

# Men's and carers' experiences of care for prostate cancer: a narrative literature review

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## Abstract

**Objective** To review studies of patients' and carers' experience of prostate cancer care.

**Design** Narrative literature review.

**Methods** Search strategies were developed for the following databases: MEDLINE (1966–2006), EMBASE (1980–2006), CINAHL (1982–2006) and PsycINFO (1987–2006). A search of SIGLE (System for Information on Grey Literature in Europe) was also undertaken. Experience was defined as patients' and carers' reports of how care was organized and delivered to meet their needs. A narrative summary of the included papers was undertaken.

**Results** A total of 90 relevant studies were identified. Most studies reported on experiences of screening, diagnosis, the treatment decision, treatment and post-initial treatment. Few studies reported on experiences of the stages of referral, testing, and further treatment and palliative care, and no studies reported on monitoring or terminal care.

**Conclusions** Although some phases of care have not been investigated in detail, there is evidence that: (i) many patients have a low level of knowledge of prostate cancer; (ii) patients with prostate cancer and their carers need information throughout the care pathway to enable them to understand the diagnosis, treatment options, self-care and support available; and (iii) increasing patient knowledge and understanding of prostate cancer (e.g. through interventions) are often associated with a more active role in decision making (e.g. screening, treatment decision).

## Introduction

In many health systems, the design and delivery of services to meet the preferences of patients has become a priority. In the NHS in England, this is an explicit policy objective,<sup>1</sup> and has been promoted in the USA in influential reports.<sup>2,3</sup> In association with initiatives such as these, there has been an increase in the use of patient surveys to collect data about experiences of care.<sup>4,5</sup> Attention has also been given to methods of developing survey instruments and clarifying the issues that are important to patients. For example, greater emphasis is now placed on reports of patients' experiences rather than satisfaction,<sup>6</sup> and the significance of patient involvement in decisions about their care is increasingly accepted.<sup>7,8</sup>

In England, a national policy to improve the care of people with cancer has been introduced, influenced by concern that outcomes, including outcomes for prostate cancer, have fallen behind other European countries. The NHS cancer plan acknowledged that patients' experiences of cancer care had been variable, and in addition to setting goals for improving outcomes, initiated cancer service collaboratives to redesign services taking account of patients' views.<sup>9</sup> In 2000, the Department of Health commissioned a national survey of the experiences of care of patients with either breast, colorectal, lung, ovarian or prostate cancer.<sup>10</sup> The survey was completed by 65 000 patients and the findings indicated that the experiences of patients with prostate cancer tended to be less positive than the other patient groups. They had longer waits for treatment, were more likely to have first appointments postponed or cancelled, and to report that their carers had not been involved or given the right amount of information. In a recent national investigation of cancer care, progress was reported in improving aspects of patient experience, although prostate cancer patients continued to have worse experiences than those with other cancers, including experiencing less discussion about the side-effects of treatment, receiving less information on the outcome of treatment, and about the availability of support.<sup>11</sup> The report recommended paying partic-

ular attention to improving prostate cancer care, including the provision of urological cancer specialist nurses. More recently (2008), NICE<sup>12</sup> has published guidelines for best practice on the diagnosis and treatment of prostate cancer. It notes that 'there is evidence of practice variation around the country and of patchy availability of certain treatments and procedures'. The clinical guidelines are intended to help address these issues and offer guidance on best practice. The first key priority set out in the guideline concerns the provision of information and support for patients and their partners.

Treatment options for localized prostate cancer include active monitoring (sometimes referred to as watchful waiting), radical prostatectomy and radical radiotherapy. In some centres, laparoscopic prostatectomy, brachytherapy and cryotherapy are being increasingly used. Hormonal therapy is the mainstay for advanced disease and is often administered in primary-care settings. It follows that patients' experiences of care will vary, depending on the stage of the disease and the treatment(s) experienced.

