctioning help-seeking behaviour. That is, family input can mitigate delay. The influence of a person's wider social network on their likelihood to seek help has also been investigated. Scott et al. (2006) found that those who did not disclose symptoms to others soon after discovery were more likely to go on to delay; thus significant others influenced patients' decisions to seek help.

1.3.2 Knowledge of cancer

Studies assessing awareness and knowledge of prostate cancer have produced mixed results. Some studies have found a poor awareness of prostate cancer (Fitzpatrick et al., 1998; Smith et al., 1997) whereas more recent research has found better knowledge levels (Fitzpatrick et al., 2009; Hevey et al., 2009), possibly due to recent awareness campaigns. Some research has looked at the influence of knowledge of cancer on the likelihood of delay when experiencing potential cancer symptoms. One study assessed public knowledge of prostate cancer and linked greater knowledge to the likelihood of seeking help in a hypothetical situation (Fitzpatrick, 1998). Sunny et al. (2008) noted that the amount of information sought from the internet or other sources was associated with reduced delay. Knowledge of cancer and symptoms have been explored in other cancers, for example, the relationship between greater knowledge of oral cancer symptoms and shorter delay was reported by Scott et al. (2006; 2008). It appears there is agreement that the better informed someone is, the more likely they are to present sooner in the event of experiencing symptoms which match their expectations for the disease. One potential issue with raised public awareness of a disease and its typical symptoms is identified by Meechan et al. (2003), who found that people experiencing breast cancer symptoms which did not fit with expectations and knowledge of the typical signs were likely to delay for longer.

1.3.3 Symptom experience prior to diagnosis

Related to knowledge is awareness of cancer-related symptoms and symptom interpretation. Symptom interpretation is influenced by appraisal of how serious the symptoms are deemed to be and the nature and type of symptom experienced. In a worldwide systematic review of the literature on the most common cancers Macleod et al. (2009) looked at the risk factors for delayed presentation and referral of symptomatic cancer. They found that "non-recognition of symptom seriousness" (p92) was the main barrier to presentation. This finding was also reported by Macdonald et al. (2006) in their review of the factors influencing delay in patients seeking medical attention with gastro-intestinal cancer.

There is consensus across the cancer literature that onset of vague non-specific symptoms can lead to greater delay in presenting to the GP (Molassiotis et al., 2010) compared to specific highly recognisable cancer symptoms. As noted above, Meechan et al. (2003) found that the type of symptom experienced was significantly related to delays in seeking healthcare advice in breast cancer. Women with breast lumps were less likely to delay than those with other breast symptoms. Vague symptoms are more easily attributed to benign sources (for example age-related problems,

trauma or co-morbid conditions) and are more likely to result in self-medication. There is also a reluctance to consult a GP with symptoms seen as trivial (Smith et al., 2005). This is particularly relevant in prostate cancer where symptoms generally have a slow, gradual onset. The nature of the symptoms can also prompt help-seeking behaviour, with symptoms perceived as “more serious”, e.g. bleeding, resulting in faster presentation (Macleod et al., 2009).

Scott et al. (2007) looked at the process of symptom appraisal and how this changes over time. When symptoms persist, do not respond to self-medication, worsen or new symptoms appear, this is more likely to trigger help-seeking behaviour. Finally, the impact of symptoms on everyday life influences the patient’s help-seeking behaviour with symptoms which restrict ability to attend work or participate in activities of everyday living more likely to result in prompt presentation (Molassiotis et al., 2010; Smith et al., 2005).

Symptom interpretation is further complicated by the high prevalence of urinary symptoms, which may not be related to prostate cancer. Indeed, many symptoms typically associated with prostate disease may be related to benign prostatic hyperplasia, prostatitis, or bladder infections. Recent data indicate that UK prevalence of urinary symptomatology is at 60.6% in men, with a mean age of 56.6 (Coyne et al., 2009), and 83% of men in several European countries aged 70 and over (Irwin et al., 2006).

1.3.4 Co-morbid conditions and behavioural delay

Existence of co-morbid conditions can reduce delay; for example, by more regular access to primary care to discuss concerns and symptoms. This effect was found in a review of the factors influencing delay in patients with gastro-intestinal cancer (Macdonald et al., 2006). However, other studies have found an increase in delay related to co-morbidity due to cancer symptoms being attributed to an existing condition and thus masking the disease (Molassiotis et al., 2010).

1.3.5 Practical and psychological barriers

Practical barriers such as being too busy or not being able to get an appointment are also possible barriers to help-seeking. In their qualitative study of people with oral cancers Scott et al. (2006) found that those who delayed were more likely to report ongoing other commitments or significant events. Scott et al. (2008) used the Social Readjustment Rating Scale to assess the presence of competing events in participants’ lives as part of their study investigating the likelihood of patient delay with oral symptoms. The findings indicated that the severity of life events were significantly related to the duration of patient delay.

Emotional barriers such as embarrassment, concern over troubling the GP, and fear of diagnosis and treatment all contribute barriers to presentation. In their synthesis of 32 qualitative papers Smith et al. (2005) reported that fear was a reason why many people delayed. This delay was related to a fear of embarrassment (e.g. being perceived as a time-waster or hypochondriac, embarrassment related to location of symptoms) and a fear of cancer (e.g. pain, treatment, loss of sexuality / sexual function).

Some studies (Sirois, 2004; 2007) have found a link between the trait “procrastination” and wellness behaviours. This link may indicate that procrastinators are more likely to delay seeking help when experiencing symptoms.

1.4 Study aims

This study aimed to identify the social, demographic and diagnostic pathway features of men diagnosed with prostate cancer in Glasgow.

1.4.1 Research questions

The study had two primary research questions:

1. What are the demographic and pre-diagnosis symptom profiles of men presenting with high and low risk PCa in Glasgow?
2. How do men describe and account for the timing of their presentation and subsequent diagnosis of PCa in Glasgow?

2 Methodology

2.1 Defining terms

Clinical definitions of disease do not allow for adequate conceptualisation of what constitutes a “late” presentation. Grade and stage of disease together give a guide as to the clinical prognosis, but it is not always known whether a cancer has had a rapid or slow trajectory, which would then be associated with an appraisal of a “late” presentation.

For the purposes of this study, we adopted the definition of clinical risk used in the STAMPEDE trial (a randomised treatment trial for prostate cancer entitled: Systemic Therapy in Advancing or Metastatic Prostate cancer: Evaluation of Drug Efficacy) (James et al., 2009).

The STAMPEDE study offers two risk classifications (low and high), defining high risk as one of the following:

1. Fulfilling at least two out of the three following criteria:
 - o Stage T3/4NOMO (locally advanced non-metastatic) histologically confirmed prostate adenocarcinoma,
 - o PSA $\geq 40\text{ng/ml}$
 - o Gleason sum score of 8-10.
2. Stage T_{any} N+ MO or T_{any} N_{any} M+ histologically confirmed prostate adenocarcinoma
3. Multiple sclerotic bone metastases with a PSA $\geq 100\text{ng/ml}$ without histological confirmation.

A non-clinical model of delay is also applied, drawing on the notion of the time elapsed from noticing first symptoms to the time of gaining a diagnosis. Within this definition, all patients would be considered delayers unless a symptom was noticed, reported and diagnosed on the same day. Thus, this provides a continuum of delay rather than a notion of absolute delay.

The following classifications are used to quantify delay from first noticing a symptom to taking action: short delay (1 day to <4 weeks), medium delay (4 weeks to <12 months) and long delay (12 months or longer). In the data chapters, the terms “behavioural delay” and “length of delay” are used to report these periods.

For some men, it was anticipated that there would be no delay. For example, men whose diagnosis was made during other investigations/procedures such as through hospital admissions related to co-morbid conditions would be categorised as having had no delay.

2.2 Design

An embedded mixed methods design was applied, using a quantitative postal survey of men diagnosed with PCa in Glasgow and qualitative interviews. The survey ascertained core details of symptom profile, duration, intensity, triggers to action, route to diagnosis and demographic information.

Interviews with men explored similar terrain to the survey, but in more depth, such as awareness of risk factors and physical signs of prostate disease, routes to definitive diagnosis, initial symptoms, prompts to first presentation, interactions with primary care, diagnosis through PSA request/PSA prompted by GP.

Telephone interviews were offered to men who expressed this as a personal preference, and (where possible) to those who did not have a partner. Consequently, in the majority of face-to-face interviews, men were joined by their partners. In two instances partners agreed to take part in a phone interview.

The methods sought to locate men's experiences within the particular social context and life stage, comparing findings with other published sources. The qualitative and quantitative data are presented together in the findings chapter of this report.

2.3 Sample

Survey: The survey was administered to all men who received a PCa diagnosis in 2008 and 2009 in Greater Glasgow; the sample was derived from clinical pathology records. A second copy of the survey was sent to people who had not responded within four weeks.

The study focused on men diagnosed in the last two years, to restrict recall bias. This timeframe also recognises the likely disease progression/prognosis of men diagnosed prior to 2008.

Sample size: 570 men were diagnosed with prostate cancer in Glasgow in the specified timeframe. Clinic records were unavailable for 112 men who were excluded because the man was identified on hospital/GP records to have died or where GPs had no ongoing record of the man at their practice or where GP details were unavailable.

Of the 458 men who received the survey, seven patients were unable to be classified using the STAMPEDE classification due to missing clinical data (TNM scores) in their medical records.

Interviews: Men completing the survey were asked to opt-in to a further interview. Of 320 respondents to the survey 184 (58%) opted into a telephone or face-to-face interview. A further 30 (9%) responses were not clear regarding whether the man consented to this contact.

Sample: 30 individual/dyadic interviews were conducted. This size allowed for data saturation of the accounts in the lead up to diagnosis. Partners were included in dyadic interviews wherever possible. Recent research identifies that family members often play an important role in someone presenting with symptoms which lead to a diagnosis (Forbat et al., 2009). Stratification was focused on respondents from affluent and deprived backgrounds, high and low clinical risk (as classified by STAMPEDE), and varying routes into diagnosis. Interviewees were also restricted to men diagnosed in 2009, to manage recall bias.

2.4 Ethical considerations

The study received NHS ethical approval through NHS GGC, committee 3 (study reference: 10/SO701/35). The study was also reviewed by the In-house Trials Advisory Board (IHTAB). R&D management approval was also confirmed.

The data is presented with identifying characteristics removed, to preserve respondent anonymity. Consequently, identifiers have been used to indicate patient (P) and partners (C) alongside study identifiers.

2.5 Data analysis

Survey data were analysed using descriptive statistics in the first instance. Inferential statistics (chi-square and Spearman's correlation) were subsequently used to explore hypotheses regarding statistically significant relationships between variables.

Interview data were analysed thematically in the first instance. Transcripts were also scrutinised with reference to Anderson's model of "total patient delay" (Andersen et al., 1995) which has been applied to delayed diagnosis in ovarian cancer (Evans et al., 2007). In Andersen's model, delay is conceptualised as having five stages, each of which have their own distinct decisional and appraisal processes (see Section 1.2 above: "Timing of presentation and diagnosis of prostate cancer" for an outline of the model).

Anderson's psychological model was combined with analysis that is cognisant of the social context in which people experience illness, thereby exploring facilitators and barriers to diagnosis, perceptions of primary care and service organisation/delivery.

Deprivation was categorised and analysed with reference to postcode data. The Scottish Index of Multiple Deprivation (SIMD) (Scottish Executive, 2010) identifies small area concentrations of multiple deprivation across Scotland, by postcode. Scores are derived from analysis of the following variables: income, employment, health, education, skills and training, geographic access to services, housing, and crime. Scores range from 1 indicating most deprived to 6,505 as least deprived. SIMD scores are aggregated as quintiles (0-20%, 20-40%, 40-60%, 60-80% and 80-100%) with 0-20% representing the most deprived.

Analysis of postcodes, age and clinical risk data for the total patient population of 2008/9 allowed for comparison of whether there were clinical or demographic differences between people who responded to the survey and those that did not.

2.6 Service user involvement

Following best practice in research, this study was guided throughout by a group of men who have personal experience of prostate cancer. Their roles included shaping the content and wording of the survey, identifying and refining interview questions, and analysing and interpreting the data. This group of service users also informed the dissemination strategy.

