



“Good care” throughout the prostate cancer pathway: Perspectives of patients and health professionals

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ABSTRACT

Purpose: Men in follow up for prostate cancer represent the largest proportion of patients with the illness. In the United Kingdom, primary care is increasingly involved in caring for these patients. Little is known however regarding the factors that determine men's evaluation of their care and primary healthcare professionals' perceptions of the care they provide. This study aimed to investigate patient and primary care based health professionals' perspectives of what constitutes 'good care' for men with prostate cancer, including limiting or facilitating factors.

Method: Semi-structured interviews were conducted with ten patients and eight primary care based healthcare professionals and thematically analysed in collaboration with a patient representative group.

Results: Good care was identified by patient participants, with aspects of communication, including information, active participation, sensitivity of approach and context being highlighted. Healthcare professionals also prioritised communication as the basis of good care and recognised the benefits of locally based services.

Conclusions: Treatments in prostate and other cancers continue to improve with corresponding increases in survival. To further develop and sustain the good care that patients require to help them cope with diagnosis, treatment and long term adjustment, investment in resources, training and innovative communication systems between patients, generalist and specialist services are required.

1. Introduction

More men are being diagnosed with prostate cancer each year (Cancer Research UK, 2018), and the number of men either living with or after the disease in the United Kingdom has reached an estimated 330,000 (Prostate Cancer UK, 2018). Men post-treatment now make up the biggest proportion of patients in the prostate cancer care pathway (Yip et al., 2015). In the UK, stratified models of care have been widely introduced in response to the growing pressure on secondary care resources with primary care increasingly taking on responsibility for 'stable' patients in line with National Institute for Health and Care Excellence guidelines (NICE, 2014).

Earlier investigations of patients' views of cancer follow up in primary care reported equivocal findings with patients in some instances concerned at a perceived lack of expertise (Lewis et al., 2009; Sheldon et al., 2009). Studies also demonstrated anxiety amongst primary care teams regarding their developing role in prostate cancer follow-up, due to a lack of guidance on what this should involve and concern over

training, resources and communication with specialist secondary care (Neal, 2008). More recently, since primary care based follow up and a role in the administration of long term androgen deprivation therapy (ADT) have become more widely embedded, high levels of acceptability and positive ratings of general practitioners (GPs) in terms of patient centred care have been reported. Despite initial concerns expressed by some specialist clinicians, similar clinical outcomes have been observed among men seen in primary care to those cared for in specialist clinics (Emery et al., 2016). For the National Health Service (NHS), 'shared care', involving primary care based follow up has demonstrated advantages in terms of significant cost savings (Emery et al., 2016).

While benefits of primary care based follow up are becoming apparent, little is known regarding the views of primary care teams on the quality of the prostate cancer care they currently provide, perceptions of their role and its potential and their relationship with specialist care. Men appear satisfied and to value locally based care, yet the basis of this evaluation is poorly understood. Evidence indicates the continuation of unmet needs in many men with prostate cancer for some years

Abbreviation: ADT, Androgen Deprivation Therapy; AS, Active Surveillance; NICE, National Institute for Health and Care Excellence; NHS, National Health Service; p.d, post diagnosis; PSA, Prostate Specific Antigen; RP, Radical Prostatectomy; RT, Radiotherapy

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post treatment regardless of care pathway, suggesting a complex relationship between experience of care and perceptions of need (O'Brien et al., 2011; Watson et al., 2016).

The complexities of implementing patient centred care have been widely discussed (Sitzia and Wood, 1997). Patient satisfaction too has been measured in a range of contexts and the multidimensional aspect of the concept incorporating outcome and process elements has been usefully elucidated (Wensing and Elwyn, 2002). One Swedish study highlighted 'being encountered as a human being' as the primary determinant of older people's appraisal of their community care (Johansson et al., 2002). A literature review of assessments of nursing care has been conducted by a Spanish research team, which pointed to personal qualities, individualised care, communication skills, knowledge and technical skills as the determinants of patient's evaluation (Olano-Lizarraga and Vivar, 2012). Process factors appear to be of major importance in determining patients' views of 'good' nursing, community and primary care. Concepts of 'good care' however have received relatively little attention in the UK.

