

**Men's experiences of prostate enlargement and lower
urinary tract symptoms: What is 'bother'?**

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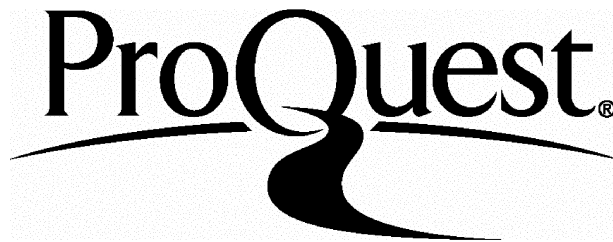
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ABSTRACT

This study aimed to explore men's experiences of having lower urinary tract symptoms and/or an enlarged prostate. Of particular interest was understanding the concept of 'bother', because treatment decisions are generally made on the basis of how 'bothered' an individual is by his symptoms, rather than on any objective measures of symptomatology.

The study was phenomenological and descriptive in nature, using repertory grid methodology and interpretative phenomenological analysis. Participants were a random sample of sixteen men aged over fifty, who had been referred to an outpatient urology clinic with lower urinary tract symptoms. The men were interviewed and completed a repertory grid either before or after their initial appointment at the clinic, before they received any results.

The results are presented separately for the repertory grids and for the interpretative phenomenological analysis and two illustrative case examples are provided. A lot of the findings from this study are consistent with the public perception of male stereotypes and how men cope with health related issues and life events in general. In terms of psychological well-being, the overall picture that emerges is a positive one. The men in this study reported low levels of bother, anxiety and depression and minimal impact on their current sense of self. The findings also suggest that 'bother' might be related to issues around ageing, shame/social embarrassment, effect on sexual relationships and worries about future health problems (e.g. cancer).

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CHAPTER ONE

INTRODUCTION

The prostate is the organ most frequently affected by disease in men over the age of 60 and prostate disease is even more widespread than heart disease or cancer (Ragg, 1993). An estimated 70% of men between the ages of sixty and seventy years have some degree of enlargement of the prostate (BPH) and/or experience the lower urinary tract symptoms (LUTS) commonly associated with an enlarged prostate (Garraway et al, 1991; Donovan 1994). Appropriately managed, an enlarged prostate and/or lower urinary tract symptoms are not life-threatening, but the symptoms can cause anxiety for those affected (Kirby, 1996) and present major cost implications for health services (Holtgrewe, 1996).

Epidemiological evidence suggests that men are affected to varying degrees by their symptoms: some men present to GPs with mild symptoms, whilst others seek no medical help for severe conditions (McIntosh et al, 1994). Quality of life studies (e.g. Donovan et al, 1997) have examined the impact of lower urinary tract symptoms on daily functioning, but to date no studies have explored the emotional meaning attached to these experiences. This is a descriptive study, employing repertory grid technique (Kelly, 1955) and interpretative phenomenological analysis (Smith, 1995). The aim is to explore men's experiences of having lower urinary tract symptoms and the meaning they attach to those experiences.

Chapter One: Introduction

This chapter begins with an explanation of medical terms. This is followed by a discussion about the implications of prostate disease, current treatment options and how decisions are made about treatment. The focus then shifts to the psychological literature that has potential relevance to understanding men's experiences. Finally, the methodology is introduced and the study's aims are summarised.

Definitions

The prostate is a small accessory sex gland that sits in the pelvis at the base of the bladder. The urethra, the tube that carries urine out from the bladder, runs through the centre of the prostate. Whilst it is not totally clear what the prostate actually does (Ragg, 1993), its main role appears to be keeping sperm and urine separate, as both travel down the urethra at different times. Muscles in the prostate act as sphincters to stop urine flowing during ejaculation and to stop semen flowing backwards into the bladder (retrograde ejaculation). In addition, the prostate makes and stores fluid that become part of the semen. The prostate has an inner and outer part and each part can be affected by different diseases (Ragg, 1993). The inner part is susceptible to Benign Prostatic Hyperplasia (a non-cancerous enlargement of the prostate), while the outer part is more likely affected by cancer.

Benign Prostatic Hyperplasia (BPH) is a slowly progressive enlargement of the prostate that occurs in most men over 55 (Wasson et al, 1995). It becomes a cause of concern when the enlargement obstructs the flow of urine, leading to difficulties in urination and, in severe cases, to acute urine retention. The

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symptoms associated with prostate enlargement are commonly referred to as LUTS (lower urinary tract symptoms, Abrahms, 1994). The types of LUTS men experience fall into two categories: “irritative” symptoms (i.e. frequency; urgency and nocturia) and “obstructive” symptoms (i.e. hesitancy; weak stream; incomplete emptying). Most men will experience only some of the symptoms and some men report no lower urinary tract symptoms at all.

The terms BPH, LUTS and enlarged prostate will be used interchangeably in this study, reflecting the debate in the literature as to an appropriate term (Abrahms, 1994). LUTS is increasingly becoming the preferred term, as it encompasses those men who have the irritative and/or obstructive symptoms, but do not have an enlarged prostate.

Prevalence

Throughout the world the incidence of BPH increases with increasing age (Kaplan, 1996). Large community studies suggest a prevalence of 10% in 40 year olds and almost 90% at the age of 80 (Garraway et al, 1991). Autopsy/post-mortem studies show that about 70% of men aged over 70 have histological evidence of BPH (Donovan, 1994). These figures are similar in many different countries, although some ethnic groups have been found to have a lower incidence (e.g. men of oriental origin living in their native country) (Ragg, 1993).

The most dramatic rise in incidence would appear to occur between the age of 50-60 years and three times as many men in the 60-69 age group have been found to suffer from BPH as those in the 40-49 age group (Garraway et al, 1991).

Implications of LUTS

For the Individual

BPH is rarely, if ever, life-threatening, but is nonetheless a major source of disruption and anxiety to millions of men beyond middle-age (Kirby, 1996). An enlarged prostate can cause embarrassment, inconvenience and discomfort. For example, having to stand at the urinal for several minutes waiting for the urine to flow, having to get up in the night to use the toilet, or having a sudden urge to urinate, but being unable to get to the toilet in time (Ragg, 1993).

Furthermore, various studies suggest that some aspects of daily life are considerably affected by LUTS (e.g. Doll et al, 1993; Donovan et al, 1997). Quality of life is defined as the patient's self-evaluation of their condition and its impact on their functional status and well-being (Schipper et al, 1990). Severe symptoms of BPH have been found to have a substantial adverse effect on quality of life (Doll et al, 1993), with the most frequently affected areas being sex life, social life and holidays.

In the long term, prostate disease, if left unchecked for too long, can cause kidney disease, urinary tract infections and damage to the bladder (Ragg, 1993).

Costs to Health Services

The health care costs of BPH are considerable. In 1990 alone, over £96 million was spent in England on surgery for BPH (Holtgrewe, 1994). With the combined effects of an ageing male population, improvements in education about prostate disease and increased demands for less invasive treatments it has been predicted

that there will be a dramatic increase in BPH expenditure (Kirby, 1996). In the context of a health care system where various medical specialities compete for their chunk of the budget, there is increased demand to justify expenditure on a disease that, if properly monitored, is non-lethal.

Current Treatment

Men presenting with lower urinary tract symptoms and/or an enlarged prostate usually undergo initial investigations to rule out prostate cancer. These investigations include the prostate specific antigen blood test (PSA), a digital rectal examination and recording of irritative and obstructive symptoms. Some men do not present with symptoms but, on presenting to a well-informed doctor for other reasons, may be offered the investigations and an enlarged prostate (with no obvious symptoms) may be detected.

For advanced disease surgery is considered mandatory (Wasson et al, 1995). For those with mild or moderate symptoms the options include “watchful waiting”, medical and surgical interventions. Many doctors initially recommend “watchful waiting” for men with mild and moderate symptoms (Kirby, 1996). ‘Watchful waiting’ usually means 6-monthly or annual check-ups, although some GPs and specialists combine this with advice on behavioural techniques, such as relaxed voiding and avoidance of coffee or alcohol (Wasson et al, 1995).

Traditionally BPH has been regarded as a disease best managed by surgery, in the form of Transurethral Resection of the Prostate (TURP). This is an operation, usually performed under epidural, involving surgical removal of the inner portion

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of the prostate by inserting an electrically heated wire loop into the penis and up the urethra, to cut away the core of the prostate. Symptomatic relief following TURP is generally maintained for at least 15 years, although there can often be complications. For example, retrograde ejaculation and associated infertility (66-75% of patients); Urinary Tract Infections (5-10% of patients); impotence (4-10% of patients); temporary incontinence (2%); total incontinence (1%) and, in the worst cases, the operation can lead to death (Thorpe et al, 1994). For about 10% of TURP patients a repeat operation is required within 10 years (Thorpe et al, 1994).

Barry et al (1988) and Fowler et al (1988) found that for those patients undergoing surgery for mild and moderate symptoms, there were no statistically significant beneficial effects of surgery on quality of life. One potential reason for this is that surgical interventions are aimed at relieving obstruction, whereas most men cite irritative symptoms (frequency, urgency or nocturia) as having a greater impact on their quality of life than obstructive symptoms (hesitancy; weak stream; incomplete emptying) (Dept of Veteran Affairs, 1993). Irritative symptoms do not respond well to surgical treatment, yet decisions to undergo surgery are often made on the basis of patients' subjective reports of such symptoms (Donovan et al, 1996).

Increasingly, specialists are turning to medical treatments in the form of anti-antigen drug therapy (e.g. 5 alpha-reductase inhibitors) as first line treatment for men with symptoms of BPH (Holtgrewe, 1996). Drug therapy is appealing because it is less invasive and more cost effective than surgery (Holtgrewe,

1996). The drawback, however, is that patients who are severely symptomatic are unlikely to benefit and many patients with mild to moderate symptoms will ultimately be treated with TURP (Holtgrewe, 1996). The end result is that many men who are initially treated with drugs eventually undergo surgery, resulting in a “cascade” of treatments at an increasing cost to the health service (Holtgrewe, 1996).

‘Bother’

There is widespread variation in the type of treatment offered to men with BPH (Emberton et al, 1995). As previously mentioned, in the case of advanced disease, surgical treatment is considered mandatory (Wasson et al, 1995). For the vast majority of men, however, their symptoms are mild or moderate and the recommendation in the literature is that treatment decisions should be based on how ‘bothered’ each individual is by his urinary difficulties, rather than on the symptoms per se (Dept of Veteran Affairs, 1993).

The problem with determining treatment decisions on the basis of ‘bother’ is that there does not appear to be a link between degree of bother and any objective clinical measure of symptomatology (e.g. size of obstruction; rate of flow) (Simpson et al, 1996). Nevertheless, how bothered a person is by his symptoms appears to have a strong correlation with how much he will benefit from surgery.

For example, Wasson et al (1995) conducted a study with 556 men exhibiting moderate symptoms, who were randomly assigned to either surgery (TURP) or watchful waiting. Surgery was carried out two weeks after randomisation.

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'Bother' and symptomatology were measured at baseline, 6-8 weeks after randomisation and twice a year for three years thereafter. Those who were most bothered at baseline benefited most from surgery (91%), compared with 62% of those who were less bothered. In the men assigned to watchful waiting, 31% who were most bothered at baseline ultimately went on to have surgery, compared with 16% of those who were less bothered.

The results of the Wasson et al (1995) study suggest that psychological factors may play an important role in determining outcome. 'Bother' appears to be a psychological construct, which suggests that psychological interventions to reduce bother may be a helpful alternative treatment for some men with mild or moderate symptoms.

However, despite being an important construct for urologists, 'bother' does not appear to have been operationalised in any of the literature. In some cases patients are simply asked how bothered they are, at other times bother is measured using a questionnaire (e.g. Dept of Veteran Affairs, 1993). Some researchers refer to 'bother' and quality of life interchangeably, which adds to the confusion about what is being measured. For example, in the Wasson et al (1995) study, the authors state that they are measuring quality of life using a 100-point scale. They then state that "a typical question about the bother or urinary difficulties was: in the past month, how much has concern about being too far away from a bathroom been a problem for you?" (Wasson et al, 1995).

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A further example is the ICS-male questionnaire (Donovan et al, 1996). Peters et al (1997) initially describe the ICS-male as a questionnaire “to measure the prevalence and severity of lower urinary tract symptoms and their effects on quality of life”. They then state that “each question concerning occurrence is followed immediately by one regarding the degree of bother that the symptom causes (e.g. does urine leak before you can get to the toilet? ...How much of a problem is this for you?).

Donovan et al (1997) appear to suggest that quality of life and ‘bother’ are, in fact, different. This is evidenced by the fact that research groups appear to have split in to two camps: “some groups have examined the ‘bothersomeness’ of symptoms...and some groups have sought to devise single sets of questions to address effects on quality of life” (Donovan et al, 1997). The current study takes the stance that quality of life and ‘bother’ are indeed concerned with two different sets of experiences: quality of life is related to functional limitations and ‘bother’ is concerned with an individual’s emotional response.

The most well validated and widely used questionnaire for assessing ‘bother’ is the American Urological Association Symptom Index for Benign Prostatic Hyperplasia (Barry et al, 1992). However, even this questionnaire, otherwise referred to as the International Prostate Symptom Score Index (I-PSS), is used differently by different researchers. For example, Emberton et al (1995) included supplementary questions to each component of the AUA symptom index to address degree of bother associated with each symptom. Furthermore, the AUA symptom index, as it is reported in the original literature, appears to be slightly

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different to that currently used. Barry et al (1992) stated that the final index comprised 7 symptom-related items and 2 items measuring 'global bother' (i.e. 'overall, how bothersome has any trouble with urination been during the last month?' and 'if you were to spend the rest of your life with your urinary condition the way it is now, how would you feel about that?'). The questionnaire, as it is currently used, appears to include only the second bother question and to have dropped the first.

In summary, what the literature suggests is that 'bother' is influential in determining treatment options and outcome. Ultimately, however, if we look at what it is and how it is measured, it would seem the meaning of 'bother' has yet to be fully understood and defined. It could be argued that bother differs from quality of life, because the former relates to an emotional response, whereas the latter relates to functional limitations. The term 'bother' implies that it relates to how people respond to what is going on in their life. Bother might be related to:

- 1) The social embarrassment/shame associated with frequent use of the toilet (Ragg, 1993);
- 2) Worry/anxiety (Roberts et al, 1994);
- 3) The tiredness and associated inconvenience related to disturbed sleep (Calais Da Silva et al, 1997);
- 4) Effect on intimate and sexual relationships (Doll et al, 1993);
- 5) Worries about aging and one's ability to adapt to a different life stage when confronted with a disease most often associated with 'old age' (Kaplan, 1996).

Beginning to Understand 'Bother'

If we can understand the nature of bother the implication is that, for some people, help may be given in the form of advice and reassurance. This might include psychological approaches, such as cognitive therapy, to help people manage their anxiety. Alternatively, clear advice, addressing individuals' concerns and suggesting behavioural management strategies, may improve watchful waiting and enable more people to self manage their symptoms, rather than have surgery. Clearly, 'bother' is an important construct to investigate and, given that it appears to have a psychological component, exploring the meaning of men's experiences of lower urinary tract symptoms may help in developing a more empirically grounded definition of the term.

The lack of any psychological research into men's experiences of lower urinary tract symptoms (LUTS) means that any conceptual base from which to begin this exploration must be drawn from findings in other areas of clinical health psychology. It would seem appropriate to refer to BPH as a chronic illness, because it is "multiply determined, slow developing, incurable and often degenerative" (Leventhal et al, 1999). Looking at the literature on models for understanding chronic illnesses, therefore, seems most useful. Quality of life research (e.g. Doll et al, 1993) has explored the functional impact of lower urinary tract symptoms, but this is examined primarily at a sociological level. At the psychological level that impact may translate into concerns about ageing and shame. Leventhal et al's (1980) illness representation model is one way of looking at chronic illness from a meta-psychological level and focuses the

researcher on conceptualising illness for the individual, taking into account variables such as ageing and shame.

The next section introduces literature on ageing, shame and illness representations. This literature sets the scene for exploring men's individual experiences of having lower urinary tract symptoms.

Illness, Identity and Ageing

Some researchers have explored how people with chronic illnesses struggle to create a sense of self and identity (e.g. Charmaz, 1987). Charmaz proposes that when people develop chronic illnesses their “former identities and future plans become questioned, undermined, altered or negated because of the physical, social and psychological consequences of their illness”. Men with prostate problems are not only faced with a potentially chronic illness, but an illness that is generally perceived as an indication of ageing (Ragg, 1993). Given that the ageing process itself presents a challenge to the maintenance of a stable sense of identity over time (Whitbourne, 1996), it is likely that issues concerning personal identity become paramount for these men.

Whitbourne's (1996; 1996b) model includes the notions of ‘identity assimilation’ and ‘identity accommodation’ in an attempt to explain individual responses to illness. She considers this model specifically in the context of the ageing individual. In this model, any event or experience that can have a potential impact on identity is assimilated or accommodated by the individual depending on their current identity self-conceptualization. ‘Identity assimilation’ is said to

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include: self-justification, identity projection, defensive rigidity and lack of insight. 'Identity accommodation' involves changes in the self in response to experiences and includes self doubts, looking at alternatives and responding to external advice and feedback.

Whitbourne (1996) comments that, in most cases, an event that "reflects unfavourably on one's identity" will first be processed through assimilation, and only if that proves unsuccessful will identity accommodation follow. It is generally believed (Whitbourne, 1996) that, in order to adapt to life changes, an individual needs to adopt a balance of both the identity processes.

According to Whitbourne (1996), the on-going nature of physical changes during the ageing process present a greater challenge to the individual's sense of identity than the more transient experiences generally encountered in adulthood. Whitbourne (1996) suggests that individuals who adopt a primarily identity assimilation approach would be seen to deny the importance of age-related changes. They would be more likely to attribute physical change to transitory states of health, in an attempt to protect their sense of self as competent and consistent over time. The end result is that they maintain a subjective sense of emotional well-being. Heidrich & Ryff (1993; cited in Whitbourne, 1996) suggest that individuals are capable of such assimilation for many years, "even in the face of objectively defined declining health".

On the other hand, those older adults who rely more on identity accommodation are said to catastrophize more on the basis of single events. When faced with an

age-related change, or, in this case, symptom, they are more likely to overreact and to feel old. Such individuals might be seen to withdraw from activities that were formerly important to them and increasing negative self-evaluation could lead to them becoming depressed or hopeless (Whitbourne, 1996).

In order to preserve a sense of identity and emotional well-being, Whitbourne (1996) suggests that the individual must combine both assimilation and accommodation. In order to do this, it is important for the individual to acknowledge that ageing is taking place and to take the necessary precautions and adapt to inevitable losses at appropriate points in time. It is possible that 'bother', in the context of the present study, arises when individuals do not engage in an appropriate balance between identity assimilation and accommodation.

Stigma and Shame

It is possible that stigma experiences might be an issue for men experiencing lower urinary tract symptoms and prostate problems. Stigma results from being identified as "flawed, discredited or spoiled" (Goffman, 1963) and is a common experience for people with chronic illnesses (Charmaz, 2000). Charmaz (2000) argues that: "any illness that sets a person apart as different or diminished" has stigma potential, but highlights loss of bodily control as one characteristic that might increase stigma potential (Charmaz, 2000).

Scambler & Hopkins (1988), in their study of adults diagnosed with epilepsy (also a chronic illness), highlighted a distinction between 'enacted' stigma and 'felt' stigma. Enacted stigma occurs when one is seen and treated by others as

different. Felt stigma, on the other hand, reflects a person's own feelings about their illness and is associated with a fear of discovery and shame. Scambler & Hopkins (1988) found that their epileptic participants seldom encountered enacted stigma, because their experience of felt stigma led them to conceal their illness and thus avoid being labelled. Concealing their illness enables the individual to preserve their prior identity. The long-term result, however, can be that the illness takes on an "enlarged meaning for personal identity and self-concept" (Charmaz, 2000). A person's self-concept is at risk, because, without normal social comparison, they cannot put this aspect of self into perspective. Shame is a key emotion associated with stigma (Charmaz, 2000). Shame is defined as an intense negative emotion concerning the self (Lewis, 1992). It occurs when one experiences failure relative to a standard (one's own or other people's), feels responsible for the failure and believes the failure reflects a damaged self (Lewis, 1992). Shame has been found to increase when ill people view themselves as unable to uphold basic social rules about cleanliness and bodily functioning, particularly when such inadequacies are revealed in public (Charmaz, 2000). Some theorists have argued that shame and embarrassment are distinct emotions, although others argue that they are the same emotion, but differ in terms of intensity of affect (e.g. Borg et al, 1988; cited in Tangney, 1999). In a community study of two thousand men, Roberts et al (1994) found that men with moderate to severe urinary symptoms were 4.1 times more likely to be embarrassed about urinary function than those men who had mild or no symptoms. They also found a relationship between embarrassment and depression in men with moderate and severe symptoms.

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There are many theories of shame, but this introduction will briefly outline just one theory (Gilbert, 1997) that seems to offer most potential relevance to this study. Gilbert (1997) adopts an evolutionary approach to understanding shame and argues that shame serves “to alert the self and others to detrimental changes in social status”. The basic tenet of this theory is that, in pursuing access to territory or sexual partners, animals enter into competition with each other, often involving a fight. Given that all organisms are primed with a desire for survival, a psychological mechanism is needed that will de-escalate the situation and cue the animal to withdraw from the fight when it becomes apparent they are going to lose. The victor is likely to be the animal that can instil this submissive reaction (termed an “aversive internal state”) in his opponent.

In humans, fighting ability alone is often a poor way to secure social status and reproductive success (Gilbert, 1997). In general, successful individuals must be attractive to other people in order to form and maintain relationships with them. It is when something occurs to decrease signals of attractiveness and a person becomes devalued or unattractive, that social bonds are threatened and feelings of shame are induced.

In relation to this study, it is the potential stigma threatened by family and friends or society as a whole that might instil a shameful internal state in the man with urinary tract symptoms. Experiencing a disease that is generally associated with old age may alert a man to his change in social status, particularly if it comes at a time when he is planning retirement or has recently retired. If the family, society or culture in which he lives has a negative attitude towards older people, or

indeed if the man himself has an internalised negative message about old age, then this may evoke the same submissive feelings outlined above. The man may feel shameful and attempt to conceal his illness or potentially withdraw from social interaction. It is in these circumstances that lower urinary tract symptoms might be more bothersome.

Self Regulation Theory (Leventhal et al, 1980)

Leventhal et al (1999) suggest that research on adaptation to illness needs to be disease-specific “because each chronic illness has a specific biological, psychological and social imprint”. They have, however, developed a model that can be adapted to try and understand individual responses to different types of illness. Leventhal et al (1980) outlined their ‘model of illness representations’ to describe and predict how people represent and respond to health-related stressors. The model draws on social cognition theory and the coping literature to provide “a broad and adaptable framework for understanding illness-related behaviour and adjustment” (Kemp et al, 1999). The basic premise of the model is that patients actively construct a cognitive representation of their illness, which then guides their coping behaviours and, via coping, influences such adaptive outcomes as psychosocial functioning and quality of life (Heijmans, 1999).

A substantial body of research within health psychology (Leventhal et al, 1999) has shown peoples thoughts about illness (illness representations) to be organized around five main cognitive concepts:

1. identity (patients beliefs about symptoms and diagnosis or label);
2. cause (beliefs about the original cause of the condition);

3. timeline (the perceived duration of the illness);
4. consequences (the perceived physical, psychosocial and economic implications of illness);
5. cure or controllability (patients' beliefs about cure and control over illness).

Aside from some major differences in intensity (eg: concerning timeline and consequences) the five concepts are found to be relevant in understanding illness representations for both acute and chronic conditions (Leventhal et al, 1999). In the case of both acute and chronic conditions, illness representations may vary across individuals and within individuals over time (Leventhal et al, 1986).

Whilst most people, however, experience various acute illnesses during their lifetime (e.g. flu; stomach bugs; chicken pox), encountering a chronic illness is less common. Leventhal et al (1999) argue that people develop a model of acute illness that defines illness as the result of physical disease, caused by external pathogens (e.g. a virus), a relatively well-defined and brief timeline, controllable symptoms (e.g. use of medication) and limited consequences. The result is that when they encounter a chronic illness people fall back on their model of acute illness and attempt to apply it to their chronic illness.

