

Prostate cancer survivorship

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The authors present pilot study results from a new scheme for prostate cancer survivors developed at Worcestershire Acute Hospitals.

Approximately 2 million people in the UK are cancer survivors.¹ Traditionally, prostate cancer services have focused on surveillance and monitoring for recurrence.² According to the National Cancer Institute, cancer survivorship encompasses the 'physical, psychosocial, and economic issues of cancer from diagnosis until the end of life'.³ Yet we as physicians consistently do not address these needs as part of prostate cancer follow-up.

A survey conducted by the National Picker Institute of 70 breast cancer patients found that 87 per cent did not have a care plan, 34 per cent did not know what to expect at future appointments and 58 per cent found insufficient information and advice.⁴ Thirty-one per cent did not know whom to contact within daytime hours, and 74 per cent did not know whom to contact out of hours.⁴

The Institute of Medicine's report on survivorship emphasised the importance of care plans to facilitate communication.⁵ Both physicians and clinical nurse specialists (CNS) need to work together in a team effort to aid holistic care.⁶⁻⁸ The effectiveness of a shared-care model, both community- and hospital-based, has also been shown.⁹ Health promotion and empowerment of patients to take control of their own health behaviours should be part of this.

PATIENT DATABASE

The programme developed at Worcestershire Acute Hospitals includes patients who have had radical therapy for prostate cancer, and is assessed over a one-year period. The bespoke database records information on patient demographics and also draws information from other databases, such as pathology (PSA). Part of the holistic assessment of the patient includes the distress thermometer, which enables identification of issues that are important to the patient, such as social, emotional and psychological issues.

Inclusion criteria specify that patients must be two years post-radical prostatectomy with an unrecordable PSA reading, three years post-external beam radiotherapy with no metabolic relapse (Phoenix criteria) or brachytherapy with no metabolic relapse (Phoenix criteria; Figure 1). Recurrence is monitored via the PSA reading.

The database is run by a full-time CNS, who acts as the patient's key worker. Patients are brought back to the clinic if the PSA is elevated, if they have symptoms/signs of recurrence, adverse effects of treatment or at the patient's request. This is supplemented by a survivorship conference once a year.

There are 158 patients on the database, eight of whom have undergone brachytherapy, 67 radiotherapy and 78 surgery. No patients have been referred back to the clinic and none has had a recurrence.

ANNUAL CONFERENCE

At the conference, patients have access to healthcare professionals discussing a range of topics, including adverse effects of

treatment, symptoms and signs of recurrence, nutrition, diet and physical exercise.

Messages that attendees took away from the conference included:

- there is a lot of support, information, help and advice available to prostate cancer patients and their families
- positive progress and developments are being made in the field of prostate cancer research and treatment.

When asked if the conference was worth attending, 51 out of the 55 attendees would re-attend.

Patients completed an outcome questionnaire before the conference and one month afterwards. As expected for this cohort of men with stable prostate cancer, the scores for anxiety and depression were below clinical levels both before and after the conference. In addition, quality-of-life measures also remained stable. Patients' perceptions of control, concern and understanding about prostate cancer (self-rated on a scale of 0 to 10) improved following the conference.

The advantages of the survivorship conference were: patients valued meeting

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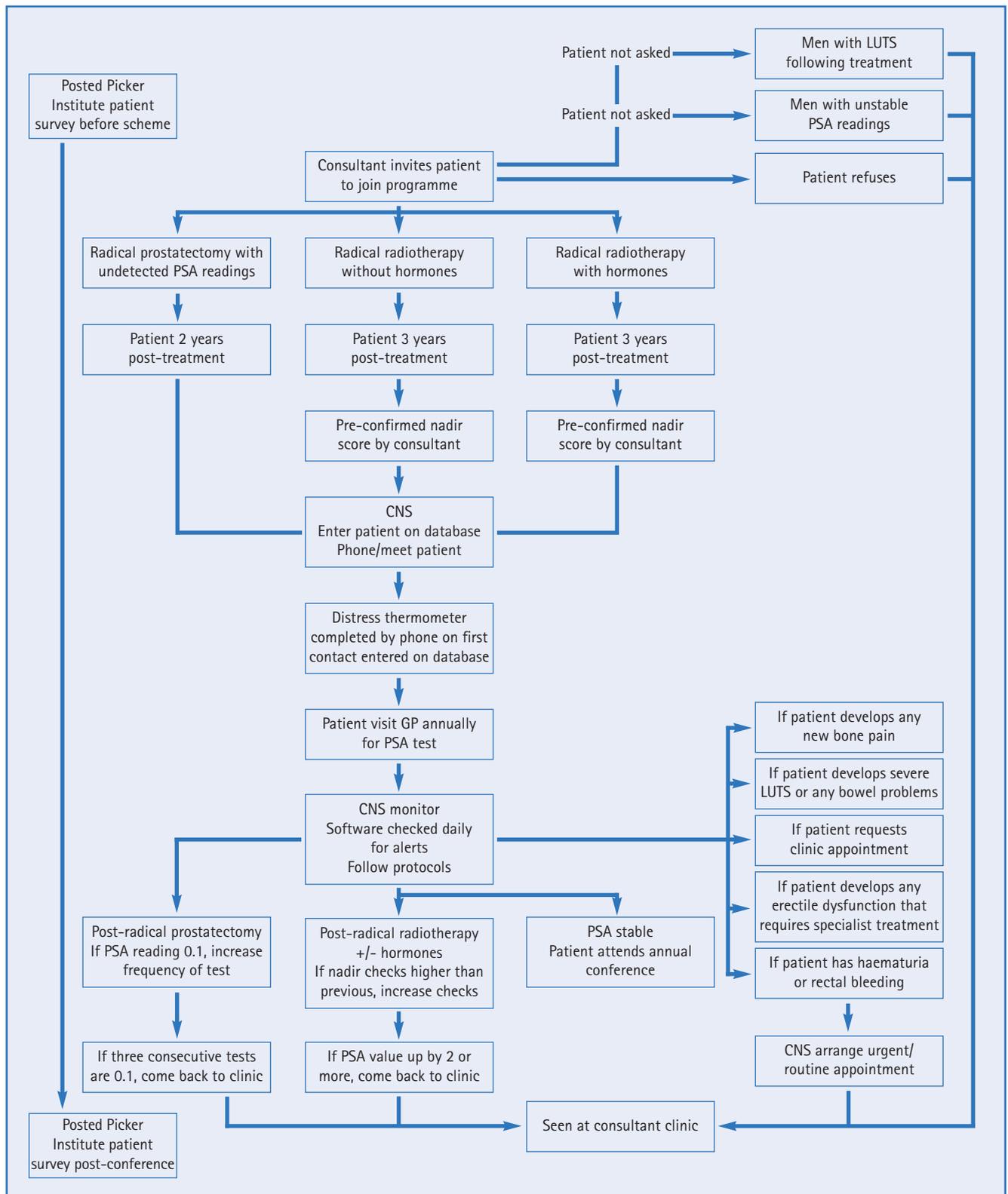


