An Exploratory Study of the Information and Support Needs for Men aged 75+ With Prostate Cancer

Commissioned by: The Prostate Cancer Charity

Centre for Health Services Studies
University of Kent

July 2005
An Exploratory Study of the Information and Support Needs for Men aged 75+ With Prostate Cancer

Commissioned by: The Prostate Cancer Charity

July 2005
Further copies can be obtained from:

Executive Officer
Centre for Health Services Studies
George Allen Wing
University of Kent
Canterbury
Kent  CT2 7NF
Tel. 01227 824057
Fax. 01227 827868
chssenquiries@kent.ac.uk
http://www.kent.ac.uk/chss
An Exploratory Study of the Information and Support Needs for Men Aged 75+ with Prostate Cancer

Hilary Bungay & Rose Cappello
Centre for Health Services Studies (CHSS)

The Centre for Health Services Studies (CHSS) is one of three research units in the University of Kent’s School of Social Policy, Sociology and Social Research. It contributed to the school’s Research Assessment Exercise 5* rating. This put the school in the top three in the UK. CHSS is an applied research unit where research is informed by and ultimately influences practice. The centre has a long history of working with public health practitioners, both as members of staff and as honorary members of staff who are active as consultants to the centre and as practitioners in the field.

CHSS specialises in the following disciplines:

- CARE OF OLDER PEOPLE
  - Ethnic minority health
  - Public health and public policy
  - Risk and health care

Researchers in the Centre attract funding of nearly £1 million a year from a diverse range of funders including the Economic and Social Research Council, Medical Research Council, Department of Health, NHS Health Trusts and the European Commission.

Funding and acknowledgements
This research was funded by The Prostate Cancer Charity
Executive Summary

An exploratory study of the information and support needs for men aged 75+ with prostate cancer

Introduction

The project was funded by a grant from The Prostate Cancer Charity. The Prostate Cancer Charity are concerned that fewer men aged over 75 are using their support and information services, particularly their Helpline, than would perhaps be expected given the prevalence of the disease in this age group and would like to know whether these men are missing out on information and support, and if so how the organisation could address this in the future.

Context

In recent years prostate cancer has become an important public health problem worldwide with considerable social and economic consequences. Prostate cancer is the second most common cancer in men. The number of prostate cancer cases has risen by 25% over the past five years to 27,000. Prostate cancer tends to affect older men, and by the time they reach the age of 80, about half of all men will have a form of prostate cancer. The fact that prostate cancer incidence increases with age means it significantly affects the lives and well-being of older men and yet there is a paucity of information about older men with prostate cancer. There is little evidence in the literature on the effect of prostate cancer on older men and even less information about the information and support needs of older men.

Aims

The aim of the study of men aged 75 and over who have prostate cancer, is to define the information and support services that The Prostate Cancer Charity could offer now, or in the future, specific to their needs and preferences.

Objectives

- To determine the support (medical, social and psychological) and information needs and preferences of older men who have prostate cancer;
- To identify appropriate formats, media and content for the provision of information that addresses the needs and preferences of older men;
- To explore ways to promote the support and information services provided by The Prostate Cancer Charity to this particular client group.
Methods

The research team undertook a review of current research evidence on the information and support needs of older men with prostate cancer. The literature was used to develop questions for the qualitative in-depth interviews for this study. The purpose of interviews was to develop ideas and hypotheses rather than gather facts and statistics, to try and understand how people think about the topics of concern to the research. A flexible approach to interviewing was used allowing a list of issues to be covered but not in a fixed sequence in order to allow the discussion to flow in a way that seems natural.

Key Findings:

- The information and support needs of men over the age of 75 with prostate cancer cannot be defined purely on the basis of age. The group interviewed were heterogeneous, and factors such as marital status, education, and co-morbidities also need to be taken into account when defining need.

- For a number of the men with prostate cancer there appeared to be no significant impact on their lives. However for those who experienced side effects of the hormone therapy there were noteworthy quality of life issues.

- A significant number of the men mentioned impotence as a side effect of their treatment which suggests that for men in this age group it should be discussed by the health care professionals involved in their care.

- The knowledge of some of the men concerning their treatment raises some concern regarding informed consent.

- On the whole they would like to receive information voluntarily from the doctors who treat them rather than having to ask the doctors to answer specific questions.

- When the word cancer is first mentioned at diagnosis it appears to produce anxiety, suggesting that this is the time when support in terms of information would be beneficial to most men.

- Only one of those interviewed was aware of The Prostate Cancer Charity and had used its Helpline, none of the others interviewed had heard of the Charity or what it offers.

- From the data it was not evident that the support needs for men with prostate cancer were above and beyond those of the age and social factors faced by elderly men in general.
Recommendations

- To reach these men and to provide them with information and support when required, The Prostate Cancer Charity needs to raise awareness of the services they can provide. This could be achieved through advertising in newspapers or magazines.

- Advertising would be expensive and it would be necessary for the marketing department to consider how to most effectively target resources.

- It may be unrealistic to think in terms of a national campaign to reach the affected men and their families but rather to target health care professionals particularly clinical nurse specialists to remind them what The Prostate Cancer Charity can offer in terms of information and support.

- It would also be worthwhile considering changing the name of the ‘help-line’ to an ‘advice’ or ‘information line’, as men may not feel they need help, but would contact an advice or information line.

- The format of The Prostate Cancer Charity card also could be adapted to provide information about the services provided by The Charity and in a format that takes account of visual impairment in the elderly.

Suggestions for further research projects

- Quality of life and consent issues surrounding hormone therapy and treatments.
- Older men’s attitudes and responses to the diagnosis of prostate cancer.
- Study of information and support needs of men aged 60+ with prostate cancer.
Introduction

In recent years prostate cancer has become an important public health problem worldwide with considerable social and economic consequences. It is the second most common cancer in men. In the United Kingdom the number of prostate cancer cases has risen by 25% over the past five years to 27,000 (Cancer Research UK 2004). The rise in cases has been attributed to an increase in early detection due the increased availability of PSA testing (Prostate Specific Antigen). Although its incidence fell by 8% between 1994-1997, it remains the second most common cancer in men, and it is predicted that it will overtake lung cancer as the leading cause of male cancer deaths in a few years (DH 2002). Prostate cancer tends to affect older men, and by the time they reach the age of 80, about half of all men will have a form of prostate cancer (DH 2002).

Although prostate cancer is a leading cause of death among men, many men live with the disease for a considerable length of time, the implication of this situation is the morbidity of the disease, treatment, and quality of life take on greater significance particularly as there are common debilitating problems (Gray et al. 2002). Such problems include: difficulty in passing urine, and passing urine more frequently than usual especially at night.

The fact that prostate cancer incidence increases with age means it significantly affects the lives and well-being of older men and yet there is a paucity of information about older men with prostate cancer. There is little evidence in the literature on the effect of prostate cancer on older men and even less information about the information and support needs of older men. Many studies use standardised tools to assess information needs but do not specifically consider older men. This review extracts important topics, and results from a selection of literature, drawing on nursing, medical and psychology journals. Material for the review was obtained from computerised searches of: Med-line, EBSCO, and Science Direct. The search terms ‘prostate cancer’ and ‘older men’ were searched alone and in combination with ‘information needs’ and ‘support needs’. Citations in retrieved articles provided an additional source of references.

Information and support needs of People with Cancer

The Policy Context

Since the late 1980s there has been a growing political awareness of the importance of patient information in health care. There has been a strong political drive to improve the quality of patient information with successive governments recognising its significance. The importance of providing information for people with cancer was first acknowledged in the Calman-Hine Report (DH 1995) one of whose general principles was that patients, families and carers should be given clear information and assistance in a form they can understand about treatment options and outcomes available to them at all stages of treatment from diagnosis onwards. The Calman-Hine proposals were later reinforced in The NHS Cancer Plan (DH 2000) which announced the introduction of a Cancer Information Advisory Group, set up to oversee the development, content, and availability of cancer information for patients. In 2000, the Cancer Information Strategy Team published Towards a Cancer Information Strategy aiming to: improve the effectiveness and efficiency of care delivery for those with actual or suspected cancer throughout the patient journey, support the
implementation of the Calman-Hine framework, and develop a disease specific information strategy. The strategy considered information needs from three distinct perspectives: patients and public, health care professionals, policy makers and planners. From the patient and public perspective it determined information needs as:

- Access to reliable information about cancer prevention, screening, availability of services and advice;
- Fast reliable communications about appointments, test results, treatment and care;
- Sensitive, appropriate information about their diagnosis, and the ‘cancer journey’;
- Information to help those who wish to make decisions about their own treatment and care.