According to Leventhal et al (1999) patients will initially treat their symptoms as though they are part of an acute illness (e.g. seeking medication to cure it), but as time passes a view of themselves as 'diseased' will gradually assume a prominent location in their overall self-conception. They argued that abstract conceptions

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about disease, treatment and social and physical consequences create a challenge to the pre-illness self. For example, whereas a person might attribute the cause of an acute illness to an external pathogen (e.g. a virus), the occurrence of a chronic illness is more likely to be perceived as reflecting an internal weakness (e.g. genetic vulnerability). An individual's behavioural responses to the threat to self presented by illness involves both personal and social actions aimed at preserving or restoring the pre-illness self and warding off possible future selves that are feared or depressogenic.

Leventhal et al (1991) suggest that although our sense of ourselves as physical beings is always available to consciousness, it is typically in the background. Most people pay little attention to their bodies and to the physical functions that they perform daily. However, all illness, whether acute or chronic, generates changes in bodily sensations and function. Processing these events involves an altered focus of attention, linking the somatic event with the model of one or another disease, appraising its implications for the self and evaluating one's physical strength and resources for defeating the disease (Leventhal et al, 1999). A striking aspect of disabling chronic illness is its ability to focus attention on physical activities and bodily functions previously taken for granted (in this case, urination). Disruption of automatic performances previously not central to one's conception of self now creates a threat to the physical self (Leventhal et al, 1999). Conscious awareness of previously automatically regulated physical and biological functions presents one with novel information and the task of learning how to place these activities under voluntary control. Leventhal et al (1999) suggest that disruption of functions that are automatic or taken for granted raise

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core questions: “Who am I?”; “Can I function as a human being?” The questions raised by the symptoms and functional decline create pressure to rethink and to restructure a physically evolving self.

The illness representation model has also been explored with regard to its relationship with coping. Researchers have highlighted a link with emotion-focused and problem-solving focused coping. For example, recent studies of chronic fatigue syndrome (CFS) (eg: Heijmans, 1998) found that patients who considered their illness to be a serious condition, thought their illness was out of their control and believed their illness to have serious consequences were found to use more passive, emotion-focused coping strategies. On the other hand, patients who considered their illness less serious and experienced greater control over their illness were found to engage in more active, problem-focused coping strategies. A representation of CFS as a serious and uncontrollable disease together with passive, emotion-focused coping was found to be associated with greater physical disability and less psychological well-being. In another study, comparing patients with recently diagnosed versus chronic epilepsy, Kemp et al (1999) found that patients who believed they had some control over their epilepsy reported more problem-focused coping. Those patients who felt they were less able to control the effects of epilepsy engaged in more wishful thinking and avoidance coping.

With regard to ‘bother’, it is possible that men who feel less in control of their symptoms and/or who engage in more emotion-focused coping may be those who are more bothered by lower urinary tract symptoms.

Ageing and Illness Representations

Leventhal & Crouch (1997) explored age as a moderating factor in the illness representation model and tentatively concluded that age can affect the way diseases and symptoms are experienced and interpreted, as well as emotional reactions and coping strategies. They argue that comparison of the current body with the prior body is common in all individuals experiencing somatic change, but for older people that is the core issue. They suggest that 'wait and see' may be less effective for older than younger people, because older people have "the difficult task of evaluating the significance of symptoms that are slow to change against a complex background of age related change". In addition, they suggest that older people may have difficulty distinguishing illness specific symptoms from those attributable to normal ageing and, as a consequence, fail to report them to their GP. It could be argued that this failure to report symptoms may be due to embarrassment about the symptoms, but Brody & Kleban (1981; cited in Leventhal & Crouch, 1997) found that 60% of the participants in their study failed to report symptoms of difficulties passing urine, whereas only 39% failed to report on constipation.

On the other hand, despite these factors, Leventhal et al (1993) also found, in two separate studies, that older people (aged over 65) are generally quicker than their middle-aged counterparts in deciding when they do have an illness. When they asked the middle-aged participants what they believed led to the delay in seeking medical attention, the response was generally that they did not want "to hear bad news" or that they were "waiting to see what it might be". They suggested that middle-aged patients were more likely to engage in avoidance behaviours than

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older patients. Once again, these were only tentative conclusions, due to the relatively small numbers involved in their studies.

In summary, the psychological literature outlined above points to the significance of changes in self concept and identity that arise when confronted with a chronic illness, particularly one that is most commonly associated with ageing. The illness representation model (Leventhal et al, 1980) and Whitbourne's (1996) model of identity assimilation and accommodation both seem to suggest that, when faced with a chronic illness, the individual embarks on a process of self-evaluation and reflection on his/her current, past and future identity. A large component of shame is also associated with one's perception of oneself and the perception of how one is viewed by others.

In keeping with a descriptive, phenomenological stance, the literature review above is not intended to suggest hypotheses about the findings in this study. Instead, it was 'bracketed', along with any other previous knowledge about prostate disease, in order that the researcher might keep her own "biases, assumptions and expectations" separate from the informants' experiences (Husserl, 1931, cited in Barker et al, 1994).

Rationale for Methodology

The main aim of this study was to explore the meaning men attach to their experiences of having lower urinary tract symptoms and to begin to understand 'bother' in the context of those experiences. Given the focus on individual perceptions and the fact that no previous research has looked at psychological

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aspects of these experiences it was considered appropriate to adopt a phenomenological approach.

The different bodies of research outlined above independently emphasise issues around identity in experiencing chronic illness. It was decided that repertory grid technique would, therefore, be a suitable methodology, because it enables the exploration of views about the self at different points in time, as well as providing the opportunity to explore attitudes towards ageing and chronic illness. One of the benefits of this methodology is that it can elicit attitudes which the subject cannot verbalise because he is not fully aware of them (O'Farrell et al, 1993). The main benefit of this approach is that it makes no assumptions and allows an exploratory focus. Repertory grid methodology is, therefore, in keeping with the phenomenological stance of this study. The study is "phenomenological in that it is concerned with discovering and recording the [men's] account of their experiences, rather than testing any preconceived hypotheses" (Smith, 1999).

Repertory grid methodology was combined with a semi-structured interview and interpretative phenomenological analysis in order to enrich the qualitative material obtained from the participants. These two methodologies have been previously combined by researchers in clinical health psychology (e.g. Smith, 1999) to good effect.

Repertory Grid technique is an interview method based on personal construct psychology and stems from the belief that each individual has a theoretical framework that he/she uses to make sense of the world (Kelly, 1955). The

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repertory grid was devised as a method of exploring personal construct systems: “it is an attempt to stand in others’ shoes, to see their world as they see it, to understand their situation, their concerns” (Fransella & Bannister, 1977). Constructs are the descriptions individuals use to understand people and events and are bi-polar (eg: good/bad; mean/generous). By exploring the kinds of constructs people use to describe specific situations it is possible to gain a picture of what are the most important aspects of that situation to them. In addition, information is elicited about the way they perceive aspects of themselves and others. Repertory grid methodology has the added advantage of being a task-focused methodology, which might assist the men in talking about a subject that is potentially embarrassing for them.

An interpretative phenomenological approach (IPA) was used to guide the collection and analysis of interview data. IPA is concerned with understanding what a person thinks and feels about a particular subject or experience and with the chain of connection between verbal report, cognition and physical state (Smith, 1995). It has been argued that a dialogue between IPA and health psychology is possible because illnesses provide “a useful backdrop against which to consider personal accounts of physical processes” (Smith, 1995). The benefit of incorporating a brief semi-structured interview was that it allowed participants to tell their own story and facilitated exploration, on the part of the researcher, of issues that had not previously been considered (Smith, 1995). This interview style could then be adopted during the grid elicitation process when interesting issues arose that warranted further exploration.

Summary of Study

Decisions regarding treatment for LUTS are generally decided in accordance with how 'bothered' the individual is by his symptoms. Given the extensive use the term 'bother' has in determining treatment plans, it is surprising to find no research exploring its meaning and, more generally, the meaning men attach to having lower urinary tract symptoms. This is a descriptive study using qualitative methodology to address three main questions:

- (1) What does having lower urinary tract symptoms mean for men?
- (2) What factors are related to 'bother' in the context of LUTS?
- (3) Why are the symptoms bothersome to some men and less so to others?

CHAPTER TWO

METHOD

Overview

This was a descriptive study using repertory grid methodology and interpretative phenomenological analysis. A total of sixteen men attended an appointment where they were interviewed and completed an individualised repertory grid and two short questionnaires (the Hospital Anxiety and Depression Scale and the International Prostate Symptom Score). The entire process was tape-recorded, to aid analysis of the qualitative data.

This chapter details the design of the present study, highlights ethical considerations, describes the measures, explains how the data was analysed and discusses issues of credibility.

Setting

All potential participants were identified on the basis of information in referral letters to the Urology Clinic of a London teaching hospital. The clinic took referrals from GPs and hospital doctors working with patients from an ethnically and socially diverse inner-city population. The interviews took place either in the participant's own home or in an office at University College London (where the main researcher was based). To ensure confidentiality and that participants understood the research was not related to their medical care, no interviews took place in the urology clinic.

Participants

Participants were sixteen men. Fifteen were white British and one was white American.

The inclusion criteria were:

- symptoms suggestive of LUTS and/or enlarged prostate;
- no evidence of prostate cancer;
- aged 50+.

The exclusion criteria were:

- evidence of prostate cancer;
- previously undergone prostate surgery;
- evidence of a urinary tract infection;
- evidence of psychiatric illness;
- evidence of alcohol or substance abuse;
- inability to speak or understand spoken English.

Recruitment Process

Some referrals were addressed directly to the consultant urologist involved in this study, others were addressed to the clinic and then randomly divided between three consultants by a specialist senior registrar. All referral letters received by the consultant between August 2000 and March 2001 were screened by him, marked as suitable for this study and handed to his secretary. The secretary copied the suitable referral letters for later collection by the main researcher. All

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participants would have been sent appointment letters to attend the urology clinic for a medical consultation before letters were dispatched concerning this study.

There was some variability in the detail of the referral letters and the extent of investigations GPs had conducted themselves. For example, some men were referred without any investigations, but following complaints of lower urinary tract symptoms, others had no symptoms but their GP found elevated levels of prostate specific antigen in a blood test (PSA), others, following a digital rectal examination, showed evidence of an enlarged prostate, with or without symptoms. Appendix 1 contains three examples of referral letters, amended to remove identifying details.

Letters explaining the study (Appendix 2) and an information sheet (Appendix 3) were sent to a total of fifty-five men. They were invited to complete and return a reply slip indicating either that they would like to take part or that they would like further information before deciding to take part. The letter and information sheet explained to the men that we were interested in learning about their “experiences of having lower urinary tract symptoms”. No reference was made to the “prostate” or “prostate difficulties”. The rationale for this was that we did not want to suggest a link with their symptoms and prostate difficulties that may not already have occurred to them; it is possible some men may not have associated their lower urinary tract symptoms with an enlargement of the prostate.

Examples of the types of symptoms that they might be experiencing were provided in both the letter and information sheet (e.g. “having difficulties passing

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urine, finding it hard to start”). This was to ensure an agreed conceptual base between the researchers and potential participants. To try and obtain a sample of men who had varying degrees of difficulty coping with their symptoms, we highlighted the fact that we were interested in “men who find it very difficult to cope with their symptoms and men who do not find it difficult to cope”.

Those men who replied were subsequently telephoned to discuss the research in more detail and to arrange an appointment. Of the fifty-five men to whom letters were sent, twenty-eight (51%) replied. A total of sixteen men (57% of those who replied) completed the initial interview. Three of those men had replied that they “might like to take part...but would like to discuss it further”. All three expressed concern that they might not be suitable, because their symptoms were not really a problem for them. They were reassured that we were interested in men for whom the symptoms were not a problem as well as men for whom they were a problem. All three agreed to take part in the study. All 16 men who were offered appointments attended; there were no non-attenders.

Of the remaining twelve replies (43%), six indicated that they did not want to take part; one letter was returned because the addressee was “not known”; two men were not offered an appointment after discussion on the telephone revealed difficulties with spoken English; three men were not offered an appointment after discussion on the telephone revealed a possible cancer diagnosis (e.g. blood in their urine or pain when urinating that had not been mentioned in the referral letter).

Ethical Considerations

This study was reviewed and agreed by the Joint UCL/UCLH Committees on the Ethics of Human Research on 8th June 2000 (Appendix 4).

Appropriate ethical considerations were taken into account in designing this study and drawing up the original contact letter, the information sheet and consent form. Given the potentially embarrassing nature of their difficulties and the fact that they had not yet had direct contact with the urology clinic, it was considered appropriate to make first contact with potential participants by letter rather than telephone. In order that the men might make an informed choice about taking part in the research, as much information as possible was included in an information sheet that was sent with the initial contact letter. To give the men some idea of what would be asked of them, the information sheet explained that they would be asked to complete two short questionnaires and an interview that would take approximately one and a half hours. It was anticipated that some men might be embarrassed or worried about their symptoms, therefore some reassurance and normalising of their experiences was deemed necessary in the letter (“this is a very common experience for men”). The information sheet highlighted issues of confidentiality and the fact that the men did not have to take part in the study if they did not want to. It also offered reassurance that anything they discussed and any decision to take part or not would not affect their medical care in any way.

Potential participants were given the opportunity to ask further questions when they were subsequently telephoned about the study and once again before signing

the consent form at their appointment. In order to ensure participants felt as comfortable as possible during in the interview, they were offered the opportunity for the interview to be conducted in their own home. One reason was that men for whom frequent use of the toilet might be embarrassing might feel less embarrassed interrupting the interview on their own territory.

Procedure

Participants were offered an appointment either at their home or in an office at University College London at a mutually convenient time. Nine of the sixteen appointments took place in the participant's home. If they preferred to be seen in their home it was ascertained that there would be privacy for approximately one and a half hours. All appointments, whether at home or in the office, proceeded without interruption for between one hour and one hour forty minutes.

Each participant was seen either prior to their first appointment with the medical consultant, or shortly after their first appointment (but before they received any results). At the beginning of the appointment, participants were asked if they had any further questions and were asked to sign the consent form, (Appendix 5). They were each asked questions to determine demographic details and were then engaged in a semi-structured interview to explore the development of their symptoms, how they affected them and what had led to their referral. At an appropriate point, and to signify the end of this interview component, participants were asked to complete the two questionnaires. An individualised repertory grid was also completed and, at the end of the appointment, participants were asked: "Is there anything that hasn't come up during this interview that you feel is

important, or you would like me to know?” The entire process was tape-recorded to aid analysis.

Measures

To obtain descriptive information about the participants, basic demographic information was collected and the men were asked to complete the International Prostate Symptoms Score Index (Barry et al, 1992) and the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983). Information on participants' experiences with lower urinary tract symptoms and their views of themselves and others was then obtained through semi-structured interview and repertory grid methodology.

Demographic Information

For all participants, demographic information (age; occupation; marital status; ethnicity) was obtained through discussion at the beginning of the interview, in the context of building a rapport and orienting participants to the research.

International Prostate Symptom Score (I-PSS; Appendix 6)

This symptom index for Benign Prostatic Hyperplasia (BPH) was developed and validated by the American Urological Association (Barry et al, 1992). Barry et al (1992) conducted validation studies, using a long and short form of the index, with two separate groups of BPH patients and control subjects.

The final index comprises seven symptom-related items and two items measuring “global bother” (Barry et al, 1992). The symptom questions cover frequency,

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urgency and nocturia (irritative items), weak urinary stream, hesitancy, intermittence and incomplete emptying (obstructive items). The global bother questions are: “Overall, how bothersome has any trouble with urination been during the last month?” and “If you were to spend the rest of your life with your urinary condition just the way it is now, how would you feel about that?”. The index was found to be internally consistent (Cronbach’s Alpha = .86), to have excellent test-retest reliability ($r = .92$), and to powerfully discriminate between BPH and control subjects. The final index (I-PSS) was also compared with other similar indexes and found to be strongly correlated ($r = 0.77$ to 0.93) (Barry et al, 1992).

A total score is obtained classifying patients as mildly symptomatic (0-7), moderately symptomatic (8-19) or severely symptomatic (20-35). Normative data (Barry et al, 1992) indicates that men with scores of seven or below more commonly rate their urinary condition as not at all bothersome. Men with scores of eight to nineteen generally give intermediate ratings of ‘bother’. Men with scores of twenty or above are generally most bothered. Using these cut-offs, Barry et al (1992) report that 21% of their BPH patients fell in the mild range, 57% in the moderate range and 23% in the severe range in terms of symptomatology

In the original short index there were two questions related to ‘bother’. The current index, as it is used in the clinic involved with this study, comprises only one of the bother questions (“If you were to spend the rest of your life with your urinary condition just the way it is now, how would you feel about that?”) and it

is unclear from the available literature why one was removed. Barry et al (1992) make no distinction between the two bother questions and there is no suggestion that one is any more or less reliable or valid than the other. The response scale for the bother question is 0=delighted; 1=pleased; 2=mostly satisfied; 3=mixed; 4=mostly dissatisfied; 5=unhappy; 6=terrible.

Netto & DeLima (1995) conclude that this index shows good reliability and validity, regardless as to whether it is self-administered or administered by a clinician. For the purposes of this study it was used as a self-report measure.

Hospital Anxiety and Depression Scale (HADS; Appendix 7)

The Hospital Anxiety and Depression Scale is a self-report measure that was developed to assess the differentiation of clinical anxiety and depression in non-psychiatric patients suffering physical illness. The scale consists of fourteen items, which alternate equally between anxiety and depression and have been found validly to sidestep the concomitant effects caused by the presence of physical illnesses. Items from the anxiety subscale include: *“I feel restless as if I have to be on the move”* and items from the depression subscale include: *“I still enjoy the things I used to enjoy”*. Items from each subscale are rated on a four-point scale (0-3), with some items being reverse scored, so that for one item the first response indicates maximum severity and for another item the last response indicates maximum severity.

In their original study, Zigmond & Snaith (1983) found HADS scores to give good separation between cases, to reflect well the severity of anxiety ($r = .74$) and

depression ($r = .70$) and to be a reliable instrument. Aylard et al (1987) used the Montgomery-Asberg Depression Rating Scale and the Clinical Anxiety Scale as the external criteria for validation of the HADS. They found no relationship between the HADS' anxiety and depression subscales ($r = -.04$), indicating its ability to differentiate clearly between these two psychiatric disorders. However, Herrmann (1997) in a review of eighteen separate studies using the HADS ($n = 8160$), concluded that the mean correlation between anxiety and depression subscales was $r = 0.63$; "subscale scores are clearly correlated in most patient groups". He suggested that the HADS could be used as a two-dimensional instrument or as a single measure of emotional distress, but that, for most purposes, the subscales should be used separately.

Herrmann (1997), following his review of two hundred studies using the HADS, concluded that "there is no single, generally accepted cut-off score". In their original study, Zigmond & Snaith (1983) recommended two cut-off scores for both subscales: 7/8 for possible and 10/11 for probable anxiety or depression. They also proposed a third cut-off of 14/15 for severe disorder, but Herrmann (1997) highlights that no empirical evidence was provided to support this latter. Most investigators have used one of the lower two cut-offs. The cut-off scores used in the present study were 8 and 11.

Semi-structured Interview

Smith (1995) suggests that a semi-structured interview allows the researcher to "gain a detailed picture of a respondent's beliefs about, or perceptions or accounts of, a particular topic". This interview was intentionally short as it was

intended to supplement the grid data. The main aim of the interview was to encourage participants to talk about their experiences in their own words and to investigate two broad areas: effect of the symptoms on self and accessing the medical system for help. To this end, the interview was guided by the following four questions:

- “Can you tell me about when your symptoms started?”
- “What led up to your referral to the clinic?”
- “What has it been like for you since these symptoms started?”
- “What has been the worst thing about having these symptoms?”

The questions were intended mainly as cues to encourage the men to discuss their experiences, and the researcher intervened only to prompt further elaboration. The interview also served to orient participants to the research, before asking them to think about themselves in relation to others. Each interview was tape-recorded and transcribed.

Repertory Grid Procedure

Repertory grid technique is an interview method from which both quantitative and qualitative data can be derived by considering an individual's constructs in relation to a set of elements (in this case elements = people). It assumes that a mathematical relationship between a person's judgments reflects psychological assumptions underlying those judgments (Fransella & Bannister, 1977). By exploring the kinds of constructs that people use to describe themselves and others it is possible to gain a picture of the most important aspects of a situation to them.

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In repertory grid technique “*elements*” are chosen to represent the area in which an individual’s construing is to be investigated. In this study the grid was used to examine perceptions of self and others and so the chosen elements were people.

All participants were provided with the same elements, which were:

Me now

My Ideal Self

Me before prostate problems

Me in the prime of my youth

Me in 5 years time

Me at work

Me as close family/friends see me

A person I admire

A person I dislike

My partner

A typical man of my age

A typical old man

A typical man with prostate problems

A typical man without prostate problems

Each element was written on a separate card in the presence of the participant. In this way some cards could be appropriately personalised (e.g. partner’s name, not just “my partner”) and for other cards a brief discussion could take place to ascertain the participant’s ability to hold in mind a particular stereotype (e.g. a typical man with prostate problems) or view of themselves (e.g. me in 5 years

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time). It was emphasised that ideal self should be self as they would like to be, rather than self as someone else might like them to be. Participants were asked to name a person they disliked and a person they admired, as reference points. They were asked to think of an age when they were in the prime of their youth. It was this age that was written on the card. The elements typical man of my age and typical old man were included to assess a stereotype and to explore attitudes towards ageing. Me before prostate problems was included to explore how/whether prostate problems had changed the person's life. Similarly, me in 5 years time was intended to explore participants' views of the future (with or without prostate problems). Me at work, me as close family/friends see me and my partner were included to explore the impact of prostate problems on daily life (occupational, social and sexual functioning respectively). The element cards and reasons for participant choices were briefly discussed. Participants were not informed of the rationale for using particular elements.

“Constructs” are the descriptors an individual uses to make sense of his or her world. Each person's construct system is composed of a finite number of bipolar constructs (Winter, 1992). At their simplest level such constructs might include, for example, good/bad or happy/sad. Constructs were elicited for each participant using the “minimum context card form”, also known as the triadic method (Fransella & Bannister, 1977). This method is the traditional method used to obtain constructs (Smith, 1990).

Each participant was presented with three of the elements on separate cards and asked to identify an important way in which two were similar and different from

the third. To elicit the opposite pole of the construct (“the contrast pole”) they were asked in what way the third was different. This procedure was repeated with different three card combinations until no new constructs were elicited. Constructs were elicited, rather than provided, in line with Kelly’s original idea of personal constructs (i.e. they must be the individual’s personal constructs, not those of the investigator or others). There is consistent evidence that “The individual prefers to express himself and to describe others by using his own personal constructs” rather than construct supplied by the investigator (cited in Winter, 1992).

Participants were then asked to rate each element on each construct pair using a 7-point numeric scale. The points of the scale were placed on the table in front of the participant and all elements were rated on each construct pair in turn. A construct card was placed at each end of the pole to provide a visual aid and reminder of the construct being rated. The interviewer recorded ratings on a separate form (Appendix 8).

The entire process of grid construction was tape-recorded to aid thematic analysis.

Analysis of Data

Grid Analysis

In general, it would seem that there is no standard way to analyse data obtained through repertory grid technique (Beail, 1985). Kelly encourages researchers to stay close to the raw data, because elaborate statistical analysis can result in the

more obvious and accessible characteristics of the person being lost (Smith, 1995). Beail (1985) states that “interpretation will depend on how the grid was designed, produced and the purpose for which it is used”. All methods of analysis have in common the fact that they attempt to reveal patterns of relationships between entities in the grid (Beail, 1985).

For the purposes of this study, the nature of constructs across the grids was examined through content analysis of constructs (Landfield, 1971). The nature of constructs and elements for each individual grid was examined using a standard grid analysis package (Flexigrid 6, Tschudi, 1998). This package also subjected each individual grid to a principal components analysis with varimax rotation. To provide an overall picture of participants’ construing, median and range scores across the grids are reported. In order to remain close to the raw data, examples from individual grids are also provided, to highlight the nature of variations around the median and in men’s ‘stories’ of their experiences.