The national survey of patients' experiences of cancer care used a generic questionnaire, which did not provide detailed information about the experiences of people with particular types of malignancy. In order to assist service providers to improve the care of patients with prostate cancer, we have developed a set of measures for use by providers to monitor patients' experiences of prostate cancer care.<sup>13</sup> In this paper, we report the findings of a narrative literature review undertaken to describe available evidence about the issues that are important in patient and carer experience of care for prostate cancer, across different phases of care including testing, diagnosis, treatment and monitoring. This may help in understanding why prostate cancer patients have been reporting worse experiences of care than patients with other cancers.

## Methods

We sought to identify studies of patients' and carers' experiences of care for prostate cancer. All phases of prostate cancer care were included,

from screening through to end-of-life, and all aspects of prostate cancer care including information provision, decision-making and psychosocial distress and support. We defined patient experience as patients' reports of how care was organized and delivered to meet their needs. We excluded studies of the clinical effectiveness of care, for example studies of symptom control, quality of life, the incidence of side-effects or survival, but instead focused on studies of patients' experiences of how the healthcare system and health professionals helped them through care. Thus, studies of the information and support needs of patients and carers relating to pain were included, but studies of clinical interventions to reduce pain were not.

Through discussion by the team and an Information Scientist, search strategies were developed for the following databases: MEDLINE (1966 to December 2006), EMBASE (1980 to December 2006), CINAHL (1982 to December 2006) and PsycINFO (1987 to December 2006). A search of the SIGLE database (System for Grey Literature in Europe) was also undertaken to identify any theses and unpublished reports. A set of structured search strategies was drawn up, which were developed through an iterative process adding terms found in relevant papers. These included both medical subject headings (MeSH) where available, and free text terms, and are summarized in Table 1. Copies of the search strategy are available on request to the authors.

We included published quantitative and qualitative studies reported in English involving a minimum of 10 subjects being screened,

investigated for, or having been diagnosed with prostate cancer and at any stage of treatment or care, and being concerned with patients' and/or carers' experiences of prostate cancer care. Studies that reported solely on quality of life, pain, the incidence and management of side-effects following treatment, and developing tools (e.g. designing decision aids) were excluded. Studies involving patients with different types of cancers were also excluded unless they clearly differentiated those with prostate cancer. Literature reviews were excluded to avoid double reporting of studies, although the studies from such reviews were included. Two literature reviews of aspects of prostate cancer have already been completed and these focus on psychosocial adjustment in partners of men with prostate cancer<sup>14</sup> and why men chose one treatment over another<sup>15</sup>. However, the literature review reported here has a different and broader focus, covering both patients' and carers' experiences of prostate cancer care.

Two reviewers independently checked the resulting titles and abstracts against the inclusion and exclusion criteria to identify potentially relevant publications. Articles identified as potentially relevant by at least one reviewer were obtained in full text for further examination. The reference lists of included articles were also scanned for additional papers not identified by the original searches. We used standardized forms to extract data and reviewed them to decide whether to include or exclude articles. Where the two reviewers failed to agree the paper was referred to a third member of the research team. The data from each included

**Table 1** A summary of the search terms used to identify potentially relevant papers

Categories	Search terms: used primarily in health care	Search terms: additional and alternative terms
People	Patient, carer	Consumer, user, spouse, couple, partner, wife, wives, family, families, relative
Disease	Prostate cancer	Exp Prostatic neoplasm/(MeSH), tumour, malignancy
Aspect of care	Experience of care for prostate cancer	Exp patient centred care/ (MeSH) Experience, attitude, value, feeling, view, perspective, preference, choice, report, information need, unmet need, involvement, care pathway

study were summarized in tables and reported the following data: method of data collection, number of participants, country where the study took place, phase(s) of the care pathway, aspect of care and reported experiences of patients and issues considered important by them (see online Supplementary Information, Table S1). In view of the heterogeneous designs and methods used in the studies identified, a quantitative synthesis of the findings has not been undertaken. Instead, we undertook a narrative summary, drawing on our experience of investigating methods of synthesizing qualitative and quantitative evidence. Narrative summary is often used in systematic reviews and typically involves the selection and ordering of evidence to produce accounts of evidence. 'Narrative summary can "integrate" qualitative and quantitative evidence through narrative juxtaposition – discussing diverse forms of evidence side by side'.<sup>16</sup> This process involved repeated study and discussion of the summarized findings by the research team to agree the meaning of the data, supplemented by reference to the articles in full when necessary, followed by the organization of the findings into the phases of care experienced by patients.

