Views of health professionals on the role of primary care in the follow-up of men with prostate cancer

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Background. Follow-up care for prostate cancer has traditionally been led by secondary care in hospital out-patient clinics. As the number of men with prostate cancer increases and secondary care resources face pressure, alternative follow-up models are being sought. Current National Institute for Health and Clinical Excellence guidance recommends follow-up outside the hospital setting for patients who are stable 2 years following radical treatment and for those undergoing ‘watchful waiting’.

Objective. To describe current practice in a sample of relevant health care professionals and to seek their views on the role of primary care in prostate cancer follow-up.

Methods. Semi-structured telephone interviews with 38 UK health care professionals, from both secondary and primary care. Transcripts were analysed using the constant comparative method.

Results. There are marked variations in current follow-up practice around the country, with hospital-based follow-up ranging from 6 months to lifetime. The predominant, although not universal, view expressed was that there is both scope and support for primary care to play a greater role, particularly for men with stable disease. This was qualified by the need for supporting education, including guidance on interpretation of prostate-specific antigen values, introduction of robust follow-up systems in primary care, easy access back into secondary (hospital) care, a mechanism for ensuring follow-up data can still be collected for audit purposes and appropriate resourcing.

Conclusions. If primary care is to play a significant role in providing high-quality follow-up care for men with prostate cancer, then steps need to be taken to address the barriers to increased primary care involvement identified by this study.

Keywords. Follow-up, primary care, prostate cancer, qualitative.

Introduction

In 2005, there were >34 000 new cases of prostate cancer in England and Wales, and each year there are ~10 000 deaths from the disease.1 Incidence rates are rising, and the number of men living with prostate cancer will continue to increase as the population ages, prostate-specific antigen (PSA) screening becomes more widespread and treatments continually improve.

Traditionally, patients with prostate cancer receive regular follow-up appointments in hospital out-patient clinics. The purpose of follow-up is generally perceived to include: the early diagnosis of recurrent disease, the effective management of any side effects of treatment and the identification and treatment of any psychosocial problems.2 The value patients place on hospital follow-up care is well documented.3 However, the evidence base regarding the effectiveness of follow-up (and differing modes of follow-up) in terms of improving survival and reducing morbidity is still very limited for most cancer sites, including prostate cancer. For breast cancer, a recent Cochrane review of breast cancer follow-up regimes concluded that there was no advantage in a more intensive clinical follow-up regime or in secondary care compared to primary care-based follow-up.4 In the case of
colorectal cancer, meta-analyses have shown that more intensive follow-up can improve survival.\(^5\)\(^6\)

The course of prostate cancer can extend over many years and, with increasing numbers of survivors, attention is increasingly being paid to seeking alternative models of follow-up. Prostate cancer is one of the few cancers where there is an easily available blood marker (PSA) to enable disease monitoring and detection of potential relapse, hence making it a cancer which is particularly amenable to primary care having greater involvement in follow-up care. Furthermore, the psychosocial implications of prostate cancer are well recognized but not always dealt with effectively. Primary care is well placed to provide psychosocial support to patients and their families.

Recent National Institute for Health and Clinical Excellence (NICE) guidance recommends that for men who have had stable disease for at least 2 years following radical treatment, follow-up outside of the hospital setting (secondary care) should be offered, with direct access to the urological multidisciplinary team available. The guidance also recommends that primary care take on the responsibility for following up men with localized disease who have chosen a watchful waiting regimen. This should be done in accordance with locally agreed protocols and should include at least annual PSA monitoring.\(^7\)

In this context of increasing interest in primary care assuming a greater role in cancer follow-up and acknowledgement that medical aspects of follow-up need to be augmented with greater attention to psychosocial issues, we have conducted a qualitative study with a range of health professionals who care for men with prostate cancer, exploring current practice and their views on the role of primary care in providing follow-up care. The study was carried out as part of a multi-centre study exploring different aspects of primary care involvement in prostate follow-up care. The findings presented here complement the findings of a systematic review of existing guidelines on prostate follow-up\(^8\) and a qualitative study exploring the follow-up experiences of men with prostate cancer.\(^9\)\(^10\)