Construct System Structure

The mean rating for each construct, and variation around that mean, is examined for individual grids. This is to establish whether a particular construct is being employed in a “lopsided” manner (i.e. most elements are assigned to only one of the poles). The variation about a construct mean is a measure of the extent to which the construct discriminates between elements and therefore of its usefulness (Winter, 1992). Lopsidedness in construing can limit optimal functioning and has been associated with severe psychopathology, such as depression and panic attacks (Winter, 1992).

Content Analysis

Winter (1992) indicates that there are several systems of construct classification in use, but the most commonly employed is that devised by Landfield (1971). Some authors argue that the Landfield system is too unwieldy, but can be used as a basis from which to develop themes “more pertinent to the subject being investigated” (Large & Strong, 1997). In order to ensure a more comprehensive classification, the constructs elicited in this study were categorised into themes based on Landfield’s system: some additional categories were provided and some of Landfield’s categories were removed. A full list of the categories, including definitions, is in Appendix 9. Of the nineteen categories, fifteen are from the Landfield system and four were designed specifically for their relevance to this study.

Constructs were classified by two independent raters, who were provided with a list of all the construct pairs and all the categories and given the following instructions:

“Please read through the list of categories to become familiar with the definitions. Then work through the list of construct pairs, taking each pair in turn and deciding to which category it should be assigned. Place the code for the appropriate category in the box to the right of each construct pair. If constructs have more than one descriptor, score each of the descriptive elements separately”.

The raters agreed on classification of 42% of the constructs. Where they did not agree the rating of a third independent rater was taken into account and the construct scored according to the majority view. In the event all three ratings were different, the construct was rated as unclassifiable. In total, twelve (7%) of constructs were unclassifiable.

Tightness of Construing

Tight construing is where the individual construes elements in a rigid manner, with no room for flexibility. Loose construing is where construing of elements is constantly shifting (Winter, 1992). A principal components analysis (PCA) was conducted to explore tightness and looseness of construing. The results of the PCA are presented, commencing with the variance accounted for by the first two components extracted. The constructs relating to the first component are described. The higher the percentage of variance accounted for by the first principal component, the more tightly organised and unidimensional is the individual's construing (Winter, 1992). In a sample of normal subjects, the mean percentage of variance of the first component in a grid of sixteen elements and sixteen constructs was found to be 39.4 (Ryle & Breen, 1972). The PCA also provides a visual representation of each participant's construct system.

Further evidence of the tightness of individual construing is obtained by examining the intensity score (Bannister, 1960). A subject's intensity score is obtained by squaring the correlation between each pair of constructs in the grid, multiplying the result by 100 and summing the scores thus obtained (Winter, 1992). For this study, the computer package calculated this score. An intensity

score above 0.5 suggests tight construing, whilst a score below 0.5 suggests loose construing (Bannister, 1960).

Inter-Element Distances

Median inter-element distances were calculated across all sixteen grids. Large & Strong (1997) suggest that it is permissible to do this, in spite of the constructs for each participant being different. The computer package incorporates a standard procedure for calculating inter-element distances (Winter, 1992; Large & Strong, 1997).

A distance of less than 0.8 suggests that two elements are viewed as similar, while a distance of more than 1.2 suggests that two elements are viewed as dissimilar (Slater, 1972). A distance between 0.8 and 1.2 suggests that the elements are neither similar nor dissimilar.

To remain focused on the subject being investigated, elements were looked at in terms of how participants viewed themselves in relation to others and how they viewed a typical man with prostate in relation to others.

Analysis of Transcripts

Transcripts from the interviews, incorporating the semi-structured interview and discussion during the grid process, were analysed for common themes using Interpretative Phenomenological Analysis (Smith, 1995). This too was in keeping with the overarching aim to explore the men's individual accounts of reality, rather than any objective reality (Smith, 1999). Smith (1995) states that "there is

no correct way to do qualitative analysis”, but he makes some suggestions upon which the analysis in the present study is based.

The transcript from the first interview was read through twice and any ideas or emergent themes were noted. Subsequently, a separate list was made of all the emerging themes and examined for connections. Themes that seemed to be connected were clustered together under a single theme heading (a superordinate theme) that appeared to describe the cluster. As themes were gradually clustered together, the original transcript was checked and re-checked to ensure that the superordinate themes continued to reflect what the participant actually said. Sub-themes were then grouped underneath the appropriate superordinate theme, along with examples from the original text.

This approach was repeated for each of the transcripts in turn. It was possible to do this, although the numbers were slightly larger than is ideal for such an analysis (Smith, 1995), because the transcripts were relatively short. Superordinate themes from each of the transcripts were then compared, to produce a consolidated list of superordinate themes, with sub-themes grouped together underneath. As this consolidated list was drawn together, each of the transcripts was checked and re-checked, once again to ensure that the themes were still closely related to the original data.

The superordinate themes and sub-themes are explained in detail, with examples from the original data.

Credibility

Of specific relevance to the repertory grids, Winter (1992) reviewed a large number of studies and concluded that there was “considerable evidence of the validity of the repertory grid measure in relation to a wide range of characteristics and aspects of the behaviour of ‘normal’ subjects...and as indices of disorder” (p65). Winter (1992) also highlighted that, in terms of reliability, grids are more reliable if constructs are elicited from the individual, rather than provided by the researcher. Constructs were therefore elicited in the present study to increase reliability.

As there is no standard form of the repertory grid, Winter (1992) suggests that attempting to apply traditional concepts of reliability and validity is “meaningless” (p46). It can be argued, therefore that repertory grids fall under the rubric of other qualitative methodologies when reviewing issues of credibility.

Although there is on-going debate about what constitutes ‘good’ qualitative research, Elliott et al (1999) have suggested a number of guidelines for reviewing such research. These guidelines were taken into account throughout the course of the present study.

“Owning one’s perspective” (Elliott et al, 1999, p.221) is one means of enabling the reader to review qualitative research. The present study was conducted by a final year psychologist in clinical training who had some, although limited, experience of clinical work within a health psychology setting. The study was

Chapter Two: Method

supervised by a qualified clinical psychologist who had considerable experience in the field of health psychology and a senior lecturer in health psychology. The theoretical orientation of the researchers was cognitive-behavioural, although all were open-minded to the value of other theories. The consultant who identified patients for this study had clinical and research interests in urology and a particular interest in educating men about “lifestyle” approaches (behavioural and dietary strategies) to managing their lower urinary tract symptoms. The main researcher and first supervisor were female; the consultant and second supervisor were male.

An important credibility check was also implicit in the use of two complementary methodologies. Elliott et al (1999) suggested that comparing two or more qualitative perspectives was one of the means by which the researcher could check the credibility of emerging themes. A further credibility check involved the two supervisors as auditors of the process. Both supervisors contributed to the reading and interpretation of the original data and in deciding on suitable themes.

Finally, the results are presented in such a way as to enable the reader to check the credibility of the study. For example, the participants and their life circumstances are outlined, to enable the reader to judge for themselves the types of people and range of situations to which the data might be relevant and examples of the original data are provided, in order that the reader might conceptualise possible alternative interpretations for themselves.

CHAPTER THREE

RESULTS

This chapter begins with a brief description of the sixteen participants. This is followed by descriptive data obtained from the International Prostate Symptoms Score (I-PSS) and the Hospital Anxiety and Depression Scale (HADS). Data obtained from the men's grids are then presented, followed by a report of correlational analyses exploring both. Next comes a description of the transcript themes and the chapter ends with the presentation of two illustrative cases.

Description of Participants

Participant 01 is a 63 year old professional¹. He is divorced, but currently lives with a long-term partner. He has no children. He had noticed the need to urinate more frequently than others since he was nineteen years old, but over the past six months had been aware of additional symptoms: urgency, weak stream and nocturia. He was referred to the clinic following a general check-up by his GP.

Participant 02 is a 57 year old, university educated, senior civil servant. He lives with a long-term partner and has no children. He first noticed symptoms of nocturia about four or five years ago. About a year ago these symptoms worsened and he noticed additional symptoms: hesitancy, weak stream and

¹ To preserve confidentiality, the term 'professional' is used to cover jobs such as lecturer, architect, accountant, computer programmer, etc.

frequency. He was referred to the clinic after approaching his GP specifically about the symptoms.

Participant 03 is a 57 year old, recently unemployed professional¹. He is married with young children. He first noticed nocturia, hesitancy and intermittency about two or three years ago and was referred to the clinic after mentioning symptoms during an annual hospital check-up for Hodgkin's disease.

Participant 04 is a retired, 71 year old, manual worker. He was widowed twelve years ago and currently lives with his adult son. He first noticed symptoms of frequency twelve years ago, shortly after his wife died and was given medication about two years later, which appeared to reduce the frequency. Gradually over the past ten years other symptoms (intermittency, urgency, weak stream and straining) had emerged. He was referred to the clinic after a rectal examination, in A&E following a fall, revealed a slightly enlarged prostate.

Participant 05 is a 60 year old, self-employed professional. He is divorced, but has a long-term partner of ten years. He first noticed symptoms of incomplete emptying and urgency about five years ago. He was referred to the clinic after approaching his GP specifically about the symptoms.

Participant 06 is a 63 year old, unemployed professional. He is divorced, but currently lives with a long-term partner. He first noticed symptoms of weak stream about ten years ago and had annual check-ups thereafter. Symptoms of

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weak stream, plus frequency and intermittency, worsened about two years ago and he was referred to the clinic following a change from a private to an NHS GP (due to unemployment).

Participant 07 is a 63 year old, white American, professional¹. He is divorced, but currently has a long-term partner. He first noticed symptoms of nocturia, frequency and incomplete emptying about one and half years ago, but was reassured by GP investigations at that time. He was referred to the clinic when the symptoms worsened about 6 months ago.

Participant 08 is a retired, 65 year old, skilled manual worker. He is married with adult children living at home. He had never noticed any symptoms, but was offered the blood test (PSA) by a well-informed GP and was referred to clinic about six months ago after the results returned inconclusive on two separate occasions. He has noticed symptoms of urgency, intermittency and weak stream since then.

Participant 09 is a retired, 65 year old, senior civil servant. He lives with a long-term partner. He first noticed symptoms of nocturia about five years ago. He was referred to the clinic after a rectal examination, following a hernia operation, revealed a slightly enlarged prostate. Since then he has noticed some symptoms of incomplete emptying, urgency and weak stream.

¹ To preserve confidentiality, the term 'professional' is used to cover jobs such as lecturer, architect, accountant, computer programmer, etc

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Participant 10 is a retired, 75 year old, manual worker. He is married. He first noticed symptoms of nocturia about a year ago and was referred to the clinic by his GP following a check-up for another health problem. He said he had no other symptoms, but on the questionnaire endorsed frequency, intermittency and weak stream.

Participant 11 is a 61 year old, married, professional¹. He first noticed symptoms of frequency about ten years ago and visited his GP at that time, but did not follow it up. Symptoms worsened about a year ago to include incomplete emptying, urgency, weak stream and nocturia. He was referred to the clinic after approaching his GP specifically about the symptoms.

Participant 12 is a retired, 80 year old, professional. He was widowed three and a half years ago and currently lives alone. He first noticed symptoms of frequency, nocturia and urgency after retiring about sixteen years ago. Since then he had not noticed any worsening of symptoms. He was referred to the clinic about three months ago, following a check-up for other health problems.

Participant 13 is a 56 year old, self-employed shop owner. He is married. He first noticed symptoms of urgency and intermittency about a year ago. He was referred to the clinic after routine a check-up by his GP for another health problem.

¹ To preserve confidentiality, the term 'professional' is used to cover jobs such as lecturer, architect, accountant, computer programmer, etc

Participant 14 is a 62 year old, self-employed professional¹. He lives with a long-term partner. He noticed a change in his orgasm and nocturia about a year ago and was referred to the clinic following a check-up by his GP.

Participant 15 is a 75 year old self-employed professional. He is married. He said he had not noticed his pattern of urination to be any different than it had been all his life. He was referred to the clinic after an annual GP check-up, where a blood test revealed elevated levels of prostate specific antigen.

Participant 16 is a 58 year old unemployed manual worker. He is married. He first noticed symptoms of nocturia about two years ago and was referred to the clinic after his GP initiated a blood test, which revealed slightly elevated levels of prostate specific antigen.

Results from Questionnaires

International Prostate Symptoms Score (I-PSS)

Individual scores on the International Prostate Symptoms Score are presented in Table 1. One participant (02) scored in the upper range, suggesting that he is severely symptomatic, ten participants scored within the moderately symptomatic range (03-07; 09-13) and five participants (01; 08; 14; 15; 16) scored within the mildly symptomatic range. Individual scores for irritative and obstructive symptoms are also reported separately in Table 1. The majority of men (9) reported more irritative than obstructive symptoms.

¹ To preserve confidentiality, the term 'professional' is used to cover jobs such as lecturer, architect, accountant, computer programmer, etc

The ‘bother’ score is reported in the final column of Table 1. In terms of how they would feel if they had to spend the rest of their life with similar symptoms, one participant indicated that he would feel “unhappy” (02); one participant stated he would feel “mostly dissatisfied” (11); four participants said they would feel “equally satisfied and dissatisfied” (04; 06; 07; 12); six participants indicated that they would feel “mostly satisfied” (03; 05; 08; 09; 10; 13); three participants said they would be “pleased” (01; 14; 16) and one participant said he would be “delighted” (15)

Table 1: Participant’s scores on the International Prostate Symptoms Score

ID	Total*	Irritative	Obstructive	Bother**
01	4	3	1	1
02	29	12	17	5
03	12	5	7	2
04	19	8	11	3
05	14	8	6	2
06	13	3	10	3
07	8	5	3	3
08	6	4	2	2
09	9	4	5	2
10	11	7	4	2
11	15	10	5	4
12	11	6	5	3
13	12	7	5	2
14	3	3	0	1
15	5	2	3	0
16	4	2	2	1

* 0-7 = mildly symptomatic; 8-19 = moderately symptomatic; 20-35 = severely symptomatic

** 0-3 = low bother; 4-6 = high bother

Hospital Anxiety and Depression Scale (HADS)

Individual scores on the Hospital Anxiety and Depression Scale are presented in Table 2. For this study, a cut-off score of 8 was used to indicate “possible” clinical anxiety/depression and a cut-off score of 10 to indicate “probable” clinical anxiety/depression (Hermann, 1997). Two participants (03; 11) obtained

scores suggesting possible clinical anxiety and one participant (06) obtained a score suggesting probable clinical anxiety. On the depression sub-scale, no participants scored in the range suggesting possible clinical depression.

Table 2: Participants' scores on the Hospital Anxiety and Depression Scale

ID	Depression*	Anxiety*
01	2	1
02	1	0
03	2	8
04	5	7
05	1	7
06	7	11
07	3	5
08	6	4
09	2	3
10	5	0
11	6	9
12	1	1
13	0	1
14	2	0
15	0	5
16	2	1

* 0-7 = not clinically significant; 8-10 = possible clinical significance; 11-21 = probable clinical significance

Results from Grids

As it is not feasible to present the entire data set, only the main results are presented in this section. This data is presented in terms of median and range scores and with illustrations from individual grids.

Process of grid elicitation and rating

Eliciting element names for admired person, disliked person and me in my prime proved relatively easy for most men. Participant 04 was the only man who could not identify somebody he knew whom he admired and chose to use a deceased footballer. Participant 14 was the only man for whom me in my prime was not

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provided as an element, as he insisted that he is currently in his prime, therefore this was captured in the element me now. For the partner element, most men had current partners who were supplied. Two men were widowers and they were asked to think about their wives as they remembered them (04 and 12).

Most men were able to hold in their mind's eye stereotypes for a man my age, an old man, a man with prostate problems and a man without prostate problems. Those who struggled with any of these concepts were encouraged to think of a person they knew who met the criteria and that name was supplied on the appropriate element card. This was the case for four men (01; 02; 07; 10). Element cards for some of the 'typical' elements were not supplied for three men, because they had strong feelings against stereotyping (02; 07) or they could not capture in their mind's eye a suitable stereotype (12).

Most of the participants found it relatively easy to understand the instructions for eliciting constructs. Two men, however, had difficulty thinking in terms of similarities and differences and constructs were arrived at as a result of discussions around each triad as it was presented (10; 16). Most participants provided positive poles first in 50% or more of their construct pairs. Three men, however, provided mostly negative poles first: 05 and 11 provided negative poles first on 8 out of 11 pairs; twelve provided negative poles first on 2 out of 6 pairs. Construct elicitation was stopped for each individual when no new constructs were emerging. This led to variability in the number of constructs elicited across the group. The mean number of elicited constructs was 10 (range = 6-15).

None of the participants appeared to have difficulty in using the rating scale. All of them used the full range of the scale (i.e. incorporating both positive and negative ratings) for the majority of their construct pairs. All participants used the mid-point for some of their construct pairs. Some of the participants were openly using the mid-point as “I don’t know”, for others it was not possible to determine how it was being used.

Construct System Structure

None of the participants employed constructs in a “lopsided manner” (Winter, 1992), that is, none of them assigned most elements to only one of the poles. This suggests they do not have significant problems with adaptation. The total mean rating of constructs across the group was 3.64 and the total mean variation was 2.73 (rating scale range = 1-7). The mean use of the mid-point for any individual element was 2 (range = 0-6). These results indicate that there was sufficient variation about the construct mean for each participant to conclude that the elicited constructs are “useful” and discriminate between elements (Winter, 1992).

Content Analysis

There was considerable variation in the type of constructs elicited. The constructs were categorised on the basis of three independent raters’ views. Table 3 sets out the list of categories and illustrates how many of the elicited constructs fell into each category. A complete list of construct pairs for each participant is presented in Appendix 10.

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The median number of categories used by participants was 6 (range = 4-9). The most frequently used constructs across the group were those relating to social interaction (13%), forcefulness (11%), attitude to life (10%) and health (10%). These were also the most commonly used construct categories, with at least half of the participants employing constructs from each of these categories: twelve (75%) participants employed constructs from the social interaction category; ten (62.5%) from the forcefulness category; ten (62.5%) from the attitude to life category; and nine (56%) from the health category. The majority of constructs employed by the participants in this study related to interpersonal and emotional characteristics.

Table 3: Construct categories, overall frequency of rating and number of participants rating each category at least once

Category	Total Frequency (%)	No. of Participants (%)
Social Interaction	23 (13%)	12 (75%)
Forcefulness	19 (11%)	10 (62.5%)
Attitude to Life	17 (10%)	10 (62.5%)
Health	17 (10%)	9 (56%)
Emotion/Affect	13 (7.5%)	7 (44%)
Self-sufficiency	11 (6%)	7 (44%)
Work	10 (5.5%)	5 (31%)
Tenderness	9 (5%)	8 (50%)
Morality	9 (5%)	6 (37.5%)
Egoism	7 (4%)	6 (37.5%)
Factual Description	6 (3.5%)	4 (25%)
Organization	4 (2%)	4 (25%)
Intellective	4 (2%)	3 (19%)
Humour	3 (1.5%)	3 (19%)
Financial	3 (1.5%)	3 (19%)
Time Orientation	2 (1%)	2 (12.5%)
Sexual	1 (0.5%)	1 (6%)
Self-Reference	1 (0.5%)	1 (6%)
Unclassifiable	12 (7%)	9 (56%)

Tightness of Construing

Table 4 shows the percentage of variance accounted for by the first and second principal components. In the case of seven participants, component one accounts for half or more of the information in the grid. For all sixteen participants, two principal components account for the majority of the variance. Other components accounted for the remaining percentage of variance, but are not examined in detail in the principal components analysis.

The median score on the first principal component was 49% (range = 32-84%). Fifteen participants scored above the cut-off of 39.4% on the first principal component (Ryle & Breen, 1972) and one scored below. This suggests that fifteen participants were construing in a more rigid and unidimensional fashion than the subjects in Ryle & Breen's (1972) study.

However, given that the grids in this study comprised, on average, fewer constructs and elements than the 16x16 grids in Ryle & Breen's (1972) study, it is also necessary to consider another measure of tightness of construing. Intensity is a measure, developed by Bannister (1960), of the tightness of organisation in an individual's construct system. An intensity score above 0.5 suggests tight construing, whilst a score below 0.5 suggests loose construing. Table 5 illustrates the intensity scores for each participant. These scores suggest that seven participants are tight construers (01; 03; 04; 08; 09; 14; 15) and nine participants are loose construers.

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Taking both of the measures together, seven participants can be said to construe in a tightly organised manner and one participant in a loosely organised manner.

Table 4: Percentage of variance accounted for by the first and second principal components

ID	Component 1*	Component 2
01	50%	23%
02	40%	23%
03	80%	7%
04	66%	13%
05	32%	22%
06	47%	17%
07	41%	20%
08	84%	7%
09	62%	16%
10	40%	21%
11	47%	18%
12	53%	25%
13	49%	24%
14	49%	33%
15	70%	16%
16	40%	27%

* >39.4% suggests tight construing

Table 5: Intensity scores for each participant

ID	Intensity Score
01	0.52
02	0.41
03	0.79
04	0.63
05	0.37
06	0.46
07	0.41
08	0.83
09	0.60
10	0.34
11	0.47
12	0.49
13	0.49
14	0.54
15	0.68
16	0.44

Intensity score < 0.5 = loose construing; Intensity score > 0.5 = tight construing

Construing Prostate Problems

Table 6 presents the three constructs for each participant that most described the typical man with prostate problems. Most of these constructs are related to health, self-sufficiency, attitude to life and social interaction.

Table 6: Constructs used to describe the Typical Man with Prostate Problems

ID	Constructs
01	Not physically active; Unwell; Demanding of self/others
02	Ongoing medical condition; Positive; Self-seeking
03	Concerned about health; Burdened with difficulties; Reclusive
04	Unfit; No sense of humour; Finds it difficult to cope
05	Can't look after self; Feels socially left out; Cautious
06	Has real ailments; Loves routine; Riddled with medical problems
07	Checking waterworks; Disturbed sleep; Young at heart
08	Grumpy; Likely to stay indoors; Irritable
09	Worries about physical problems; Content to stay at home; Financial worry
10	Walks around like a zombie; Enjoys life; Doesn't boast
11	Has unexciting life; Incontinent; Unemotional
12	Does not go out; Thinks of self as old; Laid-back
13	Bit of a moaner; Bit of a bore; Lazy
14	Problems distort them; Has integrity; Nice
15	Has health problems; Always tired; Can get in a state
16	Is old; Tired and worn out; Unhappy

Inter-element Distances

Inter-element distances allow the researcher to examine how similarly participants construe pairs of elements. This section reports the median and range scores for pairings related to self-concept, construal of the typical man with prostate problems, construal of the typical old man and construal of the self in relation to the typical man with prostate problems and the typical old man. Median scores were deemed most meaningful in describing the data, because of the variation in scores across the data set. Median scores are a truer reflection of the typical score and the range scores illustrate the wide variation in scores across the group. Appendix 11 contains data on individual scores for each of the main element pairs.

An inter-element distance less than 0.8 indicates that elements are viewed as similar, whereas an inter-element distance greater than 1.2 indicates that elements are viewed as dissimilar (Slater, 1972). Inter-element distances between 0.8 and 1.2 indicate that elements are viewed as neither similar nor dissimilar, although trends can be interpreted.

Self-Concept

Current self-concept was explored by examining inter-element distances between self now and ideal self, disliked person, typical man my own age and self seen by others. Table 7 illustrates the median and range scores for the group. The median scores suggest that, as a group, the men view themselves now as reasonably similar to their ideal self and very similar to the typical man of their own age and the self as seen by others. At the same time, they construe

themselves as dissimilar from their disliked person. These results suggest that the men, as a group, have a reasonably high level of self-esteem.

Changes in self-concept were explored to establish whether the men saw prostate problems as impacting on their sense of self over time. Self before prostate problems and Self in 5 years were examined in relation to ideal self and disliked person (Table 7). These results suggest that participants construe themselves before prostate problems as similar to their ideal, but the trend is to construe themselves as increasingly more dissimilar over a period of time. The trend is also for them to construe themselves as more dissimilar to the disliked person over a period of time.

Table 7: Median and range scores illustrating inter-element distances related to Self-Concept

	Median Distance	Range
Self Now -		
– Ideal	0.82	0.21 – 1.46
– Disliked**	1.4	0.93 – 1.78
– Typical man my age*	0.64	0.38 – 1.82
– Self seen by others*	0.51	0.33 – 0.78
Self Before Prostate -		
– Ideal*	0.69	0.23 – 1.10
– Disliked**	1.26	0.75 – 1.71
Self in 5 Years -		
– Ideal	0.86	0.32 – 1.47
– Disliked**	1.41	0.83 – 1.87

* similar elements (< 0.8)

** dissimilar elements (> 1.2)

Construing Prostate Problems

Table 8 presents the inter-element distances across the group in relation to how they construe the typical man with prostate problems. It can be seen that the typical man with prostate problems is construed as dissimilar to the ideal self, but also dissimilar to the disliked person. The typical man with prostate problems, is, however construed as similar to the typical man of their own age and also to the typical old man. These results suggest that having prostate problems is associated, for these men, with being old.