A further factor influencing the change of emphasis in information giving has been the promotion of patient autonomy (Mills & Sullivan 1999) and the acceptance of the concept of the ‘expert patient’. At one time it was deemed acceptable for the doctor to decide which information patients required and what information should be withheld in the patients’ best interests. Now it is recognised that patients have the right to be told about their condition, and studies have found that the majority of patients want all the information pertaining to their condition (Jenkins et al 2001, Mills & Sullivan 1999). Wider access to medical information encourages a balanced encounter between patient and health professional.

However, the Audit Commission (1993) found that the average consultation time for a man with prostate problems in a urology clinic was 7 minutes. In this time he was examined, expected to hear everything about his condition, treatment, potential risks and outcomes of treatment. There is no updated information about average consultation times but if more than a decade later it remains the situation that consultations times are short, then this will make it difficult for health care professionals to inform patients about all the issues which may concern them. Furthermore it is widely accepted that in stressful situations patients fail to retain all the information given to them. Indeed there is a risk of overwhelming patients with information leading to unnecessary fears, confusion and anxiety for patients and their families (Stenchever 1991). Yet providing information to men who are newly diagnosed with prostate cancer has been found to increase participation in decision-making, decrease levels of anxiety, and improve communication of illness-related information to the family (Davison & Degner 1997). In addition, Mills & Sullivan (1999) identified from published research findings that information giving has been found to improve compliance, help individuals gain control, creates realistic expectations, promotes self-care and generates feelings of safety and security.
Information Needs

Most of the literature surrounding cancer information needs concentrates solely on information needs relating to the disease and its medical treatment, with little reference to the need for other information on other issues such as available financial and community resources (Van Der Molen 1999). Traditionally health care professionals have relied on their own perceptions of patients’ informational requirements when planning and developing health care, but if health care professionals have knowledge of what information patients perceive as important this will lead to more efficient management of the time they spend with their patients (Lufer 1995). McDaniel & Rhodes (1998) believe that patients’ perceptions are crucial in developing any information material to be used in their care. For example, a study which compared nurses and patients perceptions of the learning needs of cancer patients identified a misalignment of priorities, with nurses ranking dealing with the patients’ feelings as a priority, but the patients’ priority was how to minimise the side effects of treatment (Lauer et al 1982).

Cancer patients need and demand information, not only to give them an understanding of the disease and its treatment, but also to prepare them for changes in lifestyle and the uncertainty inherent in the diagnosis (Grahn & Johnson 1990). Faced with cancer, some individuals choose to discover more information about their disease and its consequences, to question their doctor about their options, and to seek support. Others prefer to place their trust in health professionals or to rely on family members to make decisions. The degree to which a patient with cancer seeks information about his or her illness depends not only on individual preferences for control, but also on educational, cultural and financial background. Socio-economic factors have impact on the patient’s ability to access health care resources, support, and information, whereas culture shapes perceptions of the meaning of illness (Harris 1998).

From a review of over 200 articles relating to cancer and specifically breast cancer, Bilodeau & Denger (1996) generated a list of nine information needs: the extent of the disease, likelihood of cure and prognosis, how treatment will affect social activities, effect on family and friends, self-care and return to normal lifestyle, psychological effects of treatment, types of treatment available and the advantages/disadvantages of each, risk of family members getting cancer, side effects of treatment. However individuals require information in different quantities at various stages of the cancer journey (NCA 1996) and it would be wrong to assume that every patient wants to receive all the available information at the point of diagnosis. The cancer journey is divided into diagnostic, treatment, and recovery/remission phases, and research has shown that information needs vary at different points of the journey: in the diagnostic phase patients require information on the potential diagnosis, types of treatment, stage of diseases and likelihood of cure; during treatment information about the disease and the likelihood of recurrence are important; and during the remission/recovery phase information on the likelihood of cure and the risks to other family members becomes important (Rees & Bath 2000).

In another review Mills & Sullivan (1999) explored the factors that influence information seeking, and found some opposing views, concluding that information is an individualised aspect of care, and that it is not possible to predict information needs on the basis of whether someone is male or female, old or young or with a certain level of education. There were limitations to many
of the studies cited by Mills & Sullivan (1999) in that there were small sample sizes, most were based on populations in the USA and Canada, and more than half the empirical studies cited investigated patients with breast cancer and consequently were predominantly female. Although Mills & Sullivan conclude that information needs are individualised and cannot be predicted on the basis of age, gender or educational level, other authors have found that factors such as age and gender do influence whether or not people request or seek information and are active or passive in encounters with health care professionals.

Support Needs

Exploring support needs in the literature is difficult because there are many different definitions and interpretations of what support means. Some authors refer to social support, but social support in cancer care has not been well-defined, and indeed there are many different definitions of social support in the literature (Hutchinson 1999). It is seen to be important because of the potentially strong impact of supportive resources on the maintenance of health, patients' participation in their care, adaptation to chronic illness and recovery from acute illness (Hutchinson 1999). It is also recognised as being critical to cancer patients' psychosocial well-being, Bloom (1982) stated that when diagnosed with cancer, the need for social support increases to help the patient address the fears and ambiguities of the situation. The function of social support is to enable people to believe they are cared for, loved, esteemed and valued (Van Der Molen 1999).

Other authors have categorised support into three areas; emotional support, informational support, and instrumental or tangible support (Dukes Holland & Holahan 2003, Nordin et al 2001, Van Der Molen 1999).

**Emotional Support:** encompasses the expression of positive affect, the information that one is cared for, loved or esteemed. Emotional support has been found to assist adjustment in women with advanced breast cancer (Bloom & Spiegel 1984).

**Instrumental Support:** is the provision of material aid or practical help.

**Information Support:** Information is perceived as supportive as it helps individuals to deal with feelings of vulnerability (Van Der Molen 1999). Informational support can help people to cope better with the sense of confusion that may arise when they are diagnosed with cancer through helping them understand more about the illness.

People may be reluctant to ask for help/support for fear of upsetting or hurting loved ones by talking about the disease or because they believe that health care professionals are too busy for conversations about concerns or fears. The need for support by people with cancer is increased by their feelings of uncertainty and fear and yet the stigmatising nature of the illness is likely to contribute to the problem of obtaining adequate support. Older men may not be used to eliciting information and support in the context of their own health and this could make it difficult for them to initiate requests. Knowing how to get access to support can be a further problem. Many people may have visited the same GP surgery for years and know the local hospital but have not used social services, they may therefore use the GP as a starting point to ask where they might get help with housework etc. but GPs are often poorly informed about the range of services available. Therefore there needs to be readily available information about the 'ways into' other services.
Do age and gender impact on the use of information and support services?

Cancer is diagnosed as frequently in men as in women, yet studies have consistently demonstrated that men are low users of cancer information services, as well as other health and support services (Boudioni et al 1999, Manfredi et al 1993, Slevin et al 1988.). Moody (2003) found that in the first six months of a local cancer information centre opening just over 35% of the contacts were from men, similarly Boudioni et al. (1999) audit of Cancer BACUP found that 78% of first time users were female. In a study of the role of gender in participation in decision-making Blanchard (1988) found that whilst there was no gender difference in individuals wanting to participate, they noticed that twice as many men as women preferred not to participate. What makes men use these services less, and men less likely than woman to participate in decision-making in health care matters?

One explanation is that ‘real men’ are supposed to be unconcerned about health matters, and ‘real men’ don’t fuss over their bodies (Watson 1993 cited in Gray et al 2002). The male gender identity has been characterised as: the strong silent type, with toughness and violence, self sufficiency (no needs), being a stud, no sissy stuff (such as emotional sensitivity), and being powerful and successful (Kiss & Meryn 2001). It could be debated that such an identity seems stereotypical and exaggerated but there is some evidence that these characteristics are still real (Good & Sherrod 2001).

The traditional masculine characteristics, such as inexpressiveness, are shown to be significant predictors of poor health practice in men (Moynihan 2002), and there is some evidence that older men prefer not to ask questions about their disease to avoid discussion of recurrence and death (Leydon et al 2000). The notion of the ‘stiff upper lip’, ‘men don’t cry’, and presenting ‘a brave face’ to others may also explain why men find it difficult for them to talk about or seek information regarding cancer. Leydon et al (ibid) felt that men preferred not to ask questions of the medical profession, or people in the wider social networks so as to avoid discussions of disease recurrence and thus maintaining hope through silence.