The objective of this study was to explore men's perceptions of their care throughout the care pathway and to identify factors influencing their views. We also sought to explore good care from the primary care healthcare professional perspective and the current barriers and facilitators to its provision.

2. Method

This qualitative investigation draws on data collected during the first stage of a feasibility study of a model of primary and secondary cancer care integration supported by digital technology (Nanton et al., 2017a). Ethical approval was granted by the East Midlands - Nottingham 2 Research Ethics Committee (REC reference: 15/EM/0534) before recruitment commenced. Written consent was obtained from all participants prior to the interview and no identifiable data was included in the transcripts.

2.1. Recruitment

Our recruitment target was 10 patients and 10 healthcare professionals. Participants were recruited from five GP practices whose practice nurses were attending a training course in cancer follow up provided by Macmillan Cancer Support, the largest third sector organisation in the UK providing support for patients, carers and training for healthcare professionals. Healthcare professionals from these practices were eligible if they cared for men with prostate cancer, either giving ADT injections, undertaking prostate specific antigen (PSA) testing or general consultations following treatment. We sought to interview at least one healthcare professional per practice, and to include both GPs and nurses in our sample. Healthcare professionals were invited to take part through a combination of email communication, including information about the study, and follow up phone calls.

Box 1

Extract from the patient interview topic guide

The example below relates to a hypothetical man with locally advanced disease, currently stable on hormone treatment.

Experience of prostate cancer and care.

Perhaps we could start by you telling me a bit about your prostate cancer – how you came to be diagnosed and what has happened since? So who are you seeing at the moment? How long is it since you were seen at the hospital?

How often do you come to the surgery for you hormone injections?

Do you have any problems relating to the hormone treatment?

Do you talk to the nurse or doctor about these - is that at the same time or at a different appointment?

Do you have any other health problems? Do you ever talk about your prostate troubles when you come in about anything else? How often do you come to the surgery roughly?

How well does your care work for you now do you think?

Is there anything else you think is important in the way men with prostate cancer are looked after and how the hospital and the practice communicate with one another.

Is there anything else you think we should talk about in relation to your prostate cancer care?

Men were eligible to take part in this study if they had ever received a diagnosis of prostate cancer, and were registered to one of the participating GP practices. Study information packs were sent out to a sample of eligible patients identified by the practice nurse using a convenience sampling approach, containing information on how to respond if interested in taking part.

2.2. Data collection

Interviews were conducted by two members of the research team (RA and VN) following a semi-structured topic guide which was adapted depending on participant stage in the care pathway and treatment type (see example in Box 1). Semi-structured interviewing was also undertaken with healthcare professionals (see Box 2). Interviews took place either in participants' homes or in their GP practice, depending on preference. Interviews were audio recorded and transcribed verbatim.

2.3. Participants

In total, 15 patients and 12 healthcare professionals were invited to take part, and 18 interviews took place (10 patient participants and 8 healthcare professionals). If patients did not return the reply slip then it was assumed that they did not want to take part. The most common barrier to healthcare professionals' participation was being too busy or not responding to invites from the study team. Table 1 summarises the characteristics of both patient and professional participants.

2.4. Analysis

Thematic analysis was carried out in accordance with the method specified by Braun and Clarke (2006). Transcripts were read multiple times by each researcher and initial codes were developed collaboratively. Some key themes were identified through discussion among the study team, which formed the basis for a data analysis workshop involving the study team and four patient representatives from local prostate cancer support associations. After a short training session on first steps in qualitative analysis, the representatives coded a proportion of the transcripts and compared similarities and differences between them. These codes were then discussed by the group and themes developed. In the final stage the representatives were presented with direct anonymised quotes from transcripts which were assigned to the themes identified.