Table 8: Median and range scores illustrating inter-element distances related to the Typical Man with Prostate Problems

	Median Distance	Range
<u>Man with Prostate Problems</u>		
– Ideal**	1.44	0.93 – 1.74
– Disliked**	1.26	0.61 – 2.03
– Typical man my age*	0.79	0.50 – 1.34
– Old man*	0.67	0.47 – 1.31
– Self Before	0.97	0.68 – 1.36
– Self Now	1.14	0.41 – 1.46
– Self in 5 years	0.97	0.48 – 1.29

* similar elements (< 0.8)

** dissimilar elements (> 1.2)

Table 8 also presents inter-element distances scores illustrating how the group as a whole construe themselves in relation to stereotypes of a man with prostate problems. The self before prostate problems is seen as neither similar nor dissimilar to the man with prostate problems. The self now is seen as less similar to the man with prostate problems. However, construing of the self in 5 years time suggests that participants anticipate themselves in 5 years time being more similar to the man with prostate problems than they are now. Furthermore, whilst

having prostate problems is not what the men would wish for their ideal selves, it is what they expect for a typical man of their own age.

Construing Old Age

Given that prostate disease is often associated with old age and that the men in this study construe the typical man with prostate problems as similar to the typical old man, inter-element distances in relation to the typical old man were also examined (Table 9). The typical old man is construed as dissimilar from the ideal self. Equally he is viewed as dissimilar from the disliked person.

There is a trend to view the self as increasingly similar to the typical old man over a period of time (Table 9). However, even the self in 5 years is not construed as similar to the typical old man to the degree to which the typical man my age is viewed as similar.

Table 9: Median and range scores illustrating inter-element distances related to the Typical Old Man

	Median Distance	Range
<u>Typical Old Man</u>		
– Ideal**	1.32	0.86 – 1.83
– Disliked**	1.36	0.30 – 2.06
– Typical man my age*	0.75	0.37 – 1.18
– Self Before	1.18	0.72 – 1.44
– Self Now	1.1	0.75 – 1.33
– Self in 5 years	0.92	0.55 – 1.25

* similar elements (< 0.8)

** dissimilar elements (> 1.2)

'Bother'

The Spearman correlation co-efficient was used to examine relationships between the I-PSS 'bother' score, HADS scores, mean inter-element distances on key grid pairings, and intensity of construing. Table 10 presents significant correlations.

There was a strong positive correlation between 'bother' and total I-PSS score ($r=0.73$; $p<.01$) and both irritative symptoms score and obstructive symptoms score also correlated independently with 'bother' ($r=0.57$; $p<.05$ and $r=0.72$; $p<.01$ respectively).

There was a significant positive correlation between 'bother' score and anxiety ($r=0.55$; $p<.05$) but no significant correlation between 'bother' score and depression as measured by the HADS. This suggests that the I-PSS 'bother' scale may tap the same constructs as the HADS anxiety scale.

There was a significant positive correlation between 'bother' score and 'self now-partner' ($r=0.72$; $p<.01$). This shows a trend for men to be more bothered if they think that they are dissimilar from their partner.

There was a significant positive correlation between 'bother' score and 'self now-self seen by others' ($r=0.58$; $p<.05$). This shows a trend for men to be more bothered if they think people see them differently to how they see themselves.

There was no correlation between 'bother' and tightness of construing.

Table 10: Spearman correlation coefficients for variables correlating significantly with ‘Bother’

	Bother
Total I-PSS score	0.73**
Irritative symptoms score	0.57*
Obstructive symptoms score	0.72**
Anxiety	0.55*
Self now-partner	0.72**
Self now-self seen by others	0.58*

* p < .05; ** p < .01

Results from Interviews

This section presents the key components derived from analysis of the interview transcripts, with illustrative examples. Using interpretative phenomenological analysis, the qualitative data collected from the interviews fell into four superordinate themes. Superordinate themes one, two and three were further divided into sub-themes:

Superordinate Theme One: Uncertainty/trying to understand

Sub-themes: Is it really a problem?
 What’s causing the symptoms?
 Information Seeking

Superordinate Theme Two: Implications

Sub-themes: Current physical and social implications
 Concerns about the future

Superordinate Theme Three: Means of Coping

Sub-themes: Emotion-focused coping
 Problem-focused coping
 Social Support

Superordinate Theme Four: Self concept/identity

Each theme is illustrated with the most salient quotes from participants and each quote notes the identity number of the participant. First, the interview process is briefly discussed in order to place the analysis in context.

The Interview Process

Some men began talking about their symptoms and what had led to their referral as soon as they sat down (04; 05; 12). In keeping with the idea of semi-structured interviews being flexible to the interviewee, the researcher was led by the participant and introduced the questionnaires, grid and demographic information at appropriate points, rather than dictating a structured format.

A number of participants began the interview by commenting on their motivations for taking part. Generally this included a concern that not enough is known about men's prostate problems (02; 04; 05; 07; 09; 16). Some men expressed concern that their difficulties were not really a problem for them and that they might not be helpful to the study (02; 05; 12; 14; 15). Nearly all the participants commented on how much they enjoyed the opportunity to talk about their experiences.

Some men had no symptoms, therefore the interview took a slightly different and shorter format.

Superordinate Theme One:

Uncertainty/Trying to Understand

- **Sub-theme One: Is it really a problem?**

Most participants spoke about how the symptoms had appeared and developed gradually over a period of time:

“It’s not something that happens overnight is it?” (12)

“It’s one of those things that just gradually happens”

(09)

This gradual onset appears to contribute to a lack of certainty amongst the men about whether they have a problem they need to see a doctor about, or whether it is a normal part of ageing:

“Just age I thought” (09)

“Sometimes I think I’m worrying unnecessarily and I’m

a hypochondriac” (06)

and it would seem that many of these men tolerated their symptoms for quite some time before coming to the attention of the medical profession:

“I suppose, in a very minor way, the symptoms started about 10 years ago. I was aware that I needed to go to the loo more often than other people” (11)

“I guess about 16 years ago. I didn’t really do anything about it” (12)

Whilst some of the men had some prior knowledge about prostate problems:

“One has always been aware that this can be a problem”
(01)

many did not and attributed their symptoms to urinary difficulties they had had earlier in their lives:

“I’ve always been the man who has the weak kidneys”
(08)

“All my life, since I was about 12 or 13, I’ve had a urological problem...I can’t really urinate unless I’m somewhere private” (06)

Having some knowledge about potential prostate problems prompted some men to visit their GPs:

“Because of my general knowledge about male cancers,
I went to the doctor” (09)

However, many of the men in this study only sought medical attention when prompted to do so by friends or family:

“My daughter’s a nurse and she kind of pressured me”
(06)

“I was talking to a chum of mine and he said he and a
number of friends had had cancer of the prostate and
that I should have an examination” (05)

or when they happened to be seeing their GP about something else:

“I went to see the doctor about something else and I
mentioned this to him” (12)

“When I went to my doctor because of a check-up...I
told him” (10)

The potential that symptoms might be related to cancer was more likely to prompt some men to seek medical attention:

“There is a history of cancer in the family, so I thought I should perhaps take it a bit more seriously than I usually take things” (05)

However, it seems that even then, one man only felt it worth mentioning as an aside whilst at the hospital for an annual check-up:

“I’ve heard about prostate cancer and realized I was getting to the age and I also realized some of the symptoms were perhaps an indication of something, so I thought I’d mention it to them” (03)

He suggested that this was mainly because he did not feel his GP would know anything about it:

“Mainly because I thought they’d be more knowledgeable than my GP” (03)

In the case of some men it was pure chance that they had been referred to a specialist clinic:

“I had a hernia operation last year and the consultant did some poking and said I had an enlarged prostate”

(09)

“I’ve come in having a funny turn on the street...I’m worried about my chest and they seem to be as much worried about my prostate gland” (04)

One man summed up the apparent ad hoc element associated with obtaining medical intervention:

“It’s very odd how it all turned out because I might have gone for the rest of me life not knowing” (04)

Sub-theme Two: What’s causing the symptoms?

Although one man was of the opinion that the cause of his symptoms did not matter:

“I said to my doctor, I only want to treat the symptoms, forget the cause” (12)

On the whole, the men in this study showed a strong inclination to think about what might have caused their symptoms and to understand what was happening in their body. Some believed that it was part of the natural ageing process:

“Just one of the aches and pains as you get older” (02)

“Old age is just a series of complications and interaction between slightly run down bits of the system” (14)

Although others had given this some consideration and ruled it out:

“There doesn’t seem to be any connection with getting older. Some days it’s worse and some days it’s better” (13)

In their attempts to understand their symptoms, some of the men appeared slightly confused. Many, in searching for an explanation, wondered whether they had damaged their internal organs or picked up some sort of infection:

“I don’t know if I damaged it or not, but I was very constipated one time” (08)

“I’ve had thrush a few times. I don’t know if that was the cause of it” (05)

There was a certain degree of embarrassment from one man, as he suggested his symptoms might be due to a sexually transmitted disease:

Chapter Three: Results

“It might be urinary damage, due to a particular time in my life when I was rather promiscuous” (11)

and another was very focused on his decreasing orgasms as a symptom and wondered:

“Is the testosterone running out or something? I’ve no idea. Maybe one has a limited supply of orgasms just like one has a limited supply of eggs” (14)

Some men, in an attempt to understand what was happening, began to monitor their urinary habits and to look for patterns or triggers. Two men had made a link with cold weather:

“Cold weather affects one’s wanting to pass water” (01)

“The only time I get anything during the day is when I happen to be exceptionally cold” (10)

Others were of the opinion that there were psychological elements triggering their need to urinate:

“It’s a psychological problem. If I know there’s a loo in the offing I desperately want to pee” (12)

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“Putting the key in the door, knowing that you’re a few yards from the loo, haven’t wanted to go, but then you realise you do” (11)

For many of the men they had noticed the need to urinate more when they were under stress:

“It comes on more when I’m stressed” (01)

and this was associated with the need to go less when they felt relaxed:

“If I’m generally relaxed, then I can afford to be relaxed about urinating” (11)

In general, the men admitted they did not really know what was causing their symptoms:

“I never really understood the mechanics of it” (05)

and, although they tried to understand, they had limited knowledge about what was going on in their bodies:

“I understand it, the, something which is a medical condition anyway, relaxes the muscles, which is the

bladder and, um, it seems to me there is something which constricts them” (12)

“I don’t know what it is exactly, some neurological connections or something” (01)

Sub-theme Three: Information Seeking

All of the men recognised the fact they did not really understand their symptoms and had a lot to learn:

“I’m only a learner in the prostate field. I’m still learning now” (04)

In most cases, the men in this study expressed a desire to learn more about their symptoms:

“There was a nice article in the FT about a fortnight ago which described the problem, it was only a page, but it was quite helpful” (05)

One man even commented to the interviewer that he was:

“Hoping you could tell me what to eat, what to drink, what to do” (04)

There was, however, a certain degree of frustration among some men that the information was not readily available:

“I think information is very useful and it should be more widely known than it is” (02)

“I do feel very strongly that there is little or no information and there is no campaign which says, go and get your doctor to organise a PSA at regular intervals when you get to a certain age” (09)

and that what was available was not particularly informative or reassuring:

“I looked it up in this book my wife’s got, but it didn’t say very much” (13)

“I have seen a video of the prostate, but I don’t think it really reassured me” (06)

This lack of widely available information also contributed to a view among one or two of the men that the medical profession did not really know much about it either:

“It is quite clear doctors don’t know very much about it” (011)

Superordinate Theme Two:

Implications

The current and potential implications of their symptoms appeared to fall into two sub-themes. The first relates to current physical and social implications; the second to concerns about the future.

Sub-theme One: Current Physical and Social Implications

All the participants in this study talked about the physical and social implications of their symptoms. One main topic related to the impact their symptoms had on normal patterns of daily functioning. For example, disturbing their sleep:

“The only thing is the inconvenience getting up in the night” (13)

or having to interrupt activities to relieve themselves:

“It’s a bit constricting, because when you have to go, you have to go” (12)

“Annoys me when I’m driving along in the car, I think I’m bursting, so I pull up, find somewhere to relieve myself and then...an egg cup...drive another 50 miles, jump out again” (04)

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For some men interrupted sleep was having further implications during the day:

“I don’t like the sleep patterns being broken, because I have to concentrate on head work and writing. I get irritable after a lack of sleep and it does affect my concentration, no doubt about that and I don’t like drinking too much coffee and that’s what happens when you haven’t had enough sleep” (07)

For others, needing to relieve themselves frequently was more of a problem than disturbed sleep patterns:

“The worst aspect...I don’t mind getting up in the night, so it’s partly the tiresomeness and the discomfort when I go anywhere; needing to know where the loo is” (11)

The extent to which frequently needing the toilet was a problem varied, it would seem, dependent on the man’s daytime occupation:

“Usually I can get myself to the loo without any problem, because I’m usually at my desk” (07)

“It’s a bit difficult for me to say, if I’m chairing a meeting, oh give me five minutes” (02)

There was also variation in how men coped with the need to urinate frequently.

Some men seemed to ignore the urge:

“I very often mess around and don’t go until the last minute and then it certainly does become very urgent”

(09)

whilst others ensured they took adequate precautions so that they were not caught short:

“I’m definitely aware of the precautionary behaviour, get it out of the system for later on” (11)

A number of the men joked about their need to use the toilet:

“I know the sight of practically every public lavatory in England!” (12)

“You have to husband yourself a bit. Take a pee before you leave the house, that’s a good boy!” (07)

However, one man highlighted the potential consequences of not being able to get to a toilet when it was needed:

“We were sitting in the car... then it started to pour with rain and I remember for those few minutes I couldn’t operate properly, because I was in such distress” (01)

For many men a further impact of their symptoms related to social embarrassment. For example, one man said that, despite an understanding wife, he found it embarrassing to get up in the night:

“She seems understanding...it’s me that feels a bit embarrassed. She seem to take it in her stride” (03)

Other men indicated that they were conscious of their symptoms when in public and hoped that people did not notice:

“I don’t think people on the trip realised I had a problem” (12)

“I feel quite self-conscious...thinking people can see where I’ve leaked” (11)

Despite the physical and social implications mentioned above, most men were keen to point out that their symptoms did not interfere with their lives:

Chapter Three: Results

“I’m to a certain extent on the outside looking in, because I don’t feel that my problem is so great that it’s affecting my life” (05)

“It certainly hasn’t stopped me going to the theatre and things like that...it doesn’t materially affect my life” (12)

One participant offered a suggestion as to why his symptoms did not interfere too much in his life and why some people might be more affected by their symptoms than others:

“In many ways my time is my own, it doesn’t affect my job, it’s not like I’m a taxi driver and can’t get to the loo or something. I think it’s a problem for people where it affects their lifestyle” (02)

Most of the men felt that, on the whole, their current symptoms were manageable, but they expressed concern about the future:

“It doesn’t significantly affect my life at the moment, but it’s the thought that it might that is disturbing” (01)

Sub-theme Two: Concerns about the Future

In general, the nature of the participants' concerns varied. One common concern related to the possibility of cancer:

“The worst aspect is the possibility there may be a cancer” (09)

However, whilst the possibility of cancer had been considered by nearly all of the men, many said they were not overly worried that their own symptoms were suggestive of cancer:

“I have seen it said that it can lead to prostate cancer, but I don't necessarily think what I've got will lead to prostate cancer, but I don't know” (06)

“I never have thought it was cancer, on the simplistic evidence it hasn't changed much in 15 years” (12)

A further concern among some of the men was that their symptoms might affect their sex lives:

“I guess I wouldn't be happy if it affected my sex life”
(05)

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“I definitely associate urinary problems with decline in sexual activity” (11)

All of the participants expressed concern that their symptoms might worsen:

“I assume they [the symptoms] can only get worse and I guess the future will be less comfortable than the present” (01)

The men had various concerns about the worst thing that might happen in the future. Some men were concerned about urinary retention:

“I might get urinary retention and that would be very painful” (16)

“I’m worried about being in the back of beyond and getting constipated and not being able to urinate and being in big trouble” (06)

Others wondered if they would need an operation to remove the prostate. This was something that many wanted to avoid if at all possible:

“I’d like to have it put right, rather than have an operation. If the worst comes to the worst and I’ve got

to have an operation then fair enough I'll have it done.

If I've got to" (04)

"I wouldn't go under the knife unless I really had to"

(05)

For some the reason for avoiding surgery was linked to concerns about long term implications such as sexual function:

"My chum said, if one had the prostate removed, one's orgasm is quite different" (05)

For others it was the belief that they were too old:

"As I'm 80... I think even if it was malignant, we won't be operating" (12)

Superordinate Theme Three:

Means of Coping

Sub-theme One: Emotion-focused Coping

Participants adopted a range of coping strategies. Whilst some of the men commented that they were, to some extent, always aware of their symptoms:

"It's there at the back of your mind" (02)

“It gets in your head a little bit” (07)

most said they were not worried:

“It’s nothing to worry about” (08)

“I don’t dwell on thinking I’ve got prostate cancer” (02)

Many of the men suggested that worrying served little purpose:

“What’s the point in worrying?” (10)

Others considered that it was just part and parcel of life’s challenges:

“The life that I’ve gone through...lots of difficulties
over my lifetime. I just take it in my stride” (04)

and, in the general scheme of things, it was not as serious as some other health
problems:

“I tend not to worry about difficulties with health,
because I have suffered a very serious one” (03)

“In the general scheme of things, if you haven’t got prostate cancer, if it’s just prostate trouble, then it’s nothing serious” (02)

Sub-theme Two: Problem-focused Coping

For many, the symptoms represented a problem that needed sorting out:

“If it’s able to be sorted, that would be better” (02)

“If you’ve got it then do something about it” (15)

The means by which they hoped the problem could be sorted out varied. Some of the men were hopeful that the medical profession, as experts, would sort it out for them:

“If the medical profession can do something they’ll do something about it. If I need my house painting I get the experts in, same as my skill is with working with figures, and that’s what I do” (15)

For some men, this faith in the medical profession was linked with a hope that there might be some form of medication that would sort it out:

“I feel that I’d like to leave it up to him [the specialist].

I hope he’s gonna give me some tablets that’ll see it put right” (04)

Although one man hinted that whilst he would like medication, he doubted that was going to solve his problem:

“I don’t believe there are these magic pills, I don’t believe the body quite works that way” (15)

Another indicated that he preferred to try other options before resorting to medication:

“I started taking saw palmetto, you know the natural remedy, do it yourself if you can and avoid medicine at all costs” (07)

Most of the men felt they had a role in sorting out the problem:

“For the whole of my professional life I’ve been solving problems...so I’m the problem. I tend to try and think logically, cause and effect. There’s no reason why I shouldn’t take the same approach to myself” (12)

For some men this role involved ensuring they had regular checks:

“I think it’s a good idea to have a check every year. I do believe in taking care of myself” (06)

“I think when you get to my age, if the opportunity’s there to have checks done then you have it done” (15)

Others talked about changing their diet:

“I try not to drink any tea or coffee anymore” (11)

“I’m on the circulation of some doctor who advocates non-conventional food supplements” (06)

Others developed precautionary behaviours, thereby taking control of the symptoms, rather than being controlled by them:

“To some extent I take precautions – trying to avoid a situation where one has to dash” (11)

“Empty the bladder before you go out” (13)

Sub-theme Three: Social Support

Most of the men appeared to cope with their symptoms on their own. Seeking social support was something only a few men talked about:

“I’ve talked to my step-father about it because he started this problem a long time ago. He’s the only one I’ve discussed it with. It’s not something I talk about” (07)

This man’s comments suggested that talking about his problems was not something a man did, rather that was the way in which women coped:

“They [step-father and friends] all sit around discussing their ailments. They sound like a bunch of old ladies, getting together, going on and on” (07)

Those men who had talked about their problems seemed to have heard only bad news. One man had talked to a fellow patient at a doctor’s surgery:

“I spoke to a chap quite recently...he’s had three operations and I explained it all to him. He doesn’t think it’ll get better, it’ll get worse” (04)

Another had spoken with a number of other people and this had increased his own concerns about the symptoms:

“I’ve talked to other people and if it started being like that then I’d be worried” (08)

One man talked about his faith and how that was his main source of support:

“I don’t get worried about these things. I’m convinced that, whatever happens, he’ll look after me” (15)

Superordinate Theme Four:

Self-Evaluation/Identity

In talking about their symptoms and associated experiences, most participants compared themselves with other people and with themselves in the past. For some, comparing their current selves with past selves seemed to be a means of normalising their symptoms:

“From a child I used to go much more than anybody else” (09)

For others, it highlighted their deterioration:

“Normally, as a youngster, getting up once was quite normal, but getting up two, three, four times...” (02)

For one man comparing his current self with his past self helped him to keep his symptoms in perspective:

“I tend not to worry about difficulties with health because I have suffered a very serious one” (03)

This appeared to serve a similar function to the downward comparison that other men spoke about:

“One of my brothers suffers with gout, another has Hep C. No this is not really a problem” (02)

“How fortunate you are not to have the other horrible things that people can have” (14)

Only two men compared themselves with their partners, but their comments highlighted two contrasting views. For one man, having his symptoms appeared to make him more similar to his wife:

“She suffers from arthritis, so we’ve both got a handicap” (10)

For the other it appeared to highlight difference:

“My wife’s younger than me and it seems to underlie my ageing to have to get up in the night” (03)

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Generally, when men talked about friends or associates whom they knew experienced prostate problems, there was a tendency to feel sorry for them:

“Poor chap [90 year old relative] he has to wear a nappy” (05)

Only one man, however, appeared to link his friends’ experiences with the potential that his own symptoms might worsen:

“I’ve talked to other people and if it started being like that, then I’d be worried” (08)

Finally, the way in which some of the men labelled their symptoms suggests a desire (whether conscious or unconscious) to avoid labelling themselves as ill:

“It’s more like an inconvenience than an illness” (02)

“I damn nearly [had an accident] but only because of delay, not because of any condition” (09)

Perhaps this is linked to a desire not to think of oneself as ageing. As one man appears to suggest, getting older is one thing, but having problems is not to be desired:

“I wouldn’t want to be an old gentleman with a problem” (09)

Case Examples

The following section presents detailed results for two participants: Fred (05) and Charlie (11). Names have been changed to preserve confidentiality. These two participants were chosen because they are of the same age and exhibited similar levels of symptomatology (in the moderate range), but indicated different degrees of bother. That is, Fred stated that he would be “mostly satisfied” if his symptoms remained as they were and Charlie indicated that he would be “mostly dissatisfied”. Charlie was the only participant (other than the man with severe symptoms) who indicated that he would be dissatisfied if his symptoms remained as they were. These two cases illustrate the themes that emerged across the group, but also highlight the difference in emphasis amongst individuals.

Fred (05)

To recap, Fred is a 60 year old, self-employed professional. He is divorced, but has a long-term partner of ten years. His partner does not live with him. On the International Prostate Symptoms Score, Fred’s total was 14 (8 on irritative symptoms and 6 on obstructive symptoms) (Appendix 12). On the Hospital Anxiety and Depression Scale, Fred scored 1 on the depression sub-scale and 7 on the anxiety sub-scale (Appendix 13). These scores are not clinically significant.

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Fred first noticed changes in his urinary pattern and “some symptoms of urgency and retention” about 5 years ago:

“I suppose [I’ve had the symptoms] in some form for 5 years. Very faint amount of incontinence and sometimes when I’ve finished peeing I’ll have a sort of dribble”

For some time, Fred did not consider his symptoms to be “any great problem”. Even after a friend, following his own experience with prostate cancer, advised that he had to have an examination, Fred “didn’t think very much about it”. It was only when another friend had his prostate removed due to cancer that Fred decided to visit a GP himself. Even at this stage, Fred said he was not worried and that:

“my symptoms [weren’t] of any great problem for me”

He saw the visit to his GP as a precautionary measure to ensure he did not have cancer:

“...enough to make me think: I should have this looked at and make sure there isn’t anything sinister”

Once he had visited his GP and got the results of the blood test, Fred “knew it wasn’t cancer”. He was not particularly concerned about his referral to the clinic,

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as the symptoms themselves “[don’t] really bother me”. At the same time, he shows an interest in understanding the cause of his symptoms and what is happening in his body. However, despite recently reading a newspaper article about the prostate and prostate related diseases, Fred still appeared uncertain about what might be causing his symptoms:

“I have had thrush a few times, I don’t know if that was
the cause of it”

He said that the article had been “quite helpful” but that he still did not really “[understand] the mechanics of it”.

