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How has early testicular cancer affected your life? A study of sexual function in men attending active surveillance for stage one testicular cancer

Sue Brand ^{a, *}, Hilary Williams ^{b, 1}, Jeremy Braybrooke ^{a, 2}

^a University Hospitals Bristol NHS Foundation Trust, Bristol BS28ED, UK

^b Velindre Cancer Centre, Velindre Road, Cardiff, South Glamorgan CF14 2TL, UK

A B S T R A C T

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Purpose: Testicular cancer is the most common cancer in young men, it is frequently diagnosed at key times in relationship formation. In early stage disease the vast majority of tumours will be cured by surgery alone with patients being offered active surveillance rather than adjuvant therapies. To date, research has not evaluated how surveillance alone impacts on sexual function.

Methods: The aim of this quantitative longitudinal study was to ascertain the sexual function of men with stage one disease at 3 and 12 months post diagnosis and to compare with normative data. Additional data was collected on the information men sought regarding sexual function and media they used to access this.

Results: This study shows that men's sexual function is altered at diagnosis and improves by 3 months. At 12 months, whilst not statistically significant, sexual function improves but not to the same level as normative data comparison. Men appear to find verbal information useful at 3 months, however men appear to be seeking written and online information at 12 months.

Conclusion: The intricacies of sexual function together with the low number of participants may have been best met with a qualitative approach. However, the information data indicates the importance of further research into the effects of early stage testicular cancer on sexual function. Therefore, further qualitative research is recommended to explore the effects of early stage testicular cancer in relation to sexual function.

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Introduction

Testicular cancer is the most common cancer in young men with most patients diagnosed between the age of 20 and 40. This is often a key time in relationship formation. Most early stage testicular cancers are cured by surgery alone (Orchidectomy) (Jones and Vasey, 2003). However, depending upon the pathology of the primary cancer, patients with Stage one non seminomatous testicular cancer (confined to the testis) are at 10–50% risk of developing metastatic disease depending upon the presence or not of vascular

invasion in the orchidectomy sample. Whilst platinum based chemotherapy can reduce the risk of recurrence, there is increasing concern about the potential short and long term risks from adjuvant treatment. This is particularly important for testicular cancer where the vast majority of patients with metastatic disease continue to have a curable cancer.

As such, increasingly, patients with early stage cancer are offered regular structured follow up (active surveillance) to help avoid the potential toxicity of chemotherapy. Active surveillance is usually intensive during the first one to two years following diagnosis (e.g. 1/2/3 monthly) and may include physical examination, chest x-rays, CT scans and blood tests for tumour markers. These men are at risk of developing metastatic disease, and the aim is early identification this early to expedite curative treatments, the fear of recurrence is demonstrated in this patient group, however, it is not clear whether this intensive follow up, impacts on patient

* Corresponding author. Tel.: +44 01173423472.

E-mail addresses: sue.brand@nhs.net (S. Brand), hilarywilliams@doctors.net (H. Williams), jeremy.braybrooke@uhbristol.nhs.uk (J. Braybrooke).

¹ Tel.: +44 029 2061 5888x6202.

² Tel.: +44 01173422418.

anxiety and sexual function in the way that other more intensive treatments do (Jankowska, 2012).

In general, retrospective studies of large testicular cancer cohorts, suggest men who have experienced testicular cancer maintain good quality of life in the long term (Joly et al., 2002; Mykletun et al., 2005; Dahl et al., 2005). However around 10% of patients had low testosterone levels (Huddart et al., 2005), and in general experienced more sexual problems than control populations or prior to treatment (Brydoy et al., 2007). In these retrospective studies, patients have been monitored for up to 10 years following diagnosis, and have received a range of treatment modalities, including surgery, chemotherapy, radiotherapy, and surveillance.

Prospective data on sexual function is more limited. The most detailed study (Aass et al., 1993) identified a high frequency (30%) of long lasting sexual problems at 3 years following treatment. However the majority of these patients had received additional treatments beyond orchidectomy including retroperitoneal lymph node dissection which has a potential risk of causing erectile dysfunction.