3. Findings

3.1. Patient participants

Thematic analysis identified the centrality of communication to

Box 2

Healthcare professional interview topic guide

Do you have any involvement with the care of men who have prostate cancer?
 What do you think about the current role of primary care in the management of prostate cancer?
 Do you think primary care could be more involved?
 How? What would be needed? What about training?
 What are the barriers?
 How would you feel about being more involved yourself?
 What do you think about your current communication with secondary care for patients with prostate cancer?
 Is there any way it could be improved? Would this help?

Table 1

Characteristics of participants.

Patient Participants (n = 10)		
Age	61–64 years	2
	65–70 years	3
	71–75 years	3
	76–80 years	2
	> 80 years	0
Ethnicity	White British	8
	White European	1
	Black Caribbean	1
Time since treatment	> 10 years	1
	5–10 years	3
	2–5 years	2
	< 2 years	2
	Ongoing ^a	2
Treatment type	Radiotherapy	3
	Radical prostatectomy	4
	ADT	4
	Active surveillance	1
	Radiotherapy and ADT	1
Comorbidities	Surgery and ADT	1
	Hypertension	2
	Stroke	1
	Arthritis	1
	High cholesterol	1
Other cancer diagnoses	Bowel problems	2
	Breast	1
	Bowel	1
Healthcare professional participants (n = 8):	Leukaemia	1
	GPs	3
	Practice Nurses	5

^a Including secondary care.

participants' appraisal of their care throughout the care pathway. Within this overarching theme, four sub themes were identified: 'The right information', 'Patients speaking and clinicians listening', 'Clinician sensitivity' and 'Context of the interaction'. Each of these are considered below.

3.2. The right information

Access to information throughout the care pathway was central to patients managing their uncertainty and a major factor in their evaluation of care. Some men had concerns regarding unclear or incomplete information from specialist care about prostate cancer itself or issues related to treatment or the care pathway. This was highlighted as contributing to uncertainty, leading to anxiety or distress following treatment.

'I think they could keep you in the loop a lot more, you know. I mean, I know they're busy people ...' [Participant 3, 1yr post diagnosis (p.d). ADT]

One participant described his feeling of displacement at the end of treatment,

'A fish out of water You've finished all this treatment which has

been so detailed. And I missed having, perhaps things explained more fully. When they said this will damage your bowel, I didn't quite fully understand what that would mean for me, and that now, eight years later, I'd still be taking medication for it.' [Participant 2, 10yrs p.d. ADT, Radiotherapy (RT)]

For some participants it was not until later when living with the consequences of their treatment that they re-evaluated the information given.

'the information prior to having the operation ... at the time, if you'd asked me at the time I would have said it's very good. In retrospect I would now say it's very bad, to the point I would say I did not give informed consent.' [Participant 4, 2yrs p.d. Radical Prostatectomy (RP)]

When prostate related concerns were raised in the context of a consultation in general practice, some men particularly appreciated the efforts made by a clinician to seek information on their behalf.

'The GP I've got is very good. If he doesn't understand something he'll find out and he'll phone me up and tell me.' [Participant 10, 11yrs p.d. RP]

3.3. Patients speaking, clinicians listening

As well as describing the negative impact of a lack information provision, some participants reported feelings of frustration when they felt secondary care based professionals were not listening. This breakdown in communication could result in an important concern remaining unaddressed.

'Yeah it was sort of well, we've done the operation, now you're getting better, have you got any other problems. Yes and no, but you know, I could do with a few more questions, you know, and things like that or follow ups. Because when we went, what we were concerned about was the erections afterwards ...But nobody picked up, and ever since then I've had a problem.' [Participant 10, 11yrs p.d. RP]

The value of active participation in the consultation was highlighted by several men. Talking to their GP was often successful in reducing anxiety.