Some claim that men’s refusal to admit weakness may preclude their engagement with medicine (Harrison et al 1992), and make them less likely than women to seek and receive more medical care including psychological support services. Arber and Davidson (2003) suggested that the reason many men are unwilling to turn to health professionals in later life is that compared to women they are less familiar with visiting the doctor as women routinely visit the doctor throughout life, for family planning, pregnancy, taking children for immunisations. However, they also found that some men saw visiting the doctor as a sign of weakness, and did not want to be seen to be giving in to illness (ibid).

Women are socialised to seek medical help, whereas men are taught early in life to manifest stoicism. Men generally are less aware of health issues, and less willing to seek professional help in times of illness often leaving (female) partners to seek information and assistance on their behalf (Moody 2003). Chapple and Ziebald (2002) used Seidlers argument to explain why the men they studied with prostate cancer said they were reluctant to consult doctors, that as the traditional masculine identity has been eroded, men are afraid of admitting that they need help in any way because they perceived it as a sign of weakness. The authors of
a recent study concluded that most men with prostate cancer avoid disclosure about their illness where possible, and place great importance on maintaining a normal life. This was felt to be due to men’s low perceived need for support, fear of stigmatisation, the need to minimise the threat of illness to aid coping, practical necessities in the workplace and desire to avoid burdening others (Gray et al 2000).

There is little research on the effect of prostate cancer on male gender identity, but the diagnosis of cancer is distressing and between 20-30% of patients are depressed or anxious six months after diagnosis (Nordin et al 2001). With prostate cancer and indeed other cancers men are confronted with a number of physical and psychological challenges, facing a life threatening disease as well as the experience and side effects of treatment. Older men with prostate cancer may be in a liminal state particularly if they are receiving no treatment but are under going ‘watchful waiting’, they are diagnosed with ‘cancer’ but not ‘ill’, and this may produce uncertainty and be disorientating (Navron & Morag 2003).

Age

The fear and apprehension associated with cancer often hinders individuals from asking specific information, but in the study group (men aged 75+) there may be other factors preventing them from accessing available services (Templeton and Coates 2001). For example, older people have grown up in an era characterised by doctor-centred practice where the doctor is felt to ‘know best’ and that there is concern that seeking additional information could affect the relationship with the doctor.

Early work found that negative stereotyping of the elderly was common among health care professionals (Green et al 1986). If clinicians assume that there is an increased passivity and helplessness in the elderly then it is likely that such attitudes will permeate the consultation, leading to a doctor-centred rather than patient-centred interaction, and the doctor in control of information giving. More recent work states that patients whatever their age want to be kept well informed about their illness. As part of an empirical study evaluating communication skills Jenkins et al (2001) collected information preferences of 2331 patients attending outpatient clinics for consultations about cancer and its treatment. They found that 98% of patients needed to know whether their illness was cancer and 95% wanted to know their chances of cure. 81% of patients over the age of 70 wanted as much information as possible, however significantly more of the older group preferred to leave details to the doctor compared to the other age groups. The notion that older patients prefer doctors to determine how much information to provide was only weakly upheld by the study. Although significantly more of the older (defined as aged 70+) preferred to leave details up to the doctors to decide, most (98%) still wanted specific information about treatment and side effects.

However, although older patients have a high desire for information, some data suggests that they have less desire for participation in decisions about treatment and management (Charles et al 1998), and although older people may want the doctor to make decisions about management, they still require information about the reasons for decisions affecting their care. Older people often have less expectation in relation to health care, which makes them less demanding and less likely to complain about services as much as younger people (Scott 2002). On the other hand, older people may first turn to family, friends or other informal
sources of information before formal ones but as people get older the informal
sources may decline because of retirement, bereavement or disability, and if the
informal sources fail then people will turn to professionals. Leydon et al (2000)
described people as having faith in the doctor’s expertise who did not want to
threaten the perception of being a good patient by asking questions. Being a
good patient was construed as ‘doing as you are told’ as opposed to knowing a
lot and being inquisitive. Some people over the age of 75 exhibit deference to
perceived authority and an unwillingness to question professionals. This will
change as today’s younger generation grow as they are more demanding of
public services, have higher expectations of their own autonomy and their level
of involvement in decisions affecting their lives (Cawthra 1997). Obtaining
appropriate information may be a particular problem for older people because of:
negative attitudes to cancer, less knowledge of risks/symptoms, and in the case
of older men stereotyping, with impotence and incontinence not being
considered a worry for older men.
Information needs do vary according to age, with younger people being more
likely to want to be better informed and participate in the decision-making
suggested that this might because the stigma of cancer is more ingrained in the
older population and traditionally they take a more passive stance in dealing with
illness, and have also been found to be less positive than younger groups in their
attitudes towards cancer. In Boudioni et al (2001) study, age was found to be a
determinant of the kind of information or support sought, and the authors
suggested that this could be because older men have been reported as more
likely to feel ‘helpless and hopeless’ than younger men (Akechi et al 1998) and
may therefore need more emotional support.

Although older men are more likely to be aware of prostate cancer than younger
men (MORI 1999) few feel that sufficient information has been directed
specifically to them. This may explain why they are less likely than younger men
to request general information such as publications, but are more likely to
request specific therapies information. Asking for written information may be
easier than requesting emotional support or even information on specific
therapies and may explain why younger men hide behind a ‘brave façade’
(Moynihan 1998). Boudioni et al (2001) recommended the need for further
research to enable a better understanding of how age affects prostate cancer
patient’s needs for information and support.

Conclusion

There is little evidence in the literature that there is interest in studying the
experiences or problems faced by ageing men with prostate cancer, and men
over the age of 75 are not considered separately from younger men with prostate
cancer. Yet prostate cancer incidence increase with age and it affects the lives
and well-being of older men.

Gender differences in longevity have led to an imbalance in the numbers of older
men and women. In the UK, women aged over 75 outnumber men aged 75+
approximately 1.7 times (Office of National Statistics Census data 2001). Older
women are historically a disadvantaged group, Fleming (1999) suggested that
their poverty and institutionalisation coupled with the interest of feminist scholars
over recent years has resulted in a higher profile for older women in research,
thus rendering virtually invisible the lives of older men. However the very fact that
men are considered to have more comfortable lives when compared to women, with fewer financial problems and better health, may preclude them from asking for information and support.

The Prostate Cancer Charity are concerned that fewer men aged over 75 are using their support and information services, particularly their Helpline, than would perhaps be expected given the prevalence of the disease in this age group. Possible explanations for this from the literature include: the traditional masculine role, the stigma and fear associated with cancer, and age and the passivity of older people.

This study will explore whether these men are missing out on information and support, and if so how the organisation could address this in the future.
Methods

Purpose of the Study:
The purpose of the study was to determine whether men aged 75 years and over with prostate cancer are missing out on information and support, and if so how, and what are the appropriate services that The Prostate Cancer Charity could offer them, now or in the future.

Aims and Objectives
The aim of the study of men aged 75 and over who have prostate cancer, is to define the information and support services that The Prostate Cancer Charity could offer now, or in the future, specific to their needs and preferences.

Objectives

- To determine the support (medical, social and psychological) and information needs and preferences of older men who have prostate cancer;
- To identify appropriate formats, media and content for the provision of information that addresses the needs and preferences of older men;
- To explore ways to promote the support and information services provided by The Prostate Cancer Charity to this particular client group.

Plan of Investigation

Reviewing the Literature: There is limited literature on the health and information needs of older men and it is an under-researched area. A review of the available literature was conducted to put the study into context and ensure all the issues relevant to the subject group and research brief were covered.

Choice of methods: Given the exploratory nature of this study a rigid design such as a hypothesis testing RCT was not appropriate and the concern to understand and interpret the participants’ experiences favoured the use of qualitative methodologies. Qualitative research encourages open, reflective and informative responses and can cope with complex ideas, it is also useful for accessing the context surrounding the participants’ responses. We therefore used qualitative in-depth interviews for this study. The purpose of the interviews was to develop ideas and hypotheses rather than gather facts and statistics, to try and understand how people think about the topics of concern to the research. A flexible approach to interviewing was adopted allowing a list of issues to be covered but not in a fixed sequence in order to allow the discussion to flow in a way that seems natural (Hammersley and Atkinson 1995).

The Interviews: In-depth interviews with older men with prostate cancer were conducted. The men were first asked to ‘tell their story’ from when they first realised that they had a problem, and to ensure the objectives of the research were met the interviewer carried an aide memoir (see appendix 1). The aide memoir was also designed to help the conversation flow and to ensure that each all topics were covered with each of the research participants.