Fred was keen to point out that cancer had been his only concern and that, generally, his symptoms did not impact on his life. He spent some time talking about his extensive social life and showing the interviewer rowing fixtures and invites to parties:

“I’m to a certain extent on the outside looking in,
because I don’t feel that my problem is so great that it’s
affecting my life”.

Fred stated that the only time “I wouldn’t be happy” was if it “affected my sex life”. He made a point of checking with the interviewer whether it was true what a friend had told him about prostate removal affecting one’s orgasm:

“My American chum...said that if one had the prostate removed, one’s orgasm would be quite different. Is that right? Because my sex life’s quite important you know. I’m quite active, I think, I mean by others’ standards I seem to be”

Fred’s general attitude to coping with his symptoms is summed up in a comment he made during the grid elicitation process:

“The difficulty is to what extent the typical man with a prostate problem has a problem. I think he’ll feel left out of social situations if he allows it to get on top of him. I guess in a way it becomes a self-feeding apprehension”

This comment seems to suggest that how one labels one’s symptoms might affect how one construes them and how one copes. It is possible that Fred was able to put his symptoms into some perspective, because he did not really label them as “a problem”.

Fred’s Grid

Table 11 presents the 11 construct pairs elicited for Fred. Fred employed a range of constructs, which, taken together, portray somebody whose main concerns are around work, money and enjoying life. There is a lack of emotion-related constructs or constructs related to health or ageing.

Table 11: Construct pairs elicited for Fred

Elicited Pole	Contrast Pole	Category
Not worried about money	- Worried about money	(Financial)
Smug	- Not smug	(Egoism)
Enjoying life	- Little purpose to living	(Attitude to Life)
Can't look after self	- Can look after self	(Self-sufficiency)
Feckless & incautious	- Sensible	(Unclassifiable)
Hard-working	- Less industrious	(Work)
Takes a gamble	- Cautious	(Unclassifiable)
Honest	- Dishonest	(Morality)
Respects lawyers	- Less respect for lawyers	(Social Interaction)
Feels socially left out	- Feels socially active	(Social Interaction)
Retired	- Not retired	(Work)

The first, second and third principal components derived from the Flexigrid analysis account for 32, 22 and 22 per cent of the variance respectively, suggesting reasonably loose, multidimensional construing. Further evidence of loose construing is illustrated by an intensity score of 0.37.

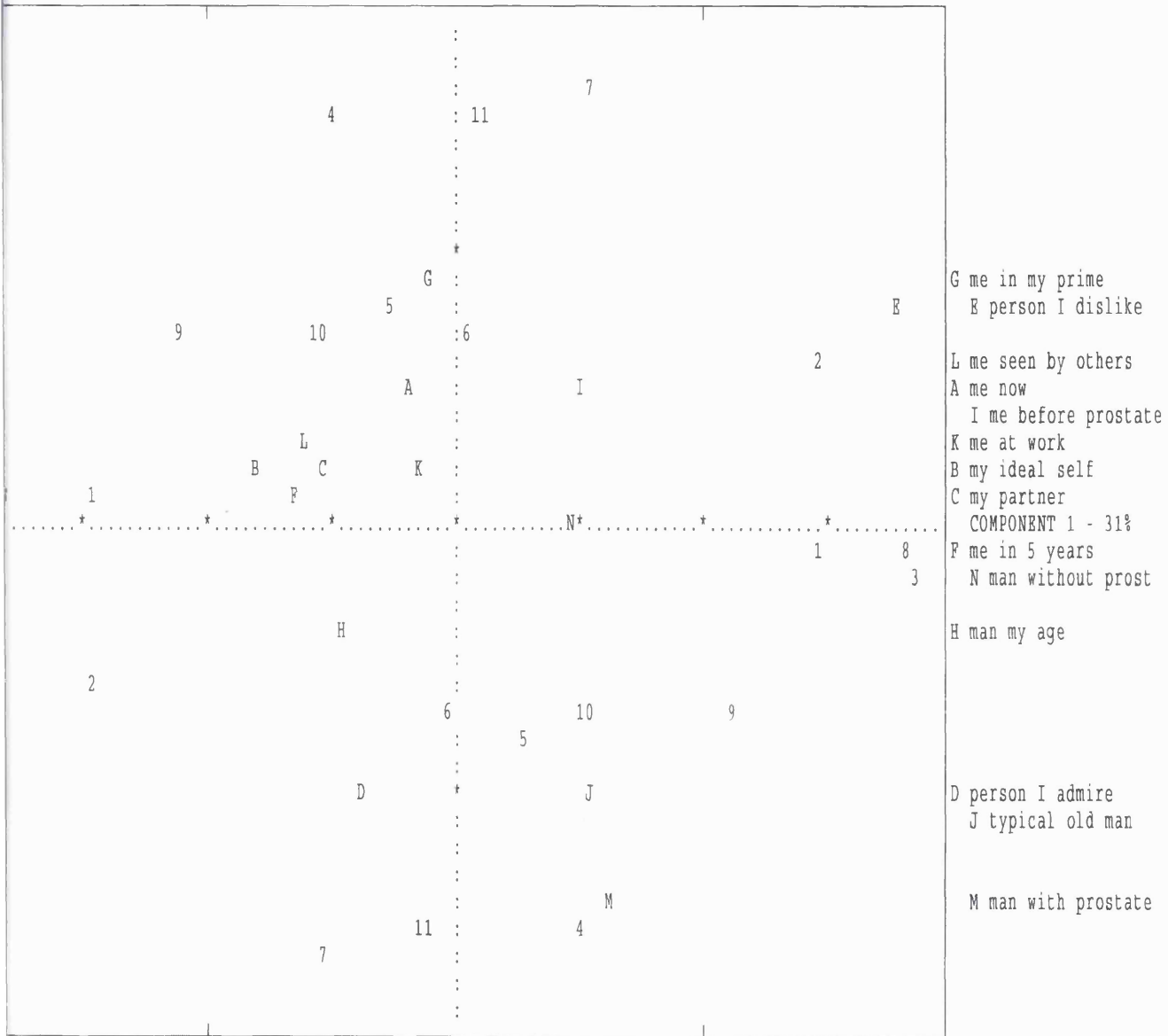
Figure 1 illustrates the plot of key elements. As this is a two-dimensional plot, only the first and second principal components are illustrated. Component one is the horizontal axis and component two is the vertical axis. The left side of the horizontal axis and the top of the vertical axis are the positive poles.

FRED'S PLOT

ed results

respect for lawyers 4 can look after self 7 takes a gamble 2 smug
 g life 5 feckless & incautious 11 not retired
 tied about money 10 feels socially active 6 hard-working

COMPONENT 2 - 23%



g 6 less industrious 10 feels socially left out 8 dishonest
 11 retired 5 sensible 1 worried about money
 7 cautious 4 can't look after self 3 little purpose to living
 9 respects lawyers

supported by data from the interpretative phenomenological analysis, which indicated that Fred did not view lower urinary tract symptoms as a problem. It is unfortunate that sexual activity did not emerge as a construct for Fred, because this was an area of his life and identity that he particularly valued and was most concerned might be affected by prostate problems.

Charlie (11)

Charlie is a 61 year old professional. He has been married for 30 years. On the International Prostate Symptoms Score, Charlie's total was 15 (10 on irritative symptoms and 5 on obstructive symptoms) (Appendix 14). On the Hospital Anxiety and Depression Scale, Charlie scored 6 on the depression sub-scale and 9 on the anxiety sub-scale (Appendix 15). The anxiety score is within the range to suggest possible clinical significance; the depression score is not clinically significant.

Charlie first noticed symptoms of frequency about 10 years ago:

“I suppose the symptoms started about 10 years ago. I was aware that I tended to need to go to the loo more often than other people”

He went to the GP regarding his symptoms about five years ago, but “did not follow it up”. The symptoms then worsened about a year ago to include incomplete emptying, urgency, weak stream and nocturia, all of which were deemed “very unusual for me”.

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Charlie had clearly given some thought to trying to understand the cause of his symptoms and had consulted a book he had about “special problems of men”. It seems, however, that he is somewhat confused about the underlying cause. He speculates that it might be hereditary:

“I was prompted by my father’s incontinence and wondered if it may be hereditary”

He also thinks that:

“it might be urinary damage, due to a particular time in my life when I was rather promiscuous”

or:

“whether it has to do with chemicals or hormones...I don’t know”

He has also considered that it might be related to getting older, but concludes that:

“there doesn’t seem to be any connection with getting older”

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It was apparent that Charlie invests a great deal of time in monitoring his symptoms and looking for patterns. He has come to the decision that “there are some aspects which can’t be taken into account by an enlarged prostate”. These aspects he thinks are possibly “psychological”. He has reached this conclusion, because he has noticed that there might be a link with when he is tense:

“It’s a lot connected with tension...if I’m generally relaxed then I can afford to be relaxed about urinating”

and he has also noticed that there is a habitual element involved:

“putting the key in the door, knowing that you’re a few yards away from the loo, haven’t wanted to go, but then you realise you do...there’s something in the situation that triggers it...there’s no doubt that if it gets into one’s conscious then one gets the urge”

For Charlie, being able to understand the triggers enables him to “take precautions” and “avoid a situation where one has to dash”. He has also reduced his tea and coffee intake, although admits: “I can’t stop alcohol”. One of his greatest motivations to take control of the symptoms seems to lie in the fact that he fears social embarrassment:

“I feel quite self-conscious – thinking people can see where I’ve leaked. I’m never sure, you know, whether people can see”

and he recognises that this, in a sense, makes the situation worse:

“In work type situations, then you start getting tense about ‘maybe’...it’s all happening and you’re under pressure, this tends to turn itself into an emergency”

In terms of longer term implications, Charlie, like Fred, is concerned that his symptoms will affect his sex life, although that is not currently the case:

“I definitely associate urinary problems with decline in sexual activity”

Charlie’s Grid

Table 12 presents the 11 construct pairs elicited for Charlie. Charlie employed a range of constructs, which appeared to be related to emotions, ageing and health.

Table 12: Construct pairs elicited for Charlie

Elicited Pole	Contrast Pole	Category
Unruffled	- Panicky	(Emotion/Affect)
Egotistical	- Sensitive to others	(Egoism)
Emotional	- Unemotional	(Emotion/Affect)
Sensitive	- Insensitive	(Tenderness)
Has an unexciting life	- Has an exciting life	(Unclassifiable)
Incontinent	- Not incontinent	(Health)
Looks forward to saga holidays	- Puts energy into achieving things	(Forcefulness/Time Orientation)
Aggressive	- No longer aggressive	(Social Interaction)
Has internal goals	- Socially determined goals	(Self-sufficiency)
Past it	- Sexually active	(Sexual)
Bullying	- Not a bully	(Social Interaction)

The first, second and third principal components derived from the Flexigrid analysis account for 47, 18 and 15 per cent of the variance respectively, suggesting that, although reasonably tightly structured, Charlie's construct system contains more than one viable dimension of construing. An intensity score of 0.47 supports the suggestion that Charlie's construing is reasonably tightly structured, but not particularly so.

Figure 2 illustrates the plot of key elements. Component one is defined by the constructs: 'sexually active', 'has an exciting life' and 'aggressive'. The disliked person (E) is construed most clearly by this component and the typical old man (J) is construed most clearly on the opposite pole. That is, the typical old man is construed as 'past it', 'has an unexciting life' and 'no longer aggressive'.

Component two is defined by the constructs: 'insensitive' and 'egotistical'. The disliked person is construed most clearly on this component and the ideal self (B) is construed most clearly on the opposite pole (i.e. 'sensitive').

CHARLIE'S PLOT

Chapter Three: Results

The plot shows that Charlie's current self (A) is close to the origin and this indicates that he does not have a very clear picture of himself. Charlie does not construe himself as particularly similar to his ideal self (B) or the typical man his own age (H) but neither is he similar to the disliked person (E). Charlie construes himself as most similar to the typical man with prostate problems (M), but anticipates that, in 5 years time, he will be less like the typical man with prostate problems and slightly more similar to his ideal self. Charlie does not view himself as particularly similar to the typical old man (J), neither does he view the typical man with prostate problems as particularly similar to the typical old man.

Charlie's grid suggests that 'bother' may be related to not really knowing who he is, but seeing himself as similar to the typical man with prostate problems, whom he views in negative terms and as very dissimilar from his ideal self. Data from the interpretative phenomenological analysis illustrates how Charlie is preoccupied with monitoring and trying to understand his symptoms. Sexual activity emerged as a main construct for Charlie, both in the interview and in the repertory grid, lending further weight to an argument that 'bother' might be associated with decline in sexual activity.

CHAPTER FOUR

DISCUSSION

This was a descriptive study, which set out to explore men's experiences of having lower urinary tract symptoms. Of particular interest was the concept of 'bother' and attempting to understand individual responses to similar sets of symptoms. The study adopted repertory grid methodology and interpretative phenomenological analysis in an attempt to capture the participants' own perceptions about their experiences.

This chapter summarises the main findings from this study and explores some of these findings in more detail, with reference to the existing literature. The findings are then discussed within the context of their potential relevance to understanding 'bother'. Throughout this discussion, an attempt is made to integrate results from the two methodologies. The chapter ends with reflections on the strengths and limitations of the study, suggestions for future research and a discussion of the clinical implications of these findings.

Summary of Main Findings

In terms of psychological well-being, the overall picture is a positive one. The men in this study report low levels of 'bother', anxiety and depression and minimal impact on their current sense of self.

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Most participants in this study reported mild or moderate symptomatology, with only one participant reporting severe symptomatology. Participants reported varying degrees of 'bother', but only two were rated as highly bothered. Higher scores on 'bother' were associated with more symptoms and this was independent of whether symptoms were 'irritative' or 'obstructive'.

Three participants scored in the range suggestive of possible or probable clinical anxiety. Higher 'bother' scores were associated with higher anxiety scores, suggesting that the two measures may be tapping the same constructs. There was no direct association between anxiety and degree of symptomatology. None of the participants scored in the range suggestive of possible clinical depression.

In general, participants had tolerated their symptoms for a number of years before coming to the attention of the medical profession. For the most part, this was due to uncertainty about the seriousness of the symptoms. Most had not actively sought medical attention for their symptoms, but had 'mentioned' them, or been asked about the presence of such symptoms, when attending the GP or hospital for another reason.

There was considerable variation in the types of constructs employed by participants in the repertory grid component of this study. The constructs most frequently elicited related to social interaction, forcefulness, attitude to life and health. Some of the constructs elicited were complex and classifying them was quite difficult, resulting in a relatively high number of constructs that were unclassifiable.

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Approximately half of the participants construed in a tightly-organised and unidimensional manner and one participant was found to be a loose construer.

In general, participants indicated that they were currently quite similar to their ideal self, suggesting reasonably high levels of self-esteem. There was, however, some evidence that self-esteem was higher before they had prostate problems and that they anticipated becoming less like their ideal self in the future.

Most participants held stereotypical views about what it meant to have prostate problems. Many men held the view that prostate problems were a natural consequence of ageing and a disease associated with old age. Overall they construed the typical man with prostate problems in terms of primarily negative constructs regarding health, self-sufficiency, social interaction and attitude to life.

Most participants did not consider themselves as similar to the typical man with prostate problems and most did not view themselves as old. Whilst being like the typical man with prostate problems or the typical old man was not something they would want for their ideal self, most participants construed both as dissimilar from their disliked person.

Most participants seemed confused about the cause of their symptoms and applied models of acute illness in an attempt to understand them. For example, wondering if they had an infection (e.g. thrush), hoping that medication would provide a 'cure' and attempting to take control over the symptoms. Linked with

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this was the adoption of problem-focused coping strategies (e.g. seeking information).

A significant positive correlation was found between 'bother' and the inter-element distances 'self now-self seen by others' and 'self now-partner'. This suggests that issues about social embarrassment and effect on intimate relationships have relevance in understanding 'bother'. Interview material also suggested that 'bother' might be related to issues around ageing, shame/social embarrassment, sexual relationships and worries about future health problems (e.g. cancer; urinary retention).

A lot of the findings from this study are consistent with the public perception of male stereotypes and how men cope with health related issues and life events in general. Social constructionist theories about gender and what it is to be male (e.g. Courtenay, 2000) have something to offer in putting these findings into context.

The next section discusses some of the findings in the context of social constructionist theories. The discussion then returns to the questions identified in the introduction to this thesis, namely to examine the meaning of lower urinary tract symptoms for men, offer suggestions as to the factors that relate to bother and comment on reasons why symptoms may be bothersome to some men and not to others.

Masculinity

The main argument of the social constructionist model is that “health-related beliefs and behaviours, like other social practices that women and men engage in, are a means for demonstrating femininities and masculinities” (Courtenay, 2000, p.1385). It proposes that health behaviours are used in daily interactions in the social structuring of gender and power and argues that men, in general, are less well represented than women in health care settings, because to acknowledge illness is to give others the message that one is weak. Illness has become socially construed as weak and therefore, feminine. Men are motivated to hide any physical frailties and in this case any suggestion of disease, especially a disease that might highlight their ageing, in order to preserve their masculine identity.

One man in this study summed up beautifully what is, perhaps, a commonly held belief about managing health threats (i.e. to talk about illness is essentially a female activity):

“...my step-father...and I think, all the boys at his [tennis] club, they all sit around discussing their ailments. They sound like a bunch of old ladies, getting together going on and on” (07).

One of the tenets of the social constructionist model is that social, economic and ethnic factors help explain the differences in attitude towards healthcare amongst men. Of importance here is the fact that more affluent, better-educated males in society have access to the material symbols that help to reinforce their identity as

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males (e.g. fast cars; expensive 'gadgets'). In contrast, the poorest males within society are forced to rely on alternative strategies. One of the principle strategies adopted is to ignore their own personal health and the health care system as a way of demonstrating their physical superiority. This might go some way to explaining why most men who chose to engage in the present study were from the professional and middle/upper middle classes.

However, the social constructionist argument is that, even amongst middle class males there is great reluctance to discuss health problems with the medical establishment. The argument is that, particularly for professional men, who are used to holding positions of power within the workforce, this is to do with preserving one's masculinity and a fear of being placed in an inferior position when interacting with a doctor or other professional. Avoiding health allows such men to maintain their status and to avoid being relegated to a subordinate position in relation to doctors and health professionals. Courtenay (2000) suggests that, for an upper middle class businessman, refusing to see a doctor can be a means of maintaining their position of power. This is a potential explanation for why men in the present study tolerated their symptoms for quite some time before seeking medical attention.

Other research has also found that men delay seeking medical attention for prostatic symptoms. For example, Jacobsen et al (1993) reported that, in their large-scale community study of 2,000 American men, symptoms alone did not predict health-care seeking behaviour. Furthermore, Kiviniemi & Suominen

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(1999), in a small-scale Finnish study, found that, in some cases, men had symptoms for 20 years before coming to the attention of the medical profession.

It is interesting to consider the only gay man in the present study in the context of the social constructionist model. He was the only participant who talked about influencing his own treatment when faced with a doctor who had a different point of view:

“He [the GP] did the usual: ‘it doesn’t seem terribly big to me and it doesn’t seem deformed in any way, why bother [referring to a specialist]?’ And I said: ‘well it’s my bum, I am going to bother’ and so off he sent me to the clinic” (09)

Furthermore, this man had recently attended a conference on men’s health and had openly challenged the medical profession on the lack of available information about prostate problems and men’s health issues generally.

It could be argued that this man had probably already had to fight against the stereotypical powerful male, in order to assert his own masculine identity and, therefore, was not fearful of being disempowered when interacting with a so-called ‘expert’. On the other hand, it could be argued that he was even more driven than other men to assert his masculine identity by speaking out and undermining members of the medical profession.

The Meaning of Lower Urinary Tract Symptoms

Whilst there are common themes, experiencing lower urinary tract symptoms has different meanings for different individuals. For some it is merely a natural consequence of ageing, for others it is a problem they have to 'solve' or have 'cured'. For most men it means adapting their daily routines and being aware of a bodily function that had previously been unconscious. The degree to which it impacts on them emotionally, or in terms of their sense of self also varies. For most men, their worries are about the future, rather than their present state. For many, it is a new challenge, something they have to learn about and seek to understand. In order to understand and learn ways of coping they resort to varying strategies. Most seek further information, including comparing themselves with others, and attempt to take control of their urinary behaviour. Many avoid talking about their symptoms and make light of their experiences.

This next section discusses some of the above findings in more detail.

Emotional Impact

On the whole, experiencing lower urinary tract symptoms does not appear to have impacted emotionally on the men in this study. Only two men reported high 'bother', three scored in the range suggestive of possible or probable clinical anxiety and none scored in the range suggestive of possible clinical depression. Approximately half of the participants in this study were found to be tight construers and one participant was found to be a loose construer. Both tight and loose construing have been considered defensive strategies to counter anxiety

(Kelly, 1955) and this might help to explain the low self-reporting of anxiety in the present study.

It has been suggested that tight construers are likely to be inflexible and have a one-dimensional view of the world, which could prove maladaptive in adjusting to change (e.g. Makhlouf Norris et al, 1970; Ryle & Breen, 1972). In turn, loose construing has been linked with thought disorder (e.g. Winter, 1992). However, Kelly (1955) argued that, while tight or loose construing may be employed as a defensive strategy to counter anxiety, an individual needs to adopt both kinds of construing, in an almost cyclical fashion, in order to develop and ensure optimum functioning. Ultimately, in order to adjust to health problems or any other challenge, it is essential that a person is able to loosen his construing (Kelly, 1955). For the men in this study it is not possible to know whether they are persistently tight or loose construers, or whether they are at a particular point in their own cycle of tight and loose construing.

Impact on Sense of Self

In general, participants indicated that they were quite similar to their ideal self, suggesting reasonably high levels of self-esteem. In the literature, poor self-esteem as measured by the distance between the elements 'self-ideal self', has been linked with depression (e.g. Sheehan, 1985). Given that the men in this study were not depressed, as measured by the HADS, it is not surprising, therefore, to find they have reasonable levels of self-esteem. This finding is consistent with other research exploring self-concept in adjusting to chronic illness. For example, Heidrich & Ward (1992) found that elderly women with

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cancer were no different in terms of self-ideal self discrepancies than women without cancer, although they had lower actual and ideal self ratings than women without cancer.

It is possible to suggest that 'bother' may be related to a discrepancy between self-ideal self ratings and that men who view themselves as less similar to their ideal self might be more bothered by lower urinary tract symptoms. Such a finding has been highlighted in a study examining psychological adjustment to cancer (Heidrich et al, 1994), where bothersome symptoms were found to be a significant predictor of higher levels of discrepancy between the actual and ideal self and lower levels of psychological well-being. The two men in this study who indicated higher levels of bother were also two of the men who rated themselves as neither similar or dissimilar to their ideal self. However, the absence of more men who are bothered by their symptoms means that it is not possible to draw any firm conclusions about links between bother and self-ideal self discrepancy.

Some researchers have found that, even where "objective" health is poor, those who compare themselves favourably with others have better mental health outcomes (Heidrich & Ryff, 1993). It is interesting that many of the participants in the present study spontaneously spoke about social comparison before being asked explicitly to compare themselves with others during the repertory grid process. This tendency to try and understand one's own illness by making comparisons with other people is something that has been identified elsewhere in the research. For example, social comparison has been construed as a coping strategy to help the individual manage distress and uncertainty (Osborn & Smith,

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1998). It is considered as particularly important in helping the individual cope with uncertainty and anxiety when information is limited (Osborn & Smith, 1998). It is perhaps unsurprising, therefore, that men in the present study, most of whom seemed uncertain about the nature of their symptoms, compared themselves with others when talking about their experiences.

Repertory grid ratings of themselves as dissimilar to the typical man with prostate problems and the typical old man could be taken as further evidence that these men coped and maintained their mental well-being by comparing themselves favourably with others. Following this argument, one might expect higher levels of 'bother' in men who do not compare themselves favourably with others.

