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Prostate Cancer Survivorship Experience: Patient Reported Outcome Measures and Focus Group Results

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Abstract

Introduction: There are an ever increasing number of prostate cancer survivors. These patients are currently followed up in secondary care. Focus of care is on recurrence and acute management, not holistic care.

Method: Over a 3 year period, patients attending follow-up appointments having completed treatment for organ confined prostate cancer and satisfying entry criteria were offered to join the programme. This comprises a database for PSA tracking and holistic assessment of patient needs run by a specialist nurse. The programme is supplemented by a Survivorship conference once a year, where patients have access to healthcare professionals discussing a range of topics related to prostate cancer. We assess patient satisfaction with questionnaires both pre and post conference and with a focus group in order to develop recommendations for the programme.

Results: We currently have 178 on the database 55 patients and friends visited the conference, with the majority specifying they would re-attend. The majority also ranked the conference as worthwhile re-attending. After the conference, we demonstrate patient concern decreases, with disease control and understanding increasing. We also show patients prefer the community based follow-up scheme, as opposed to a hospital based follow up.

Conclusion: Survivorship care has yet to be developed fully in clinical practice; this paper demonstrates how we can do this as part of a co-led approach with patients.

Keywords: Prostate cancer; Survivorship; Holistic care; Community based follow-up

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Introduction

Over 40,000 men are diagnosed with prostate cancer each year in the UK; this is over 100 per day [1]. By 2030, prostate cancer is estimated to be the most common cancer overall [1]. Even though prostate cancer has shown one of the biggest increases in incidence in the last decade (with age-standardized incidence rates rising by 22% between 1999-2001 and 2008-2010), the age-standardized mortality rate has fallen by around a tenth (11%) over the last ten years [1]. Cancer survivorship is a high priority for the National Health Service (NHS). There are around 2 million cancer survivors worldwide [2], and this figure is predicted to rise by one million per decade from 2010-2040 [2]. This is largely a result of improved diagnostics and medical treatment. Yet within this cohort, there are significant lapses in medical care and unmet need [3].

Methods

The new programme is assessed over a 3 year period. We included patients after curative treatment for prostate cancer. Inclusion criteria specify patients must be: 2 years post radical prostatectomy with an unrecordable PSA reading; 3 years post external beam radiotherapy with no metabolic relapse (Phoenix criteria) or brachytherapy with no metabolic relapse (Phoenix Criteria). Recurrence will be monitored via the PSA. Patients would be brought back to the clinic if the PSA is elevated, symptoms/ signs of recurrence, adverse effects of treatment or patient's request [2,3]. The database is supplemented by a Survivorship conference once a year. At this conference, patients have access to healthcare professionals discussing a range of topics including adverse effects of treatment, symptoms and signs of recurrence, nutrition and diet, physical exercise, financial advice, prostate cancer research [4,5]. Prostate cancer survivorship experience with this system will be measured via the Picker Institute questionnaires. The questionnaires focused on distress, perceived control of their condition and their quality of life. These will be handed out one month pre and post conference. A focus group was also conducted to collate views of the overall scheme [6-10].

Results

We currently have 158 patients on the data base, 8 having undergone brachytherapy, 67 radiotherapy and 78 post surgery. There were no referrals back to clinic or patients with recurrences.

There were eight people who kindly agreed to attend the focus group to share their views of the advantages and disadvantages of the hospital based system and the community follow up system for men with prostate cancer in Worcestershire.

The advantages with the Consultant led hospital systems were as follows: patients initially saw consultant regularly which was comforting and reassuring. As time went on, appointments became less frequent. They enjoyed seeing 'the big man' or lady, although they often see the registrar rather than consultant, especially when further from treatment (and with stable PSA), some were told they could be referred back to the consultant. Patients felt that problems could be addressed very quickly following a hospital appointment. Patients felt they were also referred on by consultant where necessary. They valued this face-to-face interaction [11-13]. The consultants would usually ask if the patient had any problems. Patients also enjoyed receiving results of PSA testing at their hospital appointment which also included a flow test if necessary (especially at diagnosis).

Comments made on disadvantages were as follows: "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". Some patients felt that the appointment system was administration-led rather than guided by the needs of the patient. There were problems on the administration side e.g. sending out wrong appointments, cancelled appointments rearranged so they no longer coincide with PSAs, possibly delayed treatment/onwards referral [14]. Mixed messages from the clinic administrator and consultant e.g. frequency of seeing the consultant. Patients also found it hard to find parking, which was expensive. Some participants live far from their local hospital. Appointments were generally 5 min - 10 min, although many felt they could take longer if necessary. Some needed to wait up to 2.5 hours to be seen, for a rather brief appointment. However, patients felt that "can't have it both ways", they can't have flexible appointment times and not expect delays. Some felt there were some questions they would not ask the consultant. The biggest fear with the new system, was 'Without the new system would you fall off the end?" i.e. be discharged and no longer followed up. This however is not the case [9,15].

The advantages of the community based Survivorship Programme: advantages are as follows: 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 very approachable. It is also useful that CNS sends wallets out for bloods plus reminders for PSA (some participants had not had this). Patients felt the CNS had made appropriate and speedy referrals. Patients specified more CNSs were needed, alleviates some of the pressure from consultants. "Frees up consultant time", for others in greater need. "if I do get a problem I feel I have a better chance of seeing the consultant quickly". Patients also felt opting in at two or three years post-treatment sounds about right.

General comments made about the whole scheme include: "The only logical way to go but if 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" (i.e. 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 [16]. They also felt saves the patients' time, less stress, no parking!

The advantages of the Survivorship conference were as follows: Patients valued meeting 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" and gave a lot of information to a lot of people. What they also really enjoyed was being able to ask anonymous questions, saving embarrassment [17]. 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 latest advances in treatment (despite being several years on) [17,18]. All the presentations given 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".

The disadvantages with the community based scheme included: Patients initially feeling as though they were being sidelined. Some participants were unsure what they were opting into as they hadn't been given the patient leaflet. Patients also felt they may not bring up some problems if the patient felt the CNS may not know. Patients also felt reluctant to call CNS as "she is so busy" [19,20]. There were still delays when being referred on, cancelled appointments etc. Another point which patients brought up were that they can get stressed waiting for monitoring. GP surgeries add to complications as they have different policies for PSA testing and accessing results. If they were not given the PSA test result, they were unsure who has responsibility, CNS or GP. However the overall message taken away by patients is summarised by "Someone, somewhere cares"[20].

Conclusions

This paper demonstrates the impact of a survivorship programme on the survivorship population. This needs to be developed further to advance patient care.

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