Prostate cancer may be considered a sensitive topic. Renzetti & Lee (1993) defined a sensitive topic as one which potentially poses a substantial threat for those involved, where the ‘threat’ is the intrusion into a private sphere, exploring
deeply personal areas. For some people the word ‘cancer’ is problematic in itself, and secondly, prostate cancer (and its treatment) may cause incontinence and impotence, subjects which may cause embarrassment to the research participants. The team were aware of the potential difficulties of interviewing older men and therefore open questions were used throughout the interviews following the participants lead in how they referred to ‘prostate cancer’. For example, once the study had been introduced if the participants referred to ‘the problem’ or ‘prostate trouble’ the interviewer mirrored the terminology adopted. Participants were not directly asked about incontinence or impotence, but if they referred to it they were questioned further again using the same language used. The interviewers ensured they were respectful in how they communicated with the participants and were careful not to invade privacy or cause embarrassment. It is acknowledged that had the interviews been carried out by older male interviewers that the men may have been more forthcoming about raising these issues. However in a recent study by Chapple & Ziebland (2002) men were given the choice of having a male or female interviewer but only one chose a male, and in their study many of those interviewed spoke spontaneously about problems around their sense of masculinity, which suggests that the gender of the interviewer does not affect the content of the interview data, and the generic nature of the questioning around the topics of information and support needs allowed the aims and objectives of the study to be reached.

Sample: In the 75+ age group the ‘radical’ management of localised prostate cancer is usually limited to radiotherapy (The Prostate Cancer Charity). Active monitoring/surveillance is more common, or men are prescribed hormones for more advanced cancer. Therefore the sampling for the study was purposive to men aged over 75 years, with a confirmed diagnosis of prostate cancer, it was hoped that between 30 and 40 men would be recruited from two different hospitals.

Recruitment: People were accessed as soon as ethically possible post-diagnosis, and were recruited from urology clinics at follow-up appointments. To aid recruitment the researchers attended the clinics, this served to remind the staff about the study and also allowed the potential research subjects to meet the researchers before the actual interview. The clinic nurses identified possible patients and marked the patients notes, the doctors then asked the patients at the end of the consultation whether they would consider speaking to the researcher. Patients were informed about the study and given an information sheet and stamped addressed envelope and invited to return the reply slip if they were willing to take part. Once the reply slip was returned contact was made with the patient and an appointment made for the interview. Before the interview took place, the research subjects were asked to sign a consent form (See Appendix).

Response Rate: In total 20 men returned the completed consent form agreeing to take part in the study. However it emerged that one of these men did not actually have a diagnosis of prostate cancer and therefore only 19 interviews were completed. The interviews varied in length from 30 minutes to 45 minutes. Not all those invited to take part accepted, but the exact numbers who were invited is not known as the researchers were not present at all the clinics all of the time, and even where men were identified beforehand by the nursing staff as being eligible it was not possible to know whether the clinicians asked them to consider taking part.
It is possible that some of those invited to take part did not return the consent form because they thought they had nothing interesting to say. Non-response does appear to be encouraged when the person does not feel (s)he is an appropriate subject of interview (Victor 1994). Victor found that a substantial number of older non-respondents refused to participate in a study because they felt it did not apply to them. In the current study 7 of those interviewed expressed concern that either they hadn’t actually anything of interest to say or that they would be wasting our time. The following is a typical comment from one of the interviewees...

“I really didn’t know what I had got to offer because I wasn’t feeling distressed and I wasn’t feeling any pain, other than I’d already got and what’s more, nothing seemed to be different” (PC 19).

A couple of those interviewed also thought that when approached by people who were working on behalf of a charity that they would be asked to contribute some money.

Sample characteristics: The sample was heterogeneous (the demographic characteristics of the study sample can be found in the Appendix). The age of men interviewed ranged from 76-88 years. Some were married living with their wives whilst others lived alone either widowed or never married. There was a range of social and educational backgrounds but no ethnic minorities in the sample. Some of the men were recently diagnosed whereas others had been living with prostate cancer for a number of years, and most had a number of co-morbidities. The men interviewed were all categorised as ‘older’ elderly being over the age of 75, they were however all very different. For example one of the men in his 80s didn’t know why the GP had referred him to the hospital, what the injections he had in his stomach were for, and was happy not to know as long as he felt that the people who were treating him knew what they were doing. Another man also in his 80s was very well informed about all his medical conditions and treatments and kept meticulous records of each encounter he had with his GP or hospital doctor.

Analysis of the Data: The interviews generated a rich body of qualitative data. This data was transcribed verbatim and subjected to coding, categorising and thematic generation (Denzin and Lincoln 1994), a software package Atlas-ti assisted the process. The research was conducted iteratively and analysis started during the data collection period and as themes emerged questions were developed to explore issues that were important to the research subjects in greater depth.
Ethical Issues

Older people may feel vulnerable because of their relationships with services and service providers, with the standard of these relationships having an impact on the quality of their life. Participants may be unwilling to be seen as complaining about the services, and may also have few expectations as to what services they should be offered. Participants were therefore reassured that their responses would be confidential and they would not be identifiable in the report, or subsequent publications. The men were assured that if they did not wish to take part in the study it would not be detrimental to them. Ethical approval was gained from the appropriate NHS ethics committees for the study, and research governance approval granted by the hospital trusts involved.

Difficulties Encountered

The Introduction of Research Governance: Ethical approval was granted for the study within eight weeks. However at the same time the study was funded new Research Governance guidelines came into effect and the two centres being used for the study introduced new requirements for research being carried out on their sites. At one of the centres the Research Governance clearance took 14 weeks and at the other it took 16 weeks. Therefore although 12 weeks had been allowed in the project proposal for ethical review, the effect of the introduction of Research Governance was not anticipated and consequently recruitment to the study was delayed by 4 weeks.

Recruitment: Although the consultants at each site reported that they had a large number of patients over the age 75 with prostate cancer on their lists, recruitment from the clinics was slow. For example, over a 10 week period the researchers attending 20 clinics only encountered 22 possible recruits, there were more men over 75 with prostate cancer attending but some of these were not included because they were suffering from dementia, and others had other cancers which would have made it difficult to separate the prostate cancer information and support needs from those needs relating to the other cancers.
Findings

Information and Support Needs of Men aged 75+ with Prostate Cancer

The diagnosis of cancer is ‘life-threatening’ not just because of the threat of mortality but also because of its effect on normal life; there is fear of the unknown, uncertainty, the possibility of pain and hospitalisation, the negative influence on family and the start of life as a patient. To be able to explore the information and support needs of men aged 75+ with prostate cancer this section will look at their experiences of living with prostate cancer to put their needs into context.

Living with Prostate Cancer

Symptoms Prior to Diagnosis
Prior to diagnosis just over half those interviewed (10) had had typical symptoms associated with prostate problems, that is increased frequency, difficulty in passing water, and/or having to get up in the night, which led to further investigation by the GP. Three were admitted to hospital with acute urinary retention where a diagnosis of prostate cancer was made. Others did not admit to any recognisable symptoms of prostate problems and were diagnosed as a result of other conditions, two were diagnosed through routine screening carried out by the GP, whilst two of the men either couldn’t remember or were unsure as to why the GP had referred them to a specialist at the hospital.

Quality of Life
As previously stated many men live with prostate cancer for a considerable length of time, and therefore the morbidity of the disease, treatment, and quality of life is potentially very important. However seven of those interviewed stated that having prostate cancer has had no affect on their lives, this is a typical comment from one of this group,

“I wouldn’t know I’d got the cancer. You wouldn’t really, they are with the medication really keeping it under control…It doesn’t touch wood, have any affect on me at all, you know. Apart from that I know I’ve got it” (PC17).

On the other hand just over half of those interviewed (9/19) reported disturbed nights with the need to get up to urinate a number of times each night,

“after I was diagnosed I had to go to the doctors about it because I had to go to the bathroom at that time about every 20 minutes and that ruins your sleep and you just feel dead and tired the next day” (PC 3).

The impact of sleep deprivation can be a significant problem at any time of life. One of the men said he could almost set his clock at night by the time he got up, another said that if he got up even more times than usual then it made him wonder whether the cancer returned as that had been how it was originally picked up. The men did monitor how much they drank in the evenings to try and minimise their disturbance and to have some control of their sleep.
Hormone Therapy
All but two of the men were on hormone therapy to treat the prostate cancer, of those having therapy five complained of hot flushes, and of these four experienced night sweats. These were a source of irritation and discomfort particularly in the night,

“\textit{you get these hot flushes beads of perspiration pour out...I've got it now, you know...you sweat and it pours off you and you have to get up in the night and change your clothes. So I went to my own doctor again and I said to her I can't put up with this, I was getting a bit fed up with having this effect on me. I didn't want my food I felt as weak as a kitten and I had these hot flushes so she said if you are having this sort of response I should give it up. Wait until you go down the hospital again and then perhaps they can recommend something else which of course, ultimately they did}” (PC9).