## Results

The searches identified a total of 1476 articles. Of these, 123 were assessed as potentially relevant and an additional 36 were identified from the references of the selected articles. After assessment of these 159 articles, 90 studies that were relevant and met the inclusion criteria were retained. They included a total of 14 363 patients and 561 carers. The smallest study included 10 patients and the largest 4226. The 90 studies included 14 trials of interventions. The methods of collecting data were 44 questionnaire surveys, six telephone surveys, three telephone interviews, 10 focus group studies, 35 face-to-face interview studies and one set of written logs (some studies used more than one method). Most studies reported on experiences of the following phases of the care pathway: screening, explanation of diagnosis, the treatment decision, treatment and post-initial treatment. Very few

**Table 2** Numbers of studies that considered different phases of the care pathway

Phase of the care pathway	Number of studies
Screening	15
Referral	1
Testing	1
Explanation of diagnosis	12
Treatment decision	28
Treatment	18
Post-initial treatment	33
Monitoring	0
Further treatment and palliative care	1
End-of-life care	0

**Table 3** Aspects of care experienced by patients and reported in studies

Aspect of care	Number of studies
Knowledge/information	59
Communication	9
Decision making	41
Facilitation of self-care/self-help	7
Support	28
Role of carer	8
Relationship with health professionals	10
Complementary therapies	4
Coping/adjustment/emotional reactions/psychological distress/anxiety	26
Satisfaction with care	4

studies reported on experiences of the phases of referral, testing (e.g. biopsy, urine flow), and further treatment and palliative care and no studies reported on monitoring and terminal care (Table 2). The aspects of care predominantly reported on by the studies were knowledge and information, decision making, support and coping (Table 3). The following sections summarize the aspects of care identified from the literature at each phase of the care pathway.

### Screening

The studies that reported on screening for prostate cancer indicated that although men tended to regard screening positively,<sup>17,18</sup> their knowledge of prostate cancer was often poor<sup>19</sup>

and they experienced deficiencies in pre-test information<sup>17,18,19</sup> and discussion.<sup>20,21</sup> Interventions to improve patients' knowledge were reported as successful in increasing knowledge<sup>19,22</sup> and enabled men to assume a significantly more active role in making a screening decision.<sup>23</sup> However, the effect of improved patient knowledge was often to reduce interest in being screened.<sup>24-27</sup> One small qualitative study of 10 couples reported that husbands were found to prefer a no screening strategy, while their wives preferred screening for their husbands.<sup>28</sup> Many of the 33 patients in one study preferred more discussion to share the screening decision with a professional,<sup>21</sup> while a larger study of 161 patients reported almost a quarter experienced greater decisional control than they wanted.<sup>29</sup> As regards experiences of the tests themselves, a small study reported that patients preferred the Prostate Specific Antigen (PSA) test to the Digital Rectal Examination (DRE) as it was less physically invasive and produced quantitative standardized results.<sup>28</sup>

#### Referral

In the only study to report on referral, all 35 patients with an elevated PSA and/or abnormal DRE accepted their GP's recommendation to see a consultant.<sup>30</sup>

#### Testing at the hospital

One study reported on the testing of 30 patients following referral. It found that men were anxious before the biopsy and during the biopsy experienced discomfort and embarrassment, in addition to needling pain. They felt that they had not been prepared for the level of pain experienced.<sup>31</sup>