Methods

Participants and recruitment

Thirty-eight semi-structured telephone interviews were conducted with a range of both secondary and primary care health professionals from across the UK. Secondary care professionals are specialists based in the hospital setting. Maximum variation was sought by purposively sampling consultant clinical (radiation) oncologists \((n = 9)\), consultant urologists \((n = 9)\), clinical nurse specialists (CNS) \((n = 9)\), GPs \((n = 9)\) and practice nurses \((n = 2)\). We sought to include specialists from different parts of the country and from district general hospitals as well as tertiary referral centres. GPs were recruited to include practices of different sizes and areas with different demographic profiles.

Interviews were conducted by RO’B following an interview topic guide which was developed according to the aims of the study and informed by relevant literature (see Table 1). The subjects covered in the topic guide were tailored to be appropriate to each participant and, within each discussion, there was scope for exploring certain issues in detail or those raised spontaneously by health professionals. Interviews with health professionals in secondary care lasted 45 minutes on average compared to those in primary care which lasted between 20 and 30 minutes. All interviews were audio-recorded.

Analysis

All interviews were transcribed verbatim and transcripts were cross-checked by RO’B for accuracy. Each transcript was read and coded by two researchers (RO’B and EKW or PWR). A coding framework was developed by independently coding the data (again two researchers engaged in this process) and regular discussion of the themes that were being identified. A more detailed analysis, using the constant comparative method,\(^11\) was conducted by RO’B who repeatedly reread and compared all the interviews and discussed any other emergent themes that could be added to the original coding framework. This analysis was used to develop the understanding of the themes that had been anticipated at the study’s conception and others that were identified through data collection and analysis.

Ethical approval for the study was granted by Trent NHS Research Ethics Committee.

Results

Overview of current practice in secondary care

The interviews revealed wide variations in follow-up practice around the country, both between and within hospitals. The length of follow-up provided in secondary care was reported as ranging from 6 months to

\[\text{Table 1} \quad \text{Semi-structured interview topic guide}\]

- Current follow-up practice for each treatment group (i.e. radical prostatectomy, radiotherapy, active monitoring, hormone therapy, watchful waiting)
- Description of consultations (including exploration of whether psychosocial factors were discussed)
- The role of different health professional in follow-up care
- Description of consultations (including exploration of whether psychosocial factors were discussed)
- Which patients that were considered suitable for follow-up in primary care
- Views on increased follow-up in primary care (potential benefits/concerns).
lifetime. The most common approach was to follow-up patients for ~3 to 5 years, and there was a tendency for surgical patients to be followed up by the hospital for shorter periods than radiotherapy patients. A range of follow-up models are currently in operation, including consultant-led, nurse-led and those formally sharing care with primary care. Some hospitals described well-established nurse-led telephone and postal follow-up systems. The various models have developed largely in response to resource and financial considerations within trusts, as well as in some cases a pull from primary care trusts to increase the amount of follow-up taking place in primary care.

We also found considerable variation in the content of secondary care consultations. Even within hospitals, for similar clinical situations, there was variation in the frequency of follow-up and which health professional actually saw the patient. Within clinic consultations, the PSA level was usually a main focus, but there was variation in the use of digital rectal examination and the extent of discussion about psychosocial issues, including the potential side effects of treatments such as erectile dysfunction and incontinence. For example, one of the CNS we interviewed described her policy of discussing sexual function with every patient:

I would ensure that it was raised every time, even if it’s somebody who’s very elderly, so that they know it’s okay to talk about it and so that they know that, if there are problems in that function, that there is help that can be offered (#18, CNS)

In contrast, this oncologist, who reported consistently asking patients about urinary and bowel symptoms, was more selective in whom he discussed impotence with