It is unclear why some men viewed themselves before prostate problems as more similar to the typical man with prostate problems than they viewed themselves currently. However, it is interesting that they anticipate once again being more similar to the typical man with prostate problems in 5 years time. This might suggest some element of denial that they currently have symptoms likening them to the typical man with prostate problems. This is further evidenced by the fact that they see themselves as similar to the typical man of their own age, whom, in turn, they view as similar to the typical man with prostate problems. Alternatively, it may be linked to an expectation that attending the specialist clinic will result in some form of intervention (e.g. medication) that might reduce their symptoms.

Uncertainty

Most participants appeared to hold stereotypical views about what it meant to have prostate problems and seemed uncertain about the function of the prostate and the cause and seriousness of their symptoms. Uncertainty has been identified in previous research as an important experience in chronic health conditions (e.g. Radley, 1994) and has also been found to correlate with helplessness (Jensen et al, 1991). Brewin (1988) argued that seeking an explanation which establishes a cause is a common response to such uncertainty. This view is also argued in Leventhal et al's (1980) model of illness representations. That is, in the absence of facts they can understand, patients with chronic illnesses construct their own representations of their illness based on whatever previous knowledge and beliefs they have already about illnesses they have encountered. In this case, many participants looked for an external cause (e.g. wondering if they had picked up an infection such as thrush or if they had damaged their urinary tract) and, on the whole, there was a tendency to hope the symptoms could be treated with medication.

In general, although they delayed seeking medical attention, many participants spent that time monitoring their symptoms in an attempt to understand triggers and some sought further information from friends and/or books. Osborn & Smith (1998) suggest that having some explanation with which to understand their symptoms is an important first step before an individual can begin to think about managing or labelling their symptoms as an illness that might need medical attention.

Problem-focused Coping Strategies

Most of the men talked with humour about their symptoms and showed a tendency to minimize their effect. Whilst many of the men in this study hoped that there might be a 'cure', most realised this was not the case and tried to take control of their symptoms themselves, either by behavioural strategies (e.g. going to the toilet before they left the house; drinking less coffee) or attempting to find out information about their condition. This attitude is not unusual for somebody facing a chronic illness: previous research (e.g. Heijmans, 1998) has found that patients who consider their illness less serious and feel they have some control over their symptoms are more likely to be involved in problem-focused coping strategies.

It is interesting, however, that, whilst most of the participants in this study spoke about wanting more information, only a few had actually been pro-active in seeking that information. Given that most of the participants were professionals and academics who are used to analysing and understanding information, it is surprising that they did not make use of library or Internet facilities and that, on the whole, they did not really understand what was happening to their bodies.

Seeking to take control of their symptoms is another example of a problem-focused coping strategy. Rodin (1986) suggests that "nonpredictable conditions appear to be physiologically more stressful than predictable conditions" and argues that having control acts to modulate the impact of symptoms. From this viewpoint, it is easy to see why men monitor and attempt to control their symptoms. They are faced with an illness that is unpredictable and taking control

enables them to decrease their stress and make their circumstances more predictable.

Rodin (1986) also suggests that people who feel they have little or no control report more physical symptoms than those who feel more in control. In this study it is not possible to make a causal interpretation, but there seems to be a link between exhibiting control over one's symptoms and reporting less severe symptomatology.

'Bother'

This section explores factors that are potentially related to 'bother' and suggests reasons why symptoms may be bothersome to some men and not to others. Most of the men in this study were not particularly bothered by their symptoms, which makes it difficult to extrapolate variables that might be associated with 'bother'. However, some issues that commonly emerged were: concerns about ageing, shame/social embarrassment, sexual/intimate relationships and worries about future health problems (e.g. cancer; urinary retention).

Concerns about Ageing

In keeping with the common stereotype, the men in this study viewed prostate problems as a disease associated with old age. This was evidenced both in the repertory grid analysis (e.g. the typical man with prostate problems was construed as similar to the typical old man) and the interpretative phenomenological analysis (e.g. "I realised I was getting to that age").

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There was, however, reluctance on the part of the men in this study to think of themselves as old. Many of the men commented on the fact that they did not feel any older now than they had ever felt and several commented on the fact that they had been busier since retiring than when they were at work. On the whole, the group viewed themselves as dissimilar to the typical old man and most men construed the typical old man as dissimilar to their ideal self.

It is interesting, however, that most participants viewed the typical man their own age as similar to the typical old man. Given that they viewed themselves as similar to the typical man their own age, it is possible to suggest that there is some recognition of their own ageing, but it is not available to conscious awareness. It is possible that men might feel more bothered by their symptoms if they hold a view of themselves as old, therefore the symptoms affirm their ageing. Future research examining differences between men who openly construe themselves as old and those who don't might shed light on whether this is a variable associated with bother.

Whitbourne (1996) suggested that denying the importance of age-related change and attributing symptoms to transitory states of health "is an attempt to protect the sense of self as competent and consistent over time" and maintain a subjective sense of emotional well-being. She refers to this behaviour as 'identity assimilation'. However, Whitbourne (1996) argues that, whilst this may be functional for some individuals, in order to accommodate to their changing bodies, people need to acknowledge and accept the ageing process and adapt to

changes in their identity. She refers to this adaptation as 'identity accommodation'.

According to this model, the most healthy approach to chronic illness (and any other life change for that matter) is to adopt first 'identity assimilation' strategies and then 'identity accommodation' strategies (Whitbourne, 1996). Adopting purely 'identity accommodation' strategies has been linked with withdrawal from activities that are important, increasing negative self-evaluation and consequent depression. Based on this argument, it is possible that those men who are more bothered by their symptoms adopt primarily identity accommodation strategies.

Embarrassment/Shame

It has previously been suggested that men find it embarrassing to talk about urination difficulties (Ragg, 1993; Kiviniemi & Suominen, 1999). Whilst, it is possible that the men who did not reply to the initial letter may have been inhibited because of embarrassment, it was evident that those men who were interviewed did not appear embarrassed; many felt comfortable enough to raise issues related to sex and to ask questions.

However, most of the men in this study had not discussed their symptoms with anybody other than their GP, although some had spoken briefly with their partner or a close male friend/relative. In general, their views about seeking social support and talking about their symptoms appear somewhat contradictory. Many of them talked about not wanting to discuss their symptoms with anybody, yet

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commented at the end of the interview for this study that they welcomed the opportunity to talk and said they would like to be asked more often.

Charmaz (1994) links men's embarrassment about chronic illness with a desire to preserve the sense of self and maintain their earlier position in the gender order. This ties in with the social constructionist theories of masculinity and illness (e.g. Courtenay (2000) that were presented at the beginning of this chapter. Charmaz argues that men who believe they might be disadvantaged if colleagues or other men know about their symptoms are motivated to keep their illness a secret. In order to keep this secret, men need to take control of their symptoms and take precautions to ensure others do not become aware of them. For the men in this study, keeping their symptoms a secret at work was not too difficult, due to the nature of their work. It is possible that this type of social embarrassment might be a significant 'bother' factor for men who are less able to keep their illness a secret.

Charmaz (1994) also suggested that those men who are unable to protect their secret, and therefore experience embarrassment in social situations, are more likely to avoid social encounters or situations in which they might be exposed. It is possible that the men who chose not to take part in this study are those who feel less able to take control of their symptoms and who avoid social situations. That is, the men who chose not to take part could be those who are more bothered by the potential social embarrassment. On the whole, the men in the present study stressed that their symptoms did not stop them having busy lives. The one man who talked about wondering if people could see he had leaked was, in fact, the

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man who had moderate symptoms, but reported high 'bother'. He did not, however, avoid social situations.

Further evidence for this need to preserve the sense of self was found in the repertory grid analysis. All of the participants saw themselves as similar to 'self seen by others'. However, there was a significant positive correlation between 'bother' score and 'self - self seen by others', suggesting that men may be more bothered if they perceive others view them differently as a result of their symptoms.

Information from the interpretative phenomenological analysis provides further evidence for a link between 'bother' and shame: the only man in this study who really talked about being embarrassed by his symptoms was the man who had recently become unemployed and who had a younger wife. This is in keeping with Gilbert's (1997) view of shame: that shame might occur when somebody feels they are becoming less attractive and are noticing a change in their social status. In this case, lower urinary tract symptoms highlight this man's ageing next to his younger wife and coming at a time when he has lost his job, therefore changed his social status, may increase the impact of the symptoms.

Generally, the men in this study did not talk about being embarrassed by their symptoms or feeling ashamed, but this may be because most of them were accepting and happy about their changing social status. For example, one man had been planning and looking forward to his retirement for some years; others were continuing to travel and/or work well beyond their retirement. It is possible

that shame and embarrassment may be related to 'bother' for men who experience a sudden or unplanned change in their social status.

Effect on Intimate Relationships

Only a minority of men talked about the current and potential effect of symptoms on their relationship with their partner. For one of the participants, lower urinary tract symptoms appeared to distance him from his wife, because she was much younger than him and it highlighted his ageing. For another man the symptoms seemed to bring him closer to his arthritic wife, because it meant they both had "a handicap". The significance of this similarity or dissimilarity from one's partner was supported by the repertory grid data: there was a significant positive correlation between bother and 'self-partner'. This suggests that the more dissimilar men feel they are from their partner, the more bothered they might be.

In a questionnaire study of three hundred men awaiting TURP, Doll et al (1993) asked participants which areas of their daily life were most affected by their symptoms (i.e. employment; social life; jobs around the home; personal relationships; sex life; interests and hobbies; and holidays). They found that personal relationships was one of the areas of life least affected by prostate problems. Sex life, however, was reported as one of the areas most affected.

The importance of sexual activity was also found in another questionnaire study (Calais Da Silva et al, 1997). In the latter study, with French and English patients, satisfaction with sexual activities was reported to be most affected by prostatic symptoms in 50% of participants. This study also showed a significant

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cultural difference in reporting sexual difficulties, with the French men reporting more sexual problems than English men. This might explain why sexual activity was only remarked upon by a minority of men in the present study.

For two men in the present study, the impact of symptoms on sexual functioning was one of their main concerns. One man was concerned that there had already been a change in his sexual functioning since the symptoms started, another man was worried the symptoms might worsen to the point that it affected a very healthy sex life. It is interesting that the man who felt his symptoms already affected his sex life was the one who reported high 'bother'. Given the degree to which these two men expressed concern about their sexual functioning, it is probable that this is a factor strongly related to 'bother' and warrants further investigation.

Worries about Future Health Problems

A relationship was found 'bother' and anxiety, as measured by the HADS. The potential causes of this anxiety are, however, unclear. Worries about the future were highlighted by a number of men during the interview and there was evidence to support this in the repertory grid. Many men anticipated becoming less like their ideal self in the future and more similar to the typical man with prostate problems. This is consistent with previous research findings that showed patients to be unworried about their current health status, but worried about their prostatic symptoms getting worse in the future (Calais Da Silva et al, 1997).

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On the basis of information provided during the interview process, it is reasonable to suggest that a main cause of anxiety was concern that symptoms might be suggestive of cancer. In general, participants in this study indicated that they were less worried about their symptoms once they had been reassured by a GP that they did not have cancer. For those men who had actively sought medical attention, a concern about cancer was their main motivation. Other men did not openly acknowledge that they had thought about the possibility of cancer, but mentioned that it was something they had considered since first being examined by their doctor.

It is interesting that cancer did not come up as a construct for any of the men during the grid elicitation process, because it was mentioned by most of them at some point during the interview and seemed to be one of their biggest concerns. However, some of the men introduced concerns about health as constructs and it is possible that concern about cancer was subsumed within such constructs. Other areas of health concern mentioned by some of the men related to worries that they might experience urinary retention and pain in the future.

On the basis of comments about health concerns, particularly cancer, in the present study it would seem appropriate to suggest that these may be factors related to 'bother'. Surprisingly, that the patient may be concerned about cancer has not been explored (to this author's knowledge) elsewhere in the literature. One article (Roberts et al, 1994) mentions that "worry or concern about getting prostate cancer was also measured" (p. 623), but the results are not reported. This is clearly an area that needs further investigation.

Inconvenience

Calais Da Silva et al (1997) found that the most affected quality of life aspects for men with BPH were sleep and limitations in daily activities. Whilst many of the men in the present study talked about the inconvenience of having to get up in the night or having to interrupt activities to go to the toilet, most stated that it did not really cause a problem for them. With regard to daily activities, all of the men in this study appeared to have very busy and active lives. Even those men who were well beyond retirement continued to work or be extremely active in their local communities. Issues of inconvenience did not emerge as constructs in the repertory grid data, except for one man who talked about having to stop to use the toilet several times when going on a car journey.

It is not possible to ascertain from this study whether heightened inconvenience is related to bother, although one man suggested the symptoms might be more bothersome if one's job meant there was limited opportunity to go to the toilet. This comment seems to suggest that the men in this study were protected from 'bother' due to inconvenience because of their social status and level of employment. Charmaz (2000) offers further support for this argument, with her suggestion that working-class jobs permit little flexibility and, therefore, working class men are less able to take control over the inconvenience of their symptoms.

Reflections on the Study

This section will present some of the methodological issues that should be taken into account when considering the findings of this study. Many limitations are intrinsic in this type of methodology, but this is compensated for by the ability to

get closer to the individual experience. Issues are presented in relation to design, generalisability and analysis. Strengths of this study are considered at the end.

Design

One drawback in the design of this study relates to the exclusion criteria. If there was any evidence from a patient's notes that he had a history of mental health difficulties then he was excluded from the study. In this process it is possible those men who are more bothered by their symptoms were selected out. Roberts et al (1994) found that men whose psychological well-being was "impaired" are more likely to worry or be embarrassed about their urinary function.

Another limitation of this study lies in the fact that there was no comparison group. As has been said before, it was never intended to test hypotheses with this study, therefore it was not deemed necessary to include a comparison group. Furthermore, choosing an appropriate comparison group would have proved extremely difficult. The ideal comparison group would have been men of the same age who did not have lower urinary tract symptoms or an enlarged prostate. Identifying such a group would have been difficult, because prostate disease is a 'hidden' disease, as we have seen, with many men experiencing symptoms, but never seeking attention for them. Furthermore, given the high incidence of prostate disease in men over the age of 50, and even more so over the age of 60, identifying men who did not have some symptoms might have proved impossible.

Another important limitation of this study is that the men were self-selected. It is possible that the men who chose not to take part in this study are those for whom

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the experience is considerably more embarrassing. It is also possible that those men who are more bothered by their symptoms may be those who are reluctant to leave their home, to go somewhere unfamiliar. It was not stated in the initial contact letter that interviews could take place in the man's home and this might have seen a slightly different response rate.

The method of recruiting participants through a clinic will also have biased the sample, especially given that so many men do not seem to come into contact with medical services. However, accessing men through the clinic seemed most appropriate for this type of study, given the necessity of a medical diagnosis of LUTS for the individual to meet inclusion criteria. To have screened men from the general population would have been too time consuming and would have required considerably more input from an already stretched consultant urologist.

The fact that the main researcher was female may have put some men off making contact. It is also possible that men might have talked quite differently about their experiences if a male researcher had been interviewing them. However, had the researcher been a man, this might have impacted in an alternative way that would equally have influenced the nature of the results. In some ways, it might have been an advantage for the men to talk to a woman, because it might have empowered them to a certain degree in that they might have felt they were the experts on the subject of the prostate (an entirely male phenomenon) 'teaching' the researcher. A further factor that might have influenced the type of information emerging could be that the researcher was considerably younger than all of the men. It is possible that some men might have felt the need to 'protect'

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the researcher from the negative aspects of growing older. This might have contributed to the degree to which men played down concerns about ageing.

With regard to the repertory grid, there could have been some discrepancy in rating of the stereotypical man with prostate problems and the stereotypical old man, because some participants held a general stereotype in their mind's eye, whereas others held a particular person who represented that stereotype. This means that, during the rating, some participants were rating on the basis of their actual experience with an individual and others were rating based on what they imagined that person would be like.

Also, with regard to the grids, when participants are rating it is not always possible to tell how much they are thinking about the ratings and whether they is any confusion about the rating scale, especially when sometimes the 'negative' pole is at one end and sometimes it is at the other end. All of the men in this study appeared to give due reflection to their rating of an element, with some men talking the researcher through their thought process and other men openly comparing elements against each other and switching them around from time to time. This in itself, could be considered a shortfall of the design, in that participants were sometimes more consciously aware of how their element ratings related to each other than would have been ideal. To avoid confusion the researcher kept verbalising and visually demonstrating the construct represented on each pole and reminding the participant of the points on the rating scale.

Additional Comments on Limitations

The design of this study might have been improved if certain measures had been introduced to ensure a more homogenous group of participants. For example, it would have been useful to incorporate a screening questionnaire at the early stages of selection. This could have ensured selection of a sample of men who had been experiencing symptoms for a similar length of time and who had received similar previous investigations and medical input.

Furthermore, it would have been beneficial to screen the men regarding their illness history. For example, in the present study, one man had a history of Hodgkin's disease and it is possible that his symptoms may have been related to that earlier disease, rather than merely to an enlarged prostate. The disadvantage of such a screening questionnaire is that fewer men might have responded and/or met the tighter inclusion criteria. As it was, the sixteen participants were the only respondents and the numbers would have been far fewer if such a screening questionnaire had been used within the participating clinic.

In order to improve the design, larger numbers of men would need to have been approached, which might have been achieved by contacting clinics at other hospitals and/or contacting GP surgeries. Such an approach would, however, raise practical difficulties. For example, many GPs do not do the range of tests that might enable them to diagnose BPH, equally the consultant urologist involved in the present study was already extremely pressed for time and it is unlikely (if not also unethical) that he would be able to make the necessary diagnosis for patients who had not been referred to his clinic. To overcome this

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difficulty in ensuring all potential participants had the same diagnosis, it might be possible to use the I-PSS as a screening questionnaire, whereby participants who scored above a certain cut-off would be deemed suitable for the study.

Some researchers might regard the small sample size as a drawback of the present study, as it raises issues about generalisability. A larger sample size might have been obtained by screening participants from other clinics and GP practices, perhaps even mail-shotting all men over 50 who were registered with certain GPs. It is argued, however, that, given the exploratory focus of this study, the sample size was adequate. Most qualitative researchers recommend sample sizes between 8 and 20 (e.g. Turpin et al, 1997) and some suggest smaller sizes make for more detailed and useful studies (e.g. Smith et al, 1999).

The addition of a comparison group would have meant that the issue of 'bother' might have been more overtly explored. The screening questionnaire could have been used to identify men who were more and less 'bothered' by their symptoms and then data from the two groups could have been compared for different and similar themes. Alternatively, the HADS could have been used as a screening measure and two groups could have been obtained using a median split, to compare more and less anxious/depressed.

Splitting the group on the basis of anxiety score could have been undertaken for the present study, as there were approximately two equal groups. The disadvantage, however, of such a median split is that anxiety was only one variable that appeared to be associated with the concept of 'bother'. By dividing

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the group on the basis of how anxious they were, it is possible that important information might have been lost about variables associated with 'bother' that did not provoke anxiety. Furthermore, HADS anxiety scores might have been indicative of other anxiety in a person's life that might not have been linked to their symptoms.

Generalisability

Participants in the present study are reasonably representative of the general age-range of men affected by an enlarged prostate and their symptom level is representative of the general spread of symptoms found in the population (Barry et al, 1992). Beyond that, however, there are limitations in terms of generalising these findings. The conclusions are based on data from sixteen men who cannot be considered as representative of the general population. They are predominantly white British, middle/upper-middle class and well-educated. The types of issues that may arise for men of other ethnic and social origins might be completely different. Another limitation is the fact that most participants were not particularly bothered by their symptoms, therefore generalisations cannot be made to men who are bothered by their symptoms.

A further drawback, in terms of generalisability, is that participants were at different stages in the process of understanding and adapting to their symptoms, mainly due to the fact they had received different input and investigations from their GPs. In a qualitative study with people experiencing lower back pain, Osborn & Smith (1998) argued that participants' accounts of their experiences are "complex, dynamic and shifting entities, formed and reformed as patients struggle to make sense of their condition and to articulate that struggle to the listener". In order to generalise these findings it would be necessary to examine them in relation to other men at similar stages in the process.

However, the aim of the thesis was simply to begin to develop a picture, from a psychological perspective, of how some men experience lower urinary tract

symptoms. The results do not claim to explain the experiences of all men with lower urinary tract symptoms, rather to be provide information as a starting point for future psychological research.

Data Analysis

IPA was used to analyse the interview data as it helps to illuminate people's perceptions about illness and explore similarities and difference between people's personal accounts. A limitation of such analysis is that themes are based on reflections made by the researcher (Smith, 1996). Although the researcher attempted to 'bracket' the theoretical material raised in the introduction, it is not possible to be entirely uninfluenced by that knowledge or equally any other knowledge obtained over the years of training in psychology. It is entirely possible, therefore, that the way in which the data was interpreted, particularly with regard to developing the themes, might have been influenced by the researcher's prior knowledge. Attempts were made to ensure that the interpretations were not entirely subjective on the part of one researcher, by discussing the themes and data with the two supervisors.

It is acknowledged that there are various ways in which the themes could be categorised. Looking across the themes it is possible to see other themes that cut across the themes presented. For example, ageing, lay accounts, coping and cancer. Information seeking can perhaps be construed as a way of coping, as can monitoring the symptoms be seen as a means of understanding and taking control of the symptoms. The same is true for taking precautions. So, where some men see taking precautions and knowing the whereabouts of toilets as a consequence

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of their symptoms, it can also be seen that taking precautions is a means of coping by being prepared for every eventuality.

An improvement on the study would have been to share with the participants the results of the analysis and to check out with them whether the themes seemed appropriate or whether there were alternative ways in which what they had spoken about could be interpreted (Smith, 1999). Richardson (1996) suggests, however, that validation of this type “should not be seen as problem free”. He suggests that power imbalances will be present and the participant may actually be more inclined to agree with the researcher’s interpretation, rather than feel able to disagree and put across their own interpretation.

Repertory grid analysis produces a large amount of data. Selection of the most appropriate information for interpretation is difficult, as there are many different statistical ways to illustrate a point. The types of data examined and reported on for this study are those that are most frequently displayed in other literature (e.g. Winter, 1992).

Strengths

This study took a phenomenological, idiographic approach. That is, the aim was to capture the men’s own accounts of their experiences and priority was given to the accounts told by the men involved, rather than the researcher. Furthermore, the study intended not to lose sight of the individual person when interpreting their accounts. The study achieved this aim through the open-ended interview and flexible approach during the grid elicitation process.

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Elliott et al (1999) stressed that the presentation of data from qualitative analysis should be 'grounded in examples' in order that the reader might see how interpretations have been made. Although the data was interpreted in relation to themes, it is still possible to trace an individual man's account through the results of this study. Every attempt was made to ensure the reader could 'track' individual participants through the data.

Elliott et al (1999) noted the importance of researchers explicitly disclosing their knowledge, values and assumptions to help readers interpret the data and consider possible alternative. This thesis set out these factors in the chapters on introduction and method.

A further strength of this study is in the 'triangulation' of the design. 'Triangulation' refers to a means of strengthening research design, for example by applying two or more measures accessing the same information (Richardson, 1996). Repertory grid data and interview data complemented each other in explaining men's experiences of BPH.

A final strength of this study is that participants were, for the most part, men who seem able to cope and adapt to their symptoms and who are less bothered. Given that most research tends to be with patient populations and with people who do not cope particularly well with health problems this study sheds some light on potential protective factors.

Future Research

One of the main issues raised by this study relates to generalisability. Future research is needed to explore the experiences of men from a wider cross-section of the community (e.g. in terms of ethnicity and social class), because the issues for such men may be entirely different. Research with men who are less self-selected and/or men of a similar age who do not have lower urinary tract symptoms is also recommended, but accessing such men poses difficulties for the researcher. Future research with a population of men who have mild or moderate symptoms, but for whom their symptoms are extremely bothersome would be extremely valuable and the information from this study could be used as a reference point against which to compare such men.

The present study provides useful information that could form the basis of future research. For example, many of the constructs elicited from these men were quite similar, which means supplied constructs could perhaps be used for future repertory grid studies. This could involve some sort of comparative study, exploring whether the same constructs are of relevance to men who do not have lower urinary tract symptoms, although, as mentioned earlier, identifying these men might be difficult.

