Patient-centred care: what are the experiences of prostate cancer patients and their partners?

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The authors have no conflicts of interest to declare.

Acknowledgements
The study was funded by the NHS Service Delivery and Organisation National R&D Programme (SDO/77/2004). They had no involvement in the research or in the writing of this paper.

We would like to thank all those who helped during the research, especially the patients and carers who agreed to be interviewed and the hospitals and charities that helped with the recruitment.
Abstract

Objective To gain an in depth understanding of the experiences of care of men with prostate cancer and their partners

Methods The study design was a qualitative analysis of semi-structured interviews of men (35) who had been diagnosed and treated for prostate cancer and their partners (10). They were recruited from two hospitals in the East Midlands of England and two charities.

Results The interviews showed that although there was no widespread dissatisfaction with care, patients reported problems throughout care. The two main problems were that throughout care patients’ and partners’ information needs were often not identified or met, and patients’ preferred role in decision-making about testing and treatment was not explored.

Conclusions If patients’ experiences of prostate cancer care are to be improved, clinicians need to identify, and respond to, the information and decision-making needs of individual patients and their partners.

Practice Implications Clinicians should identify and meet the needs of patients individually, use appropriate language and formats for communicating information, fully prepare patients for tests, explore and meet the needs of patients for involvement in decision-making, and recognise the important role that their partner plays. Systems and pathways of care should be designed to enable patients and partners to obtain information and participate in decision making throughout all stages of care.

Keywords Experience of care, prostate neoplasm, physician-patient relations, patient-centred care, partner
1. Introduction

The number of men diagnosed with prostate cancer in the UK is increasing, and it is now the most common cancer in men, excluding non melanoma skin cancer. In the UK nearly 31,900 men were diagnosed in 2003, and in 2004 there were 10,209 deaths from prostate cancer [1]. The choice of treatment rests on disease characteristics (stage, aggressiveness), and patient factors (e.g. co-morbidities) and preferences. A range of treatment options is available: active monitoring (watchful waiting), prostatectomy, radiotherapy, brachytherapy, cryotherapy, and hormone therapy and chemotherapy (for advanced disease). In the UK there is no routine screening programme for prostate cancer, patients usually being referred from primary care by their family physician to specialist services in secondary care on clinical grounds.

A national survey of cancer patients in England in 1999/2000 [2] showed that the experiences of patients with prostate cancer were often worse than those with other cancers. The NHS Cancer Plan (2000) [3] set out the government’s programme for reform and increased investment to improve cancer care, including the formation of Cancer Networks, increased availability of testing, increased staff numbers and training. Following these reforms and increased investment, patients reported improvements in their experience of care in a second national survey [4]. However, the smallest improvements were in prostate cancer care. The reasons why patients with prostate cancer reported worse experiences of care than patients with other cancers were not clear, but may include inherent characteristics of the
patients themselves, the nature of prostate cancer and the inherent difficulties in making treatment decisions, or the delivery of care by health professionals. To try to develop a better understanding of patients’ experiences of care we undertook a study to identify the aspects of care patients and their partners report as important.

2. Methods

Patients who had been tested or treated for prostate cancer within the last six months were identified from hospitals’ patient registers, and opportunistically from attendees at urology outpatient clinics at two hospitals in the East Midlands. Patients were recruited via postal invitation. An invitation to interview for partners was included with the patient letter, and patients were requested to pass this on to their partner.

A purposive sampling frame was designed [5] to ensure that we gained views from a variety of patients. We aimed to conduct 30 interviews with patients across a range of age groups, including patients from ethnic subgroups. As sampling progressed it became clear that patients from ethnic minority groups were not represented in the sample of patients recruited via participating hospitals. Consequently two cancer charities were asked to contact patients from ethnic minority groups to ensure that both South Asians and Afro-Caribbeans were properly represented in our sample. We also aimed to include patients at different stages of the disease and its treatment: (1) newly diagnosed patients yet to receive treatment; (2) patients being actively monitored without treatment; (3) patients who had curative treatment (e.g.
prostatectomy, radiotherapy); (4) patients receiving stabilising treatment (e.g. hormone therapy). Information about stage of disease and treatment was gathered during the interview, and interviewing continued until we had included patients with a wide range of experiences at different stages of care. Patients’ partners were interviewed if they consented and were available for interview.