3 Findings

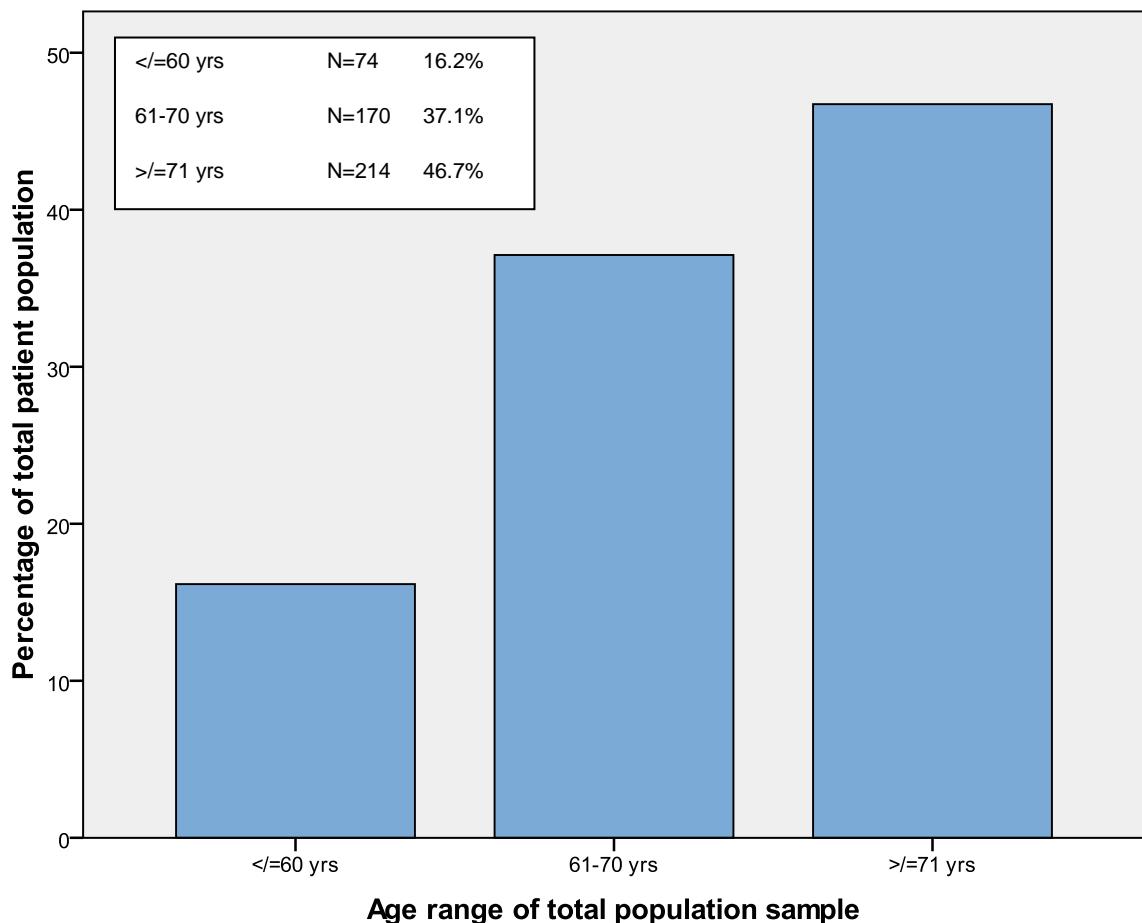
3.1 Characteristics of the sample

3.1.1 Characteristics of the total patient population sample

This section summarises the total patient population for 2008/9 (N=458 men diagnosed with prostate cancer). Subsequent sections report data for those who responded to the survey (N=320).

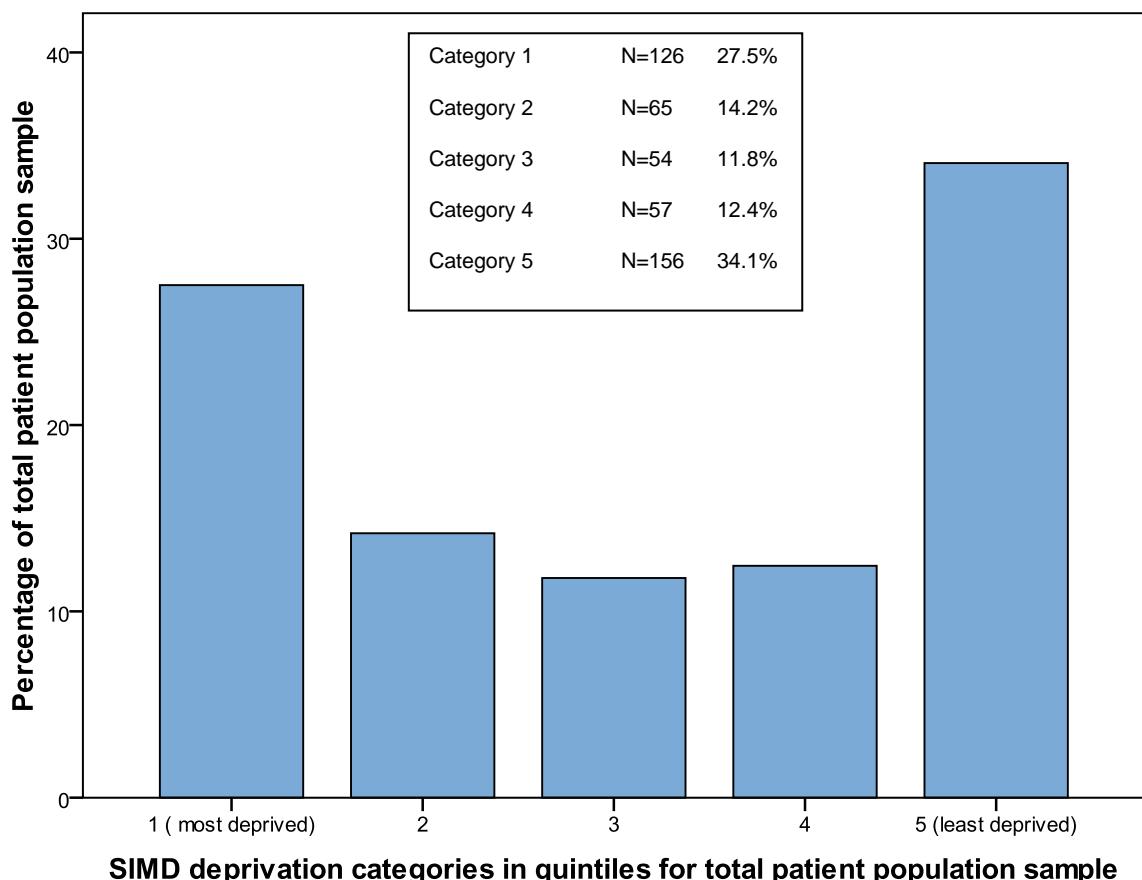
The mean age of the total population sample was 69, with a range of 47 – 88 years old.

Figure 1: Total patient population sample by age



As indicated in Figure 2, the total patient population shows distribution across each deprivation quintile, indicating that diagnoses of prostate cancer occurred across the population.

Figure 2: Total patient population sample split into deprivation categories



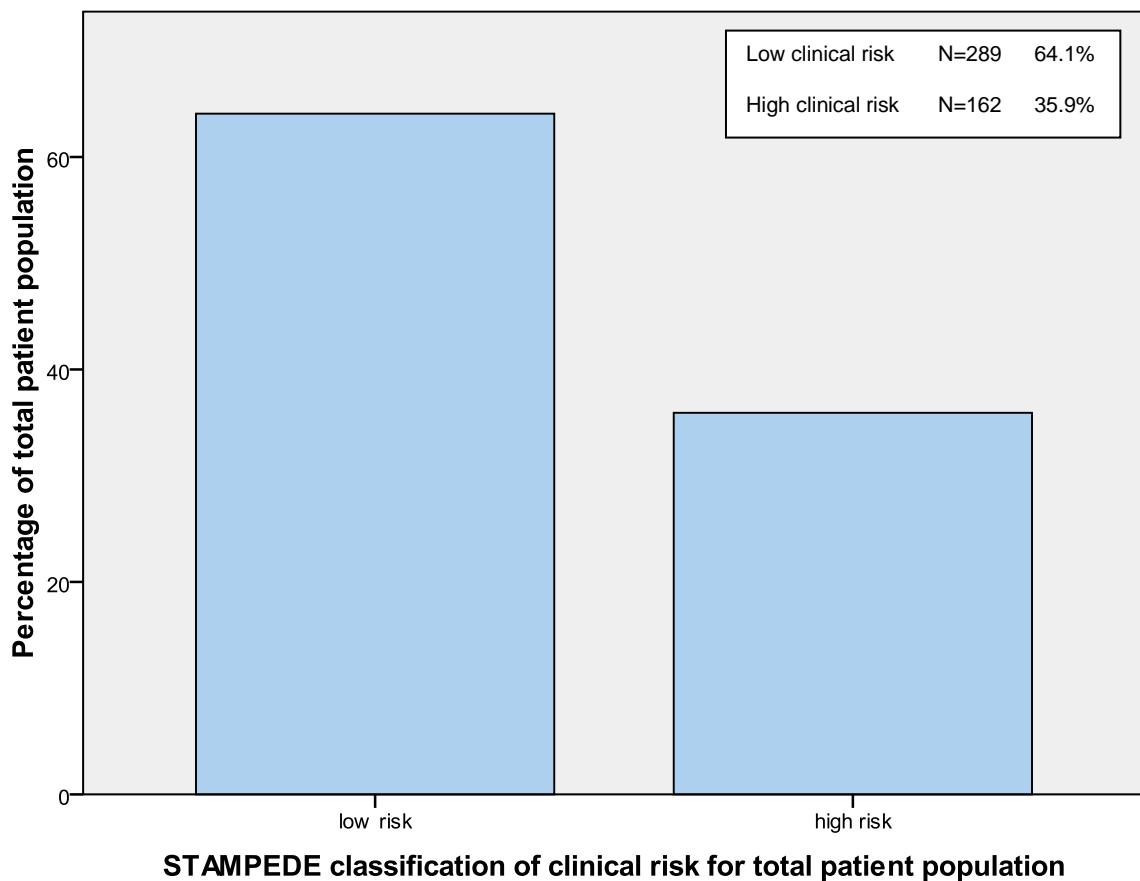
However, when comparing the total patient population of men diagnosed with PCa with the population as a whole (matched for age (47-88), male gender and health board boundaries; see Figure 3 below), our total patient population has fewer men from deprived areas, and more men from affluent areas. These data therefore support the notion that PCa is a “disease of affluence” in Glasgow.

Figure 3: Greater Glasgow population sample by deprivation categories matched for age and sex

SIMD category	N	Percentage
Category 1	112863	35.9%
Category 2	52335	16.7%
Category 3	37990	12%
Category 4	41342	13.2%
Category 5	69666	22.2%

The total patient population was classified by clinical risk using the STAMPEDE system. Thirty-six percent of men were classified as having high-risk disease.

Figure 4: Total patient population sample by STAMPEDE risk classification system



3.1.2 Deprivation, age and clinical risk

Statistical analysis identified a significant association between age and clinical risk, with older men more likely to receive a high-risk diagnosis ($p=0.020$).

There was no association between deprivation and age in our total patient population sample ($p=0.370$). Likewise there was no association between deprivation and clinical risk ($p=0.250$).

3.1.3 Characteristics of survey respondents

The survey received 320 responses, representing 70% of the total patient population sample. A further 8% of men returned their survey blank indicating that they did not wish to participate, as requested by the research team. The following analysis, which describes the survey respondents, treats those who returned surveys blank as non-respondents, since there is no survey data for them.

Respondents tended to be from more affluent areas ($p=0.04$) and younger (mean age 68.5) than non-respondents (mean age 69.5). Respondents were more likely to be in the low clinical risk group, however this difference was not statistically significant ($p=0.108$).

Respondents predominantly identified themselves as white, white Scottish, white British, white other (97.8%) as well as Asian, Asian Scottish, Asian British (1.6%) and African, Caribbean or Black (0.6%). The majority were married (80.1%), with the remainder reporting being single (8.8%), widowed (7.9%), or divorced/separated (3.2%). Respondents were educated to school level (51.6%), college level (25%), university level (19.9%) or had professional qualifications (3.2%). The majority of respondents engaged in two or more social engagements per week, indicating a sense of their social networks.

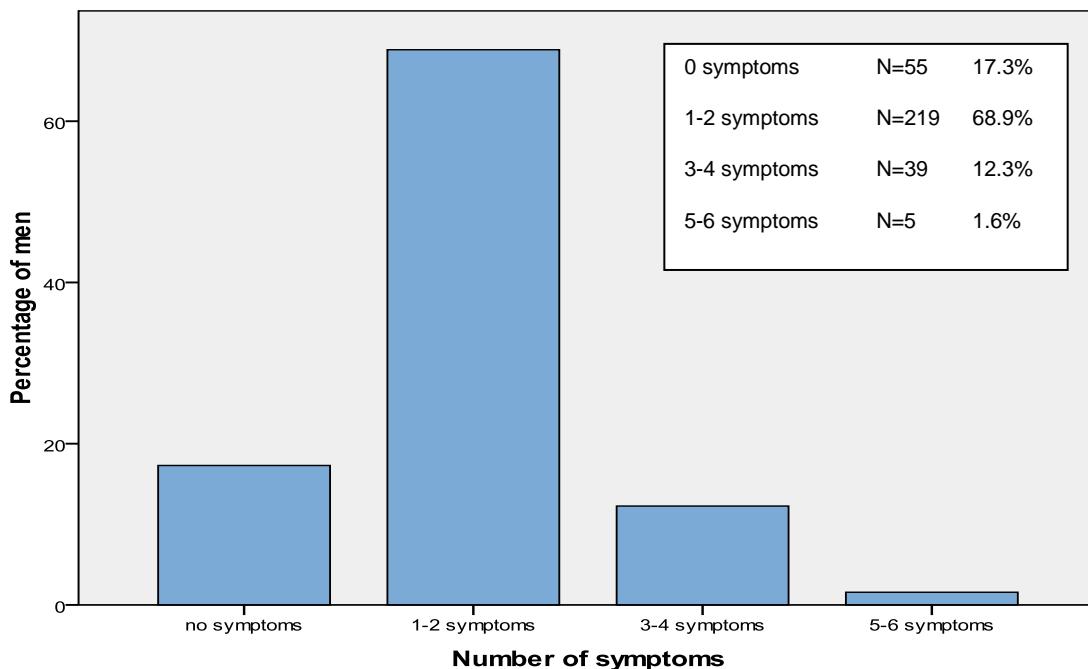
3.2 Symptom experience prior to diagnosis

Eighty-three percent of men experienced some symptoms prior to their diagnosis. The remaining 17% experienced no symptoms, and for some of these men, their diagnosis had occurred by chance:

It was purely by chance, just, just 12 months ago that our GP does an MOT for OAPs and I went along (P31).