... sometimes depending on the age of patient, and not necessarily their age but just a feeling you get when they walk in, I may not talk about sexual function as well, but that’s probably only about a third of the patients where that would be a topic (#26, Oncologist)

Current involvement of primary care in follow-up

Study participants described primary care’s current involvement with follow-up mainly as arranging PSA testing and administering regular hormone treatment (for example, three monthly goserelin injections). With respect to PSA testing, it was uncommon for GPs to be involved in the interpretation of PSA results or communication of results to patients. It was often the practice nurse who would take the blood sample, and PSA testing was not done in the context of a formal follow-up appointment. The onus was usually on the patient to arrange the PSA test. Similarly, the practice nurse would often have responsibility for administering hormone treatments and, although often the main primary contact the patient would have with the practice, it was reported that this tended to be a routine appointment, involving little, if any, discussion of the impact of prostate cancer treatment on the man. Both practice nurses included in the study could see the potential for improving their communication with patients and providing follow-up support. For example, talking about incontinence this nurse said

I think it’s something you would have to ask and I think at the moment we perhaps don’t do that (#6, Practice Nurse)

GPs reported having greater involvement with men receiving hormone treatments and those on watchful waiting regimens and less experience of caring for men who have had potentially curative treatments. However, one GP described dealing with side effects from radiation therapy, such as proctitis, and noted the following:

I think quite a lot of these problems, particularly with the radiotherapy group crop up, you know, in between hospital appointments and they present to their GP (#3, GP)

GPs described varying involvement in dealing with other potential side effects of treatment, such as impotence and incontinence. This GP noted the sensitivity, also felt by others, in dealing with these issues:

... some will ask about it and some won’t, I may bring it up at some stage maybe after the third or fourth or fifth consultation, ask them if they’ve got any problems in terms of incontinence or erectile dysfunction and make it clear to them that those things can be addressed. It depends on your patient... you don’t want to overdo it really (#28, GP)

Another GP described discussing impotence and incontinence at the start of treatment but thereafter said ‘they would not necessarily be routinely asked for’ (#16, GP). He added that he felt patients would bring the topic up if there was a problem. Some GPs reported that patients did indeed sometimes bring up problems with side effects.

One GP felt that these were issues men ‘may not have liked to raise at the hospital clinic’ (#2, GP), and another commented that discussion of side effects at the hospital seemed to take place at the beginning of treatment and that ‘maybe that’s not the priority of the patient... so they take the opportunity of discussing it at a later time’ (#40, GP).
Positive views on increased role for primary care
A broad range of views were expressed regarding the potential role of primary care in follow-up by the different health professionals interviewed. Many participants felt that there was scope for primary care to play a greater role and expressed their support for this—particularly for those patients with stable disease.

Managing demand
Some secondary care specialists were positive about greater involvement of primary care and felt that this could be an effective way of increasing the time available within the hospital setting for more complex or urgent cases. One CNS, who had what she considered to be an unrealistically large workload, made the following comment about some follow-up care transferring to primary care:

... I think it could be done equally as well ... I think there will be a transition period and you know there’s a bit of work to be done ... it’s the obvious way to go ... the current practice of being followed up in, you know an oncology setting can’t continue indefinitely purely ... again because of numbers, you know of people that are coming through (#33, CNS)

One oncologist, who had previously been based in an area where GPs were resistant to doing PSA tests because of cost, was surprised to find GPs who actually wanted more involvement and suggested a shared care model:

I think it’s a great idea ... If we can direct the service ... in a better way that these patients could be followed-up in their local surgery then that will free up a lot of time to see urgent patients more ... quickly ... We are not doing something really very specialised and we could use the experience of our GP colleagues ... that will really facilitate a lot of other, more important sort of issues that need to be dealt with (#15, Oncologist)