Figure 1. The Worcestershire prostate cancer survivorship programme: protocol for patient inclusion criteria and referral back to the clinic

others who had been through the same experience; they found this reassuring ('*You are not alone*'). They also remarked on the efficacy of the conference ('*Feels more efficient*'); it gave a lot of information to a lot of people. They may not think to ask specific questions at hospital appointments, and they also found it useful to hear answers to other people's questions. Even though patients were cured, they were still interested in hearing about the latest advances in treatment. All the presentations were helpful; the diet presentation was considered especially useful. Patients also felt it was important to be able to speak with staff, especially the consultant. Overall, the patients felt '*the conference will save time and money*'.

Eight people attended a focus group to share their views of the advantages and disadvantages of the hospital-based system and the community follow-up system.

HOSPITAL-BASED SYSTEM

The advantages of the consultant-led hospital system were: patients initially saw the consultant regularly, which was comforting and reassuring. As time went on, appointments became less frequent. Patients felt that problems could be addressed very quickly following a hospital appointment and that they were referred on by the consultant where necessary.

Comments about the disadvantages of the hospital system were: '*The NHS is a large system, you need to know it to know how to use it*'; '*Need to be fit to deal with the NHS*'; '*You do better the more articulate you are*'; '*Those who shout loudest get seen first*'; '*Had to be proactive in getting appointments*'; '*It really was a nightmare*'. There were problems on the administration side: for example, wrong appointments were sent out, cancelled appointments were rearranged so they no longer coincided with PSA readings, treatment/onwards referral was delayed. Patients also found it hard to find parking, which was expensive. Some needed to wait up to

2.5 hours to be seen, for a rather brief appointment. However, patients felt that they cannot have flexible appointment times and not expect delays.

COMMUNITY-BASED PROGRAMME

The advantages of the community-based survivorship programme are: having a primary contact; the CNS was more accessible (can phone direct rather than risk a message being left on a consultant's desk) and approachable; the CNS made appropriate and speedy referrals. Patients specified more CNSs were needed, as they alleviate some of the pressure on consultants. For others in greater need: '*If I do get a problem I feel I have a better chance of seeing the consultant quickly*'.

General comments about the survivorship scheme include: '*The only logical way to go, but if you have other problems, the old system is still available*'; '*With more people being diagnosed, it has to be the way forward*'; '*Never fall off the end*' (ie will not be discharged); '*Will probably save money*'; '*Easier*'. Patients were also able to choose where their PSA was done: at hospital or in the community. Those who preferred the community said that it saved them time, was less stressful, and the parking was easier. The disadvantages with the community-based scheme included: patients initially felt as though they were being sidelined. Some participants were unsure what they were opting into as they had not been given the patient leaflet. Patients also felt there were problems that they could not discuss with the CNS. Some felt reluctant to call the CNS as '*she is so busy*'. There were still delays when being referred on, cancelled appointments, etc.

However, the overall message taken away by patients is summarised by '*Someone, somewhere cares*'.

DISCUSSION

These results have given us several ideas for improvement. Patients would

like a better explanation of the system; they want it highlighted that they can contact the CNS via email or phone and that there is a way back into the consultant-led system. They also want a wider range of subjects covered at the conference, including a buddying system; and more consultants at the conference.

Patients have suggested the following changes to the website: links to the NHS website and prostate cancer charities; rights regarding PSA testing; case studies (anonymised); broaden the website to make it useful to people with early symptoms and at diagnosis. Patients also want to be able to log in to get PSA results and to have an online buddying system. These changes are currently being considered.

This study has been worthwhile, as it is envisaged that the follow-up will facilitate easier access to reliable information and improved support for patients and their families. This also allows an holistic approach while enabling us to monitor patients for recurrence. The overall aim is for patients to be more involved with the care process and empowered to ask questions without attending hospital.

CONCLUSIONS

Overall it is hoped that this new programme will help patients to lead a normal life incorporating the condition, increase patient satisfaction with follow-up care, reduce distress and increase control/understanding/quality of life and bring about financial savings for patients and the NHS.

Declaration of interests: none declared.

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