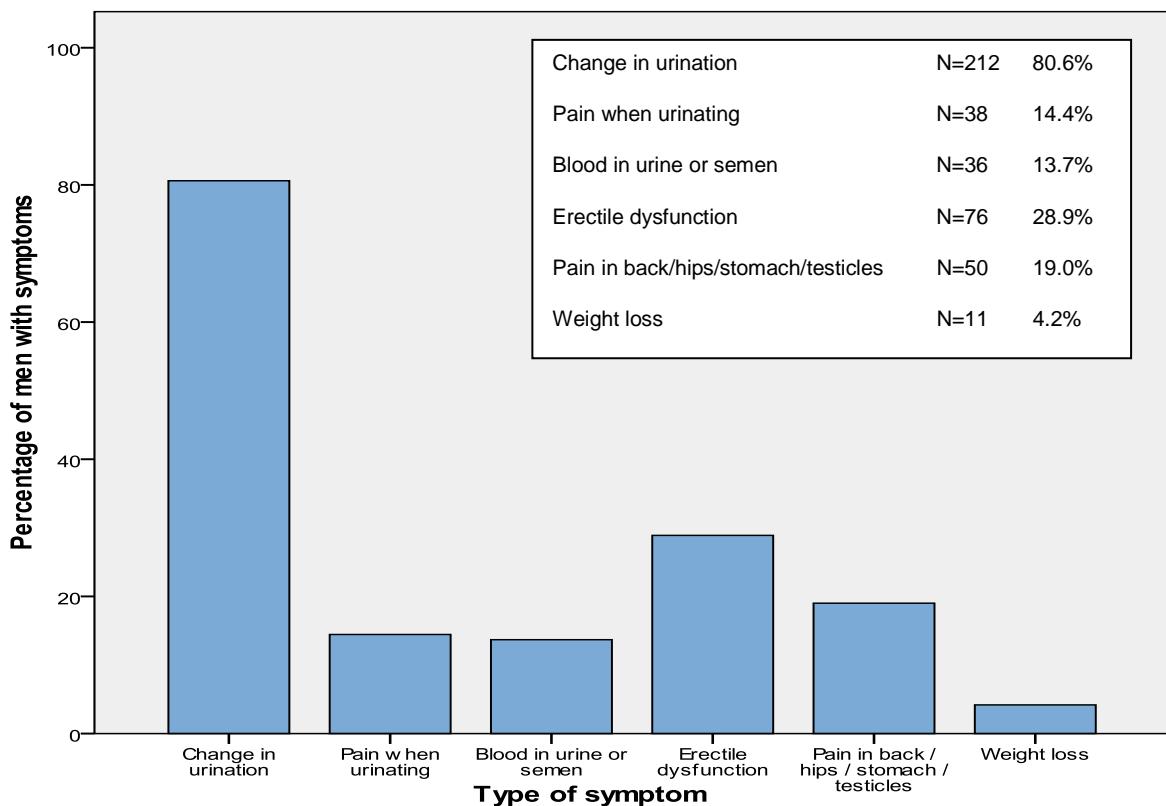
The two figures below indicate the number (Figure 5) and type (Figure 6) of symptoms men reported. Despite high numbers of men experiencing symptoms only 21% of these men sought information related to their symptoms.

Figure 5: Number of symptoms experienced



Of those who reported having at least one symptom, the majority experienced a change in urination (80.6%). Percentages in the following figure do not add up to 100, since (as noted above) many men reported more than one symptom.

Figure 6: Symptoms experienced prior to diagnosis



For some men, there was a gradual realisation that something was amiss, resulting in tests such as digital rectal exams (DREs):

Oh, just going to the toilet a bit more often and perhaps a wee bit of discomfort down there...they gave me a DRE and everything seemed to be OK and they send me off again...however when I went back they decided to do a PSA and my PSA was 29.9' (P27).

When asked to describe the nature of these symptoms in more depth these participants described them in rather innocuous terms:

I didn't give it too much attention really...it wasn't desperately painful or anything like that, it was just, you know, annoying (P27).

I was reluctant, not because I thought it was prostate cancer or anything, just because I didn't think it was all that serious (P60).

Seventeen percent of men were tested for prostate cancer without ever experiencing any symptoms. These men tended to have either requested a PSA test, been offered a PSA test as part of a routine Well Man Clinic or been attending the GP for another reason and been offered a PSA test whilst

there. Several men who reported being asymptomatic prior to diagnosis were interviewed to explore their route to diagnosis. The following interview excerpt illustrates how testing for PSA levels was initiated for one man:

My granddaughter's got very bad diabetes. (...) and I went into see the nurse (...) anyway, I took in a portion of my urine and I said 'while I'm here could you just check that for er, that illness...diabetes...?' And it was a nurse I had never met before, it was a nurse, she was age..... I'll never forget it, she was about 40 and she says 'No, you're...perfectly clear,' she says 'but your protein seems a bit high.' I said 'That's fine.' She says 'what age are you?' Then I said 'Oh I'm about 67,' and she says 'You've never been checked out for this?' I says 'Absolutely.' 'Would you mind if I do that?' I said 'Not at all.' And then er, now this is where I'm not sure, but not immediately after but I got the phone call from the doctor: 'Would you come up and see me?' So I went up and I was...I felt great, and he just says, something about that, 'Your PSA levels is very, very high' (P72).

Another patient described how he had requested a PSA test from his GP, despite having no symptoms:

When I got a leaflet through about bowel cancer where we had to give a, a sample and send it off I thought I think I'll go and get other tests done... so I went down to the GP and asked to do a range of tests, one of which was the PSA test (P14).

Later in the interview his partner explained that they found it difficult to understand why he had been asymptomatic, given the subsequent cancer diagnosis:

I found it quite frightening that (my husband) didn't have, or we thought didn't have any symptoms and yet his level was so high, I think it's quite scary, but how many other people are out there, are the same, walking about with this and not knowing anything about it? (C14).

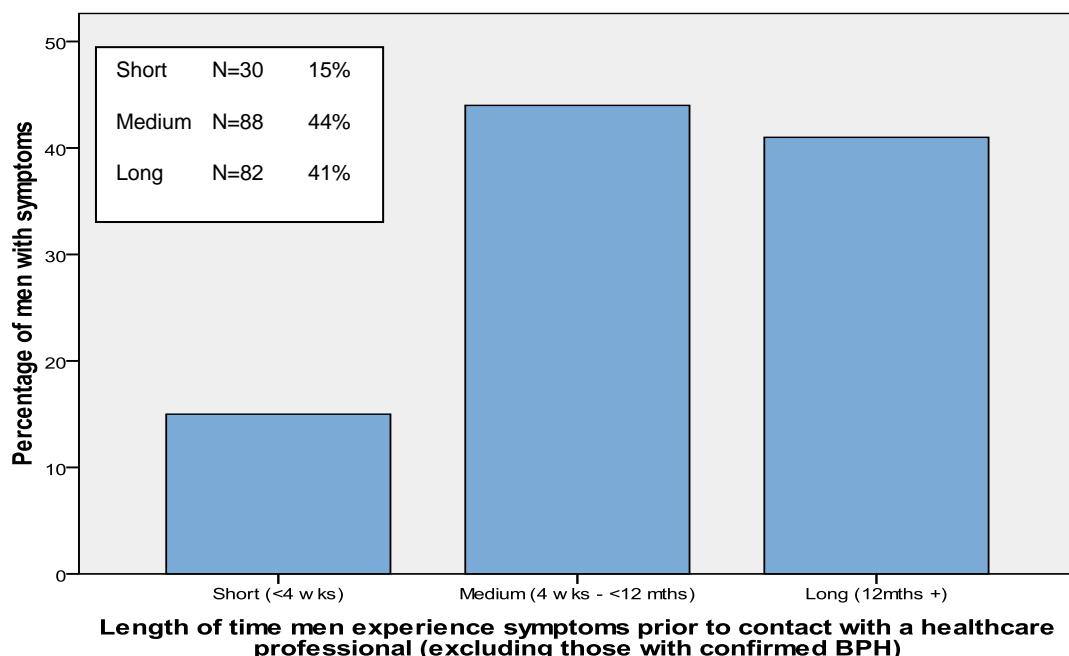
3.2.1 Length of time men experienced symptoms prior to diagnosis

Men had often experienced symptoms for months or years prior to receiving a prostate cancer diagnosis. The following classifications are based on short delay (1 day to <4 weeks), medium delay (4 weeks to <12 months) and long delay (12 months or more).

Length of time experiencing symptoms was analysed with reference to deprivation. Data indicates that men from the least deprived category had experienced symptoms for longest ($p=0.004$).

Men often experienced symptoms for 12 months or more. The following figures relating to length of symptom experience exclude those with Benign Prostatic Hyperplasia (BPH) (who are more likely to have lengthy histories of urinary symptoms).

Figure 7: Reported length of time experiencing symptoms prior to contact with healthcare professional



Though the data indicate that men had experienced symptoms for an extended time prior to diagnosis, there is no evidence to suggest that this indicates that cancer was present for all this time. Indeed, there was no statistically significant relationship between length of time men experienced symptoms before diagnosis and clinical risk. This is the case even when removing men with a confirmed diagnosis of BPH who are likely to experience symptoms over a number of years ($p=0.607$).

Despite no clinical links between length of history of symptom and the presence of cancer following their cancer diagnosis many men had interpreted their symptoms as signifying cancer, or at least querying whether symptoms had been connected. One man with a diagnosis of BPH reflected on how this may have masked cancer symptoms, which left him with a sense of uncertainty about his cancer's progression, and indicating a feeling of diagnostic delay:

The urine flow had got to you know being a nuisance ... well a lack of flow I should say, I went to the doctor again and, and he then referred me you know to the, the consultant and that lead eventually to the TURP operation. And it was, the diagnosis was, or the pathology of the TURP operation that actually diagnosed the presence of prostate cancer... so I felt, somewhere in that long chain of events couldn't somebody have done something, you know, earlier, you know? Eh ... now, obviously I don't know how soon it's detectable but, you know between this phase of it being called 'benign', you know to find out at the end of the day it wasn't benign, or maybe even it was both, I don't know but, I don't even feel I've ever found that out (P97).

3.2.2 Symptom-specific influences on the time men experienced a symptom prior to seeking advice

Among symptomatic men, those who experienced urinary changes were significantly more likely to delay longer than those who did not. Ninety-two percent of men in the “long delay” category experienced urinary changes; this difference was statistically significant ($p<0.000$).

Acute onset of urinary symptoms, often accompanied by pain, was reported in interviews as a trigger for many men to seek healthcare intervention.

P38: It really hit me bad when I was coming back from Hong Kong one year, in the plane, and I was...

C38: It's a 25 hour flight.

P38: Agony.

C38: And he was up down, up down, oh he was in agony.

P38: And I eventually was passing blood. And that's when I went to the doctor again.

The following man explains that after drinking a few pints of beer on a Friday night he experienced an acute episode where he was unable to urinate, which had prompted taking action:

P85: On Saturday morning I was in extreme pain, phoned NHS 24, went over to (hospital). The doctor said "Oh I'm afraid you've got probably an infection..."

C85: Urinary.

P85: A urinary infection. (The doctor) gave me some antibiotics and told me to drink plenty. Which I did and 24 hours later was in excruciating pain.

Int: You'd not been able to pass water at all during that time?

P85: Oh...very little. So I then had a ...back, NHS 24, back again, (hospital) doctor had one look at me, and said 'you've got a retention problem.' I then ended up (in a different hospital) where they then said 'Well, what's causing it?' And in the process of it they then discovered I had prostate cancer. So it was quite dramatic.

In contrast to those with chronic painless urinary symptoms, men who experienced blood in their urine or semen were more likely to seek medical advice quickly; this difference was statistically significant ($p<0.000$) and was the only symptom to show this trend. Men were also more likely to consider blood in their urine or semen as serious and this was the only symptom considered so by the majority of men ($p<0.000$).

The interviews provided further detail on how blood was interpreted as a signifier of a need for urgent action, and a shift from appraisal of chronic symptoms to acute onset of new symptoms.

I was the person who noticed the blood in the semen, I thought 'Aha' ...I thought ... and I pushed him up that same day (to see the GP) (C15).

Men experiencing pain (either when urinating or back/stomach/testicular/hip pain), erectile dysfunction, or weight loss were all more likely to delay for longer than those who did not, though none were statistically significant (see figure 8 below).