#### Explanation of diagnosis

The two small studies ( $n = 34$  and  $n = 21$ ) relating to the period of diagnosis reported that patients and their partners were often shocked by the diagnosis of prostate cancer,<sup>30,31</sup> which

could then affect their relationships positively or negatively.<sup>32,34</sup> The diagnosis caused many couples to seek information from a variety of sources (e.g. internet, library, charities) before discussing treatment options with the clinician.<sup>35,36</sup> While most patients (over 70%) wanted detailed information on their disease, treatment, survival, self-care and empowerment,<sup>37</sup> there was poor agreement amongst patients about their information priorities, and also between patients and their carers.<sup>38</sup> Patients found specialist nurses were acceptable providers of information, and patients valued the extra time available to them compared with doctors.<sup>39</sup> Interventions reported as helpful to recently diagnosed patients included a combination of information and physical training,<sup>40</sup> provision of an audiotape of the consultation<sup>41</sup> and individual psychological support.<sup>42</sup>

#### Treatment decision

Men's information needs centred on the stage of the disease, types of treatment available and survival.<sup>37,43</sup> Patients in two small studies experienced difficulties in understanding and remembering information, especially at the time of diagnosis, and patient knowledge of prostate cancer was often incomplete.<sup>44,45</sup> Patients found written materials helpful,<sup>46</sup> and the provision of information tailored to individual needs was associated with reduced distress and enabled patients to participate in the treatment decision.<sup>47</sup> A large study reported that more than 80% of patients obtained information from the urologist alone,<sup>48</sup> although where a small number of patients experienced several different sources, this could lead to confusion.<sup>46,49</sup> Interventions (e.g. video, interactive CD-ROM) to improve knowledge were reported as effective,<sup>45,50</sup> reduced anxiety<sup>51</sup> and helped patients to play a more active role in decision making.<sup>50,52</sup>

Several studies found that many patients and their partners wanted to be informed and were involved in treatment decisions,<sup>33,37,51,54</sup> which they preferred<sup>53</sup> even though they may experience difficulty and distress while making the treatment decision.<sup>55</sup> In another study, smaller



numbers of patients reported that they had played a passive role either through choice (58%),<sup>43</sup> or because the shock of the diagnosis left them unable to participate in the decision-making process. Initially they had welcomed the doctor's directive role, but months later some were critical of the decision-making process.<sup>44,56,57</sup> Almost all of the 150 patients in one study who were fully informed through discussion and written information reported that they were sure about their treatment choice, and were satisfied with their choice after 3 months of treatment.<sup>58</sup> Patients' choice of treatment depended on the disease, age, personal values, vicarious and personal cancer experiences, the physician-patient relationship,<sup>49,59</sup> and the potential for cure and risk of recurrence.<sup>60</sup> Patients experienced problems with the information provided on treatment options and felt that sometimes doctors did not give some of the treatment options serious consideration.<sup>48,60</sup> Over half of patients opted for surgery in one study, including patients who had received information suggesting that an alternative treatment would have been more appropriate,<sup>59</sup> and the most common reason for patients rejecting watchful waiting was fear of future consequences.<sup>61</sup> Patients in a small qualitative study reported that they rarely experienced an opportunity to re-visit the treatment decision and felt reluctant to re-open discussion themselves because they did not want to challenge the clinician.<sup>56</sup> However, patients tended to be satisfied with the treatment decision following therapy.<sup>48,50</sup> Several studies<sup>55,56,62</sup> found that most patients chose treatments on the basis that they offered better quality of life rather than better prospects of cure, and presented with the opportunity to explore trade-offs between life expectancy and side-effects, men were willing to trade-off some life expectancy to be relieved of troublesome side-effects such as limitations in physical energy and, in the case of men under 70, erectile dysfunction.<sup>63</sup> One study of patients' treatment choice reported surgery being chosen as a treatment promising cure by 53%, and that concern about potential side-effects did

not deter men from choosing surgery.<sup>59</sup> However, care should be taken in drawing conclusions as further analysis revealed that different realities are constructed by couples and reveal different pictures of the decision-making process.<sup>64</sup>