Given the finding in this study that men delay for quite some time before seeking medical attention, future research is needed to understand reasons for this delay. This would be quite difficult and would almost certainly have to be based on retrospective accounts, which would have its own limitations.

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Given that participants in the present study were only seen at one time point, it is not possible to know what stage they are at in terms of adapting to their symptoms. A longitudinal study would offer important information about the shifting views of their symptoms and how men adapt over a period of time.

Future research is also needed to more explicitly test hypotheses concerning 'bother'. For example, in repertory grid studies, 'feeling old' or 'aware of ageing' could be provided as constructs, as could 'feels embarrassed' or 'is sexually active'. Future research could also explore anxiety and causes of anxiety in more detail, given that a relationship was found in the present study between 'bother' and anxiety. Also, future research looking more specifically at how men feel their symptoms impact on other people's views of them would be valuable.

Clinical Implications

This study has important implications, both for service providers and in terms of clinical interventions. This section discusses some of these implications, including: increasing awareness about lower urinary tract symptoms, changing the setting in which services are provided, expanding the scope of watchful waiting and the role of the clinical health psychologist.

The men in this study were, in general, poorly informed about the potential seriousness of lower urinary tract symptoms if left unchecked. They did, however, highlight their desire to have more information about their symptoms and prognosis. Providing such information would need to include normalising their experiences and ensuring that men understand symptoms do not necessarily

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mean cancer and are in fact not linked to cancer of the prostate. Being more proactive in dispersing information about prostate enlargements and lower urinary tract symptoms might encourage men to seek medical attention at an earlier stage.

It is clear that men are reluctant to access conventional medical services (e.g. GP practices), therefore, service providers need to be more pro-active and creative in setting up user-friendly services for men. There are a number of ways in which service providers could increase the opportunity for men to receive the medical attention they may require. For example, taking services out to men, rather than waiting for them to access services themselves. This could include offering regular checks in the workplace setting or in places that men frequent (e.g. pubs; community centres; sports centres). Being more proactive might also involve regular screening of men, in the same way that smear tests are offered to women, once they reach a certain age.

Behavioural interventions could be more formally introduced as an element of 'watchful waiting', so that men feel they have some control over their symptoms. In the present study men talked about monitoring and trying to understand their symptoms, in order to take control and not be "caught out". The means adopted by most of these men, who are less bothered by their symptoms, could be recommended to men who are more bothered and who might not have thought about managing their symptoms for themselves. In fact, other researchers have suggested the importance of enhancing control and increasing self-management, particularly in the latter part of life (e.g. Rodin, 1986). Furthermore, beliefs about control have been found to affect stress because they influence coping: if people

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believe that they can prevent or lessen the severity of aversive events, they are less distressed by such events (Lazarus & De Longis, 1983).

The clinical health psychologist might have a role in working with men who are more bothered by their symptoms, as an alternative to referring these men for surgery. Some of the issues that were found in this study to be related to 'bother', could provide a framework for such interventions. For example, some men might benefit from cognitive therapy exploring thoughts about ageing and helping individuals adapt to the latter stages of life. Drawing on some of Coleman's work on 'successful ageing' might have relevance here (e.g. Coleman 1992; Coleman et al, 1993).

Finally, it is interesting that a number of things came up that were common experiences for men experiencing lower urinary tract symptoms, which suggests that support groups might be a useful means of helping these men. Furthermore, given the varying degrees of 'bother' experienced by men who have similar levels of symptomatology, men who are more bothered might derive some benefit from hearing how their peers cope. However, given the common stereotype that men might not come and talk in a group, it is possible that such an idea would not work in practice.

Conclusion

This study set out to explore men's experiences of having lower urinary tract symptoms, with particular reference to the individual meaning they attach to those experiences and the factors related to 'bother'.

In terms of psychological well-being, the overall picture that emerges is a positive one. The men in this study reported low levels of bother, anxiety and depression and minimal impact on their current sense of self. Most men tolerated their symptoms for a number of years before receiving medical attention. For the most part, this was due to uncertainty about the seriousness of their symptoms.

Participants drew on their understanding of acute illnesses in an attempt to understand their current symptoms and most employed problem-focused coping strategies. Prostate problems were viewed as a natural consequence of ageing for many participants and most held negative, stereotypical views about the typical man with prostate problems. Factors influencing degree of 'bother' included: concerns about ageing, social embarrassment, intimate and sexual relationships and worries about future health problems.

In conclusion, this study provides rich information about individual experiences of having lower urinary tract symptoms and can serve as a basis for future research and developing better services for men.

REFERENCES

Abrahms P (1994) New words for old: lower urinary tract symptoms for “prostatism”. British Medical Journal, 308, 929-930.

Aylard PR, Gooding JH, McKenna PJ, Snaith RP. A validation study of three anxiety and depression self-assessment scales. Journal of Psychosomatic Research, 31, 261-268.

Bannister D (1960). Conceptual structure in thought-disordered schizophrenics. Journal of Mental Science, 106, 1230-49.

Barker C, Pistrang N & Elliott R (1994). Research Methods in Clinical and Counselling Psychology. John Wiley & Sons Ltd.

Barry MJ, Mulley AG, Fowler FJ & Wennberg JW (1988). Watchful waiting versus immediate transurethral resection for symptomatic prostatism. Journal of the American Medical Association, 259, 3010-17.

Barry MJ, Fowler FJ & O’Leary MP (1992). The American Urological Association Symptom Index for Benign Prostatic Hyperplasia. Journal of Urology, 148, 1549-1547.

References

Beail N (1985). An Introduction to Repertory Grid Technique. In: N Beail (ed.) Repertory Grid Technique and Personal Constructs: applications in clinical and educational settings. Croom Helm, London.

Borg I, Staufenbiel T & Scherer KR (1988). On the symbolic basis of shame. In KR Scherer (ed.) Facets of Emotion: recent research. Hillsdale, NJ: Erlbaum.

Brewin C (1988). Cognitive Foundations of Clinical Psychology. London: Erlbaum.

Brody EM & Kleban MH (1981). Physical and mental health symptoms of older people: who do they tell? Journal of the American Geriatrics Society, 29, 442-449.

Button E (1985). Personal construct theory: the concepts. In: E Button (ed), Personal Construct Theory and Mental Health. Theory, Research and Practice. Croom Helm, London.

Calais Da Silva F, Marquis P, Deschaseaux P, Gineste JL, Cauquil J & Patrick DL (1997). Relative importance of sexuality and quality of life in patients with prostatic symptoms. European Urology, 31, 272-280.

Charmaz K (1983). Loss of self: A fundamental form of suffering in the chronically ill. Sociology of Illness, 5, 168-195.

References

Charmaz K (1987). Struggling for a self: identity levels of the chronically ill. In: JA Roth & PC Conrad (eds.) Research in the sociology of health care: the experience and management of chronic illness. Greenwich, CT: JAI.

Charmaz K (1994). Identity dilemmas of chronically ill men. Sociological Quarterly, 35(2), 269-288.

Charmaz K (2000). Experiencing Chronic Illness. In: GL Albrecht, R Fitzpatrick & SC Scrimshaw (eds.) Handbook of social studies in health and medicine. Sage Publications Ltd.

Coleman PG (1992). Personal adjustment in late life: successful ageing. Reviews in Clinical Gerontology, 2, 67-78.

Coleman PG, Ivani-Chalian C & Robinson M (1993). Self-esteem and its sources: stability and change in later life. Ageing and Society, 13, 171-192.

Courtenay WH (2000). Constructions of masculinity and their influence on men's well-being: a theory of gender and health. Social Science and Medicine, 50, 1385-1401.

Dept of Veteran Affairs Co-operative Study of Transurethral Resection for Benign Prostatic Hyperplasia (1993). A comparison of quality of life with patient reported symptoms and objective findings in men with benign prostatic hyperplasia. Journal of Urology, 150, 1696-1700.

References

Doll HA, Black NA, Flood AB & McPherson K (1993). Patient-perceived health status before and up to 12 months after transurethral resection of the prostate for benign prostatic hypertrophy. British Journal of Urology, *71*, 297-305.

Donovan JL, Frankel SJ, Nanchahal K, Coast J, Williams MH (1994). Prostatectomy for benign prostatic hyperplasia. In Steven a, Raftery J (eds) Health Care Needs Assessment. Vol 2. Oxford: Radcliffe Medical Press: 140-201.

Donovan JL, Abrahms P, Peters AJ, Kay HE, Reynard J, Chapples C, De La Rosette JJMCH & Kondo A (1996). The ICS-BPH study: the psychometric validity and reliability of the ICSmale questionnaire. British Journal of Urology, *77*, 554-562.

Donovan JL, Kay HE, Peters TJ, Abrams P, Coast J, Matos-Ferreira A, Rentzhog L, Bosch JLHR, Nordling J, Gajewski JB, Barbalias G, Schick E, Mendes Silva M, Nissenkorn I, De La Rosette JJ and the ICS-BOH study Group (1997). Using the ICSQofL to measure the impact of lower urinary tract symptoms on quality of life: evidence from the ICS-BPH study. British Journal of Urology, *80*, 712-721.

Elliott R, Fischer CT & Rennie DL (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. British Journal of Clinical Psychology, *38*, 215-229.

References

Emberton M, Neal DE, Black N, Harrison M, Fordhams M, McBrien MP, Williams RE, McPherson K & Devlin HB (1995). The National Prostatectomy Audit: the clinical Management of patients during hospital admission. British Journal of Urology, 75, 301-316.

Feifel H & Strack S (1989). Coping with conflict situations: Middle-aged and elderly men. Psychology and Aging, 4(1), 26-33.

Fowler FJ, Wennberg JE, Timothy RP, Barry MJ, Mulley AG, Hanley D (1988). Symptom Status & Quality of Life Following Prostatectomy. Journal of the American Medical Association, 259: 3018-3022.

Fransella F & Bannister D (1977). A Manual for Repertory Grid Technique. London: Academic Press.

Garroway WM, Collins GN & Lee RJ (1991). High prevalence of benign prostatic hypertrophy in the community. Lancet, 338: 469-71.

Gilbert P (1997). The evolution of social attractiveness and its role in shame, humiliation, guilt and therapy. British Journal of Medical Psychology, 70, 113-147.

Goffman E (1963). Stigma. Englewood Cliffs, NJ: Prentice Hall.

References

Gutmann MC, Pollock ML, Schmidt DH & Dudek S (1981). Symptom monitoring and attribution by cardiac patients. Paper presented to the annual meeting of the American Federation for Clinical Research.

Heidrich SM & Ryff CD (1993). Physical and mental health in later life: the self-system as mediator. Psychology and ageing, 8, 327-338.

Heidrich SM & Ward SE (1992). The role of the self in adjustment to cancer in elderly women. Oncology Nursing Forum, 19, 1491-1496.

Heidrich S, Forsthoff CA & Ward SE (1994). Psychological Adjustment in Adults with Cancer: the self as mediator. Health Psychology, 13(4), 346-353.

Heijmans M (1998). Coping and adaptive outcome in Chronic Fatigue Syndrome: the importance of illness cognitions. Journal of Psychosomatic Research, 45, 39-51.

Heijmans M (1999). The role of patients' illness representations in coping and functioning with Addisons' disease. British Journal of Health Psychology, 4, 137-149.

Herrmann C (1997). International Experiences with the Hospital Anxiety and Depression Scale – a review of validation data and clinical results. Journal of Psychosomatic Research, 42, 17-41.

References

Holtgrewe, HL (1996). The economics of benign prostatic hyperplasia. 91st Annual Meeting American Urological Association, Orlando. USA.

Husserl E (1931). Ideas: General introduction to pure phenomenology. London: George Allen & Unwin. (Original German Edition, 1913).

Jacobsen SJ, Guess GA, Panser LA, Girman CJ, Chute CG, Oesterling JE & Lieber MM (1993). A population-based study of health care-seeking behaviour for treatment of urinary symptoms. The Olmstead County study of urinary symptoms and health status among men. *Archives of Family Medicine*, 2: 729.

Jensen MP, Turner JA, Romano JM & Karoly P (1991). Coping with chronic pain: a critical review of the literature. *Pain* 47, 249-283.

Jones EE, Farina A, Hasthoff A, Markus H, Miller DT & Scott RA (1984). Social Stigma: the psychology of marked relationships. New York: WH Freeman.

Kaplan, SA (1996). A look at Minimally Invasive Therapy and Patient Satisfaction with Therapeutic Options. 91st Annual Meeting American Urological Association, Orlando. USA.

Kelly, GA (1955). The Psychology of Personal Constructs. New York: Norton. Reprinting by Routledge, 1990

References

Kemp S, Morley S & Anderson E (1999). Coping with epilepsy: Do illness representations play a role? British Journal of Clinical Psychology, 38, 43-58.

Kirby, RS (1996). BPH - where are we in 1996? 91st Annual Meeting of the American Urological Association, Orlando. USA.

Kiviniemi & Suominen (1999). 'Going to the bathroom four or five times a night...': seven men talk about experiences of benign prostate hyperplastic and the perioperative period. Journal of Clinical Nursing, 8, 542-549.

Landfield AW (1971). Personal Construct Systems in Psychotherapy. Rand McNally & Co.

Large R & Strong J (1997). The personal constructs of coping with chronic low back pain: is coping a necessary evil? Pain, 73, 245-252.

Lazarus RS & DeLongis A (1983). Psychological Stress and coping in ageing. American Psychologist, 38, 245-254.

Leventhal EA & Crouch M (1997) Are there differences in perceptions of illness across the lifespan? In: KJ Petrie & JA Weinman (eds) Perceptions of Health and Illness. Harwood Academic Publishers.

Leventhal H & Diefenbach (1991). The active side of illness cognitions. In: JA Skelton & RT Coyle (eds) Mental Representations in Health and Illness. New York: Springer-Verlag.

References

Leventhal H, Easterling DV, Coons H, Luchterland C & Love RR (1986). Adaptation to chemotherapy treatments. In: B Anderson (ed), Women with cancer. New York: Springer-Verlag.

Leventhal H, Idler EL & Leventhal EA (1999). The Impact of chronic illness on the self system. In: RJ Contrada & RD Ashmore (eds) Self, Social Identity and Physical Health, Oxford University Press Inc.

Leventhal H, Leventhal EA & Schaefer PM (1991). Vigilant coping and health behaviour. In: MG Ory, RP Abeles & PD Lipman (eds). Aging, health and behaviour. Newbury Park, CA: Sage.

Leventhal EA, Leventhal H, Schaefer P & Easterling D (1993). Conservation of energy, uncertainty reduction and swift utilization of medical care among the elderly. Journal of Gerontology: Psychological Sciences, 48, 78-86.

Leventhal H, Meyer D & Nerenz D (1980). The common sense representation of illness danger. In: Rachman (ed) Contributions in Medical Psychology (Vol 2) 7-30, Pergamon Press.

Leventhal H, Nerenz D & Steele D (1984). Illness Representations and Coping with health Threats. In: A Baum (ed) Handbook of Psychology and Health. Hillsdale, NJ: Lawrence Erlbaum.

References

Levine RM & Reicher SD (1996). Making sense of symptoms: self-categorization and the meaning of illness and injury. British Journal of Social Psychology, 35, 245-256.

Lewis M (1992). Shame: The exposed self. New York: Free Press

Makhlouf-Norris F, Jones HG & Norris H (1970). Conceptual distance indices as measures of alienation in obsessional neurosis. Psychological Medicine, 1, 381-387.

McConnell, JD (1996). BPH: Current Treatment Options. Paper given at the 91st Annual Meeting of the American Urological Association. May 1996.

Netto NR & DeLima ML (1995). The influence of patient education level on the International Prostatic Symptom Score. The Journal of Urology, 154, 97-99.

O'Farrell V, Tate N & Aitken C (1993). Attitudes and prognosis in chronic low back pain. Journal of Psychosomatic Research, 37, 415-422.

Osborn M & Smith JA (1998). The personal experience of chronic benign lower back pain: an interpretative phenomenological analysis. British Journal of Health Psychology, 3, 65-83.

Peters TJ, Donovan JL, Kay HE, Abrams P, De La Rosette J, Porru D, Thuroff J and the International Continence Society 'Benign Prostatic Hyperplasia' Study

References

Group (1997). The International Continence Society 'Benign Prostatic Hyperplasia' Study: The bothersomeness of urinary symptoms. The Journal of Urology, 157, 885-880.

Radley A (1994). Making sense of illness: a social psychology of health and illness. London: Sage.

Ragg, M (1993). Understanding your Prostate Problems. Gore & Osment Publications. Australia

Richardson JTE (1996). Handbook of Qualitative Research Methods for Psychology and the Social Sciences. BPS Books.

Roberts RO, Chute CG, Rhodes T, Oesterling JE, Panser LA, Lieber MM, Girman CJ & Jacobsen SJ (1994). Natural history of prostatism: worry and embarrassment from urinary symptoms and health care-seeking behaviour. Urology, 43(5), 621-628.

Rodin J (1986). Ageing and Health: Effects of the Sense of Control. Science, 233, 1271-1276.

Ryle A & Breen D (1972). Some differences in the personal constructs of neurotic and normal subjects. British Journal of Cognitive Psychotherapy, 1, 65-73.

References

Scambler G & Hopkins A (1988). Accommodating epilepsy in families. In : R Anderson & M Bury (eds) Living with Chronic Illness. London: Unwin Hyman.

Schipper H, Clinch J & Powell V (1990). Definitions and conceptual issues. In: B Spiker (ed.) Quality of Life Assessments in Clinical Trials. New York, Raven Press.

Sheehan MJ (1985). The process of change in the self-construing of a depressed patient – Clare. In: N Beail (ed.) Repertory Grid Technique and Personal Constructs: applications in clinical and educational settings. Croom Helm, London.

Slater P (1972). Notes on Ingrid 72. Unpublished MS. Institute of Psychiatry, London.

Smith JA (1990). Self-construction: longitudinal studies in the psychology of personal identity and life transitions. Unpublished D Phil thesis, University of Oxford.

Smith JA (1995). Semi structured interviewing and qualitative analysis. In: JA Smith, R Harre & Van Langenhove (eds.), Rethinking Methods in Psychology. London: Sage.

References

Smith JA (1996). Beyond the divide between cognition and discourse: using interpretative phenomenological analysis in health psychology. Psychology and Health, 11: 261-271.

Smith JA (1999). Identity development during the transition to motherhood: an interpretative phenomenological analysis. Journal of Reproductive and Infant Psychology, 17(3), 281-299.

Stiles WB (1993). Quality control in qualitative research. Clinical Psychology Review, 13, 593-618.

Taylor SE (1983). Adjustment to threatening events: A theory of cognitive adaptation. American Psychologist, 38, 1161-1173.

Thorpe AC, Cleary R, Coles J, Vernon S, Reynolds J & Neal DE (1994). Deaths and complications following prostatectomy in 1400 men in the Northern Region of England. British Journal of Urology, 74, 559-565.

Tschudi F (1998). Manual for Flexigrid Version 6. University of Oslo, Norway.

Turk DC, Meichenbaum D & Genest M (1983). Pain and Behavioural Medicine: A Cognitive-Behavioural Perspective. New York: Guildford.

Turpin G, Barley V, Beail N, Scaife J, Slade P, Smith JA and Walsh S (1997). Standards for research projects and theses involving qualitative methods:

References

suggested guidelines for trainees and courses. Clinical Psychology Forum, 108, 3-7.

Wasson JH, Reda DJ, Bruskewitz RC et al (1995). A comparison of transurethral surgery with watchful waiting for moderate symptoms of benign prostatic hyperplasia. New England Journal of Medicine, 332: 75-9.

Wheeler RJ, Munz DC & Jain A (1990). Life goals and general well-being. Psychological Reports, 66, 307-312.

Whitbourne SK (1996). Psychosocial Perspectives on Emotions. The Role of Identity in the Ageing Process. In: C Magai & SH McFadden (eds) Handbook of emotions, adult development and ageing. Academic Press Inc. San Diego, California.

Whitbourne SK (1996b). The ageing individual: physical and psychological perspectives. New York: Springer

Wilson TD & Hodges SD (1992). Attitudes as temporary constructions. In: LL Martin & A Tesser (eds) The construction of social judgments. Hillsdale, NJ: Lawrence Erlbaum Associates, Inc.

Winter DA (1992). Personal Construct Psychology in Clinical Practice. London: Routledge.

References

Zigmond, AS & Snaith, RP (1983). The Hospital Anxiety & Depression Scale.
Acta Psychiatr Scand, 67: 361-370.

APPENDIX 1

Examples of Referral Letters

Sent
2/2

I would be grateful for some advice on further management of this 68 year old retired

1. He had a routine PSA level taken in March 1998 which came back at 2.6. He has remained well since that time with no prostatic symptoms but requested a repeat of his PSA level a few days ago as a routine follow up as his father died from prostatic cancer several years ago.

His result has come back at 3.3 and I am unsure of the significance of this rise. Both tests were performed at the Whittington Hospital. I would be grateful if you could advise if further investigations are necessary.

Thank you for your help.

Yours sincerely

MS. Myert



11th October 2000

Dear Doctor,

Thank you for seeing this patient. He has a 2 year history of increasing urinary frequency with nocturia ++. There is some dribbling. He says the stream is fairly good. He has a smooth enlarged prostate.

I would be grateful for your advice.

Yours sincerely,

Routine → MCE

(Suitable → Marie)

29/10 ✓ initial letter sent.

4 JAN 2001

✓ sent 29/1

02.01.01

Dear

Re:

Thank you very much for seeing this man who came with a long history of nocturia. This has been unchanged for many years but he attended for hypertension and routine screening revealed a PSA of 17.

On examination he has a very large prostate which feels benign but under the circumstances I think he needs to be reviewed for more specific testing.

Kind regards,

Yours sincerely,

OPD &
soon urgent

life - Emberton

APPENDIX 2

Letter to Potential Participants

[HEADED PAPER]

Dear

We are contacting all men who have been referred to X Hospital Department of Urology to ask whether they would like to be involved in a study exploring men's experiences of lower urinary tract symptoms (ie: having difficulties passing urine; finding it hard to start, needing to go frequently and having to get up often during the night).

This is a very common experience for men, but little is understood about how they cope and the affect these symptoms have on their lives. We would like to understand better the effect of these symptoms, in order that we might improve treatment options.

It is important that as many men as possible take part in this study, so that we gain the best possible information. Attached is an information sheet about this study.

If you would be willing to take part in this study and/or would like to discuss it further over the telephone, please complete and return the attached response slip in the envelope provided.

THANK YOU.

Yours sincerely

Marie O'Neill
Psychologist in Clinical Training

I would be willing to take part in this study YES/NO

I might like to take part in this study, but would like to discuss it further YES/NO

NAME:
.....

ADDRESS:
.....

TELEPHONE:
(Daytime).....

(Evening).....

APPENDIX 3
Information Sheet

[HEADED PAPER]

Information Sheet

Study Title: Men's experiences of lower urinary tract symptoms (LUTS): What is "bother"?

You are invited to participate in a study exploring men's individual experiences of having lower urinary tract symptoms (LUTS). This study is being conducted within X Hospital Department of Urology.

Many men experience difficulties passing urine. These difficulties can include finding it hard to start, needing to go frequently and having to get up often during the night. We are carrying out research looking at what it is like for men who have these difficulties; how it affects their lives and how they cope. We are interested in talking with men who find it very difficult to cope with these symptoms and with men who do not find it difficult to cope. A better understanding of how these symptoms affect men will enable us to improve treatment options.

You would be asked to complete two short questionnaires and to take part in an interview, which will last approximately one and a half hours. This interview includes questions about how these symptoms affect your life and how you cope with them.

The interview will be tape-recorded to help with analysis. You will not be identified by name on the tape or on any questionnaires related to this study. Access to the information you provide will only be available to the researchers involved in this study and not to anybody involved in your care.

You do not have to take part in the study if you do not want to. If you decide to take part you may withdraw at any time without having to give a reason. Your decision whether or not to take part will not affect your care and management in any way.

All proposals for research using human participants are reviewed by an ethics committee before they can proceed. This proposal was reviewed by the Joint UCL/UCLH Committees on the Ethics of Human Research.