Figure 8: Symptom type and association with length of delay

Symptom	Delay	Significance level
Pain when urinating	47% delayed for >1yr	p=0.679
Pain in back / hips / stomach / testicles	51% delayed for >1yr	p=0.214
Erectile dysfunction	54% delayed for >1yr	p=0.105
Weight loss	62.5% delayed for 3-12 months 37.5%) delayed for >1yr	p=0.382

There was a significant difference between those experiencing changes in urination in the three age categories ($p=0.010$). Those aged 61 or over were more likely to experience urinary symptoms (83%) compared with those under 61 (68%). There was a significant association between those men experiencing urinary symptoms and those who explained their symptoms as “part of getting older” ($p=0.002$). These data are therefore consistent with epidemiological studies on prevalence of urinary symptoms (Irwin et al., 2006).

Figure 9: Age and association with urinary symptoms

Did man experience a change in urination?		Age range			Total
		</=60 yrs	61-70 yrs	>/=71 yrs	
No	N	14	12	25	51
	%	27.5%	23.5%	49.0%	100.0%
	% within age range split into three categories	31.8%	11.3%	22.1%	19.4%
Yes	N	30	94	88	212
	%	14.2%	44.3%	41.5%	100.0%
	% within age range split into three categories	68.2%	88.7%	77.9%	80.6%
Total	N	44	106	113	263
	% of Total	16.7%	40.3%	43.0%	100.0%

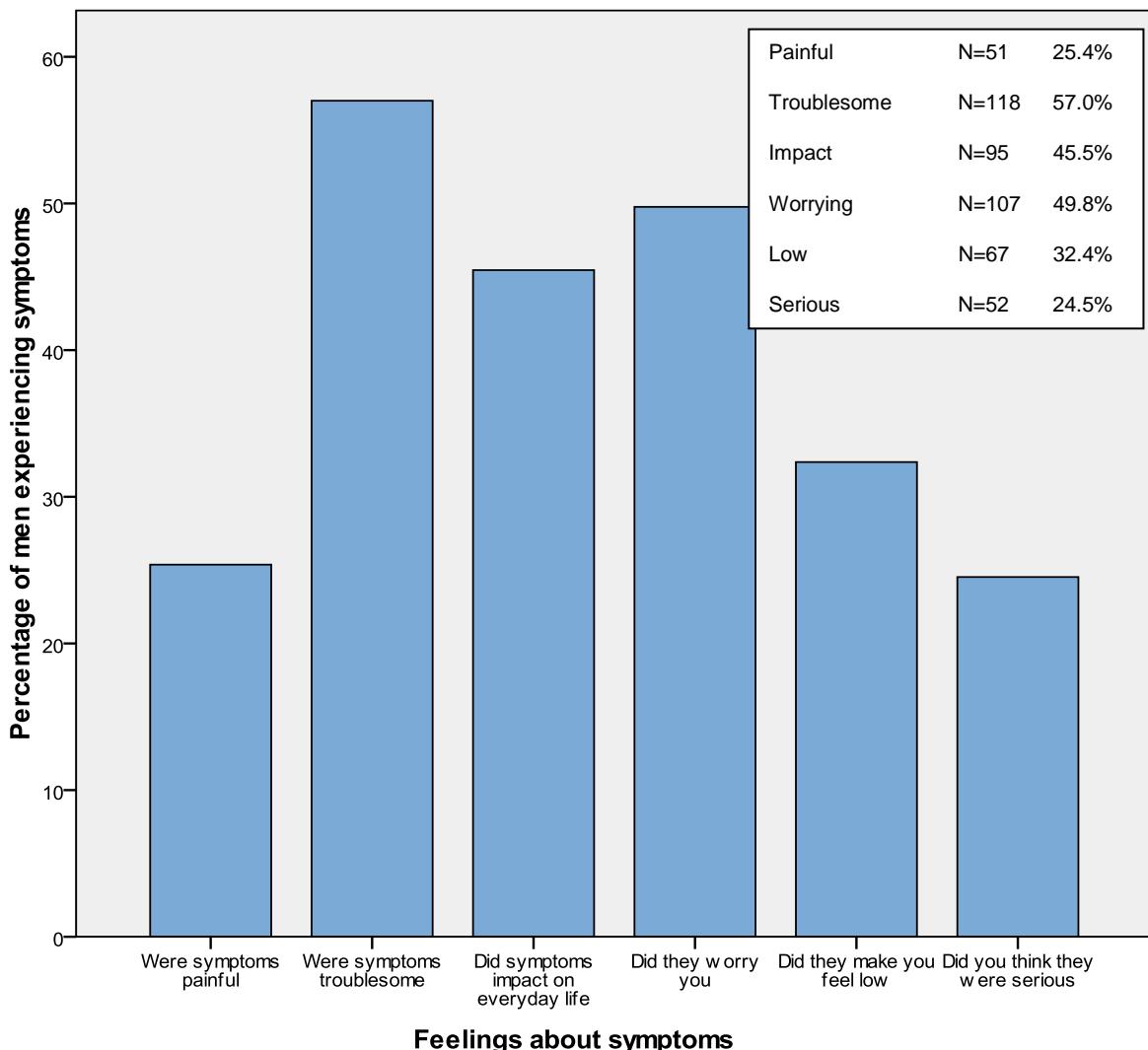
The qualitative data unravelled a number of contradictions in men’s accounts of their symptom experiences in the lead up to diagnosis. One participant, for example, indicated that he was asymptomatic, but that he also experienced blood in his semen. Thus, there is a sense that chronic symptoms (e.g. need to urinate during the night) are considered explicable with reference to age, but that more acute symptoms (no flow; blood in semen) are interpreted as warranting healthcare interventions.

3.2.3 Symptom appraisal

3.2.3.1 Feelings about symptoms and their interpretation

Figure 10 below illustrates men's feeling about their symptoms prior to diagnosis. The chart indicates that the majority of men (57%) found their symptoms were troublesome and that around half (49.8%) were worried by their symptoms. For many men their symptoms had an impact on their daily life (45.5%). One third (32.4%) of men felt depressed as a result of their symptoms and one quarter thought their symptoms were painful (25.4%) or serious (24.5%).

Figure 10: Feelings about symptoms



Men who appraised their symptom(s) as troublesome or having an impact on everyday life were more likely to have experienced symptoms for longer. This difference was statistically significant only for those experiencing symptoms as troublesome (troublesome $p=0.010$; impact $p=0.168$). This may be indicative of the fact that in order for something to be considered troublesome it must be experienced for some time, rather than a fleeting or recent event.

One interviewee reflected on the troublesome nature of their symptoms (nocturia) which prompted them to take action:

P58: My sleep was disturbed, that's what brought me to going to the (GP) surgery...

C58: ...after quite some time.

P58. After quite some time, yeah.

Men who were worried about their symptoms tended to delay less, though this difference was not statistically significant ($p=0.086$). Men who appraised their symptom(s) as serious, were significantly more likely to seek help more quickly than those who did not see their symptoms as serious ($p<0.000$). Despite this more speedy help-seeking, around a third of these men still delayed for over a year.

Figure 11: interpreted symptoms as serious and length of delay

Did man think symptoms were serious?		Length of delay			Total
		Short	Medium	Long	
No	N	11	62	60	133
	%	8.3%	46.6%	45.1%	100.0%
	% within length of delay	44.0%	82.7%	80.0%	76.0%
Yes	N	14	13	15	42
	%	33.3%	31.0%	35.7%	100.0%
	% length of delay	56.0%	17.3%	20.0%	24.0%
Total	N	25	75	75	175
	% of Total	14.3%	42.9%	42.9%	100.0%

A further prompt to seeking healthcare input was when symptoms became too challenging to manage. The following interviewee explains this, reporting that he found his frequent need to urinate was “annoying”:

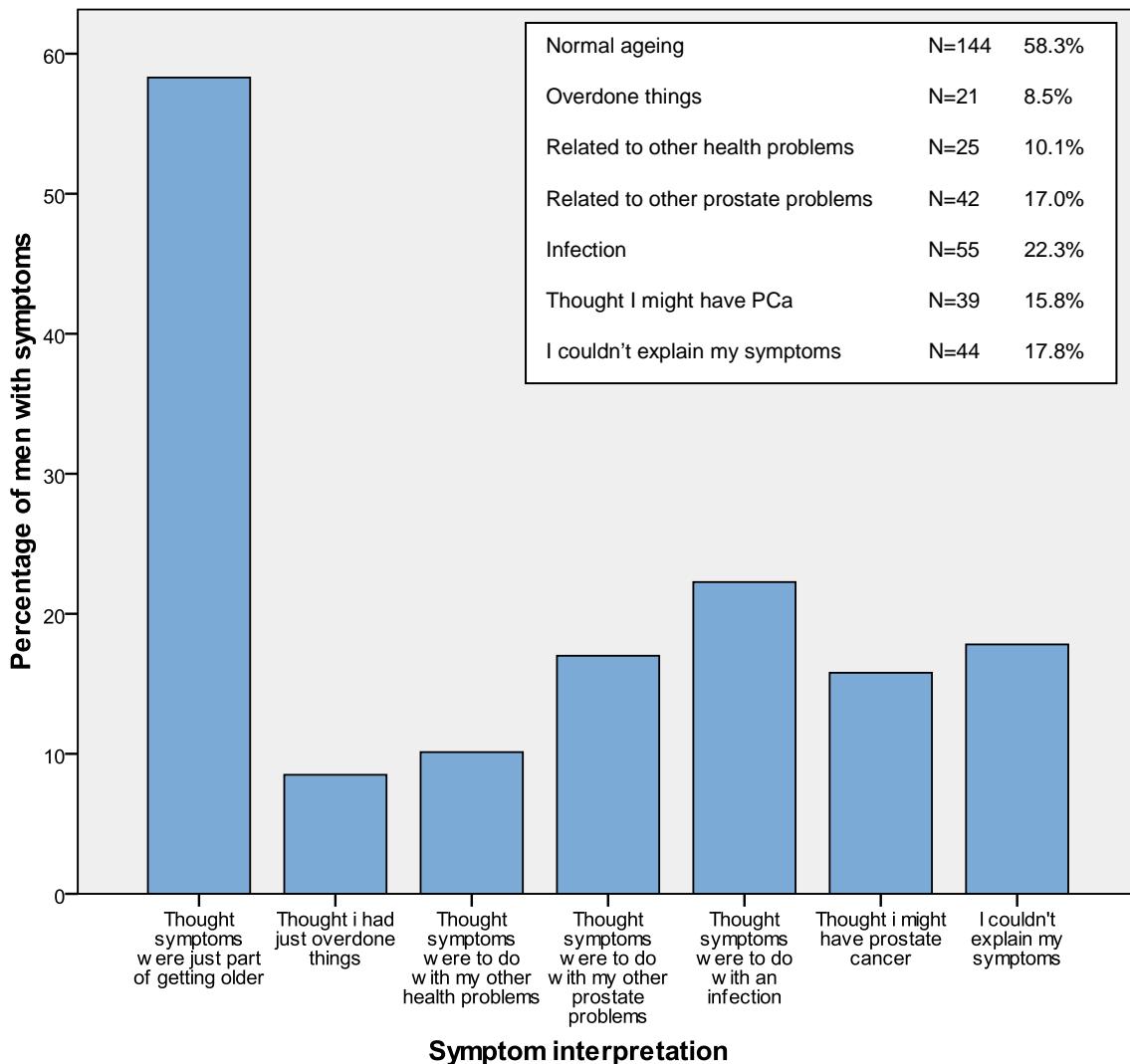
Int: What was it that got too annoying, that you actually did something...?

P1: Peeing...having to pee so often. It just became a, a, an embarrassing nuisance and it was not getting better and I had heard that there were drugs available that would, that could, that could address that, that it wasn't inevitably something insidious ...

3.2.3.2 Symptom interpretation

As figure 12 below indicates, nearly 60% of symptomatic men felt that symptoms were explained with reference to normal ageing.

Figure 12: Explaining symptoms



The qualitative data provides further evidence for the appraisal of symptoms by many men as associated with a normal ageing process rather than indicative of disease:

I didn't look for any other symptoms as I say, er...prostate cancer was furthest from my mind, as I say, I just thought it was er...perhaps a problem with me getting older and...that, I didn't you know, think it was anything major (P27).

This was also true for non-urinary symptoms, such as ejaculation dysfunction:

- P451: *I would say I knew a year before that there was something wrong but I just didn't know what it was*
 Int: *Oh really? What was going through your mind then?*
 P451: *I just, I just put it down to, well maybe it's old age or something like that or is ...*
 Int: *Mmm, what, what had you noticed was different?*
 P451: *Well it's very difficult to tell ... I was still able to sexually perform but there would be no semen coming*
 Int: *Right, okay, and that had been about a year then?*
 P451: *Yeah*

Int: More or less, yeah. So you'd had some worries in your head but ...

P451: Yeah but I just ...