A semi-structured interview schedule (see Box 1) was developed from the findings of the literature review and used in all interviews.

**Box 1: Issues for the interview schedule**

<table>
<thead>
<tr>
<th>Issues for the interview schedule</th>
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<tbody>
<tr>
<td>In order to capture experiences of care, open questions were asked about all phases of their care pathway:</td>
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<tr>
<td>- initial presentation, initial tests, referral (explanations of reasons and process)</td>
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<tr>
<td>- experience of further tests for prostate cancer (e.g. biopsy)</td>
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<tr>
<td>- diagnosis</td>
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<tr>
<td>- making the treatment decision</td>
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<tr>
<td>- experience of treatment</td>
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<tr>
<td>- discharge/end of treatment explanations and arrangements</td>
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<td>- monitoring</td>
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<tr>
<td>Patients were also asked about the involvement of their partner, and given the opportunity to make any other comments on aspects of care that were important to them.</td>
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Interviews were carried out in the patient’s own home, and were audio taped and fully transcribed. Initial coding was carried out using NUD*IST N5 software, and the data analysed using the Framework approach [6]. Framework is essentially a thematic analysis approach which can be used within different theoretical and methodological traditions [7], and in this study a stance of critical realism was adopted [8]. The issues reported in the interviews were coded according to a framework based on phases of the care
pathway. Within each phase of care, major themes were generated inductively from the data. A second researcher independently coded and analysed a sample of interviews.

3. Results

Thirty-five patients were interviewed and their characteristics are shown in Table 1. Seventeen patients were aged over 70, thirteen were aged between 55 and 70, and five were aged under 55. Twenty-six patients were White, five were Afro-Caribbean and four were South Asian. Interviews of 10 female partners of patients were also conducted. Eight of the partners were White, one was Afro-Caribbean, and one was South Asian.

3.1 Patients’ experiences of information provision and communication

Only four of our sample of 35 were asymptomatic and had requested a prostate specific antigen test (PSA) test. Most of the patients consulted with urinary problems (e.g. nocturia, difficulty urinating) and after encouragement from their partners. In response to the reported symptoms, family physicians almost always carried out a PSA test, and sometimes carried out a digital rectal examination (DRE). However, patients presenting with symptoms were usually unaware that their symptoms might be caused by prostate cancer and reported that family physicians did not routinely explain this or that they were being tested for prostate cancer. Family physicians gave partial explanations, such as the PSA score but no mention of prostate cancer, and made comments that patients found ambiguous: “something wasn’t right” (patient #15), and in some cases gave reassurance: “it’s a little bit swollen, nothing to
worry about, don’t think it’s anything serious like cancer uh but I’ll refer you” (patient #2).

One patient was unable to understand the explanation given
…I didn’t understand it anyway, they were talking some big words, I mean God, BPH and benign and all that (patient #54).

Those patients who were reassured by the family physician or were unclear why they had been referred often reported the biggest shock when they were later diagnosed with prostate cancer.

While some patients were told the results of their tests before they were referred to hospital for further investigations, only one patient, as a result of participating in a trial, was given any written information. He reported that it was very helpful to receive a written explanation of the purpose of the PSA test, the results and their implications
you can never remember everything what’s going on err, and it’s useful to have something to refer to, to read again and if necessary to look up on, on internet and, and look and find bit a little bit more about what they’re talking about (patient #47).

No patients reported being advised to take a partner/relative/friend with them when they attended the hospital outpatient clinic for further tests or being invited to go back to their family physician to ask questions afterwards.

Patients’ also reported problems with information provision and communication in secondary care. Patients’ experience of the biopsy was that they often felt unprepared for it:
when I went to have the biopsy I was not told that’s what was going to happen. So that did take me by surprise (patient #15).