This man not only had problem with the night sweats and hot flushes he also experienced sickness and generally feeling unwell as a result of his treatment. Other side effects experienced by the group included breast enlargement with breast tenderness, sickness and depression. This man was not very happy about the breast enlargement but accepted it was necessary,

“The tablets they give me have had this, and they warned me about this, they take away the testosterone, which is the male hormone and as a result of that they said you will find that you will develop breasts. I said that I wasn't really keen on that, but if the alternative is for this cancer to get worse then I'll opt for that. After all no-one else knows, nobody else sees them except for me so I'm quite happy to accept that” (PC6).

Another side effect of hormone therapy is impotence, and eight of the men described how they had become impotent. A couple of the men felt it was the lesser of two evils as at least they were still alive but others expressed sadness about the loss of their sex life. Some remarked on how they thought it would be more difficult for younger men, however only one of the men linked it with his masculinity,

“...the nurse said I'll probably be impotent when I've had this, but they didn't say why or how long. It wasn't until the last time I saw this lady doctor she sent me to [name] because was still exactly the same - no change. As I was going out the door she said 'well it can last for two years you know' and I thought 'well, why didn't you tell me that in the first place?' I wouldn't be so...my wife said it doesn't matter, but to me it does matter. It's part of you, isn't it? It's part of being a man or a woman, whatever. You don't want your bits not working properly” (PC2).

In other studies the hormone therapy and subsequent impotence effects on masculinity has been an important issue for men, but although this was the only person to articulate this view in this study it is important to consider the implications for all men having hormone therapy regardless of age, and not to assume that older people are not interested in sex or romantic relationships.
The fact that eight men in this study felt impotence was an important issue to mention suggests that information about impotence should be provided and not just to married men, as one of those interviewed was widowed but had been sexually involved with a friend when the therapy began.

**Comment**

These findings suggest that men require more information about the side effects of the hormone therapy, it also raises concern over the quality of the informed consent, do the men really understand what the therapy does? And do they comprehend the treatment options including having no treatment and watching and waiting? What is also perhaps significant were the number of men who mentioned impotence suggesting that this really is not just an issue for younger men.

**Other Medical Conditions and Age**

The term ‘old age’ usually implies (implicitly or explicitly) some sort of decline and deterioration in health and all but two of the men had other medical conditions; eight suffered with arthritis either on its own or with other problems and the others had a wide range of different conditions including asthma (4), eyesight problems (3), heart condition, gall stones, emphysema, cholesterol, lung cancer (possibly a secondary from the prostate?), psoriasis, recurrent urinary infections, and anaemia. None of them felt that the prostate cancer made dealing with these other conditions more difficult, arthritis appears to the disease which caused most aggravation and affected the quality of life most severely due to pain and limitations of movement,

“It’s always the arthritis - it never stops hurting. Always conscious of that. Sometimes it gets worse, don’t know why, but sometimes its worse than others, and the last few weeks its been getting on my nerves, so you know you do forget about the cancer” (PC13).

The men spoke about their age in relation to their health, and three main themes emerged; general deterioration of the body due to age, an appreciation of their health considering their age, and the feeling that prostate cancer was a disease of old age.

Men tend to have a poor knowledge of health matters and are more likely to delay seeking help. This could be due to the characteristics of men outlined in the literature review and also the possibly embarrassing nature of the symptoms themselves, and indeed only three of the men spoke about incontinence. However it could also be due to ignorance of the significance of symptoms, and if men are unaware of what certain symptoms may indicate they could rationalise what is happening to them in terms of age and deterioration of the body due to age. For example, this was one of several men who explained why he had not acted when he was experiencing difficulty in passing urine,

“Before I had the operation the flow of urine wasn’t very good. But I thought it was the general dilapidation of the elderly and I wasn’t really concerned about it” (PC5).
Cameron & Bernades (1998) suggested that older men tend to see symptoms as part of the ‘normal’ ageing process rather than an illness, which may contribute to their late self referral to the GP, this may explain why some men do not seek help until a disease has progressed. In the current study this was evidenced by those men who did not acknowledge that they had a problem with passing water until they were admitted to hospital in acute urinary retention.

Some of the men felt that considering their age, the prostate cancer and other medical conditions they were actually very well and were able to live a full and active life,

“But I didn’t feel ill. I don’t feel ill. In fact for my age, I suppose I am very active” (PC 16).

Those men who had problems with urgency and urinary continence had developed coping strategies so they were able to continue to do as they wished, for example ensuring that they knew where toilets were when they visited somewhere new, and moderating their drinking.

Prostate cancer does increase with age and some of the men had been told or had read in the newspapers that most men of their age would have prostate cancer,

“I think it was Dr [name] said to me, he said every man over the age of 80 has probably got it and it is not until after… it’s not until after they have passed away and have the post mortem they find that that person had a prostate problem anyway. I think there’s mention in there about men as you get older it can crop up and you may have it and not be affected by it. But yes that has been said a couple of times. It’s something that lies virtually dormant and a man can reach 100 or whatever and its just laying there semi-dormant perhaps” (PC20).

**Surveillance**

Most of the men were seen regularly at the hospital and those who had hormone injections went to the GP surgery every three months, where the practice nurse delivered the injection. They also attended the GP surgery for a blood test two weeks prior to a hospital visit for a blood test. Such regular visits must have an impact on their lives as they have to get themselves to appointments, they have to remember to make the appointments for the blood tests, it cannot be assumed that the impact of the visits was a negative one but they may experience anxiety as to what the outcome of the appointment will be. However the men described the visits in a very manner of fact way that it was just something they did, only one said that he felt anxious beforehand as to what they might say.

**Record Keeping**

Some of the men were very systematic in their approach to their disease. Seven of them kept records or notes relating to their medical conditions, these ranged from keeping all the appointment letters and written information given to them, to notes of their encounters with different doctors,
“I have got all these notes here. Let’s see what was said... Right 22nd January 2004 appointment with Mr [name] at [name] Hospital. He thinks the PSA has increased significantly. He said I probably have a slight prostate cancer. This is the first diagnosis of it in January this year. I was monitored since 1990 but this January this year, he thinks I have a... I probably have a slight prostate cancer but there’s no need for alarm because most men of my age have a slight cancer and they mostly live with it. Decided not to do a biopsy at present etc. And again I have got a note here, my own doctor my GP he agreed with the policy of avoiding a biopsy....” (PC1).

Other authors (Cameron & Bernades 1998, McGregor 2003) have also found that men in similar circumstances keep records of symptoms, treatment etc. Cameron & Bernades suggest that this is a masculine way of responding to health problems giving men the opportunity to track their own health and progress. Furthermore they suggest that as men are less likely than women to join support groups and talk about their problems, and that keeping such records is an alternative to articulating their concerns to others.

Comment

From this it can be seen that for some of the men there is little evidence that having prostate cancer made a significant difference to their lives. If they are not experiencing any difficulties and feel well then it is not surprising that they do not seek further information and support. If indeed it is the case that they do not desire information or support then perhaps it is questionable as to whether resources should be used for this purpose. For the others for whom the hormone therapy was problematic, with the hot flushes, breast enlargement, impotence etc. they potentially desire further information and support and these needs, this will be explored in the following section.

What is the nature of the information and support required?

Information

Potentially there is a vast amount of information that could be useful to people with prostate cancer. For information most of the men appeared to rely on the doctors in the hospital at their routine follow up appointments or their GPs. However, there was recognition (and general acceptance) by those interviewed of how busy the doctors are. Patients overall satisfaction with clinic attendance has been linked to the length of consultation. Smith and Sanderson (1992) found that patients whose consultation lasted more than 10 minutes were more worthwhile than shorter ones. Some of the men remarked at how short their consultation was, likening the experience ‘to traffic’ and ‘a conveyor belt’, such short consultation times don’t allow people to ask questions or for sufficient time for the information to be provided and indeed absorbed,

“They don’t do a lot. Well they don’t spend a lot of time on you. I presume that’s because they’ve got plenty of other people to see no doubt. I’m not questioning that. But what I do think is necessary is they don’t say ‘when you do this, takes a length of time and if it doesn’t work I have an alternative option for you to do and have this or that’. They don’t seem to do that. They don’t sort of go into detail. They give you no detail
whatevver. I'm no more wiser than when I first went down there. I wish they were more conversant with it. I don't mind hearing what they have got to say and if there's anything need to be done then I don't mind doing it but they sort of just ask you a few brief questions, ‘How are you? Are you feeling alright today? Not too bad and this sort of thing…” (PC9).