Int: ... you pushed them to the back

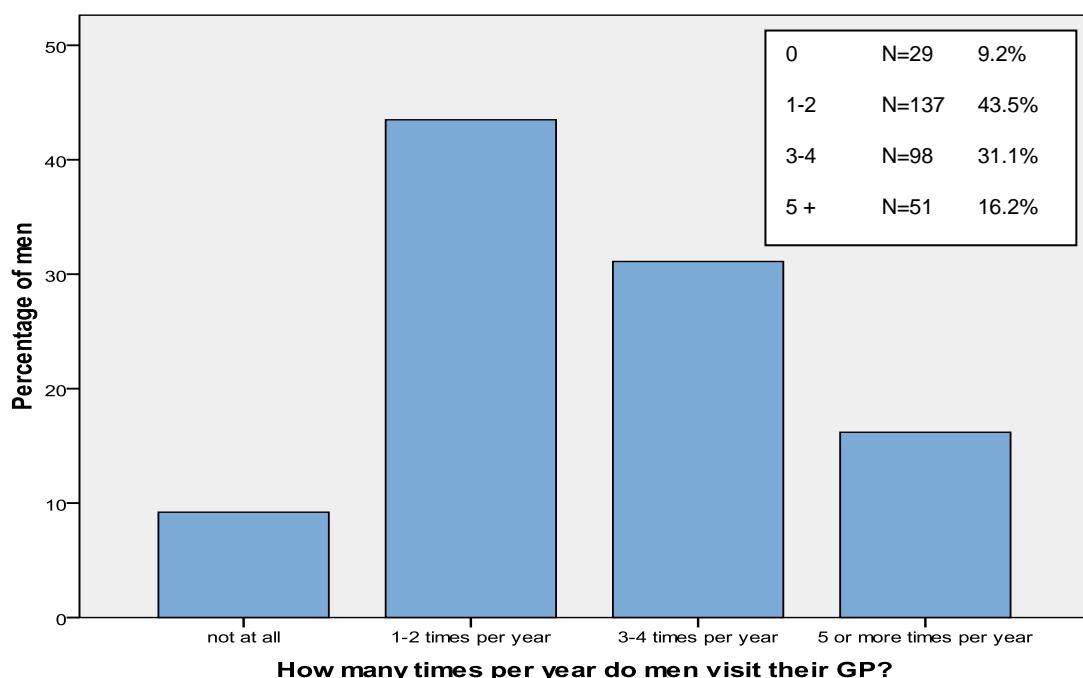
P451: ... put it to it being old age or something

Meanwhile, other men explained their symptoms with reference to other prostate conditions, such as BPH. Unsurprisingly, there was also a highly significant association between those that had confirmed BPH and men assuming their symptoms were to do with their BPH or prostatitis diagnosis rather than PCa ($p<0.000$).

3.3 GP attendance, co-morbid conditions and behavioural delay

As figure 13 indicates, most men visited their GP at least once per year with only 9% not attending at all.

Figure 13: Number of times men report visiting their GP per year



The data was examined to determine if GP attendance (and therefore opportunity to discuss symptoms) was associated with having co-morbid conditions.

Having co-morbid conditions seemed to function as a prompt to more rapid contact with primary care. The following extract from the interview data illustrates how a consultation around ongoing depression triggered a discussion about other concerns, relating to urinary symptoms:

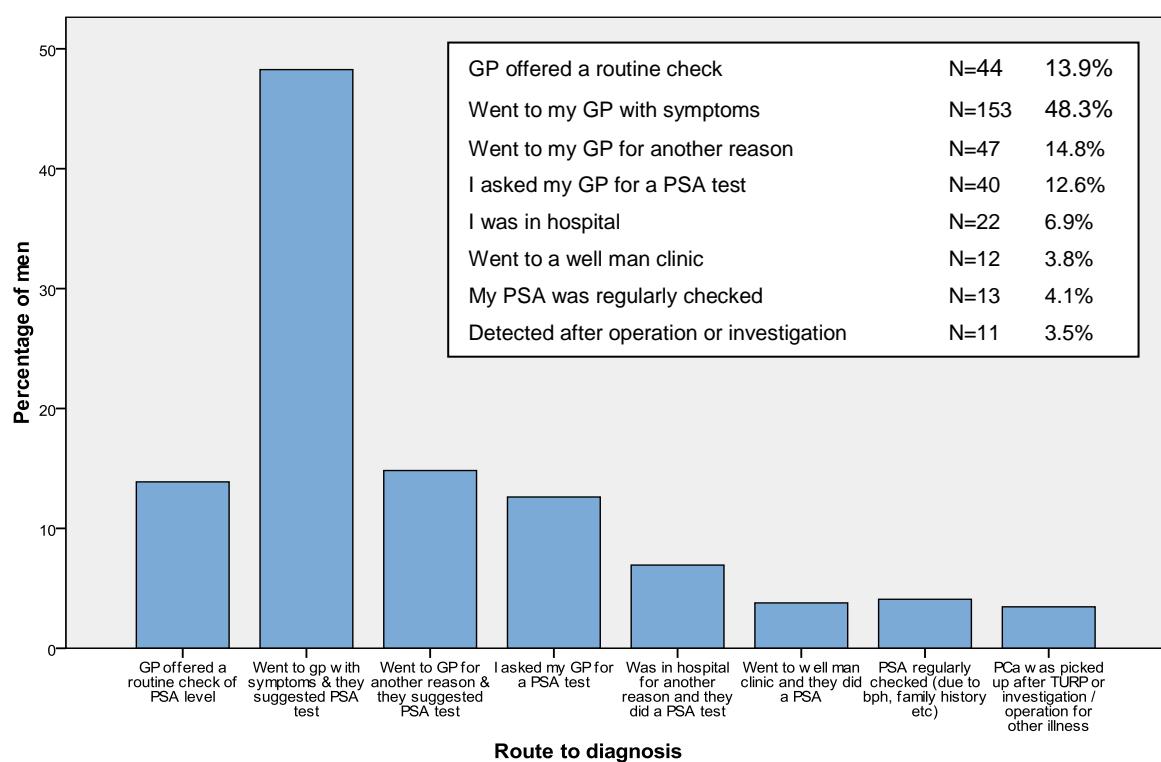
There was sexual dysfunction I thought it was to do with the, with the depression you see and I was taking, was taking some anti-depressants but I, anti-depressants anyway this time last year, and he just said 'Is there anything else?' and I said em 'Well,' I said, 'I've got this problem of going to the loo, pain' (P31).

For most co-morbid conditions, there was no significant difference in length of delay. However, those men who had a history of urinary tract infections (UTIs) did present later ($p=0.004$). This later presentation suggests that men with a history of UTIs are likely to self-diagnose, or be diagnosed in primary care, as having a recurrence. The data confirm this notion, with a significant association between those with a history of UTI, assuming their symptoms were related to infection ($p=0.003$).

3.4 Routes to gaining a diagnosis

The most common route to diagnosis for respondents was presenting to a healthcare professional with symptoms (48.3%).

Figure 14: Routes to diagnosis



Men's routes to diagnosis were analysed with reference to clinical risk, deprivation and age. Men were significantly more likely to receive a high risk diagnosis if they presented to their doctor with symptoms ($p=0.001$) and significantly more likely to receive a low risk diagnosis if they went to their GP for another reason ($p=0.048$). No other routes to diagnosis showed a statistically significant association with clinical risk although there were some strong trends present (see Figure 15). Overall, however, men with symptoms prior to diagnosis were not more likely to have a high risk diagnosis than those who were asymptomatic (34% and 30% respectively; $p=0.559$).

Figure 15: Routes to diagnosis and high/low clinical risk

Route to diagnosis	Low / High risk likelihood	Significance level
Admitted to hospital	More likely to receive <i>high</i> risk diagnosis	p=0.097
Detected after TURP or other investigation	More likely to receive <i>high</i> risk diagnosis	p=0.671
Visited a wellman clinic	More likely to receive <i>low</i> risk diagnosis	p=0.077
PSA regularly checked	More likely to receive <i>low</i> risk diagnosis	p=0.152
Offered routine check	More likely to receive <i>low</i> risk diagnosis	p=0.514

Age was not associated with any other route to diagnosis, and deprivation was not associated with any other route to diagnosis except those who requested a PSA test (see below).

3.4.1 Requesting a PSA test

Forty men (13%) requested a PSA test from their GP. These men who requested a test were significantly more likely to be from the least deprived SIMD category (p=0.005). They were also more likely to have low clinical risk disease (p=0.025), and to be asymptomatic (p<0.00).

Men requesting a PSA test were also significantly more likely to have knowledge of PCa prior to their diagnosis (p<0.00), which is unsurprising since requesting a test presupposes some information about the disease. Men who asked their GP for a PSA test were more likely to perceive themselves at high risk of PCa than those who did not request the test (p=0.013), however, despite this, only 16% of men requesting a PSA test perceived themselves to be at *high* (rather than medium or low) risk.

Those who requested a PSA test were significantly more likely to have a friend who had PCa (p<0.00), and slightly more likely to have a family history of PCa. Having a family history of the disease, however, was not at a statistically significant level (p=0.166).

Several interviewees spoke of how their diagnosis had prompted them to advise friends to request a PSA test. The following excerpt illustrates how many men are informed and educated about prostate cancer and testing through such social networks:

- P14 *People I meet socially as well em, most of them now have had their tests done*
C14: *Because of you?*
Int: *How many men would you say that you've advised?*
P14: *Oh ... certainly double figures, well, well, well into double figures.*
Int: *M-mmm, sort of closer to 50 or closer to 20?*
P14: *Well over 20 but maybe not as much as 50.*

Likewise, men in our sample had been encouraged by friends who had experienced prostate cancer to seek tests from their GP:

I was telling him (friend) about the...the trouble I had with peeing and the embarrassment etc. and he...and he says 'If you don't mind,' he says, 'I've got prostate cancer and it sounds like the start of

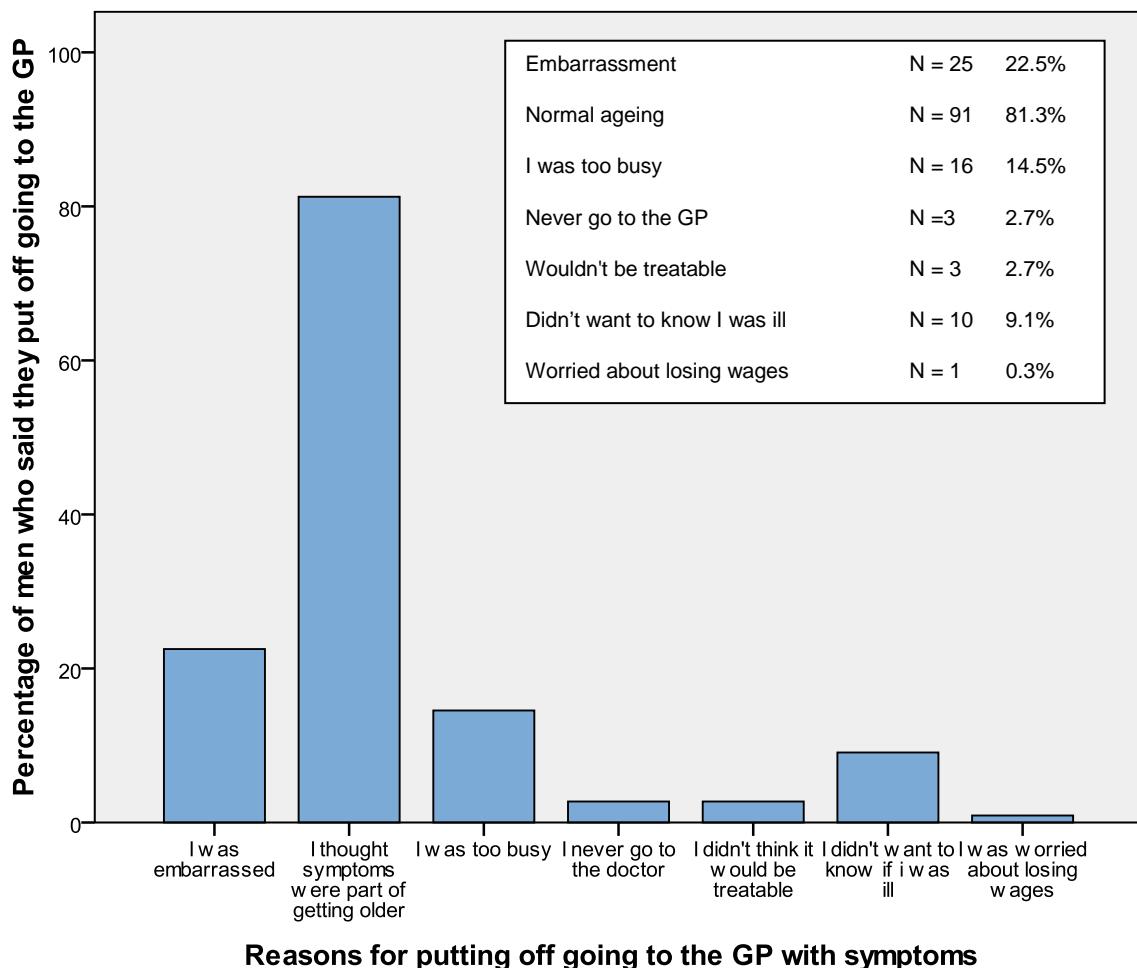
prostate.' He says, 'That's how...' he says, 'I was,' he says, 'Yeah, you're going to toilet then two minutes later you're running back to the toilet,' he said, 'I'd get it checked out.' (P77).