Investigators:

- Marie O'Neill, Psychologist in Clinical Training, Sub-Department of Clinical Health Psychology, University College London. 0207 - 679 - 1844;
- Dr L Glover, Chartered Clinical and Health Psychologist, Sub-Department of Clinical Health Psychology, University College London;
- Dr K Gannon, Senior Lecturer, St Barts & Royal London School of Medicine;
- Mr Emberton, Consultant Urologist, Institute of Urology and Nephrology, UCL Medical School.

If you have any questions about this study contact Marie O'Neill on 0207-679-1844

APPENDIX 4

Ethics Approval Letter



RECEIVED
16 JUN 2000

The University College London Hospitals

The Joint UCL/UCLH Committees on the Ethics of Human Research

Committee Alpha Chairman: Professor André McLean

Please address all correspondence to:
Iwona Nowicka
Research & Development Directorate
1st Floor, Vezey Strong Wing
112 Hampstead Road
London NW1 2 LT
020 7380 9579
Fax. 020 7380 9937

Mr Emberton,
Institute of Urology & Nephrology
UCL

12 June, 2000

Dear Mr Emberton,

Study No: 00/0127 (*Please quote in all correspondence*)
Title: Men's experiences of lower urinary tract symptoms (LUTS): What is bother?

Thank you for letting us see the above proposal which was reviewed and agreed by the Ethics committee (08/06/2000). You may go ahead with your study.

Please note that it is important that you notify the Committee of any adverse events or changes (name of investigator etc) relating to this project. You should also notify the Committee on completion of the project, or indeed if the project is abandoned. **Please remember to quote the above number in any correspondence.**

Yours sincerely

Professor André McLean, BM BCL PhD FRC Path
Chairman

→ Patricia de Witte
ETH

APPENDIX 5
Participant Consent Form

[HEADED PAPER]

CONFIDENTIAL

Participant Consent Form

Study Title: Men’s experiences of lower urinary tract symptoms (LUTS): What is “bother”?

Participant

I have discussed this study with Marie O’Neill and have read the information sheet. I have had the opportunity to ask questions and have received adequate information about the study.

I agree to take part in this study and understand that I am free to withdraw at any time, without giving a reason for withdrawing and without it affecting my future medical care.

Participant’s Signature

Date

THANK YOU.

Researcher

I have spoken to about this study and have answered his questions.

Investigator’s Signature

Date

Investigators:

- Marie O’Neill, Psychologist in Clinical Training, Sub-Department of Clinical Health Psychology, University College London. 020 - 7679 - 1844;
- Dr L Glover, Chartered Clinical and Health Psychologist, Sub-Department of Clinical Health Psychology, University College London;
- Dr K Gannon, Senior Lecturer, St Barts & Royal London School of Medicine;
- Mr M Emberton, Consultant Urologist, Institute of Urology and Nephrology, UCL Medical School.

APPENDIX 6

International Prostate Symptom Score Index

APPENDIX 7

Hospital Anxiety and Depression Scale

Please read each item and place a tick on the line alongside the reply that comes closest to how you have been feeling in the past few weeks. Don't take too long over your replies: your immediate reaction to each item will probably be a more accurate response.

I feel tense or "wound up":

Most of the time _____
 A lot of the time _____
 Occasionally _____
 Not at all _____

I feel as if I am slowed down:

Nearly all the time _____
 Very often _____
 Sometimes _____
 Not at all _____

I still enjoy the things I used to enjoy:

Definitely as much _____
 Not quite as much _____
 Only a little _____
 Hardly at all _____

I get a frightened feeling like "butterflies" in my stomach:

Not at all _____
 Occasionally _____
 Quite often _____
 Very often _____

I get a sort of frightened feeling as if something awful is about to happen:

Very definitely and quite badly _____
 Yes, but not too badly _____
 A little, but it doesn't worry me _____
 Not at all _____

I have lost interest in my appearance:

Definitely _____
 I don't take as much care as I should _____
 I may not take quite as much care _____
 I take just as much care as ever _____

I can laugh and see the funny side of things:

As much as I always could _____
 Not quite so much now _____
 Definitely not so much now _____
 Not at all _____

I feel restless as if I have to be on the move:

Very much indeed _____
 Quite a lot _____
 Not very much _____
 Not at all _____

Worrying thoughts go through my mind:

A great deal of the time _____
 A lot of the time _____
 From time to time but not too often _____
 Only occasionally _____

I look forward with enjoyment to things:

As much as I ever did _____
 Rather less than I used to _____
 Definitely less than I used to _____
 Hardly at all _____

I feel cheerful:

Not at all _____
 Not often _____
 Sometimes _____
 Most of the time _____

I get sudden feelings of panic:

Very often indeed _____
 Quite often _____
 Not very often _____
 Not at all _____

I can sit at ease and feel relaxed:

Definitely _____
 Usually _____
 Not often _____
 Not at all _____

I can enjoy a good book or radio or TV programme:

Often _____
 Sometimes _____
 Not often _____
 Very seldom _____

Thank you for your help

APPENDIX 8
Grid Rating Sheet

APPENDIX 9

Instructions for Classifiers

Please read through the list of categories to become familiar with the definitions. Then work through the list of construct pairs, taking each pair in turn and deciding to which category it should be assigned. Place the code for the appropriate category in the box to the right of each construct pair. If constructs have more than one descriptor, score each of the descriptive elements separately.

Categories:

- a) **Social Interaction:** any statement in which face-to-face, ongoing, continuing interaction (or lack of) with others is indicated;
- b) **Forcefulness:** any statement denoting energy overt expressiveness, persistence, intensity or the opposite;
- c) **Organization:** any statement denoting either the state of or process of structuring, planning or organizing;
- d) **Self-sufficiency:** any statement denoting independence, autonomy, initiative, confidence and ability to solve one's problems or the opposite;
- e) **Factual Description:** a characteristic not open to question;
- f) **Intellective:** any statement denoting intelligence or intellectual pursuits, or the opposite;
- g) **Self-Reference:** any statement in which the person refers directly to himself (e.g. I like him);
- h) **Sexual:** any direct reference to sexual behaviour or implicit sexual behaviour;
- i) **Morality:** any statement denoting religious or moral values;
- j) **Emotion/Affect:** any statement relating to feelings or an emotional state;
- k) **Egoism:** any statement denoting self-importance;
- l) **Tenderness:** any statement denoting susceptibility to softer feelings towards others, such as love, compassion, gentleness, kindness, considerateness, or the opposite;
- m) **Time Orientation:** any statement denoting a state of mind which strongly implies an individual's future or past orientation and expectancy;
- n) **Humour:** any statement specifically denoting either the ability or inability to perceive, appreciate or express that which is funny or amusing;

o) **Attitude to Life:** any statement that indicates how the individual views life in general or his attitude to living;

p) **Health:** any statement relating to well-being, health, illness or symptoms of illness;

q) **Financial:** any statement wherein references are made to money or lack thereof;

r) **Work:** any statement wherein references are made to occupational employment or lack thereof.

International Prostate Symptom Score (I-PSS)

Patient Name:	Date:						
	Not at all	Less than 1 time in 5	Less than half the time	About half the time	More than half the time	Almost always	Your score
1. Incomplete emptying Over the past month, how often have you had a sensation of not emptying your bladder completely after you finish urinating?	0	1	2	3	4	5	
2. Frequency Over the past month, how often have you had to urinate again less than two hours after you finished urinating?	0	1	2	3	4	5	
3. Intermittency Over the past month, how often have you found you stopped and started again several times when you urinated?	0	1	2	3	4	5	
4. Urgency Over the past month, how often have you found it difficult to postpone urination?	0	1	2	3	4	5	
5. Weak Stream Over the past month, how often have you had a weak urinary stream?	0	1	2	3	4	5	
6. Straining Over the past month, how often have you had to push or strain to begin urination?	0	1	2	3	4	5	

	None	1 Time	2 Times	3 Times	4 Times	5 Times or more	
7. Nocturia Over the past month, how many times did you most typically get up to urinate from the time you went to bed at night until the time you got up in the morning?	0	1	2	3	4	5	
Total I-PSS Score							

	Delighted	Pleased	Mostly Satisfied	Mixed - about equally satisfied and dissatisfied	Mostly Dissatisfied	Unhappy	Terrible
Quality of Life due to Urinary Symptoms If you were to spend the rest of your life with your urinary condition just the way it is now, how would you feel about that?	0	1	2	3	4	5	6

The International Prostate Symptom Score (I-PSS) is based on the answers to seven questions concerning urinary symptoms. Each question is assigned points from 0 to 5 indicating increasing severity of the particular symptom. The total score can therefore range from 0 to 35 (asymptomatic to very symptomatic).

Although there are presently no standard recommendations into grading patients with mild, moderate or severe symptoms, patients can be tentatively classified as follows: 0-7 = **mildly symptomatic**; 8-19 = **moderately symptomatic**; 20-35 = **severely symptomatic**.

The International Consensus Committee (ICC) recommends the use of only a single question to assess a patient's quality of life. The answers to this question range from "delighted" to "terrible" or 0 to 6. Although this single question may or may not capture the global impact of BPH symptoms on quality of life, it may serve as a valuable starting point for a doctor-patient conversation.

APPENDIX 10

Construct pairs & categories for all participants

ID	Elicited Pole	Contrast Pole	Category Code*
01	Principled/considerate	Self-centred	L
	More intelligent	Less intelligent	F
	Normal troubled	Troubled	J
	Reflexive socially	Non-reflexive socially	A
	Difficulty keeping a relationship together	Keeps a domestic relationship together	A
	Flexible	Firm	B
	Rich work relationships	Difficulties in work relationships	RA
	Physically active	Not physically active	B
	Intellectually active	Not intellectually active	F
	Demanding of self/others	Not demanding	B
	Has their physical health	Unwell	P
	Carer of own generation	Carer of children	E
	Loyal	Disloyal	I
	Egalitarian	Non-egalitarian	I
	Ethical	Non-ethical	I
	02	Easy to get on with	Self-seeking
Pretty active		Not so active	B
Easy-going		Difficult	A
Negative		Positive	O
Analytical		Gung-ho	..**
Lifestyle limited		Lifestyle not limited	D
Retired		In work	R
Diplomatic		Blunt	A
Finite medical condition		Ongoing medical condition	P
Freedom of movement		Not fully mobile	D
03	Out-going	Introverted	A
	Mobile	Infirm	P
	Whole life ahead	Thinks about life ending	O
	Has family support	Has no family support	A
	Optimistic outlook	Pessimistic outlook	O
	Depressive	Not depressive	J
	Concerned about health	Brighter outlook	P
	Youthful	Seasoned	E
	Adaptable	Set in particular ways	O
	Ambitious	Blinkered	O
	Sociable	Reclusive	A
	Burdened by difficulties	Oblivious to difficulties	D
	Lively	Sedentary	B
	Romantic	Grudging in emotion	J

04	Laughs at jokes	No sense of humour	N
	Physically fit	Unfit	P
	Positive outlook	No positive outlook	O
	Has overcome difficult experiences	Never had difficult experiences	DM
	Takes everything in stride	Finds it difficult to cope	D
	Has to work hard	Never had to work hard	R
	Doesn't appreciate anything	Appreciates everything	O
	Proud of their roots	Not proud of their roots	-.**
	Placid & helpful	Unhelpful	L
05	Not worried about money	Worried about money	Q
	Smug	Not smug	K
	Enjoying life	Little purpose to living	O
	Can't look after self	Can look after self	D
	Feckless & incautious	Sensible	-.**
	Hard-working	Less industrious	R
	Takes a gamble	Cautious	-.**
	Honest	Dishonest	I
	Respects lawyers	Less respect for lawyers	A
	Feels socially left out	Feels socially active	A
	Retired	Not retired	R
06	Spiritually charismatic	Non-spiritual	I
	Medical moaning	Stoical	P
	Young and fit	Riddled with medical problems	P
	Eager & adventurous	Boring & unadventurous	O
	Workaholic	Does minimum necessary	OR
	Practical & pragmatic	Concerned with feelings	J
	High-principled	Morally slipshod	I
	Warm & affectionate	Cold & unsympathetic	L
	Loves routine	Loves variety	C
	Hypochondriac	Dismisses problems as trivial	P
	Has real ailments	Doesn't have ailments	P
	07	Patient	Impatient
Intuitive		Wooden	-.**
Kind		Unkind	L
Complains a lot about health		Doesn't complain about health	P
Fears death		Reconciled to death	O
Good sleep pattern		Disturbed sleep	E
Unaware of waterworks		Checking waterworks	P
Quick sense of humour		Takes self too seriously	N
Optimistic		Pessimistic	O
Young at heart		Not young at heart	O
Resilient		Self-indulgent	K
08	Jovial sense of humour	Selfish sense of humour	N

08	Lively & energetic	More withdrawn	A
	Grumpy	Placid	J
	Relaxed	Irritable	J
	Enthusiastic	Likely to stay indoors	-.**
	Tired	Socialising more	B
	Less understanding	More considerate	L
	More outgoing	Stay indoors more	-.**
09	Fun to be with	Bore to be with	A
	Professionally competent	Professionally an idiot	R
	Emotionally content	Bits falling off at the corners	J
	Generally run down	Makes an effort to keep control	BP
	High achiever at work	Not a high achiever	R
	Saved lots of money	Financial worry	Q
	Highly energetic	Content to stay at home	B
	Complete	Muddled	C
	Worries about physical problems	Non-worrying	JP
	Practically concerned about health	Ineffective worrying	JP
10	Tells others what to do	Takes life as it comes	K
	Full of own importance	Doesn't boast	K
	Watches life go by	Enjoys life	O
	Adapts to difficulties	Worries about difficulties	DJ
	Makes effort to better life	Accepts things as they are	D
	Goes out with friends	Sits indoors	A
	Keeps mind working	Walks around like a zombie	F
11	Unruffled	Panicky	J
	Egotistical	Sensitive to others	K
	Emotional	Unemotional	J
	Sensitive	Insensitive	L
	Has unexciting life	Has exciting life	-.**
	Incontinent	Not incontinent	P
	Looks forward to saga holidays	Puts energy into achieving things	BM
	Aggressive	No longer aggressive	A
	Has internal goals	Has socially-determined goals	D
	Past it	Sexually active	H
Bullying	Not a bully	AB	
12	Aggressive	Laid-back	AB
	Marking time	Having plans	C
	Does not go out	Does everything	B
	Relentless	Feckless	B
	Accepts what happens	Thinks has influence	K
	Thinks of self as old	Doesn't think of self as old	O
13	Lazy	Not lazy	B

13	Sleeps a lot	Always on the go	B
	Fun to be with	Too serious	A
	Good for a laugh	Bit of a bore	A
	Bit of a moaner	Takes things in their stride	-**
	Honest	A crook	I
	Fit	Not very active	P
	Talks too much	Knows when to be quiet	A
14	Has integrity	Lacks integrity	I
	Is considerate	Lacks consideration	L
	Bully	Humane	L
	Nice	Intolerable	A
	Mature	Maturing	-**
	I don't respect them	I respect them	G
	Intelligent	Doesn't appreciate culture	F
	Has developed own talents	Wastes their talents	D
	Problems distort them	Are what they are	O
	Pathetic wreck	Functioning autonomously	D
15	Hard-working	Not hard-working	R
	Calm	Can get in a state	-**
	Not very methodical	Methodical	C
	Modest	Arrogant	K
	Has health problems	Doesn't have health problems	P
	Active	Not very active	B
	Feels young	Always tired/feeling old	B
	Can drive for hours	Has to keep stopping to spend a penny	E
16	Related	Not related	E
	Trustworthy	Untrustworthy	I
	Is old	Is young	E
	Tired & worn out	Energetic & enthusiastic	B
	Indifferent	Concerned	L
	Has everything they want	Hasn't achieved anything	B
	Happy	Unhappy	J
	Thinks they're 20	Old when they're young	O
	Works hard	Never worked hard	R
	Financially successful	Poor	Q
	Extrovert	Introvert	A
	Lonely	Not lonely	A

* see appendix 9 for category code definitions

** unclassifiable

APPENDIX 11

Inter-element Distances for Individual Participants

APPENDIX 12

Fred's I-PSS

International Prostate Symptom Score (I-PSS)

Patient Name: _____ Date: _____								Your score
		Not at all	Less than 1 time in 5	Less than half the time	About half the time	More than half the time	Almost always	
0	1. Incomplete emptying Over the past month, how often have you had a sensation of not emptying your bladder completely after you finish urinating?	0	1	2	3	4	5	
I	2. Frequency Over the past month, how often have you had to urinate again less than two hours after you finished urinating?	0	1	2	3	4	5	
0	3. Intermittency Over the past month, how often have you found you stopped and started again several times when you urinated?	0	1	2	3	4	5	
I	4. Urgency Over the past month, how often have you found it difficult to postpone urination?	0	1	2	3	4	5	
0	5. Weak Stream Over the past month, how often have you had a weak urinary stream?	0	1	2	3	4	5	
0	6. Straining Over the past month, how often have you had to push or strain to begin urination?	0	1	2	3	4	5	
I	7. Nocturia Over the past month, how many times did you most typically get up to urinate from the time you went to bed at night until the time you got up in the morning?	None	1 Time	2 Times	3 Times	4 Times	5 Times or more	
Total I-PSS Score								

Quality of Life due to Urinary Symptoms

	Delighted	Pleased	Mostly Satisfied	Mixed - about equally satisfied and dissatisfied	Mostly Dissatisfied	Unhappy	Terrible
If you were to spend the rest of your life with your urinary condition just the way it is now, how would you feel about that?	0	1	2	3	4	5	6

The International Prostate Symptom Score (I-PSS) is based on the answers to seven questions concerning urinary symptoms. Each question is assigned points from 0 to 5 indicating increasing severity of the particular symptom. The total score can therefore range from 0 to 35 (asymptomatic to very symptomatic).

Although there are presently no standard recommendations into grading patients with mild, moderate or severe symptoms, patients can be tentatively classified as follows: 0-7 = mildly symptomatic; 8-19 = moderately symptomatic; 20-35 = severely symptomatic.

The International Consensus Committee (ICC) recommends the use of only a single question to assess a patient's quality of life. The answers to this question range from "delighted" to "terrible" or 0 to 6. Although this single question may or may not capture the global impact of BPH symptoms on quality of life, it may serve as a valuable starting point for a doctor-patient conversation.

14 = no sym
Loren Synthe

APPENDIX 13

Fred's HADS

Please read each item and place a tick on the line alongside the reply that comes closest to how you have been feeling in the past few weeks. Don't take too long over your replies: your immediate reaction to each item will probably be a more accurate response.

I feel tense or "wound up":

Most of the time _____
A lot of the time _____
Occasionally _____
Not at all _____

I feel as if I am slowed down:

Nearly all the time _____
Very often _____
Sometimes _____
Not at all _____

I still enjoy the things I used to enjoy:

Definitely as much _____
Not quite as much _____
Only a little _____
Hardly at all _____

I get a frightened feeling like "butterflies" in my stomach:

Not at all _____
Occasionally _____
Quite often _____
Very often _____

I get a sort of frightened feeling as if something awful is about to happen:

Very definitely and quite badly _____
Yes, but not too badly _____
A little, but it doesn't worry me _____
Not at all _____

I have lost interest in my appearance:

Definitely _____
I don't take as much care as I should _____
I may not take quite as much care _____
I take just as much care as ever _____

I can laugh and see the funny side of things:

As much as I always could _____
Not quite so much now _____
Definitely not so much now _____
Not at all _____

I feel restless as if I have to be on the move:

Very much indeed _____
Quite a lot _____
Not very much _____
Not at all _____

Worrying thoughts go through my mind:

A great deal of the time _____
A lot of the time _____
From time to time but not too often _____
Only occasionally _____

I look forward with enjoyment to things:

As much as I ever did _____
Rather less than I used to _____
Definitely less than I used to _____
Hardly at all _____

I feel cheerful:

Not at all _____
Not often _____
Sometimes _____
Most of the time _____

I get sudden feelings of panic:

Very often indeed _____
Quite often _____
Not very often _____
Not at all _____

I can sit at ease and feel relaxed:

Definitely _____
Usually _____
Not often _____
Not at all _____

I can enjoy a good book or radio or TV programme:

Often _____
Sometimes _____
Not often _____
Very seldom _____

Thank you for your help

A = 7
D =

APPENDIX 14

Charlie's I-PSS

International Prostate Symptom Score (I-PSS)

Patient Name: _____ Date: _____

		Not at all	Less than 1 time in 5	Less than half the time	About half the time	More than half the time	Almost always	Your
0	1. Incomplete emptying Over the past month, how often have you had a sensation of not emptying your bladder completely after you finish urinating?	0	1	2	3	4	5	
H	2. Frequency Over the past month, how often have you had to urinate again less than two hours after you finished urinating?	0	1	2	3	4	5	
0	3. Intermittency Over the past month, how often have you found you stopped and started again several times when you urinated?	0	1	2	3	4	5	
H	4. Urgency Over the past month, how often have you found it difficult to postpone urination?	0	1	2	3	4	5	
0	5. Weak Stream Over the past month, how often have you had a weak urinary stream?	0	1	2	3	4	5	
0	6. Straining Over the past month, how often have you had to push or strain to begin urination?	0	1	2	3	4	5	
		None	1 Time	2 Times	3 Times	4 Times	5 Times or more	
H	7. Nocturia Over the past month, how many times did you most typically get up to urinate from the time you went to bed at night until the time you got up in the morning?	0	1	2	3	4	5	
Total I-PSS Score								

Quality of Life due to Urinary Symptoms

	Delighted	Pleased	Mostly Satisfied	Mixed - about equally satisfied and dissatisfied	Mostly Dissatisfied	Unhappy
If you were to spend the rest of your life with your urinary condition just the way it is now, how would you feel about that?	0	1	2	3	4	5

The International Prostate Symptom Score (I-PSS) is based on the answers to seven questions concerning urinary symptoms. Each question is assigned points from 0 to 5 indicating increasing severity of the particular symptom. The total score can therefore range from 0 to 35 (asymptomatic to very symptomatic).

Although there are presently no standard recommendations into grading patients with mild, moderate or severe symptoms, patients can be tentatively classified as follows: 0-7 = mildly symptomatic; 8-19 = moderately symptomatic; 20-35 = severely symptomatic.

The International Consensus Committee (ICC) recommends the use of only a single question to assess a patient's quality of life. The answers to this question range from "delighted" to "terrible" or 0 to 6. Although this single question may or may not capture the global impact of BPH symptoms on quality of life, it may serve as a valuable starting point for a doctor-patient conversation.

15 = 8

APPENDIX 15
Charlie's HADS

Please read each item and place a tick on the line alongside the reply that comes closest to how you have been feeling in the past few weeks. Don't take too long over your replies: your immediate reaction to each item will probably be a more accurate response.

I feel tense or "wound up":

2 Most of the time _____
A lot of the time _____
Occasionally _____
Not at all _____

I still enjoy the things I used to enjoy:

1 Definitely as much _____
Not quite as much _____
Only a little _____
Hardly at all _____

I get a sort of frightened feeling as if something awful is about to happen:

1 Very definitely and quite badly _____
Yes, but not too badly _____
A little, but it doesn't worry me _____
Not at all _____

I can laugh and see the funny side of things:

0 As much as I always could _____
Not quite so much now _____
Definitely not so much now _____
Not at all _____

Worrying thoughts go through my mind:

1 A great deal of the time _____
A lot of the time _____
From time to time but not too often _____
Only occasionally _____

I feel cheerful:

1 Not at all _____
Not often _____
Sometimes _____
Most of the time _____

I can sit at ease and feel relaxed:

1 Definitely _____
Usually _____
Not often _____
Not at all _____

I feel as if I am slowed down:

1 Nearly all the time _____
Very often _____
Sometimes _____
Not at all _____

I get a frightened feeling like "butterflies" in my stomach:

1 Not at all _____
Occasionally _____
Quite often _____
Very often _____

I have lost interest in my appearance:

2 Definitely _____
I don't take as much care as I should _____
I may not take quite as much care _____
I take just as much care as ever _____

I feel restless as if I have to be on the move:

2 Very much indeed _____
Quite a lot _____
Not very much _____
Not at all _____

I look forward with enjoyment to things:

1 As much as I ever did _____
Rather less than I used to _____
Definitely less than I used to _____
Hardly at all _____

I get sudden feelings of panic:

1 Very often indeed _____
Quite often _____
Not very often _____
Not at all _____

I can enjoy a good book or radio or TV programme:

0 Often _____
Sometimes _____
Not often _____
Very seldom _____

Thank you for your help

D = 6
A = 9