The communication by the doctor carrying out the tests was a problem for some patients, either because of the lack of explanation of their purpose (some patients were still unaware that they were being tested for prostate cancer), or poor communication skills, for example the doctor talking to himself rather than the patient: “I went, came away again and went back on another day for the trans-rectal examination and again he was talking to himself but not to me (patient #21); or being insensitive: “at the biopsy the consultant [specialist] said if this isn’t prostate cancer I don’t know what is” (patient #2) and when asked to explain it to his wife the specialist went into the waiting room and gave the explanation in front of the other people in the waiting room.

Many patients reported problems with the communication of the diagnosis, including being given the wrong diagnosis, and being given the diagnosis with no explanation or discussion of treatment options: “nothing about what they were going to do or what I should do or in fact what anybody else should do” (patient #8). Many patients were shocked by the diagnosis: “I was just err, well I was just stunned” (patient #27); and for those who were unaware that they had been tested for prostate cancer the shock was considerable: “my whole world just collapsed under me, legs, everything, I mean I was, you know, my mind just went completely blank” (patient #54).

The shock of the diagnosis made it difficult for patients to take in further information or take the opportunity to ask questions. However, patients who
saw a urology nurse specialist had the opportunity to spend the time they needed to get further explanations, ask questions and receive written information. Patients universally reported very positive experiences of their interaction with specialist urology nurses. However, there were other problems relating to information provision and communication including, staff making contradictory statements, lack of clarity about the arrangements for radiotherapy and hormone therapy, no explanation of the success of the treatment and lack of information and help with the practicalities of incontinence.

Some patients also reported problems with communications during their monitoring following treatment. While patients were re-assured by being monitored, some were unclear about the reason for the length of wait between PSA tests and this caused anxiety: Yes, it seems a long time, as I say… if they’d have explained it would have been better. (patient #31). A final communication issue for patients during monitoring was that the results of the tests were not always discussed with them, which they found unsatisfactory.

3.2 Patients’ experiences of making decisions

Asymptomatic patients who had requested a PSA test reported some discussion with the family physician before having the test. However, the symptomatic patients who presented did not report having the opportunity to participate in the decision whether to be tested for prostate cancer (i.e. PSA blood test and/or DRE) or later whether to be referred for further tests at the hospital:
So at that stage she [the family physician] hadn’t talked about cancer or anything like that. In fact she never did. All she did was refer me to the [local hospital] (patient #45).

Patients reported a wide range of experiences of how the treatment decision was made. Commonly, explanations and information (e.g. on treatment options, side effects) were not provided by the specialist. However, the urology nurse often played an important role in meeting these needs and some patients reported that they subsequently searched the internet for information. One patient requested an MRI scan to help him make the treatment decision, and although the specialist refused as he said it was unnecessary, it was arranged by the urology nurse.

Some specialists made the treatment decision without explanation or discussion of other treatments, and patients sometimes felt they did not know enough to ask questions. Other specialists passed the decision over to the patient, which some found disconcerting, and one patient who was distressed by this pleaded with the specialist to make the decision for him:

I looked straight at the consultant [specialist], I said what do you think? He said it’s not down to me, your choice. I said I’m asking you please…I said my life is in your hands…and he said I’m gonna do surgery, I recommend you have surgery (patient #53).

Not all patients were satisfied with these directive and non-directive approaches to choosing treatment because of the lack of tailoring to their
needs and wishes. One patient said that he would have preferred a more collaborative approach to the decision and another who had gone on his own regretted this:

*I was sitting round a table, me, the consultant [specialist], a registrar and a nurse…*I should have had someone with me* (patient #53).

