

Prostate Cancer Survivorship: A Systematic Review

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Introduction

Over 2 million people in England have a diagnosis of cancer. Of this figure, over 250,000 have been diagnosed with prostate cancer [1]. Due to increased awareness, improvement in diagnosis and treatment, prostate cancer survivors are becoming more common. Yet few studies or guidelines address the broader, multifaceted aspects of cancer.

Post cancer treatment, a new field is developing- Survivorship. More often than not, prostate cancer survivors are fit and well, requiring PSA follow-up, the only reason for a secondary care visit. Survivorship care involves risk profiling of patients, supported by community based teams and developing shared care/ decision making. Although part of Survivorship programmes involves cost efficiency, this should not compromise good care - good survivorship programmes are cost-effective as well as good for patients. Travel, parking fees, carbon footprint, better cardiovascular health, social and mental health, decreased cancer recurrence are all central points.

According to the National Cancer Institute (NCI), cancer survivorship encompasses the "physical, psychosocial, and economic issues of cancer from diagnosis until the end of life [1]". Concerns regarding this have defined survivorship care landmarks [3]. Including monitoring for recurrence, metastases, side effects and coordination between secondary and primary care and impact on quality of life.

Current services are falling short of their expectations and needs. 94% of patients expect a full assessment of their needs; 92% expect to discuss potential side effects of treatment and 89% expect a personalised care plan post treatment [5]. This was re-iterated by National Cancer Survivorship Initiative (NCSI) [5]. Key shifts in care attitudes include a focus is now more on recovery and return to work. This includes personalised approach to individual risk assessment and patient self-management. This process should enable early recognition of side effects and recurrence.

Furthermore, Survivorship patients have a number of holistic issues, which we as clinicians do not address in a five minute clinic appointment. These problems range from general health and wellbeing, to diet and exercise, physical rehabilitation, to psycho-sexual counselling. Whilst a range of research has been done on this subject, this problems still has not been fully addressed. How exactly can we help this cohort with the current system we have in place?

Current Literature

A systematic review relating to literature on survivorship programmes for men with prostate cancer was conducted. The search strategy aimed to identify all references related to prostate cancer survivorship programme components AND survivorship. The selection criteria specified papers must be related to primary research only.

All secondary research apart from published systematic reviews or meta-analyses, were excluded. Search terms used were as follows: (Prostate cancer OR prostate neoplasms) AND (survivorship OR survivor*) OR (support care OR diet therapy OR exercise OR communication) AND (post therapy OR post treatment) (Figure 6). The following databases were screened from 1984 to December 2013: CINAHL and MEDLINE (NHS Evidence), Cochrane, AMed, BNI, EMBASE, Health Business Elite, HMIC, PschINFO. In addition, searches using Medical Subject Headings (MeSH) and keywords were conducted using Cochrane databases. Primary research only was included in the systematic review. Two UK-based experts in survivorship care were consulted to identify any additional studies.

UK Studies

There are only 5 UK studies in current literature, relating to prostate cancer survivorship care, indicating how far behind in prostate cancer survivorship care we are. However, the ones they do present significant problems to be solved.

Faithfull S., 2010, examined 22 participants as part of a quasi-experimental: feasibility study with 7 weeks of group and individual sessions [9]. Outcomes were analysed via questionnaire based on urinary symptoms were measured before the intervention and again after 4 months of follow-up through International Prostate Symptom Scores. This was conducted by researchers. This pilot study provides data suggesting that a narrowly targeted, cognitive and behavioural self-management intervention can improve LUTS in men who have had radiotherapy treatment for prostate cancer (Moher 'B' quality). This emphasises the importance of contact with secondary care in the survivorship phase.

Khan N.F., 2011, conducted a descriptive controlled analysis with over 18000 survivors' vs controls, examining analysis of consultation rates/ 6 years [10]. Prostate cancer requires 3x more consultations than controls (Moher 'B' quality). This again emphasises the same point.

Ashley L., 2013, conducted a feasibility study with 886 prostate cancer survivors, over 15 months [11]. Questionnaire based analysis focused on generic, cancer-specific and cancer diagnosis-specific outcome measures. This was conducted by researchers who demonstrated a computer based system, with the potential to provide an affordable UK-scalable technical platform to facilitate and support longitudinal cohort research, and improve understanding of cancer survivors (Moher 'B' quality).

Elliott J., 2011, conducted a cross-sectional study with 780 prostate cancer survivors, using a National Health interview survey used to measure outcomes, in terms of health needs [12]. This demonstrated Cancer survivors have ongoing health needs that are not currently being addressed (Moher 'A' quality study).

Harrison SE., 2011, conducted a cross sectional questionnaire survey on discharge status, provision of time/information prior to discharge, feelings at discharge and satisfaction with how discharge was managed [13]. They demonstrated discharge of patients from hospital -requires additional time, support and information, again emphasising the extra support needed for this cohort.

Findings in Relation to Other Survivorship Studies & Trends, Literature

Concerns regarding permanent physical, psychosocial, and economic effects of cancer treatment were highlighted by the US Institute of Medicine Report [4]. These include impact on life for example, financial, occupational or performance concerns.

The Institute of Medicine produced a report on the focus of survivorship care plans including the chronic effects of cancer, monitoring for and preventing late effects e.g. malignancies, and promoting healthy lifestyles [15]. There is a lack of evidence in this field, with regard to patient follow up and whether it should be led by primary or secondary care, and also a lack of follow up into a patients' wellbeing and quality of life [15]. Survivorship care plans are recommended as an important tool to facilitate communication and allocation of responsibility as part of this [16]. Self -management is part of this, with patient driven assessment of outcomes [17].