Stable patients
There was general consensus that patients with unstable disease, those with complex metastatic disease and those undergoing active surveillance have specialist needs and therefore require hospital follow-up. Patients who have stable disease, however, were considered potential candidates for follow-up outside the hospital system, as illustrated by this quote from an urologist who had a particular interest in prostate cancer follow-up:

... I don’t think there’s a need for a lot of these patients to be seen in hospital ... Once they’ve been followed up for a year in hospital and are shown to be stable, one could argue that even a year is too long, then it’s perfectly reasonable to discharge them and then all they need is their PSA’s monitored (#8, Urologist)

Content of follow-up
Some participants (both consultants and GPs) commented on the content of some secondary care follow-up appointments. For example, this GP, who had a specific interest in the area and had been involved in trying to draw up a pathway for prostate cancer follow-up, felt that out-patient appointments were often of limited value:

there have been instances (when) a patient is going up to a hospital for an outpatient appointment, having had a PSA done here which has been completely fine, where from an outpatient letter it would appear that all they’ve gone up for is to be told that their PSA is fine and very little else (#3, GP)

Similarly, one consultant noted the following:

I do see some patients, you know they come, they wait for 2 hours to be seen and they’re in for a minute while you say their ‘PSA is fine, any problems? No, ok see you in 6 months’. And you can see their faces like thinking ‘I’ve waited all that time for that? I could have ... you know I didn’t really need an expert to tell me that (#26, Oncologist)

Convenience for patient
One GP, who was based in an affluent area and whose practice covered a higher than average elderly population, highlighted the potential benefits of primary care follow-up to patients:

patients like being followed up in primary care, they find it less stressful than going to the hospital which is a reminder of the illness they’ve had and for many it is more convenient than going to the hospital ... on the whole most people find being seen in primary care less intimidating, easier access and at more convenient times for them, and particularly in the age group of patients we’re talking about where a lot of them are elderly ... (#38, GP)

This view was echoed by an oncologist, who had recently introduced a shared care protocol with local GPs and was very positive about GP involvement:

The vast majority of people are happy to do it (shared-care with a GP) because they’re relieved to be out of the hospital setting and relieved that they’re well enough that they’re suitable for it (#13, Oncologist)
Concerns around increased role for primary care

Despite general support for an increased role for primary care in follow-up, a number of concerns were voiced by each of the groups of health professionals interviewed.

Lack of knowledge

Secondary care specialists worried about GPs lack of knowledge and experience in relation to the management and follow-up of prostate cancer, related to the fact that they see relatively few patients with the disease. For example, this oncologist commented on the types of queries he has encountered from primary care:

The questions being asked reflects the fact that, you know, GPs being general, haven’t fully got their heads around the issues (#29, Oncologist)

Specialists also expressed concerns about the ability of GPs to interpret PSA scores. Some felt that devising clear guidelines is not straightforward, and in one case, PSA interpretation was likened to ‘an art form’.

I’m slightly uncomfortable whether primary care have the appropriate acumen to monitor these patients because it’s not just a blood test...I don’t feel that prostate cancer is such an easy condition (#25, Oncologist)

Detection of late effects

Some clinical oncologists felt strongly that long-term hospital follow-up was important for monitoring the effects of varying radiotherapy treatment modalities and hence did not support a move to primary care follow-up where they feared valuable toxicity information would be lost. This is illustrated by this quote from an oncologist who was opposed to primary care follow-up:

personally I feel that every person given radiotherapy, particularly radiotherapy because you get late side effects, should have an active policy of prospective audit, long term of their tumour outcome and toxicity and I can’t, I cannot see how Primary Care can do that...I think it would be a bad thing, really strongly (#19, Oncologist)

Related to this concern, some hospital specialists preferred alternative nurse-led follow-up systems (e.g. postal, telephone) thereby, they felt, retaining important patient information within the hospital system.

Lack of time and willingness

There were also concerns about the time primary care practitioners would have available to devote to prostate cancer follow-up and their willingness to take this on.