On the other hand he went onto say that the visits were reassuring and supportive,

“They do it very well and I'm glad to say that perhaps I'm having an eye kept on the situation. That I do agree is excellent” (PC9).

At the hospital they are given their blood test result with their PSA level and asked how they feel. Most of them knew that the PSA level gave an indication of how they were doing. Eight of the men quoted an actual figure and knew whether their level had gone up or down since the last test and the significance of this. This fits with Tannock’s (2002) description of men clutching their printouts with their PSA levels in their hands, he suggests that the knowledge of the PSA creates a disabling anxiety, and that there is also a lead time from when the PSA figures rises following prostatectomy until symptoms become apparent. It did appear that for most of the men that the consultation revolved around this figure. The actual length of the consultation was also used as an indicator as to how well they are doing,

“It’s quite a short interview, I mean if the PSA count is down or it is not rising it’s just a question of presumably they look to see if I’m still alive and I mean they probably notice signs if something is wrong otherwise, but I suppose if I look reasonably healthy and the PSAs alright I mean it’s just a formality” (PC5).

In addition to time constraints and pressures there may also be social or cultural factors which restrain people from asking for more information. They may also be uncertain who is best able to answer specific questions if they are being seen by a number of different health care professionals. The men tended to see different doctors at each visit to the clinic which did not allow them to build relationship with the doctor. This can also be a source of frustration when they don’t feel that the doctor they are seeing knows about them or their individual case. Some of the men did feel that the consultations were short and that they weren’t told much although they were asked whether they had any questions. This is problematic as unless you have a basic knowledge or understanding of a subject area how can you know what question to ask?

If people are seeing different doctors and doctors from different specialities is it important that they receive the same information and advice. This has been a problem for women with breast cancer, where individuals complained they received contradictory information (Van Wersch et al 1997).

There were a number of instances where this had happened to men in this study this being the most notable,
“Last time we went and we saw [oncologist] and it had doubled, but she still wasn’t concerned. She said it was very low and she said they could give him something else if it continued to rise but she’d leave it for six months. That was that. Then we had a yearly appointment with [urologist] and when we got there we saw the other doctor, and he said that he needs to go on these tablets immediately [..............................] so we didn’t quite know what to do, we had such conflicting…” (The wife of PC17)

During consultations people may not be able to remember the information because of the stress of the situation or even because of the use of unfamiliar medical terminology, and this is when written information can be useful. But not all people want to be informed because they feel there is no need, one man (PC4) said he did not want written information as he felt he couldn’t understand the words but also felt he was doing well, and therefore there was no need. Some people may prefer to rely on or to trust the doctors to tell them what they want or need to know. Women with breast cancer have been found to prefer information delivered by a doctor or nurse, because they find them trustworthier than other sources (Freimuth et al 1989). However when information is provided verbally it may not all be processed at the time and it was noticeable that not all the men understood what the hormone injections they were having did or could accurately articulate their purpose, suggestions ranged from “don’t know, don’t care as long as the doctors know what they are doing”, “its to stop infection”, “its something to do with the red and white blood cells”, “to control the cancer”, to ultimately “chemical castration and the removal of the male hormones”. If it is assumed that all the men were told what the treatment they were having was for, then this raises a number of questions, firstly did they understand what they were told? Second, have they just forgotten the detail? And finally, does it matter if they were told and now don’t know the answer?

When appointments are spaced apart, questions may arise and the individuals have to wait for the opportunity to raise them with the appropriate person, written information may help alleviate anxiety if they can access the information for themselves. Some men had not received any written information, but thought it would have been useful to have some as they could read it in their own time,

“I think after discussion, if it could be confirmed in a leaflet or something, confirming what they’ve said so that you can read it at your leisure later on. As you get a bit older your senses are not quite so, it takes a bit longer to sink in” (PC 11).

Eleven of the men had written information about prostate cancer either given to them by their GP, by staff at the hospital or they had picked up leaflets/booklets in the hospital waiting room. Most of the men liked the way the information was presented and felt it supported what they had been told, however two of the men said that they found the information difficult to understand and they would have liked it to be more in ‘layman terms’, preferring information from the doctor,

“I would say a lot of the booklet tied me up in red tape which through my ignorance I don’t understand, not understanding cancer, but I expect they wrote it in what they thought were layman’s terms but some of the explanations I couldn’t understand” (PC3)
Written information has evolved as an important reference for patients and their families in response to limited consultation times, recognition that patients have difficulty recalling verbal information, and also patient demand. Health information content for older people should not be dissimilar to health information for the adult population as a whole. However the mechanism for disseminating that information may be different (Cawthra 1999). The written information needs to be readily accessible, distribution points for written information should be placed where older people are likely to be for example; GP surgeries, day centres, libraries, and supermarkets. Although some of the study men had spotted information leaflets in the hospital waiting room, others had not and it could be that it either should be handed to the men during the consultation or be placed so it is easily visible.

The visibility of information is important particularly for older people as visual impairment increases with age. One of the men reported seeing a poster about ‘prostate cancer’ at his GPs surgery (he hadn’t made contact because he had started to make a note of the number and then was called into see the GP and completely forgot to go back for the number). He remarked that the poster was eye catching because it was red. A survey by Age Concern (1997) found that material (posters and leaflets) about illnesses, entitlements to assistance did not seem targeted towards older people, or that the comments were alarming. Many older people say that a lot of leaflets are difficult to read because of poor layout, font size and jargon. Three of the men interviewed were visually impaired and needed large print versions of written materials.

Other Sources of Information

Mass Media
There are a number of mass media sources of information including: printed or electronic materials, e.g. leaflets, newspapers and magazines, medical books, TV and radio, and the Internet. Gender is an important factor determining the source of health information used, with women more likely to seek advice from peers, magazines, books and television than men (Banks 2001). Information needs change over time and preferences as to where that information comes from can also vary. Once again drawing from the literature surrounding women with breast cancer it has been reported that at diagnosis women breast cancer preferred verbal information from the hospital consultant and breast care nurse supported by some written information, but at 21 month post diagnosis, the women preferred mass media information such as women’s magazines, television and radio (Luker et al 1996).

To determine sources of information favoured by the men in the current study they were asked whether they had read articles about prostate cancer in newspapers or magazines, and twelve of them described reading such articles. One of these men had read in the daily newspaper about the symptoms of prostate cancer including having interrupted sleep due to the need to get up in the night to go to the lavatory. As a result of reading this he had decided to take action and visit his GP with his problem. Some had read about other men’s experiences of living with prostate cancer and commented on the ‘dramatic slant’ placed on stories by the media, but others felt they got more information from the newspaper than they did from the clinic. As a result of reading about research a couple of the men had approached their consultant for further information on the
new drugs and therapies. Generally those who did read articles in newspapers commented on them positively, but the men did not appear to go actively searching for information,

“If I happen to see something, if I’m in the dentists or in the doctors and you pick up a magazine, and there’s an article in it then I’ll read it then, but I don’t try and find anything out about it” (PC 13).

Banks (2001) suggested that it is the macho male maxim of ‘strength in silence’ that has an important impact effect on the men’s desire (or lack of it) for information, while they are being treated for a medical condition. However three men made a point of not reading any articles they came across, preferring to rely on the doctors but also they could not see the point as they felt well,

“I never bother. I’m alright - I feel alright. No need to panic. If something goes wrong then obviously I’d start rushing around, but nothing’s ever gone wrong so I think carry on” (PC15).

For these men although the fact they are diagnosed and medicated, and so labelled as someone with prostate cancer, in themselves they feel well and this could be the explanation as to why they do not want or need to seek further information about their condition, because they do not see themselves as being ill.

**Family and Friends**

Of those interviewed seven of the men admitted to knowing other men with prostate cancer and a couple of these did talk to each other about symptoms and treatment,

“It's a nuisance getting up in the night, but I know 3 or 4 people and they all say the same and yet during the day you can go 5 or 6 hours and you don't need to go to the toilet” (PC 16).

Four of those interviewed deliberately did not talk to friends and even family about the prostate cancer, one even had not told his wife when first diagnosed for a few weeks,

“Shattered. Yes I felt that...well it just made you wonder how long you have got left. I didn't tell anybody for a few weeks - kept it to myself. I was in a bit of a...I don’t know, a bit... I don’t know how to explain it - you had it on your mind, but one minute you think you’ll be all right and just see how you go sort of thing. Eventually I got round to telling my wife and daughter but I kept it quiet for a few weeks, but when you start the treatments, it’s a bit difficult isn’t it” (PC 13).