3.4.2 Delays in presenting in primary care

Of those men who had symptoms, 41% reported putting off seeing their GP, and offered a range of reasons for this delay. Fifty-three percent of men who perceived their cancer to have been caught late recorded that they had put off going to their GP with symptoms ($p=0.001$). The vast majority of men (81.3%) who had put off going to their GP with symptoms (e.g. erection difficulties and back, hip, stomach or testicle pain) were more likely to attribute their symptoms to "normal ageing".

Men who thought their symptoms were just part of getting older were significantly more likely to experience symptoms for over one year before seeking help ($p=0.001$).

Figure 16: Reasons for delaying presentation with symptoms



Nine percent of those admitting to having put off seeing their GP with symptoms cited "I didn't want to know if I was ill" as the reason for delay. Embarrassment was another reason given for delaying presentation at a GP with 22.5% giving this reason. Although men were more likely to report

embarrassment when experiencing erectile dysfunction than any other symptom, this was not at the level of statistical significance ($p=0.099$).

One man reported feeling embarrassed by his initial symptoms (and his sense that his symptoms were related to a sexually transmitted infection) and reported that health system delay was a feature of his experience:

(It took) a year for them to finally tell me that there was, that there was a problem...I think there was delay on their part... I feel that this was slow (P224).

Men with blood in their urine or semen did not attribute their symptoms to normal ageing ($p<0.000$). Likewise, the majority of those experiencing pain when urinating did not attribute their symptoms to “normal” ageing although the difference was not statistically significant ($p=0.068$).

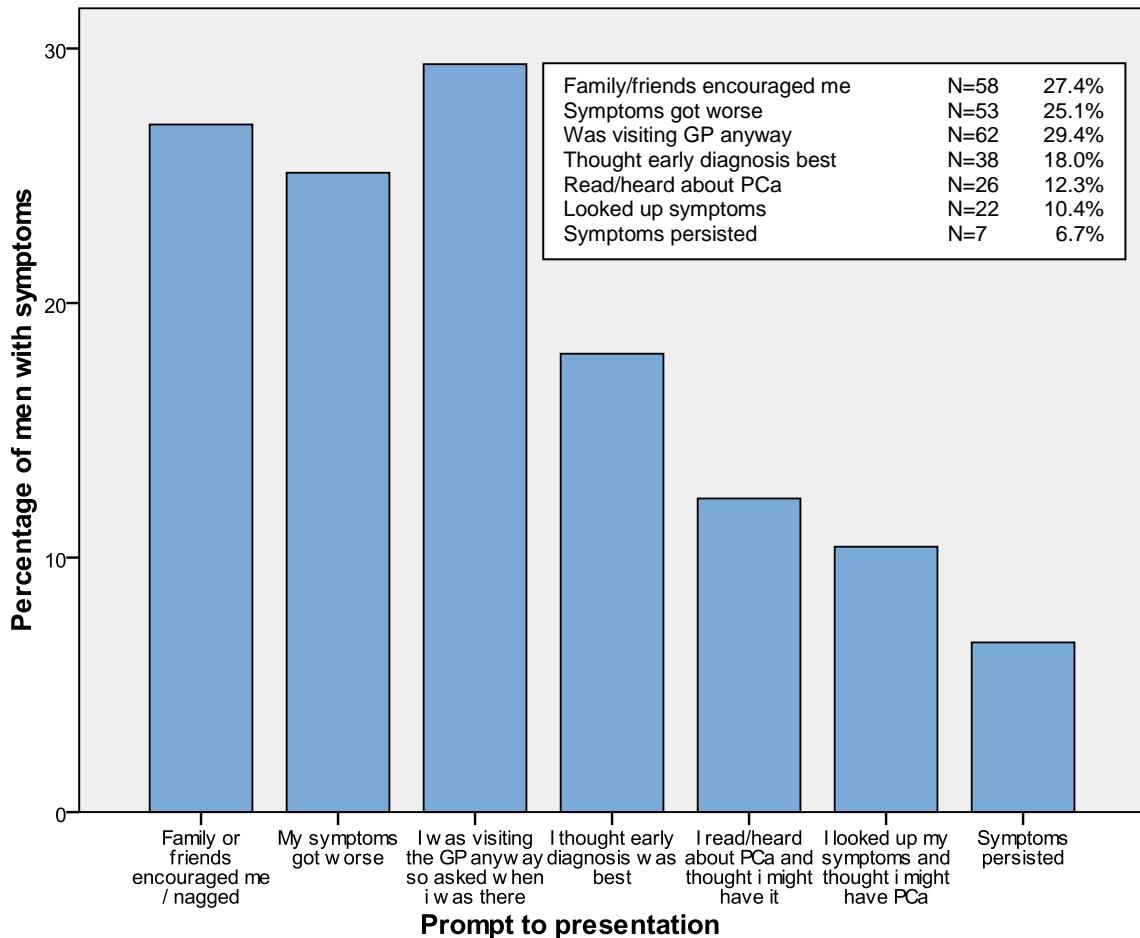
Only 16 men gave the reason that they were too busy to present to their GP with symptoms and none said they could not get an appointment. Of those men who reported being too busy, 61.5% did delay for over one year compared with 50% of those that did not cite being too busy as their reason for delay. This difference was not statistically significant, however ($p=0.723$). Thus, practical factors were not the main barriers to prompt presentation for the men in this sample.

Despite these reasons for putting off seeing the GP, many men offered explanations for why they did present.

3.4.3 Prompts to presenting at the GP

Family and friends were important in prompting men to visit their GP with symptoms with 27% citing this as the reason they attended a doctor. Twenty-nine percent were at the GP anyway and raised concerns when they were there. The high percentage of men raising concerns at another GP appointment may reflect the fact that many respondents (74%) had one or more co-morbid condition, and therefore may have been attending the GP for a different illness. As seen in Section 3.4 (“routes to gaining a diagnosis”), men with multiple co-morbidities were significantly more likely to receive a low-risk diagnosis.

Figure 17: Prompts to presentation



Those who said they were prompted to go to their GP because their symptoms got worse were more likely to have a long delay ($P=0.006$). This may be explained by virtue that in order to describe symptoms as worsening, men would need to have experienced them for some time in order to judge a change in severity. The following excerpt from one of the interviews illustrates this idea:

- Int: So, it lasted for about a year but it sounds like, did it get worse over that time or was it...?*
P77: It was getting steadily worse and worse
Int: Steadily worse, yeah. And that embarrassment must be quite difficult to manage then?
P77: Yeah, you know, people...my wife would say 'Have you peed yourself?' I went, 'No, I've not, no, I've been at the toilet,' you could see the stains, know? And I got to the stage I didn't want to go out. And if you've got a pair of navy blue or dark trousers, you know?

3.4.4 The role of relationships in prompting presentation

Partners were shown to play a significant role in encouraging men to see a GP about symptoms. Twenty-seven percent of men experiencing symptoms felt their friends/relatives were key to them seeking a GP appointment (see Figure 17 in Section 3.4.3 “prompts to presenting at the GP” above). The interview data also highlighted that friends/relatives were instrumental in getting men to the GP

promptly. This is also reflected in the finding that men who were married or who had a partner prior to diagnosis were significantly more likely to have a low-risk diagnosis ($p=0.036$).

The following interview data reports the role of wives in symptom interpretation and prompting men to present at the GP:

- P91: *I didn't notice it (weight loss), my wife noticed it, she commented on it a few times and I'm saying 'Och, you're talking rubbish, no it's ...'*
- Int: *What, what sort of things was she saying?*
- P91: *'You better watch what you're doing, you're eating like a horse here and you're losing weight' or (...) no problem at all, but it never seemed to drop, but it was only, say inside maybe a good 8/9 month anyway, when this weight actually started going down, the trousers were starting to fall off me.*
- Int: *So how, how did you understand that then, the weight loss?*
- P91: *As I say, it wasn't really annoying, or put it that way, it was the wife that actually talking me in to going to see the doctor... and I says 'Okay', just to keep her quiet sort of thing, I says 'Okay, fair enough, I'll go to the doctor's.'*

Many men had discussed their symptoms and worries with partners prior to taking action. Sometimes this had occurred as a consequence of nocturia and night-time pain which had woken their partner:

I think also it did start to create a problem in the sense that I was so restless at night, I said to (wife) 'You know, I'll go and sleep in another bedroom.' (My wife) didn't want me to go and sometimes I did go, simply because I'd have the light on and sit up, you know, or read... I didn't want to disturb her and it, it didn't create a problem in, in our relationship but you know I was trying to sort of... (my wife) wanted me to get something done about this and I was not doing anything about it, and, and so therefore in some respect it did create a little bit of friction (P33).

Some respondents described how conversations with other men had prompted them to seek help:

Probably like most men on my age, you're up through the night on a regular basis and possibly like most men as well you talk about it in the pub, they say 'Oh yeah, I'm the same and just that's what happens when you're 65 or 66.' So you're...you're always reassured that there's nothing particularly wrong with you or you're not unique in the situation you're in. I think my wife was aware that I was spending longer in the toilet as well, when I did get up and her sleep was broken, she was conscious I was away for a longer time (P28).

Importantly and paradoxically, although friends and family had an important role in prompting men to take action in relation to symptoms, *some* men do not discuss their symptoms with others, citing gender stereotypes of men "not talking with each other" as a reason.

Data indicate that the man's number of social contacts was not associated with whether they knew someone with PCa before diagnosis ($p=0.377$). Further, there was no association between risk perception and the number of social contacts ($p=0.251$) reflecting the notion that men often did not routinely speak about risk of prostate, or other cancers, prior to diagnosis.

Many men described keeping symptoms to themselves, often to prevent their partner from worrying, to manage their own embarrassment or because they had not appraised their symptoms as noteworthy:

- P85: *And so...and I didn't even think about telling you, (wife). So...probably just...no, embarrassing myself you know, but, no not so much embarrassed about telling you I just...*
- C85: *It wasn't such a big problem to you either, I mean it was something you...you could live with*

One woman used the interview to share her thoughts for the first time regarding what she felt had driven her husband's reticence at discussing symptoms. The day after she had completed emigration forms for moving abroad, her husband saw the GP about his symptoms:

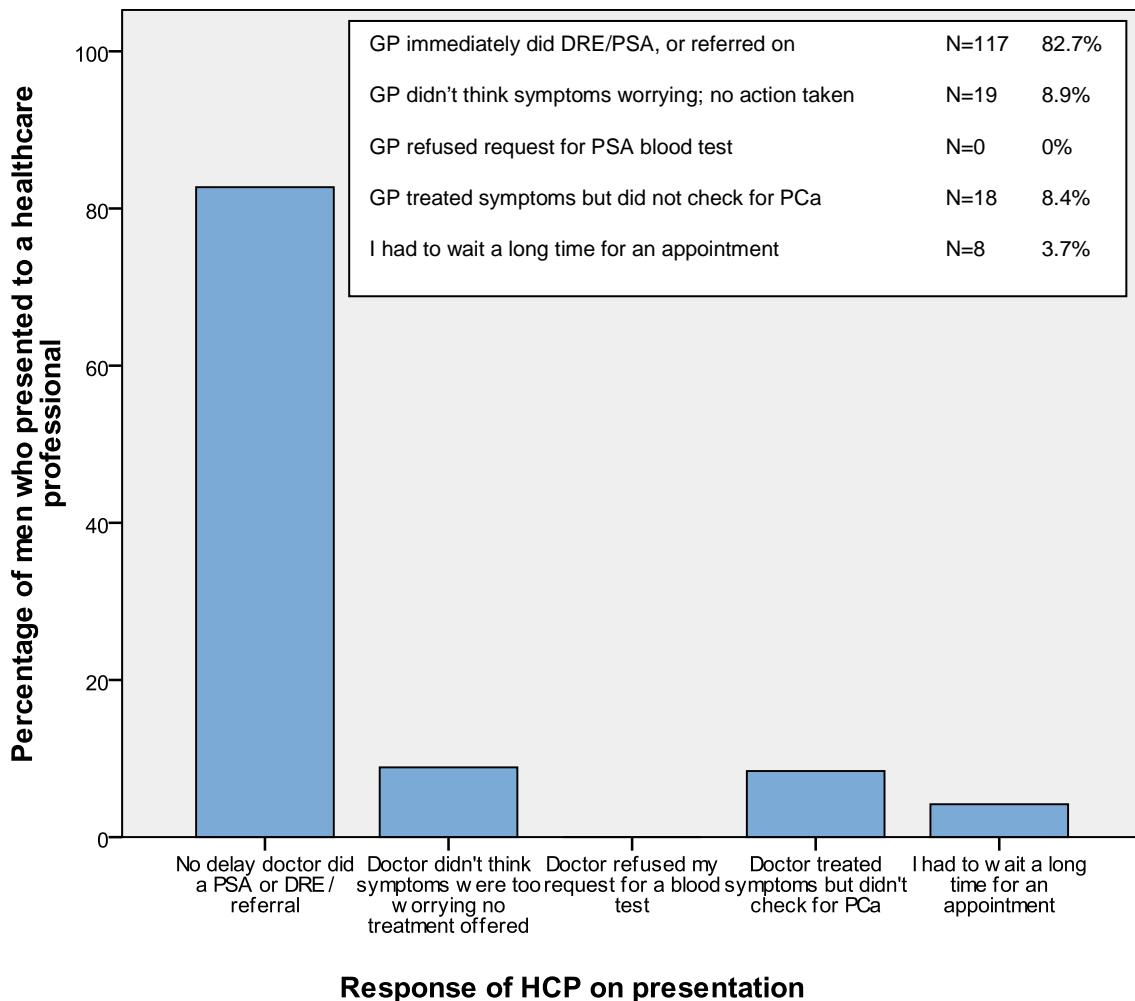
- C202: *(My husband) was wanting to go to the doctor's to see about this (symptoms), but he didn't want to go until he was sure that my (emigration) forms were (sent) away, before he went to the doctor's and was diagnosed... that's what I think, and I think I'd like to share that with you. Now you can ask (my husband) what (he says).*
- P202: *Mm, I knew there was something wrong with me, I knew there was, I knew. Oh aye, aye. I knew there was something quite serious, yeah, yeah.*
- C202: *But you wouldn't...say...mm mm.*
- P202: *Hmm.*
- Int: *Yeah, so you'd admitted that (something was wrong) to yourself that...*
- P202: *Oh uh huh. I knew there was (something wrong), I knew there was, yeah.*

Thus, when friends and partners are aware of worries about prostate cancer they are often key in facilitating swifter access to primary care, but symptoms are not always discussed openly between the couple.