Clinical experience suggests some men with testicular cancer experience considerable problems adjusting to their diagnosis and this impacts on their lives in many ways (Jankowska, 2012). Men may notice marked changes in their sexual function in particular their sexual drive (Joly et al., 2002), but it is difficult to ascertain if this is linked to the disease process or the anxiety of the diagnosis (Mykletun et al., 2005). This can have an overwhelming impact on their lives, frequently impacting on current relationships or the formation of new relationships. These are very sensitive and often difficult issues to address in routine clinical practice. As well as patients struggling to raise these issues, it is clear from studies in other cancer sites that sexual difficulties are not frequently discussed with clinicians (Katz, 2005). Oncology health care professionals have little training in these areas (Katz, 2005) and this may lead to reluctance to address these very personal issues (Stead et al., 2003). However we know, from groups such as the Teenage Cancer Trust, and studies in other cancers, such as breast cancer (Schover, 2008) that information provision around these difficult issues is vital to patients. Importantly a study in cervical cancer has shown that provision of appropriate information reduced sexual difficulties following treatment (Capone et al., 1980). However, different groups of cancer patients have different needs in terms of provision of information and service organisation (Hiley, 2006) and this may vary by age, sex, ethnic background and sexual orientation. There is very little information available on how young men would like to receive information and support about sexual issues (ICR, 2001).

At present it is not clear whether interview or questionnaires give the most information on cancer patient's experience of sexual function (Fossa and Dahl, 2008). The leading quality of life research tools, the European organisation for research and treatment of cancer (EORTC) and the functional assessment of chronic illness therapy, (FACIT), do not have specific testicular cancer modules suitable for patients on surveillance, or appropriate sexual function modules. One of the most widely used scales in urology is the 'Brief Male Sexual Function Inventory for Urology (BMSFIU)' (O'Leary et al., 1995). The scale is designed to be self-administered, is well validated and has been tested in men with and without sexual dysfunction. Normative data is available, for both American and Norwegian populations, with very similar outcome scores for all domains of the scale and with data broken down by age group (Mykletun et al., 2005). The scale has been used in studies in testicular cancer (Dahl et al., 2007) and patients did not find it distressing or difficult to complete (Fossa and Dahl, 2008).

Patients and methods

Patients

The study data was drawn from 21 men commencing active surveillance for stage one germ cell cancer, with (pT2) or without (pT1) lymphovascular invasion. All potential participants were identified at the multidisciplinary meeting for testis, approached at their first consultation and given written information. Eligible patients were between the ages of 18–50 years, with no planned adjuvant therapy, completed a consent form and were entered into the study within 3 months of diagnosis. In the recruitment stage only one patient declined to participate in the study and one patient outside of the eligibility. The upper age limit of 50 years was chosen to reflect the incidence of testicular cancer (Jones and Vasey, 2003).

Method

Prior to ethical application the questionnaire was viewed by a patient user group of 5 men of the similar age and disease of the proposed participants. The purpose of this was to add a patient perspective to the study. The user group suggested administering the questionnaire at 2 time points (within 3 months and at 12 months), as they perceived there would be a reduction in anxiety with time. The study was reviewed by local ethics and approved. The questionnaire was in two parts; part one had introductory questions with the aim of 'setting the scene' of sexual function and its importance prior to diagnosis and the validated BMSFIU. Part two explored information seeking patterns on sexual function. The questionnaire was administered within 3 months of diagnosis and at 12 months following diagnosis, in the testicular cancer clinic during attendance for medical review. All participants were given a private room to complete the questionnaire.

Analysis

The study design and statistics were based on the number of patients who were diagnosed within the eligibility criteria in the previous year. The aim was to compare the total score of the BMSFI from the study cohort at both time points (3 months and 12 months), with the normative data available in the public domain (Mykletun et al., 2005). The normative data was age-weighted to be comparable with the study group. If the scores were found to have a normal distribution, the total scores would be compared using a *t*-test. If the scores were not normally distributed statistical tests were not possible but, results could be presented as basic graphs with the analysis of sub-scores. The original intention was to take the mean score for the BMFSI at 3 and 12 months and compare using a paired *t* test based on a sample size of 19. However, the data did not have normal distribution; therefore the data is demonstrated using graphs of the mean scores of each of the BMFSI dimension.

The rest of the questionnaire was summarised using simple frequencies.

Results

Setting the scene of sexual function

35% ($n = 7$) of men at screening were very satisfied with their sex life and 40% ($n = 8$) were mostly satisfied. The majority of men did not find attending the clinic stressful, not at all (40% $n = 8$) a little bit (60% $n = 12$), with main concerns being, physical appearance (10% $n = 2$), about having one testicle (10% $n = 2$), about my

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