Whilst this man felt shattered by the diagnosis and unable to share it with his family, Cameron and Bernades (1998) reported that one of the men in their study had not told his wife of 60 years about his prostate problem preferring to keep it to himself believing firmly in ‘mind over matter’ and a positive view of health. Men appear not to rely on the experiences of their peers preferring to live life as normal, and this could explain men’s reluctance to talk to others and share their experiences of the prostate cancer,
“It’s just the women - they all talk about their aches and pains. It’s not the thing that you go out and...you don’t want to ignore and pretend it’s not there, but it not the thing normally you want to talk about. As you get older everyone is falling away, but it’s not something you normally discuss” (PC1).

None of the men attended any support groups although one thought that there was one locally. Where such support groups do exist it has been found that most men attending them are concerned with the giving and receiving of information, rather than support, and previous work found that prostate cancer self-help groups revolve primarily around helping men access what they need to know - not around emotional support (Gray et al 2002).

**Internet**
The Internet is a vast source of information and older people (Silver Surfers) increasingly have access to the Internet. Cawthra (1997) reported that in the USA 1 in 12 people has online access from home, In the UK the Office of National Statistics (2003) reported that 17% of Internet users were aged over 65. Age and gender have been shown to affect Internet use, with older people and women being generally underrepresented amongst Internet users, women have been found to use the Internet more than men for accessing health information (Fox & Rainie 2000). Internet health information challenges established norms whereby the provider of information decides how the information should be delivered, but one married couple expressed distrust and concern about the quality of information available.

Only one of the men interviewed was a ‘silver surfer’ and used email and the internet, but it hadn’t occurred to him to look up anything about prostate cancer

“I had a computer installed about a year ago which I use for emails to keep in touch with the family. I haven’t used it for anything like checking health problems. I don’t use it fully do I? I could do that that couldn’t I? If I Google ‘prostate’ I’d find out all sorts of interesting things wouldn’t I?

Possibly yes
Well, why don’t I? There are other things I have got my mind on” (PC1).

Ziebland (2004) described how on the Internet an experienced user can swiftly access a wide range of different types of information, focusing on specific issues and particular interests, whilst remaining anonymous. In theory for these reasons websites may appeal to men more than women because of the anonymity they provide allowing men to seek information in their own space and time, without challenge to their masculine identity.

**Helplines**
The average age of callers accessing The Prostate Cancer Charity Help-Line hovers consistently around 63, and many fewer men aged 75 and over than perhaps would be ‘expected’ considering the incidence of prostate cancer in the older age group are utilising the service. The use of telephones by older people has changed greatly over the past 20 years making Help-lines more accessible and relevant to the older age group (Cawthra 1997). Although some research has shown that men are less likely than women to access telephone help lines (Boudioni et al 1999, Moody 2003), other work has shown that The NHS Direct telephone advice line is used equally by both sexes, and the Impotence
Association Help-line receives tens of thousands of calls from men about erectile dysfunction (Banks 2001). This suggests that it is probably not a gender or age issue. The problem seems to lie in a lack of awareness of The Prostate Cancer Charity service. Only one of the men in the study sample had used the Help-line, and this man was given information about the Charity by his GP. The other men had not heard about The Prostate Cancer Charity and therefore could not be expected to have contacted the service.

**Comment**

The strength of help-lines and websites is that patients can access help/information at a time that’s right for them, when they are ready to receive information and support, and allows them to assimilate knowledge at their own pace. This study found that the men did not actively go looking for information in line with current theory that men do not seek help or information for health problems. In order to promote the Help-line service it will be necessary to raise awareness, this could be achieved through advertising in daily or weekend newspapers or through targeting the women in the men’s lives (their wives or daughters) by advertising in women’s magazines.

In the modern world there are also other methods of information giving which could be considered for example: video, continuous loop videos in GP surgeries and hospital waiting rooms, and interactive packages with touch screens available in hospital reception areas or GP surgeries. Digital TV also offers the capacity to deliver interactive services in the comfort of the patients own home.

**Support**

In Chapter One, three types of support were identified, one was the support that was gained through information, the other two are emotional and tangible support.

*Emotional Support:* When women receive a diagnosis of breast cancer they may be given ‘cues’ (Lynne & Poole 2000, Bungay 2001) which give them an indication that they have breast cancer before the doctor gives them their diagnosis. For example they may be told to bring someone with them to the appointment for the results of investigations or they may be accompanied into the consulting room by the clinical nurse specialist. These ‘cues’ can help to prepare the women for bad news but they also allow them to have the support of someone accompanying them through the diagnosis.

None of the men in this study received such ‘cues’ the ones who received their diagnosis following the monitoring of the PSA levels over a period of months or years had some indication that they could eventually have a diagnosis of prostate cancer. Five of the men had been told by their GP that they had prostate cancer after having blood tests and a rectal examination, they were then referred to the hospital for a specialist opinion, for some of these men the diagnosis was totally unexpected. There were a range of responses to the diagnosis; shock, shattered, unable to drive self home, others were not too worried ‘as these things happen over the years'.
Most of the married men were accompanied by their wives to the clinics but one had gone on his own and then had not told his wife the diagnosis for some weeks. Those who lived alone had received their diagnosis on their own. In the following extract the man who did not know why his doctor had referred him to the hospital was told he had prostate cancer by the specialist and when asked if anybody was with him at the time said,

“No, by myself, he said is there anything you want to ask me about it, I said no, I was just numb, and I just…he said are you alright? And I said yes I’m alright, no numb. Then I crossed the quadrangle at the back to catch the bus, as I walked slowly by the time I got the bus, I’m not playing the hero stuff…when you’ve got it you’ve got it, there’s no use crying, no need upsetting yourself, these people are here to help you, so that’s how it turned out” (PC4).

‘Cancer’ is still viewed with a negative attitude and it is commonly associated with pain and death (Fridfinnsdottir 1997). However the men were generally quite positive about prostate cancer seeing it as a disease that can be cured, and if not cured, then controlled, it is something they will die with and not of. This was the message that was given to them by the specialist and the GPs.

“But altogether one gets the impression that the word ‘cancer’ I used to think this is dreadful, but when you find that pretty well all men of my age do have this and it was explained to me right at the outset by my doctor that it is nothing to get alarmed about. Men older then you die and they don’t know they’ve got it and it’s only when they do a post mortem they died of something else” (PC1).

Tangible Support: In modern society the need for independence is stressed, this does not allow for the fact that as people get older some are unable to preserve their autonomy and require the assistance of others (Victor 1994). The need for information and support varies throughout the cancer journey but because these men are also elderly they may well have support needs in spite of and as well as those due to the cancer.

The men were asked about their support needs and most of them at the time were coping well with their condition. One had a district nurse visiting weekly and was supplied with pads for his incontinence; he had been offered help from both Age Concern and the Red Cross but had refused it because he preferred to be independent. Another man with advanced prostate cancer had had regular visits from the hospice nurse to help with pain medication, both he and his wife felt that the nurse had been very supportive and was someone to talk to and made them feel that they weren’t alone. None of the other men had any formal support from the statutory services but on the whole did not want or need it. Some of the men expressed concern that they were finding it more difficult to manage with the house, garden and shopping, however this was for reasons to do with other medical conditions and age rather than problems due to the prostate cancer,

“The big problems is things like gardening, but we’re going to…[wife] does a lot of it, but if we need anybody, if we need the house cleaned or the gardening, then we will get someone in” (PC17).
How do needs differ between different groups of men?

From the study characteristics it can be seen that the group interviewed were heterogeneous and that because of the small numbers involved it is not possible to draw conclusions about their responses in terms of length of time since diagnosis, marital status, treatment etc. Although where the men were married the women often sat in on the interview and at times contributed, they seemed to have more knowledge or at least be more open about the man’s condition. There were however a couple of men interviewed who lived on their own and were possibly educated to a lower level compared to other men in the sample, these men did appear to the least informed and supported and further research would be worthwhile to explore this particular group in greater depth. Any perception that elderly people form a homogeneous group with particular needs which are different for the rest of the population can lead to an ageist approach (Victor 1994). It was certainly the case that these men did have a number of opinions, views and perceptions in common and had had similar experiences of health care upon which to draw and form their position. It was also the case that compared to men’s experiences reported in other prostate cancer studies that they were more accepting, less worried, and less threatened by their condition. Could this be due to age or the care and information they had received from their health care provider?