'And sometimes it's just a matter of listing the things, and the doctor saying well, you know, there's not really any major problems there, it's just something simple. Which is peace of mind.' [Participant 9, 3yrs p.d. RP]

Several participants prepared for GP appointments by writing lists of questions,

'Whenever I go to see the doctor, so I don't forget things I really want to ask her, I jot it down before I go in to see her' [Participant 7, 4yrs p.d. AS (Active Surveillance)]. Thus patients would 'store up' a list of questions to ask the GP at their next appointment.

Where patient management had been taken on by primary care, a build-up of trust in the GP was often important in engendering a sense of confidence.

'Dr X is a very nice doctor and he looked after me. I don't go too often because I think he's probably pleased with my health and that's it.' [Participant 5, 2yrs p.d. ADT, RT]

3.4. Clinician's sensitivity

Some of the men described the emotional impact of a diagnosis, expressing feelings of vulnerability they had experienced at that time and during treatment. Some felt these emotions were more difficult for them as men, and that they struggled to communicate these feelings with their clinician:

'... we as men try our best to say we are alright, we cover up ... Yeah, you cover up, we cover up things, and say well, nothing is wrong with me.' [Participant 5, 2yrs p.d. ADT, RT]

Men remembered situations where communication by specialist clinicians was perceived as too blunt, as in this instance where a participant recalled being given his diagnosis:

'I always thought they sort of broke it to you sort of fairly gently. But in actual fact I sat down and the consultant said how are you. And as you can probably see now, I'm really fit, I'm still working. And I said oh, I'm fine. And he just looked straight at me and he said no, you're not. You've got cancer.' [Participant 3, 1yr p.d. ADT]

Positive experiences were reported when clinicians in secondary or primary care were seen as sensitive to men's emotions and appreciative of their anxieties:

'Professor X especially was very thorough, nothing was ... well both of them. Nothing was ever rushed and they took time and I really valued that' [Participant 2, 10yrs p.d. ADT, RT]

Men could be reticent in disclosing their concerns, particularly when these related to personal topics:

'Men don't do that we talk about football and they don't ever never ever talk about healthI'll be alright tomorrow' [Participant 9, 3yrs p.d. RP]

'When it comes to your private life, you hardly want to discuss those areas' [Participant 5, 2yrs p.d. ADT, RT]

There was a feeling that clinicians could do more to facilitate discussion of intimate issues. One man's hesitation in response to a direct question was interpreted by his clinician as meaning that he had no problems to report.

'They ask you a straightforward question and you think oh my God how do I reply. But they don't pick up on anything like that. It was too late to speak' [Participant 10, 11yrs p.d. RP]

For several men a consultation in general practice facilitated discussion of such issues and was particularly welcomed when offered by the GP:

'I came and had my second injection here and that was handled very wellwe had a good chat about it and the fact that Dr X offered to have a talk with me ... ' [Participant 3, 1yr p.d. ADT]

3.5. Context of the consultation

As well as the information given and the opportunity for dialogue the context of the consultation also influenced men's appraisal. General practices were perceived as being friendlier, less intimidating, less hurried environments than outpatient clinics:

'I feel that there's more of a personal touch here than at the hospital because the hospital is so busy and so big ' [Participant 3, 1yr p.d. ADT]

However long waits for appointments or waits in the surgery could be off putting:

'If I wanted an appointment (at GP practice) I'd probably have to wait a fortnight, or come to open surgery, which means then I'm probably sitting for a couple of hours with people that have got all kinds of ailments, which I don't really fancy doing.' [Participant 3, 1yr p.d. ADT]

Continuity with a GP who knew the patient and his history and comorbidities was highlighted as important and a switch to an unfamiliar GP could be unsettling:

'It's a bit strange. I always used to see Dr X and he knew us well didn't he and then Dr Y took over. ... if I'm ill I have to go and see whoever, you know. But if it's something concerning that I'm worried about.' [Participant 9, 3yrs p.d. RP]

3.6. Health professionals

Analysis of the health professional interviews was carried out by two members of the research team. Three overarching themes were identified: 'men's preference for primary care' 'primary care resources and training' and 'communication'.