### 3.3 Experiences of partners

Symptomatic patients often reported that it was the encouragement of their partners that led them to consulting the family physician, but were unaware that their symptoms might indicate prostate cancer. Partners often encouraged the patient to go to their family physician with their symptoms but did not attend the appointment themselves. Consequently their understanding of the situation was often limited by the extent of the family physician’s explanation and the ability of the patient to remember and report what had been said. The responses of some partners revealed that neither they nor the patient understood the reason for referral:

*I had never heard of a PSA test um obviously I read up about it afterward and I know a little bit about it now but at the time I didn’t know that’s how a diagnosis, you know one of the ways of diagnosing* (partner #4).

Partners usually accompanied the patients when they attended the hospital for further tests even though they had not been invited or encouraged to do so by the family physician or the hospital. They were pleased that they had attended the hospital to support the patient and reported positive experiences (e.g. the hospital facilities and their treatment by staff), as well as negative
ones (e.g. unclear what was happening and felt ignored or excluded during explanations). Partners generally attended this consultation with the patient as they felt it important to give support and one South Asian patient was accompanied by his son in case of possible language difficulties. Some patients reported that they were not given a choice of treatment, and this was confirmed by their partners. They also confirmed that the urology nurse specialist provided an important source of information. Partners identified the provision of written information as useful, and felt that it was important that they were invited to attend the appointment with the specialist because having heard what was said first hand they found it easier to take part in subsequent discussions.

Partners were keen to support the patient, by accompanying them and asking questions about issues that the patient was unlikely to raise. Some felt that their concerns were not taken seriously or that they were perceived as trouble, as the specialist gave the impression that they did not wish to be questioned. Partners sometimes had to take the initiative to be included in consultations and, where they reported that they had their own information and support needs, these were not met in the consultation. Other unmet needs included practical support with shopping and support for themselves. One partner reported that she made regular contact with a charity to build a supportive relationship. Many of the partners referred positively to their experience of attending a support group and the access they had to the urology nurse specialist at these meetings.
Partners echoed the concerns raised by patients about the importance of being clear about practical arrangements for dealing with side effects of treatment (e.g. where to get supplies of continence pads, erectile dysfunction):

_Erm I think one thing that I didn’t have at that stage which might have been helpful is to have a one to one with somebody just on my own cos I don’t think that ever happened_ (partner #44).

The monitoring of patients was reassuring for their partners, some of whom took a leading role, developing a better understanding of the process and requesting tests on behalf of the patient.

4. Discussion and Conclusion

4.1 Discussion

It is important to note that patients did not express widespread dissatisfaction with care, and some very positive experiences were reported. However, these interviews show considerable variation in experiences which can in part be explained by changes in service provision, such as the introduction of specialist nurses. While our study was not designed to identify the reasons for poorer patient experience than in other cancers it does highlight three aspects of care that deserve attention. The first two aspects of care discussed below were also highlighted as key findings in a recent report on patient-centredness in the NHS [9].
First, where experiences were less positive, they suggest failure to consistently recognise patients’ and partners’ needs for information and for it to be communicated appropriately. Previous studies have identified that patients have experienced information deficits at particular times, for example at initial presentation in primary care [10,11,12], for further investigations at hospital [13] and post initial treatment [14,15,16]. This study interviewed patients about their experiences of care to date and the identified information deficits throughout their care pathways. This resulted in some patients receiving a diagnosis of prostate cancer without having been aware that their symptoms may be indicative of prostate cancer or that they had been tested for prostate cancer. The lack of written information left patients without anything to refer to for assisting recall or understanding. Information interventions (e.g. video programme, leaflets) have been shown to be successful in improving knowledge and understanding [17,18] and therefore consideration should be given to the planned provision of information at appropriate points throughout the care pathway and in formats that the patient can refer to at his convenience. This will involve co-ordination between primary and secondary care to ensure that the patient understands their care pathway and passes between the two health care sectors as seamlessly as possible. The design of pathways of care should include arrangements to ensure that relevant information is provided at each stage.