3.4.5 Actions taken by GPs

Often when men had reached the GP, they reported that tests and referrals happened at an appropriate pace, indicating that there were limited scheduling delays experienced. All men who requested a blood test were offered one, and the majority of men presenting with symptoms were examined for prostate conditions by a PSA test or DRE, or promptly referred for these to be conducted elsewhere.

Figure 18: Response of healthcare professional on presentation



One interviewee explained his rationale for asking for a PSA and his GP's response to this request:

I worked for the health board for, all my life and worked in (laboratory) em, and I'm so used to getting tests done em, cause I was involved in their research projects and signing up for research projects so, after I retired I enjoyed life, well I still do, and when I got a leaflet through about bowel cancer where we had to give a, a sample and send it off I thought I think I'll go and get other tests done ... so I went down to the GP and asked to do a range of tests, one of which was the PSA test and because some of my staff in the past a guy found out just by getting it tested that he was, well he'd gone because he had a lump in his groin and he ended up with a very, very, very, very high PSA which came as a shock em, so ... and we had got PSA and the GP was 'Why do you want that?' and you know, not in any, restrictive way or any manner but, I said 'Well, you know, I'm going through all these tests and I think it's time that a man my age gets these tests done', he (the GP) said 'Do you (have) any symptoms?' I said, 'No, not really, I mean I have to get up, do the toilet, but I've been doing that for years' (P14).

Another man reflected on the appropriateness of the actions his doctor took:

By the time I'd actually seen the doctor was when (the) thing started rolling, I won't consider there to be any delay (P91).

Despite the overall positive pattern of action within primary care, some men had experienced GP practices “losing” test results which had caused a delay in referral to secondary care, while others felt as though their symptoms had been misinterpreted, leading to a wrong differential diagnosis. There was a strong association ($p=0.003$) between those that felt their cancer was caught late and those who perceived that their GP had not acted immediately. That is, unsurprisingly, men who did not have a straightforward route through primary care to diagnosis were more likely to perceive their cancer to be caught later than necessary.

Several men illustrated this predicament in the interviews:

I wish the, the PSA measurement which I had three months before had actually been noticed (P15).

- P92: *I explained to him and the first thing he done was a...up the back passage, you know. To feel the prostate and at first he said ‘Aye, your prostate’s enlarged,’ he says, ‘but I don’t think it’s anything to worry about because of your age.’*
- C92: *Well you got tablets.*
- P92: *Aye.*
- C92: *He thought it might have been an infection.*
- P92: *An infection, he gave me...*
- C92: *He gave you antibiotics.*
- P92: *Antibiotics. He says, ‘It’ll...that’ll probably clear it up.’ But obviously it didn’t.*
- Int: *Mm, right and at that point your GP didn’t do a PSA test?*
- P92: *No, no, he just gave me the...(DRE)*

3.4.6 Delays in secondary care

Delay within secondary care, such as scheduling delays for treatments, were reported. The camaraderie that existed in hospitals was remarked upon, and any discussions about delay were explained in terms of the pressure that the unit was under:

- C473: *There was a very friendly bunch of fellows and as they said, ‘We’re all the same boat,’ you know?*
- Int: *Was there any discussion about delays or problems?*
- C473: *I think we decided that this delay was only because the hospital can only take so many people at one time...we kept thinking we would hear and we would hear...I think most of them had you know (waited)....It went from the September until the April.*

Further, the attitudes of professionals were commented on in the interviews, and at times this was linked with the lack of clarity people received about their cancer and how long they had had it. One partner commented on a physician’s communication style:

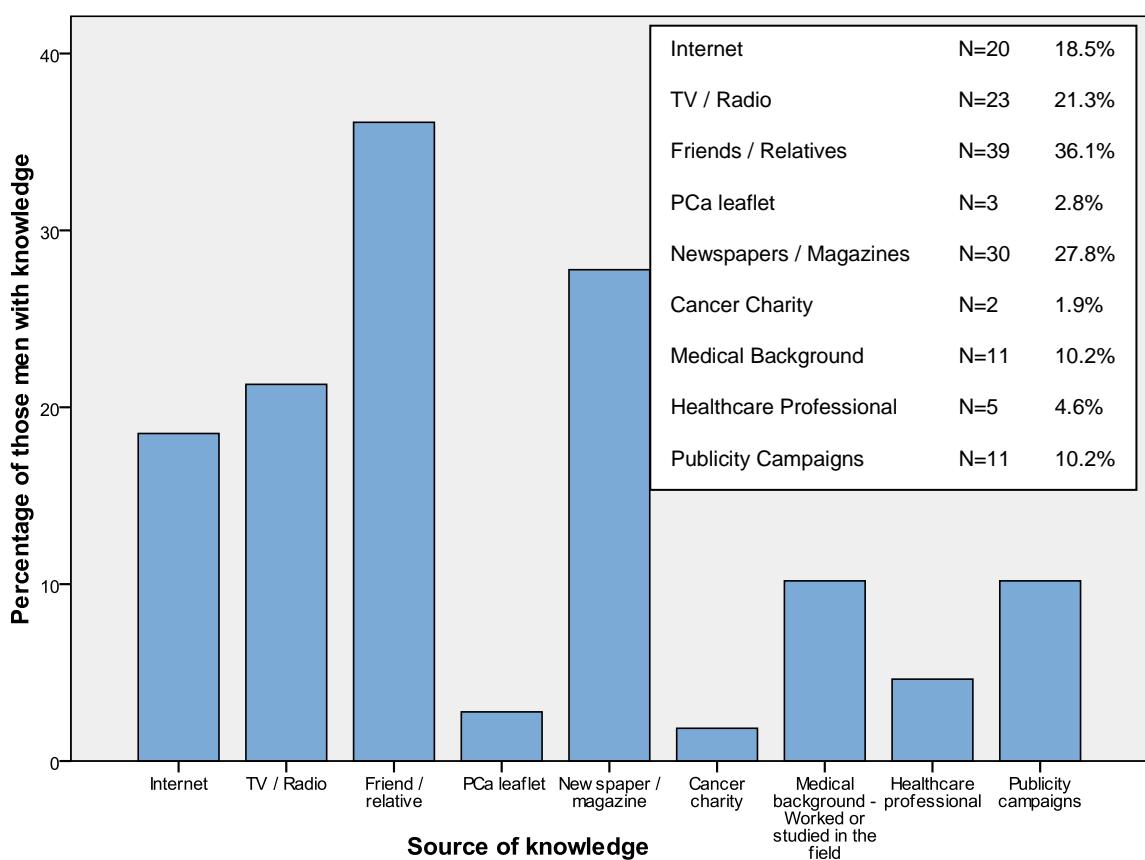
We didn’t really like his attitude. He said, ‘Oh I’ve got no idea how long you have had this, we could do several tests and it’s the last one that will actually show this.’ (C473).

Thus, men are more likely to perceive themselves as having been affected by a delay as a consequence of sub-optimal communication with clinicians.

3.5 Knowledge of prostate cancer

Thirty-six percent of all respondents said that they had some knowledge of PCa prior to their diagnosis, indicating that the majority of men diagnosed with PCa had no knowledge. Figure 19 indicates where men's information came from, demonstrating that very few men consume information from cancer charities (less than 2% of the sample) and a limited number access information over the internet (less than 19%). Information primarily comes from informal channels of personal contacts, such as friends or families (36%).

Figure 19: Sources of knowledge



Men who delayed for over one year were more likely to have knowledge of PCa than those with a short delay period although this difference was not statistically significant ($p=0.202$). This knowledge of prostate cancer may be explained by these men having more time to research symptoms, talk to other people with similar symptoms, and gain other knowledge prior to presentation. Despite there being no significant association between knowledge of PCa and length of delay, interviewees indicated that their lack of knowledge about prostate cancer was a factor in delaying acting on their symptoms, as the following participants articulated:

In hindsight ... I delayed because I didn't know anything about prostate problems, you know. I just assumed that what I had was something that was, that would clear up. And therefore I didn't have to push it with the doctor (P27).

I delayed in so far as I should have gone to the GP and said 'Look, I've got slow flow, you know, I'm dribbling and so on,' and I'm sure he would have then said, 'Well, look, that's classic symptoms of ...you know, something wrong with your prostate, we'll send you up and get it seen to.'... I would need to have more information... make it more obvious to men, 'Look, if you've got this problem, you have to go and get it seen.' To me it (symptom) was just an inconvenience (P85).

Other interviewees made it clear that they had little knowledge of prostate cancer, or its causes, even after diagnosis:

P406: *If I remember right now, I'm not a 100% obviously, but I think they said to me, they felt I've got a tumour in my rear end ... so I just put that down to all sitting on ma arse all day, you know, driving.*

Int: *Uhh uhh. Had you heard of prostate cancer before?*

P406: *No.*

Information consumption from the media took a number of different and at times surprising forms. At interview, one man noted that it was media coverage of a deportation decision that sparked his awareness of prostate cancer:

Int: *You mentioned that you, you didn't know too much about prostate ...*

P451: *No*

Int: *... but you'd seen bits and pieces of information somewhere*

P451: *Well you read about it in the paper or something like that and, for instance, I'll give you one instances of that, the Lockerbie bomber that got prostate...*

Knowledge about prostate cancer was based heavily around the interpretation of urinary symptoms as indicators of disease. The following man articulates his belief that he expected to be diagnosed with prostate cancer because he had experienced incontinence and flow difficulties.

P77: *I was still expecting (to be told I had prostate cancer)...*

Int: *Oh really? On the basis of what exactly?*

P77: *On the basis of what I'd read. And people had been saying...*

Int: *Mm. What was it that you were reading, what had you come across?*

P77: *Well, see these...like you've got the Sunday Times magazines. Or any of these kind of magazines you get in dentists', er, I always read those and was it last year? Marks and Spencer's had a kind of prostate week...And they were giving out pamphlets. And I'm reading, saying to myself, well I did suspect...I've got this, I've got that...you know, how you can say...But especially about the toilet, you know.*

Despite having read about prostate cancer, however, the respondent above describes the catalyst to taking action as being a conversation with a friend who had also experienced prostate cancer. Relationships played a key role in men's pathway to diagnosis.

3.5.1 The role of relationships in knowledge of prostate cancer

Eighty-one percent of the sample knew someone with cancer prior to their diagnosis. Forty-nine percent knew someone with prostate cancer, and 11 percent reported a family history of prostate cancer.

Of those who cited personal contacts as being the source of their knowledge about PCa, 95% were as a consequence of knowing someone who had previously had prostate cancer. Those who had knowledge of PCa prior to diagnosis were also statistically significantly more likely to know someone with PCa prior to diagnosis ($p<0.000$). This suggests, as does the data on sources of knowledge, that many men gain knowledge of the disease from informal channels such as family or friends.

One interviewee stated the following process of linking symptom appraisal to experiential knowledge:

I found I was getting up, starting to get up in the middle of the night, and I have a friend who has had prostate cancer, has had radiotherapy etc., etc., etc., and obviously picking up information from him, or having picked up information, I realised that eventually that 'I've got a problem', went to visit the doctor and I said, 'I think I have a problem peeing' ... and I was referred to the (hospital) (P445).

Another man explained how he had discussed his symptoms with a friend who had had prostate cancer, and that this conversation led to him contact his GP:

Int: Did you talk to anybody about whether you should go to the doctor's?

P224: Yes I did, a, a friend of mine's got it, he had, he had it about two year before me ... aye about two, two and half year before me and he says, 'Listen,' eh ... he says, 'Definitely don't wait,' he says, 'Go to the doctor's,' and I knew he'd, he had cancer of the prostate cause he told me all the symptoms and everything, I had pains in my back ... he says, 'Well, that's your, that's your, the beginning, beginning of it.' (...) I told him about my water works, how I was going to the toilet a lot you know, stopping and starting. Then that's when he says to me, 'cause he had already had it and he'd told me, he says, 'What you will do is you will get your (...) get blood taken, he'll try your PSA.'