3.7. Preference for primary care

Most healthcare professionals perceived that their patients preferred to visit their local GP practice compared to travelling to the hospital for an appointment:

'I think if patients can go somewhere locally I think they always prefer it, especially as they get older.' [HP1, practice nurse]

Interviewees also commented that primary care is able to offer more holistic care than specialist services as GPs are involved in managing any comorbidities and are aware of the patient's history and family circumstances:

'I think we are good at looking at the whole patients as opposed to just the prostate. And obviously a lot of these men tend to be older with lots of other comorbidity and helping them sort of tease out which is the prostate and which ... is critical.' [HP6, GP]

3.8. Primary care resources and training

All healthcare professional interviewees stated the advantages of general practice based prostate cancer follow up care and expressed a view that this could be extended and developed. However to support this initiative and to provide optimum care for patients more staff and training were needed:

'... to do these sort of things well you've got train up nurses, you've got to train up staff ... it doesn't come free of charge.' [HP6, GP]

'I think it's only fair to the patient I think if we asked them to ... come to the GP surgery, I think us having the knowledge that they require ... ' [HP1, practice nurse]

3.9. Communication

Two sub-themes were identified within the broader theme of communication 'men not talking about their health' and 'communication between primary and secondary care'.

3.10. Men not talking about their health

Most healthcare professionals mentioned men's reluctance to talk

about potentially embarrassing health problems with their doctors with several reporting that they tend to 'play it down' or just 'don't talk about it' [HP4, GP].

A more general reticence amongst men was also identified reflecting the observation made by several men.

'I think men find it difficult to sort of talk about, you know, sort of their private lives generally anyway, and their health generally' [HP1, practice nurse].

3.11. Communication between primary and secondary care

Efficient communication between all members of the clinical team was reported as an essential element of good care. Healthcare professionals mentioned the slowness of communication from secondary to primary care, especially when relying on letters in hard copy:

'... a lot of the patients will come and you will have to wait for them to tell you what happened at their appointment. We do get letters eventually through ...' [HP3, practice nurse].

Several of the healthcare professionals commented on the value of 'a direct route to contact somebody' [HP3, practice nurse] in order to be able to ask questions or raise concerns with a specialist based in secondary care.

4. Discussion

This qualitative study enabled us to explore the views of prostate cancer patients and primary care based healthcare professionals of what constitutes good care in prostate cancer. Negative experiences are easier to elicit than positive views; however, several factors of importance clearly emerged from our data. The main feature identified by both participant groups involved aspects of communication, though these differed in emphasis. While information was critical to patients, other elements including their own active participation in consultations, which could itself be problematic, sensitivity of clinicians and the contextual aspect of consultations were also important. Men's feelings of vulnerability were identified by our patient representatives during the analysis, and the importance of these feelings being recognised and responded to by clinicians at all stages of the care pathway. It was notable that men, no matter how long it had been since their diagnosis, recalled exactly what had been said and how the news was conveyed - a finding we had noted in an earlier study (Nanton et al., 2009). The context and manner in which a diagnosis is delivered may have an impact on men's perceptions of the care they have received that is not directly related to their evaluation of their treatment.

It was also felt that clinicians should do more to help men talk about sensitive topics, due to men's reluctance to raise personal issues during a consultation. Although patients spoke highly of the treatment they had received by their specialist teams, they often felt as though clinicians were too busy to be able to discuss their concerns about their illness or treatment. Patients valued the care received in general practice and expressed confidence in the primary care team. Despite the time pressures in general practice, patients generally perceived their primary care consultations as less rushed than those with the specialists contributing to their sense of being well cared for.

Efficient and timely communication between different members of a patient's healthcare team in both secondary and primary care was identified by health professionals as important to good care. However, a continued reliance on letters as the method of contact between the two settings was identified as a continuing barrier and leading to unnecessary delays and frustration for patients.