The second aspect of care is the role of the patient in decision-making, in particular with regard to testing and, later, the treatment decision. Clearly information provision and communication is closely linked to the decision-
making process, and will influence patients’ willingness and ability to engage in treatment decisions [19]. Several asymptomatic patients asked to be tested for prostate cancer but none of them reported being involved in the decision to proceed with the tests, although such a discussion may have little impact on the patients’ decision [20]. In previous studies many patients reported some level of dissatisfaction with the decision-making process that they had encountered [21,22,23,24] and our findings showed that the treatment decision-making process appeared to be more a function of the specialist’s preferred style rather than a response to the patient’s needs. This varied from the specialist making the decision with no patient input, to passing the decision entirely over to the patient. Consequently, more effective approaches by health care professionals to identifying and responding to individuals’ preferences for involvement would improve the experience of some patients. One approach would be to expand the role of the urology nurse specialists, as we found that their involvement from the treatment decision stage onwards improved patients’ experiences of care. Another approach would be to identify the patient’s preferences for involvement in decision making at an early point in care, and to reassess their preferences throughout the care pathway [25].

The third aspect of care is the role of the partner and their needs, which may be different for different age cohorts [26]. Partners play an important role in encouraging some patients to consult initially and this supports the findings of another study [27]. However, partners often do not attend this first appointment and, as patients reported a lack of explanation and written
information, partners were unlikely to have any proper understanding of the patient’s care. They generally attended with the patient from the hospital referral onwards, but invariably on their own initiative. Partners focused primarily on supporting the patient through the different phases of the care pathway as reported in an earlier study [28]. They too, often had unmet information needs, particularly in relation to help with coping and on-going support after initial treatment. Consequently consideration of how to meet the information needs of partners and help to improve partners’ ability to cope [29] would offer a dual benefit, for both patient and partner.

Caution should be exercised in generalising from this study as a small sample of patients and partners were interviewed, although we did include patients at different stages of care and from different ethnic groups. The study was undertaken mainly in two hospitals, and the experiences of patients of other hospitals may differ. Nevertheless, the interviews allowed detailed exploration of the issues, and the findings do have implications for services.

4.2 Conclusion
There are three main issues for further research. First, research is needed to explore the reasons for the lack of explanations and information given to patients and how this may be overcome. Second, evidence is needed on why patients do not have the opportunity to play the role they would like in decisions about being tested and treated. Third, the role of the partner deserves more attention as they often have a significant impact on the patient’s experience of care and satisfaction with the outcomes that they both
have to cope with. Partners of prostate cancer patients are overwhelmingly female, likely to be elderly and have health care needs of their own that must be addressed if they are to play the role that is commonly anticipated. Research into ways of identifying and addressing their needs would have the double benefit of helping to improve the experiences of both patients and partners.

4.3 Practice Implications
The NHS Plan’s (2000) [3] goal of patient-centred care still appears to be some way off in the experience of prostate cancer patients. The recently published Cancer Reform Strategy (2007) recognised that there is still much to be done, and pledged that the NHS would do more to support and empower patients throughout their cancer journey [30]. In order to realise this goal an overall plan for providing information at appropriate times and in appropriate formats across primary and secondary care is required. An important finding from this study is that the information and involvement needs of patients extend throughout care rather than relate to discrete stages of care. Services should be designed and delivered to ensure that these needs are met consistently. Information must be tailored to the patient (and their partner) so that they can understand their care pathway and be involved in decision-making as they wish. This may require each patient having a “key worker”, and urology nurse specialists would be well placed to undertake this role, building on the improvements to care that they have already made.
In addition to the need for managers to design services to ensure consistent provision of information and involvement in decisions, individual clinicians need to address the following issues:

- identify and meet the information needs of patients, as well as those of their partners, at each phase of the care pathway (including directing patients to sources of information and support)
- use appropriate language(s) and formats for communicating information (do not rely solely on verbal explanations)
- prepare patients fully for the tests that they are to undergo (e.g. the possible pain of the biopsy)
- explore and meet the patients’ needs for involvement in decision-making (e.g. testing, treatment)
- recognise the importance of the partner (e.g. by inviting their attendance to support the patient, identifying and meeting their information and support needs)

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I confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.