One has to be aware of the fact that GPs might not all be of the same interest in this condition. Some are willing and able, some are willing and unable and some are unable and unwilling ... (#27, Urologist)

Finance

Financial considerations were a relatively common theme across the interviews. One nurse was specifically concerned that moves towards increased primary care follow-up were being driven by financial rather than quality issues:

... Is it purely to do with a funding issue? A ‘who gets the money’ issue. Has the quality been looked at? Has structures and strategies been looked at? (#22, CNS)

GPs stressed the importance of appropriate financial remuneration if primary care are to take on greater responsibility with respect to follow-up. This GP, who currently did not have a lot of involvement with prostate cancer patients, commented:

... so long as it wasn’t done as a cost-cutting measure to reduce costs in secondary care, as long as there was proper investment for proper follow-up in primary care I don’t see any problems (#16, GP)

Conversely, if primary care do take on more follow-up, one nurse expressed concerns that they (secondary care) could ‘still end up spending a lot of time giving advice’ and that the hospital would start saying ‘well why aren’t we being paid for this advice?’ (#23, CNS).

Primary care systems

The current lack of recall systems in primary care was also acknowledged as a concern by each of the groups of professionals interviewed with some expressing fears that patients may become ‘lost in the community’. An example of this was provided by one GP, who described his practice as undertaking a lot of prostate follow-up work:

one of our partners discovered that one of his patients had been given his first hormone injection and hadn’t come back ... he thought it was just a one-off thing (#20, GP)

A mechanism for rapid access back into secondary care was also considered to be very important by both secondary and primary care:

... what is really, really important (is) that there’s a fast-track way of getting them back to an oncology clinic if need be, if there’s any doubt ... (#33, CNS)
Patient choice/patient expectations
While some study participants identified primary care follow-up as being more convenient for patients, other secondary care specialists felt that the patients were reassured by attending the hospital for follow-up and would not feel comfortable being discharged to primary care. For example, this CNS perceived nervousness on the part of her patients:

> the patients that I’ve been involved in get nervous about being discharged out to GPs … they’re worried they’re not going to be able to organize things so they’ve got regular follow-up (#5, CNS)

One consultant expressed the view that it was all about patient expectations and if patient did not expect long-term hospital follow-up from the beginning it would be fine

> … my honest opinion about what patients feel is they’ll do what they sort of expect to be told to do … So, if you say to a patient, ‘look, we’re going to nurture you and look after you for life’, they’ll expect that (RO: Right) and it’ll then be very surprising if you said ‘look, you’re going to not come under my care any more (#14, Oncologist)

Continuity and quality of care were also proposed as a reason for continuing hospital follow-up. This oncologist, who said he personally gained satisfaction from continuing to see his patients, noted that:

> So it’s not purely ‘you’ve had your treatment, goodbye we don’t want to see you again’. We’re actually taking an active interest in how they’re continuing to do (#14, Oncologist)

Discussion
Summary of main findings
This qualitative study conducted with a range of secondary and primary care health professionals found marked variation in current follow-up practices but also perceived scope and support for an increased role for primary care in the future. It was acknowledged that the alternative methods of follow-up for stable patients are needed to free up resources in secondary care for those who most need it. The support for increased primary care involvement was, however, qualified, and a number of barriers were identified. These were a perceived lack of knowledge, time and/or willingness on the part of some GPs to take on a greater role; a need for clear policies around financial remuneration to providers of follow-up; a concern on the part of some specialists that important late effects of treatment could be missed by primary care; a lack of robust recall systems in primary care to ensure men are not lost to follow-up and some concerns around patient expectations and choice.

Strengths and limitations of this study
The strengths of this study were that it included a range of different health professionals from a number of different health care settings across the UK and explored, in detail, current practice and the issues that are likely to affect follow-up in future. Interviews continued with the different groups of health professionals until it was felt that data saturation had been reached, with the exception of practice nurses. As a result of practical and time constraints, we were only able to include two practice nurses in the study.