GPs and practice nurses are keen to do more to support primary care based follow up for men with prostate cancer. The main barriers identified to the extension of the role of general practice were a lack of resources and appropriate training. Results from our interviews with

healthcare professionals reflected a recognition of the particular needs and characteristics of men with prostate cancer. They also demonstrated confidence in providing follow up care and a willingness to do more, providing resources and training are in place - as was argued in a 2010 commentary (Weller, 2010).

Overall, patients and primary care professionals were positive regarding the involvement of general practice in the care of prostate cancer patients. Unmet needs however remain a constant finding of the research into the quality of life of prostate and other cancer patients (Armes et al., 2009). While primary care healthcare professionals are able to manage patient's comorbidities and offer a holistic approach to care, our research has illustrated how communication issues may impact negatively on patient's experience of care in any setting. Earlier studies had demonstrated the central role of communication between primary and secondary care in the provision of safe, high quality care (Sheldon et al., 2009). Healthcare professionals in our study too, identified problems of gaps or delays in communication with secondary care teams. UK health policies place a great emphasis on the developing role of technology and our data illustrate its potential value. Improved communication through increased use of email and electronic record sharing could improve patient care throughout the pathway (Houses of Parliament, 2016). In addition, innovative systems are needed that will enable men to easily disclose their concerns to their healthcare providers and to facilitate communication between teams. Our current feasibility study aims to utilise the potential of digital technology to deliver this (Nanton et al., 2017a; Nanton et al., 2017b) without increasing workload. Further research is needed around the training needs, training methods and the ongoing secondary care input required to further involve and support primary care teams in the care for men with prostate cancer. 'Good care' should be measured both in terms of patient experience and perceptions and in terms of its impact on unmet needs and quality of life.

4.1. Strengths and limitations

A particular strength was the involvement of our patient representatives in the data analysis as it enabled us to refine the themes identified by the study team and ensure the findings are relevant from a patient perspective. During the analysis, our patient representatives identified feelings of 'vulnerability' in our data and which related to their own experiences of diagnosis, treatment, and follow up. The representatives' insights ensured that we emphasised the importance of health professional communication style as well as the need for information. A further strength is that interviews were carried out with both patients and healthcare professionals, allowing us to explore views of prostate cancer follow up in primary care from both perspectives.

One limitation is that our recruitment procedures may have resulted in a biased sample. Patient participants with particularly positive or negative experiences may have been more inclined to take part than those who did not respond, and healthcare professionals who were too busy to take part or lacked interest in the topic area may have different views to those reported here. The healthcare professionals were recruited from practices already engaged with Macmillan Cancer Support follow up training which may explain their willingness to provide more care for men with prostate cancer. We were also unable to meet our recruitment target of healthcare professionals during the specified time period due to GPs lacking time to complete the interviews.

5. Conclusion

The paramount importance of excellent treatment in prostate and other cancers is self-evident and is readily defined in terms of survival and other hard outcomes. Though its constituent elements are less easily defined, the importance of good care and its value to patients is beyond question. Our study sought to elucidate the concept and the priorities and barriers identified by both patients and healthcare

professionals. Perceptions were closely aligned, although healthcare professionals were more focussed on organisational and resource factors and patients on the quality of personal interactions. Patients express deep appreciation of their treatment and also gave many examples of good care. There were however instances where perceptions of care were less than optimal and areas where healthcare professionals felt care could be improved.

Increases in survivorship in cancer are reflected in rising numbers of patients requiring long term support from health services, both specialist and generalist, for a variety of clinical and broader holistic needs. In parallel with investment into improvements in treatment, it is essential that health services are sufficiently resourced to provide good care for patients. Clinicians should receive appropriate training, and innovative communication systems have the potential to link patients and their healthcare teams more effectively. Further development of sustainable good care is needed to help patients cope with the impact of diagnosis and treatment and to adjust to life with and beyond cancer.

Conflicts of interest

The authors declare no competing interests.

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