Comment

In the literature review possible explanations as to why men use information and support services less than women were outlined. In this study the men were asked why they thought men were reluctant to talk about prostate cancer. There was a variety of answers which support the literature: pride, bashfulness, sign of weakness, boring to talk about health, nothing to talk about, will put up with symptoms, all valid reasons but there was no consensus opinion. In future work it could be worth probing this line of questioning further as to whether it is the way in which men of this age are given the diagnosis, i.e. nothing to worry about, lots of men have it etc. Such language by clinicians could inhibit men from talking about and therefore seeking information or support. In contrast to women receiving a diagnosis of breast cancer which is perceived as ‘serious’ and life-threatening and so worth talking about whereas in the 75+ age group the impact of prostate cancer is possibly minimised by health care professionals so inhibiting men from talking about it.

Conclusion: What could The Prostate Cancer Charity Offer?

For those who provide care and support for people with cancer, the challenge is finding a way of providing information that is appropriate for patients who may benefit from knowing something about their illness and its treatment, but may not wish to know everything about it all the time (Leydon et al 2000). Professionals need to acknowledge that patients may want to hear information more than once and also to see it in different forms and just as information needs change over time the preferred information source may also vary over time. Manfredi et al (1993) found that callers to a cancer information service were not necessarily seeking information because it was unavailable to them through their own health care professionals, but wanted information from several sources in order to feel that they had pursued all their options before making a decision.
To reach these men and to provide them with information and support when required The Prostate Cancer Charity needs to raise awareness of the services they can provide. This could be through publicity in newspapers, women’s magazines, posters in hospitals, doctors’ surgeries, and other venues such as libraries and supermarkets. However, the cost of such advertising would be expensive and it would be necessary for the marketing department to consider how to most effectively target resources. It would be important to word an such advert in a way that people did not think it was an appeal for funds as the word ‘charity’ may be off putting to some people who feel worried that they would be asked for a contribution. The ‘older’ elderly are often some of the poorest people in society and contributing even a couple of pounds is significant when it comes from a state pension.

It may be unrealistic to think in terms of a national campaign to reach the affected men and their families but rather to target health care professionals particularly clinical nurse specialists to remind them what The Prostate Cancer Charity can offer in terms of information and support.

It would also be worthwhile considering changing the name of the ‘help-line’ to an ‘advice’ or ‘information line’, as men may not feel they need help, but would contact an advice or information line. The format of the card could also be adapted to provide information about the services provided by The Charity and in a format that takes account of visual impairment in the elderly.
Appendices
We are a group of researchers at the University of Kent, conducting a research project on behalf of The Prostate Cancer Charity. The aim of the study is to identify the information and support that The Prostate Cancer Charity could offer to men aged over 75 who have prostate cancer. In particular it will identify suitable types of information and support, to take account of the preferences of older men, and look at ways to promote the services provided by the charity. If you would be interested in being interviewed about your experience and how you think information and support could be given to people in a similar situation please complete the attached form and post it using the prepaid envelope, or phone us on the number given below.

The interview can be conducted at the University or in your own home and will take between 30 and 45 minutes. We will reimburse your travel expenses if the interview is undertaken at the University. You would be free to answer any questions and the interview could be stopped at any time you choose. We would like to record the interview to make sure we can represent what you say as accurately as possible. If you consent to being recorded the tape will be identified by a number only and will be destroyed once the study is completed, to ensure your confidentiality.

We anticipate that the information you provide will help The Prostate Cancer Charity develop their services so helping others in the future. If you consent to take part the information that you give will be completely confidential and it will not be possible to identify any individual in the report. If you do not want to take part in the study, your relationship with the hospital would not be in any way affected and we will not contact you again with respect to this study. If you would like further information about the study before agreeing to take part you can speak to Dr Hilary Bungay on xxxx or Rose Cappello on xxxx.

Thank you for taking the time to read this and we hope to meet you soon

Yours sincerely

Hilary Bungay & Rose Cappello
I have read the information sheet about the above study and would like to discuss it further before agreeing to take part.

I can be contacted at: Telephone No (or address if no phone)

Name
Signature
Information and support needs of men aged 75+ with prostate cancer

Interview Schedule

- Can you tell me your story from when you first realised you had a problem

- Please tell me about the effect your condition has had on your life, do you have other health problems and are they made more difficult by having prostate cancer?

- Tell me about the effect if any your condition has had on your family, friends, or significant others.

- Can you tell me about any services/support that you have used or been offered as a result of your condition
  - What has been the most useful?
  - What has been the least useful?
  - Have you received the help you wanted or expected?

- Have you experienced any difficulties finding out about services/getting access or help?
- Do you think there is any reason why you experienced these difficulties?

- What makes it easier to live with your condition?

- Are there any services or support that you would like to be available for you or other men in your position?

- Can you tell me about any information that you have been given about your condition

- When you saw the doctor how long were you with him for? Was this time sufficient?

- Were you given information to take away?

- Issue of control
- Who or what has been your most useful source of information
  - What has been the least useful?
  - Have you received the information you wanted or expected?

- How successful have you been in finding out what you want to know?
- Have you experienced any difficulties finding out what you want or need to know?
- Do you think there is any reason why you experienced these difficulties

- Where do you prefer to get your information from?
  Health care professionals/Support group/Written information leaflets etc. (examples)/Newspapers/ magazines (which)/Family or friends/The Internet (any favourite site & why?)

- Why did you say ‘Newspaper/hcps/family’?

- What would you like information about, from whom and when?

- Is there anything I haven’t asked you which you think is important and could be helpful to other people in your position in the future.
## Study Participants Characteristics

<table>
<thead>
<tr>
<th>Study Participant Number</th>
<th>Age</th>
<th>Lives With</th>
<th>Treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>88</td>
<td>Alone</td>
<td>Hormone Therapy</td>
</tr>
<tr>
<td>2</td>
<td>76</td>
<td>Wife</td>
<td>TURP, radiotherapy, hormone therapy</td>
</tr>
<tr>
<td>3</td>
<td>81</td>
<td>Alone</td>
<td>Hormone Therapy</td>
</tr>
<tr>
<td>4</td>
<td>82</td>
<td>Alone</td>
<td>Hormone Therapy</td>
</tr>
<tr>
<td>5</td>
<td>76</td>
<td>Wife</td>
<td>Prostatectomy &amp; Hormone Therapy</td>
</tr>
<tr>
<td>6</td>
<td>76</td>
<td>Alone</td>
<td>Hormone Therapy</td>
</tr>
<tr>
<td>7</td>
<td>77</td>
<td>Alone</td>
<td>TURP, &amp; hormone therapy</td>
</tr>
<tr>
<td>8</td>
<td>82</td>
<td>Wife</td>
<td>R/T, Chemo &amp; Hormone Therapy</td>
</tr>
<tr>
<td>9</td>
<td>83</td>
<td>Wife</td>
<td>Hormone Therapy</td>
</tr>
<tr>
<td>10</td>
<td>87</td>
<td>Wife</td>
<td>Hormone Therapy</td>
</tr>
<tr>
<td>11</td>
<td>79</td>
<td>Wife</td>
<td>Hormone Therapy</td>
</tr>
<tr>
<td>12</td>
<td>77</td>
<td>Wife</td>
<td>Hormone Therapy</td>
</tr>
<tr>
<td>13</td>
<td>77</td>
<td>Wife</td>
<td>Hormone Therapy</td>
</tr>
<tr>
<td>14</td>
<td>78</td>
<td>Alone</td>
<td>Hormone Therapy</td>
</tr>
<tr>
<td>15</td>
<td>77</td>
<td>Wife</td>
<td>Prostatectomy &amp; Hormone Therapy</td>
</tr>
<tr>
<td>16</td>
<td>83</td>
<td>Alone</td>
<td>Hormone Therapy</td>
</tr>
<tr>
<td>17</td>
<td>78</td>
<td>Wife</td>
<td>Hormone Therapy</td>
</tr>
<tr>
<td>18 (No 20)</td>
<td>76</td>
<td>Wife</td>
<td>Watchful Waiting</td>
</tr>
<tr>
<td>19</td>
<td>81</td>
<td>Wife</td>
<td>Hormone Therapy</td>
</tr>
</tbody>
</table>
References

1. The Views of Older People Expressed through Focus groups. (1997) Age Concern London.
   www.doh.gov.uk/cancer/prostate (accessed on 04/02/2004)


73. Van Der Molen B. Relating information needs to the cancer experience: 1. Information as a key coping strategy. (1999) European Journal of Cancer Care, 8 238-244.