Men without experiential knowledge of prostate cancer (that is, not having a friend/family member with the disease) often did not interpret symptoms as worrying, as the following quotation illustrates:

I just thought it was one ...one of the things that I was bothered with, I wasn't going to...you know, I didn't think of asking anybody about...prostate problems because really I had no history of it in the family. And I didn't think there was any thing there (P27).

Conversely, those with family/experiential knowledge of prostate cancer found their symptoms worrying, as the following man indicates having previously mentioned a close friend who had been diagnosed with PCa:

I feared that I knew the answer em, but em, I went, I went fairly promptly (P1).

The interview data clearly demonstrate, however, that post-diagnosis many men discover a wide network of others who have had the condition and encourage others to seek tests for themselves. Thus experiential knowledge of prostate cancer spreads through family and friendship networks after one person's diagnosis:

We tell people and (my husband) tells people that he's got it, you know and a lot of people prefer not to say things like this but I think (my husband)'s very frank about it and, and you know we don't want sympathy we want ... but it certainly makes it easier for people to talk to you afterwards about their own experience (C15).

Several interviewees spoke of how their diagnosis had prompted them to advise friends to request a PSA test. The following excerpt illustrates how many men are informed and educated about prostate cancer and testing through such social networks:

Now that I'm aware of it, if I get the opportunity to bring the subject up or I'm involved in it, I will advise any young man to go (P163).

3.6 Perceptions of risk

Men reported that prior to their diagnosis they largely considered themselves to be at low risk of prostate cancer. Only 21 respondents considered themselves to be at high/fairly high risk of PCa; of these, 40% felt they were at high risk of both prostate and other cancers, while the remaining 60% reported being at high risk only of prostate cancer. Thus, some men discriminated between their risk of *any* cancer compared with prostate cancer; this difference was statistically significant ($p<0.000$).

Figure 20: Perceived risk of prostate cancer

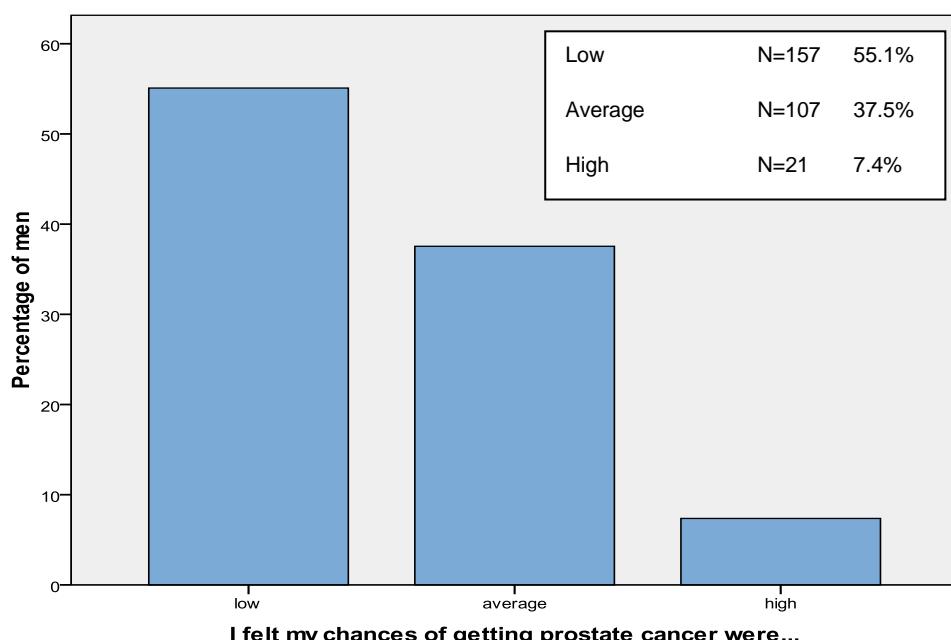
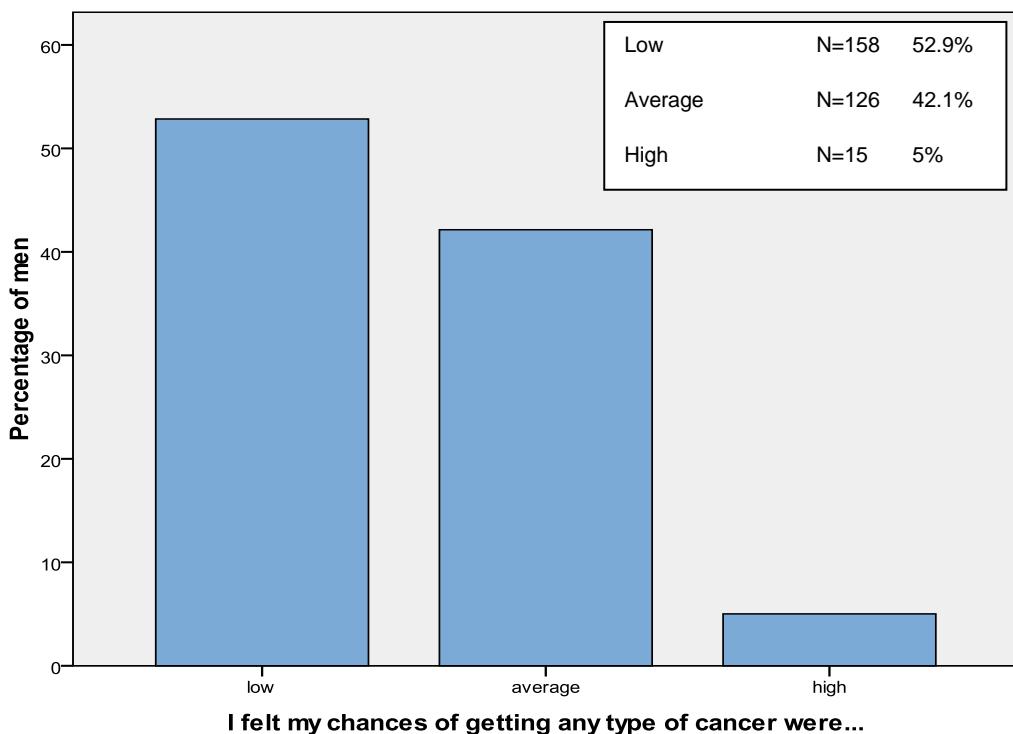


Figure 21: Perceived risk of any type of cancer



Despite falling into a risk age category for prostate cancer (respondents' mean age: 68.5), only a small percentage of survey respondents reported feeling at risk of developing the disease and there was no association between age and risk perception. Men in the older age categories were no more likely to perceive themselves as at high risk of PCa than younger men ($p=0.286$). Again, this suggests that on the whole, men are unaware of the risk factors of PCa.

Eleven percent of respondents had a family history of PCa. Men with a family history of PCa were slightly more likely to perceive themselves as at risk of PCa, however, this difference was not statistically significant ($p=0.294$). This indicates that this clinical risk factor was not integrated into men's perceptions of their overall risk in most cases.

Those who knew someone with PCa (N=152), however, were significantly more likely to perceive themselves to also be at risk of the disease ($p=0.002$). In addition, men who perceived their symptoms to be serious, were significantly more likely to feel at high risk of getting prostate cancer ($p=0.001$).

4 Limitations

The study identified significantly longer appraisal and behavioural delay (that is the duration between noticing symptoms which men found worrying and seeking healthcare) than previous Scottish studies. However, measuring delay is an inherently complex task. This study adopted a psycho-social definition based on the notion of the time elapsed from noticing first symptoms to the time of gaining a diagnosis. Thus, delay is a continuum rather than absolute. Men were asked "how long did you have symptoms before you were tested?" This was intended to refer to initial PSA/DRE tests; however, some men may have been tested several times before a cancer diagnosis was made. Consequently, responses to this question of delay may have included both patient and primary care dimensions.

Comparing findings with other studies on delay in prostate cancer diagnosis are complicated by different measures of delay. Baughan et al. (2009), for example, gathered data on GPs' analysis of clinical notes of consultations. Men's reports of symptoms may have been tailored to that healthcare context, making it perhaps less likely that they would report a delay of two years (as data from this study identified).

Despite these limitations in defining delay, the link between symptoms and prostate cancer does not have high clinical salience, even though many men link the presence of symptoms with malignant disease.

5 Discussion

Once men had engaged with their GP, they were on the whole referred quickly to secondary care for further investigations. Consequently men considered there to be minimal health service delays in their diagnosis. Recent evidence from the National Awareness and Early Diagnosis Initiative (NAEDI, operating through the National Cancer research Network) has identified that 9% of diagnoses of prostate cancer are made through emergency admissions, and 38% through routine GP referral. Further, 20% were referred by GPs as urgent, that is, with a strong suspicion of cancer (National Cancer Intelligence Network, 2010). Findings from this survey of the prostate cancer patient population of Glasgow in 2008/9 indicate that 82.7% of men were tested using PSA/DRE in primary care (or referred elsewhere for these tests). The data also indicate that 6.9% were diagnosed via the hospital route and a further 3.5% were picked up after TURP or investigation for another disease (for example, bladder cancer). Thus, the patterns of action within Greater Glasgow compare favourably with the pattern reported by NAEDI.

Men's experiences pre-diagnosis are characterised by noticing urinary and erectile symptoms and explaining these with reference to normative ageing. Indeed, clinically this is an appropriate appraisal, since such symptoms have high incidence in this age group and are not considered indicative of prostate cancer. Nevertheless, men's understandings of prostate cancer are frequently related only to these marginal symptoms, and not to defined clinical risk factors.

Thus, following Fitzpatrick et al. (2009; 1998) this study confirmed that men in the community have limited knowledge of PCa. Where men do display knowledge of the condition (and reflect on their individual risk), this tends to be linked with urinary symptoms rather than clinical risk indicators such

as age and family history. As Andriole (2010) indicates, such clinical risk factors rather than urinary symptoms, should act as triggers to testing for prostate cancer.

The findings indicate that knowledge, and subsequent risk perceptions, are primarily informed by personal contacts, such as friends/or families who provide support and advice, which results in men being tested for PCa. Such experiential knowledge plays a key role in encouraging symptomatic *and* asymptomatic men to present at the GP for prostate cancer tests. The influence of interpersonal relationships on risk perception, symptom interpretation and help-seeking behaviour has significant implications for health promotion messages. Since health messages have led to the currently low levels of disease information, relational systems can be exploited to increase awareness in groups who have the highest clinical risk of the disease.

There are implications for clinicians from these data; if a man and his partner are seen to be given significant news, and they may feel that delay has occurred then they are more likely to require extra support and time to become accustomed to this situation. This is an implication for all services dealing with newly diagnosed cancer patients, but may have special relevance for men whose trajectory towards a diagnosis with prostate cancer has been problematic, or considered delayed, in some way.

The data indicate that health services for men with prostate cancer should be shaped by the features of their lifestyles as well as the locality. A number of issues need attention across the cancer trajectory, some of which are specific to Glasgow but many are more generic and apply to all men facing prostate cancer. Improving the number of men being diagnosed with earlier stages of prostate cancer in the future will require a review of all stages of the journey from initial symptom recognition to recovery or supportive care. This study offers a number of suggestions for how to move towards achieving this goal.

6 Recommendations

The primary delay in gaining a diagnosis is in understanding the risk factors for developing prostate cancer (age and family history), and second to this are symptom interpretation (appraisal delay) and seeking help (behavioural delay). Thus any planned intervention and future research should focus on these issues.

Knowledge of prostate cancer appears to be low in this at-risk population. To increase men's timely diagnosis of prostate cancer, it is essential that information about risk factors are effectively communicated. Consequently, techniques in improving knowledge and therefore increasing early diagnosis may mean breaking from established health promotion approaches, and building on systemic principles whereby relationships are used to drive communication and information about risk. The findings indicate that men are often prompted to seek tests from primary care following conversations with friends and family about symptoms. While symptoms themselves may be misleading as a signifier of disease, the process by which health-related decision-making is progressed is important.

The data indicate that a viable intervention would be one which draws from informal networks, such as golf clubs, bowls clubs and family relationships, to encourage PSA testing where there are clinical risk factors.

Men diagnosed through PSA testing made through Well Man clinics was associated with low clinical risk diagnoses. Follow-up of this cohort of men is warranted to identify if such testing is likely to prolong life, or (as with population-based screening) identify those who are unlikely to have prostate cancer as disease-specific mortality. Additionally, consideration could be given to the marketing and uptake of testing through Well Man clinics to target those at highest risk.

Further, given the high prevalence of co-morbid conditions in men in the high-risk age group, there is an opportunity to explore how this may provide a direct route to targeted health promotion. Clinics providing regular monitoring checks and pharmaceutical companies printing drug information leaflets could offer rapid and specific access to this high-risk group.

Conversely, for those men without co-morbid conditions who rarely access a GP, but who experience worrying urinary symptoms, there is a need for services that provide rapid-access information in a clear and reassuring manner to men and their partners. For those who are already diagnosed there is also a need to ensure that information flows effectively and that support is available outside of the limited time available in clinic consultations.

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