### Treatment

One small study (27 men) of experience of radiotherapy reported that some patients experienced a fragmented approach to their care, as well as having unmet information needs.<sup>65</sup> The information patients wanted at the treatment stage was about their disease and treatment,<sup>37,66</sup> in particular information about the likelihood of the cancer spreading, and to address concerns about the worries of close family and changes in sexual feelings.<sup>66-68</sup> Lack of appropriate information may in part be due to patients, partners and professionals having different opinions on the most troublesome problems associated with treatment,<sup>69</sup> and patients not stating their unmet needs.<sup>70</sup> A pre-operative class that developed couples' expectations of the treatment and recovery period helped them feel more in control of the situation and less anxious.<sup>36</sup> Almost half of patients in one study thought that the use of complementary therapies was beneficial,<sup>71</sup> and the most commonly adopted were dietary changes, vitamins and herbal and nutritional supplements, with their use being associated with lower psychological distress.<sup>72</sup> An intervention that combined a diet and exercise regime contributed to feelings of optimism.<sup>34</sup> Information and educational interventions (e.g. tape recordings of patients' experience, booklets and nurse teaching) helped patients cope with treatment, maintain usual activities<sup>73</sup> and improved quality of life and satisfaction with care.<sup>74</sup> An intervention of five weekly telephone calls from a nurse for men who had opted for active monitoring (watchful waiting) helped participants manage the uncertainty.<sup>75</sup> However, in a small qualitative study ( $n = 50$ ), some patients opting for watchful waiting experienced pressure from family members, doctors or support groups to change their decision.<sup>76</sup>

### Post-initial treatment

Patients who had undergone radical prostatectomy placed emphasis on regaining control over their lives and recovering their physical capacity quickly.<sup>77,78</sup> However, patients often experienced unmet informational needs,<sup>67,79</sup> which changed over time,<sup>80,81</sup> with particular needs at the time of discharge from hospital.<sup>82-85</sup> The need for information at this time was due in part to failure to retain information that had been given pre-treatment.<sup>82,86</sup> Both patients and spouses wanted information about treatment side-effects and ways to manage them<sup>37,83</sup> as well as information on emotional reactions and alternative therapies.<sup>87</sup> Patients were often unaware of the self-help resources that were available and were not directed to them.<sup>88,89</sup> In a large study ( $n = 650$ ), many patients wanted help with emotional well-being, living with side-effects and information.<sup>90</sup> They needed a supportive environment in order to cope,<sup>91,92</sup> and experienced self-help groups as useful in terms of accessing information<sup>93,94,95</sup> and providing emotional support.<sup>96</sup> They also obtained information from fellow patients and medical staff,<sup>97</sup> via the telephone,<sup>98</sup> face-to-face<sup>99</sup> and online.<sup>100</sup> Little has been reported about the support needs of ethnic minorities with prostate cancer, although the support used by African Americans has been reported as centring on family, friends and church.<sup>95,101</sup>

Partners' information-seeking behaviour was individualistic, with some seeking voluminous information and others avoiding information. In a small, in-depth study (six patients, six partners), some partners changed their information-seeking over time and their needs differed from the patients.<sup>102</sup> General distress in spouses did not differ from patients, and was reported as modest in spouses of men treated for early-stage prostate cancer.<sup>103</sup> The same study ( $n = 165$ ) also found that distress was more likely to be predicted by psychosocial than medical factors. Couples needed more information to help them look after themselves at home (e.g. catheter care) but many men managed their own care.<sup>34</sup> Wives' efforts

focused on emotional support and working out care routines with their husbands.<sup>77</sup> Improvements in wives' adaptive coping and indicators of psychological growth were reported as a result of a psycho-educational group intervention.<sup>104</sup>