A survey conducted by Macmillan demonstrated 70 % of patients living with and beyond cancer could self-manage their symptoms. The focus is now more on recovery and return to work[19]. This includes personalised approach to individual risk assessment and patient self-management. Further results from mapping exercises conducted by NCIS include psychological, physical and occupational problems, with a lack of information [20].

The patient consensus meeting concluded patients are not averse to new approaches to follow-up care and support [22]. However they need to have access to good quality information and rapid access to specialist treatment - should they need it [21].

An important pre-requisite for survivorship care, is a good insight into the patients' needs and preferences. Providing cancer patients with information about their disease and treatment helps them to make decisions about treatment. In addition they are able to overcome fear, develop realistic expectations, manage side effects and comply with treatment [23]. Individualised information sessions have been associated with lower anxiety, better psychological well-being and higher treatment satisfaction [24]. Continuity and coordination of care is difficult, with many patients unclear about who is responsible for their ongoing survivorship care [25]. However, to date, there has been little consensus on the value and organisation of follow-up [26].

One area which is infrequently addressed is that of sexual dysfunction. This affects many prostate cancer survivors [27]. The incidence of varies between 20% and 88% [28]. Changes in body image, pain, and loss of desire, long-term physical and psychological side effects from cancer treatments can affect sexual functioning.

Worldwide, there is conflicted evidence regarding follow-up of this cohort, especially over value of follow-up once cured and in the Survivorship phase. This gives us the opportunity to examine how we review these patients, and why we do it. We propose a programme with a more holistic approach empowering patients to take responsibility for their own clinical assessment, whilst at the same time, keeping them under the clinical governance umbrella of secondary care in the community, allowing local treatable recurrence to be detected early. There is a period following treatment with curative intent during which there is no clinical decision making to be made. During these hiatus patients when patients are 'in limbo' they can be encouraged to take on their own health and well-being management. Moreover there is emerging data that proper diet and exercise management correlates with a lowered incidence of recurrence in solid cancers - e.g. breast and colorectal. In addition, most deaths when they occur in prostate cancer patients are still not from prostate cancer itself but from cardiovascular and other causes. Enrolment into a survivorship programme will mitigate against this through encouraging attention to general health.

The New Programme

Based on these facts, we have developed a new survivorship model- this was set up as a National Cancer Survivorship Initiative. This programme was initially devised when it was identified specific areas of care were lacking in this cohort, when followed up on a clinic basis. It aims to address the holistic need of the survivorship cohort, at the same time, allow monitoring for acute recurrence and follow-up care as-well with community based follow-up and patient support.

Our Survivorship programme is for patients post curative therapy for organ confined disease (surgery, external beam radiotherapy or brachytherapy). Patients are offered the option of entering into the survivorship programme and discharged from clinic (please see Figure 1). Inclusion criteria specify patients must be two years post radical prostatectomy with an unrecordable PSA, or three years post radiotherapy or brachytherapy with a stable PSA. These figures were chosen, as they provide the cohort, with the lowest risk of recurrence (less than five percent). We currently have over five hundred patients on this programme. The patients' demographic, disease and treatment details are entered onto a password protected web based database. The IT programme allows patients to be monitored for recurrence via automatic extraction of PSA

results from the hospital database. It is a bespoke database. Alerts are automatically generated if the PSA is above a previously set range. The clinical nurse specialist (CNS) running the programme will contact the responsible Consultant once an alert- is generated with the patient reviewed in clinic, if required. The CNS will also go through a 'Distress thermometer' with patients on admission to the programme, to identify areas where the patient needs support, psychological, social etc. The specialist nurse would act as the patients' keyworker, should they develop any side effects of treatment, or any recurrence.

At its' initial inception, a focus group of patients was conducted, as part of participatory action research, to find out what they wanted as part of this programme- a user led system. Specifically, they mentioned a conference where they have access to health care professionals and specific topics covered including, diet and exercise, nutrition, psychosexually counselling. This conference is held annually, with a range of healthcare professionals advising on identified patient issues e.g. psychological care, health promotion, research, and welfare. The conferences allow patients to draw on their strengths and share experiences with each other. Topics such as identification of recurrence, long-term complications, rehabilitation services, quality-of-life issues, pain and symptom management, and treatment of recurrent cancer are examples of areas covered.

There are over 700 patients currently on the programme; a mixture of post-surgery; radiotherapy and brachytherapy (please see Table 1). Of these patients, 29 have been referred back to clinic. When asked at the pilot conference if it was worth attending, 100% said yes. As a result of the initial focus group, comments have been made in support this programme.

Conclusion

According to disease risk stratification and in line with personalised patient care and key shifts in culture, we have proposed a community based survivorship follow-up scheme for prostate cancer patients. The aim of this is to provide a better standard of care for patients whilst bringing savings to the NHS and can also be applied across other tumour sites. Whilst this programme is currently only for patients post curative treatment, the next steps forward, are to see if patients undergoing active surveillance or on hormone therapy can be followed up using this programme. There are all sorts of spin off positive effects from this kind of programme. Green issues are also resolved. Less people would drive to and from hospital. They would also spend less time wasted waiting in overbooked clinics. As a result, greater access to clinic appointments for others would occur. Lastly there are 260,000 prevalent cases of prostate cancer in the UK. This will rise to 600,000 by 2030 and will be an impossible task for us in secondary care to manage completely alone.

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