This is a qualitative study and we cannot assume that these findings are representative of the views of health professionals across the UK. However, detailed studies such as these, offering insight into current practice, can be the foundations for designing larger quantitative studies that have the aim of understanding the practices in a wider population of health professionals.

Although the authors of this study have a specific interest in the role of primary care, both positive views and concerns about an increased role for primary care were presented and care was taken to present data which best illustrated the range of practice-based experiences of, and views on, follow-up that were expressed within the sample.

Comparison with existing literature
The variation in current practice described in this study is perhaps not surprising given the variation in existing guidelines on the management of prostate cancer, as reported in a recent systematic review. The review concluded that the diversity of recommendations on the provision of follow-up care reflects the current lack of research evidence on which to base firm conclusions and highlights the need for robust research to inform future evidence-based models of follow-up care for men with prostate cancer.

Our finding of general support for an increased role for primary care in prostate cancer follow-up adds to existing literature indicating that GPs are willing to become more engaged in the routine follow-up of cancer patients. We also found general consensus in this study that while primary care could potentially take on responsibility for the care of stable patients and those undergoing watchful waiting, those with more complex needs would be better cared for in the hospital setting. It is encouraging that these views are in broad agreement with the recent NICE guidelines, published in the interim.
Implications for practice

Prostate follow-up protocols are currently very varied and do not always cater for all of the patients needs. The Department of Health is currently drawing up recommendations for new pathways of care that address psychosocial and informational as well as physical needs. This study lends support for this approach which will ensure that all aspects of follow-up are addressed but also highlights the need for flexibility so that patients with the highest needs still get specialist care, whereas those with a more straightforward pathway could be cared for in primary care with the improvement in access and convenience for patients. Table 2 summarizes the key issues raised in the study and some possible solutions. Primary care would need to address both the educational needs of health professionals and the development of recall systems to ensure that the follow-up is robust and of high quality and meets the health and supportive care needs of patients. The planned introduction of Cancer Survivorship Care plans as part of the National Cancer Survivorship Initiative should enhance communication between secondary and primary care and the introduction of a formal cancer care review within 6 months of diagnosis (as part of the Quality and Outcomes Framework) presents one opportunity for follow-up care, although current evidence would suggest greater guidance to practices is needed to maximize the potential usefulness of these reviews. It may be possible to arrange follow-up at a supra-practice level so that it can be led by interested health care professionals who would more rapidly build up expertise.

Conclusions

This study has revealed that currently there are considerable variations around the country in the way men with prostate cancer are followed-up. We were particularly interested in the potential role for primary care and although participants expressed support for primary care to play an increased role, a number of important barriers were identified. It is important that these are addressed if primary care is to play a greater role in future. Well-designed evaluations of new follow-up models, which include psychosocial and economic as well as clinical outcomes, are required to ensure that the quality of care being delivered to patients is improved or at least maintained.

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Declaration

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<td>Variation in follow-up protocols</td>
<td>Follow national guidance</td>
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<td>Develop more detailed care pathways locally to ensure all needs addressed within follow-up.</td>
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<td>Develop more detailed care pathways</td>
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<td>Variation in content of follow-up consultations</td>
<td>Education and training: survivorship care plans</td>
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<td>Develop systems for long-term follow-up and collection of symptom information.</td>
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<td>Survivorship care plan to include risk of late effects</td>
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<td>Concerns about increased role for primary care</td>
<td>Organize at supra-practice level with interested practitioners taking the lead</td>
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<td>Lack of knowledge</td>
<td>Incentivise GPs through Quality and Outcomes Framework.</td>
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<td>Detection of late effects</td>
<td>Develop recall systems similar to those already in place for chronic diseases eg asthma, diabetes</td>
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<td>Lack of time and willingness among primary care practitioners</td>
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<td>Lack of recall systems in primary care</td>
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