A study of men with recurrent disease found that this group of patients experienced particular problems with side-effects of treatment, anger and pain. Although they received help for their pain, healthcare professionals did not satisfy their needs to talk with someone about their cancer. They were also dissatisfied with the information they received about their medical condition and possible side-effects.<sup>105</sup>

### Discussion

A key theme running through the studies we identified was the need of patients and carers for information at appropriate times during the care pathway to enable them to understand the diagnosis, treatment options, self-care and support available, and to participate in decisions as they wish. Interventions that improved the provision of information helped patients cope, reduced anxiety and influenced decision making. The importance of information in the management of men with prostate cancer reflects the state of knowledge regarding the investigation of suspected prostate cancer and the uncertainties surrounding the choice of an appropriate treatment option. Patients and the professionals who care for them are faced with alternatives. Yet, it is clear that patients often experience a lack of information at crucial times. In designing services around the varying needs of men with prostate cancer, initiatives to improve the planned provision of tailored information should be a priority.

The studies of patient experience of prostate cancer care in this review were limited to those published in English with most having been conducted in the USA, Canada or the UK. It is likely that relevant studies published in other languages have been omitted. However, the search strategy was reasonably broad and the most important studies meeting the inclusion

criteria have probably been identified. The respondents in the reported studies were predominantly white and not socio-economically disadvantaged, in spite of attempts to recruit more widely, and therefore the findings should be extrapolated with caution to other ethnic or disadvantaged groups. The experiences of African-Caribbean men, who have a higher incidence of prostate cancer, are under-reported and need further investigation. The narrative summary approach adopted succeeds in summarizing the data from a variety of studies to produce this overview. However, it is an approach that is not without difficulties and is sometimes criticized. For example, in summarizing the data from a number of studies, the reporting of individual experiences of care of prostate cancer patients and their carers is lost and there are difficulties in quantifying experiences from different studies involving a range of methods and undertaken in different healthcare systems. Information on the size, location and methods of the studies is available in Table S1 (online). Despite the variety of settings and methods used in the included studies, there was a striking consistency in the finding that patients and carers need information and support throughout care, but often this need is not met. It should also be noted that there were relatively few randomized trials of interventions to improve patient or carer experience.

There is relatively little evidence about patients' experiences of: referral when the possibility of prostate cancer is first indicated; diagnostic investigation; experiences of receiving treatment; long-term monitoring after initial treatment; the management of relapse and palliative and terminal care. Further research into patients' experiences of these aspects of care is required.

The review also has implications for clinical practice. Healthcare professionals need to be aware that patients' knowledge of prostate cancer is often poor and need better pre-test information and discussion. The diagnosis of prostate cancer is a shock for many couples and offering a break before discussing treatment options would allow them to regain their composure so that they are better able to

understand the explanation of the treatment options before any treatment decision is made. The provision of information and sources of information is crucial for many couples to help them come to terms with the diagnosis. Support should also be offered at this stage. Interviews with patients and their carers suggest that where specialist nurses have been introduced into hospitals information and support needs are more likely to be met. Clear and unbiased explanations of all the treatment options, including active monitoring (watchful waiting), are needed for patients to understand what choices they have and they need time to weigh up their relative merits. It is crucial that patients and carers are made aware of the side-effects associated with the different treatment options so that they make an informed choice and are aware of the (potential) implications of their choice. While many patients want a shared approach to the treatment decision, healthcare professionals should be sensitive to the preferences of the individual patient, which range from wanting to make the decision themselves to asking the healthcare professional to make the decision for them. Providing patients and their carers with support and informing them of sources of support before, during and after treatment are essential to help them deal with their stress. Patients and their carers need to be clear when they are discharged what to expect and how to care for themselves.

### **Conflicts of interest**

All authors declare that there are no conflicts of interest.

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## Ethical approval

Ethical approval granted by Leicestershire Northamptonshire and Rutland Research Ethics Committee.

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## Supporting Information

Additional Supporting Information may be found in the online version of this article:

**Table S1** The studies identified by the literature review

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