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Abstract

Background: Men with prostate cancer (PCa) often experience sexual dysfunction following diagnosis and treatment, yet little is known about the support they receive to deal with this. **Aim:** To explore men's experiences of support for sexual dysfunction following PCa diagnosis. **Methods:** A UK-wide survey of men 18-42 months post-diagnosis of PCa, identified through cancer registries. The survey measured sexual function and the extent to which men perceived sexual dysfunction to be a problem (EPIC-26), access to and experience of medications, devices and specialist services for sexual dysfunction, and included a free-text question for further comments. Analysis focussed on men who reported poor sexual function, which they considered a moderate/big problem. Descriptive statistics explored the characteristics of men offered intervention and those that found this helpful. Free-text responses were analysed using thematic analysis.

Outcome: Access to and experience of medications, devices and specialist services for sexual dysfunction.

Results: 39.0% of all survey respondents (13,978/35,823) reported poor sexual function, which they considered a moderate/big problem. 51.7% of these men were not offered any intervention to aid sexual functioning. 71.9% of those offered an intervention reported trying it, of whom 48.7% found the intervention helpful. Men treated with surgery or brachytherapy were most likely to be offered an intervention. Medication was the most commonly offered intervention and 39.3% of those who tried medication, found this helpful. Although offered less often, approximately half of the men who tried devices or attended specialist services found this helpful.

Free text responses indicated that barriers to accessing support included: inadequate information and support from health care professionals; embarrassment; negative views about treatment options; concerns about side-effects and safety; and inconsistencies between secondary and primary care . Barriers to continuing use included: limited effectiveness of treatments; inadequate ongoing support; and funding constraints. Drivers of sexual recovery included: patient proactivity and persistence with trying different treatment options; ongoing support from health professionals.

Clinical Implications: There is an urgent need to ensure all men are offered, and have equal access to, sexual care support, with referral to specialist services when required.

Strengths and limitations: This study presents data from a large, UK-wide, population based study of men with prostate cancer and includes quantitative and qualitative findings. The possibility of non-response bias should, however, be considered.

Conclusion: There are significant shortcomings in the support offered to UK men with sexual dysfunction following diagnosis and treatment for PCa which need to be addressed.

Introduction

As cancer survivorship improves and the absolute number of survivors grows [1], we need to improve approaches to identifying ongoing difficulties and to plan appropriate healthcare services. Although many cancer survivors have excellent outcomes in terms of survival and quality of life [2], reduced quality of life and specific symptoms and functional difficulties may be substantial for some. For example, for the large number of prostate cancer survivors, treatment frequently results in impaired sexual functioning [3, 4]. Radical treatment of prostate cancer with surgery, external beam radiotherapy (EBRT) or brachytherapy often causes erectile dysfunction (ED) [3-5]. Androgen deprivation therapy (ADT) used in conjunction with radiotherapy for radical treatment and also as a palliative therapy leads to diminished libido and ED [6]. Sexual dysfunction can have a significant impact on psychological well-being and quality of life for both men and their partners [7, 8]. A number of treatments are available for ED including phosphodiesterase type 5 inhibitor (PDE5I) drugs, intra-cavernous injections (ICIs), and vacuum erection devices or pumps (VEDs) [6]. There is mixed evidence on the efficacy of these treatments but, to date, they are considered the main approach to ED management following prostate cancer treatment [9]. Penile rehabilitation programs are also increasingly used, although there is no standard rehabilitation protocol and a lack of evidence of efficacy [10]. Penile implants can provide effective early sexual rehabilitation and improve quality of life without compromising surgical outcomes, although utilisation is low [11]. Partners are integral to approaches to support men with sexual dysfunction and psychosexual support for couples is central to helping men and their partners manage expectations and facilitate adherence to medical treatments for ED [9].

However, there is some evidence many men are not being offered these interventions; some men do not wish to try them [4], and many experience problems and do not persist with therapy [12]. The few qualitative studies that have explored this topic have highlighted that men struggle with the lack of spontaneity and artificial nature of sex aids [13], and adoption of a stoical attitude can preclude potentially helpful discussions with health care professionals [14]. Certain groups of men have been reported to find sexual dysfunction more challenging, such as younger men, Black men and gay men [15, 16].

We have previously reported from the Life After Prostate Cancer Diagnosis (LAPCD) study, a large UK-wide population based study of over 35,000 men that 41·4% men reported being offered medications to aid or improve erections, 22·6% were offered devices to aid erections and 14·8% were offered specialist services (such as counselling) to help with sexual functioning [4]. In this paper we report more detailed findings from the LAPCD study, using both survey and free-text data, on men's experiences of support for sexual dysfunction – focussing on the cohort of men who considered poor sexual function to be a moderate or big problem.

Method

The LAPCD study design has been detailed previously [17]. Men diagnosed with PCa between 18-42 months previously were eligible to participate and were identified through national cancer registration systems in England, Wales and Northern Ireland, and through hospital activity data in Scotland. Ethical and regulatory approvals allowed men to be contacted using details held within cancer registration/hospital activity data. Men were sent a postal survey on behalf of their treating Trust/Board. All mailings were conducted by an NHS approved survey provider on behalf of the study team. Men consented to the study by returning completed surveys and declined by not returning them, returning them unanswered or opting out via a free-phone helpline. Up to two reminders were sent to non-responders. The survey was completed between October 2015 and November 2016.

The survey covered a range of topics, including:

Prostate cancer-related quality of life

The Expanded Prostate Cancer Index Composite-26 (EPIC-26) [18, 19] measures function across five domains (urinary incontinence, urinary irritation and obstruction, bowel, sexual, vitality/hormone), using 26 items. Men were asked to rate their ability to function sexually over the past four weeks on a five-point scale, anchored between very poor – very good. An additional question assessed bother associated with sexual function, where men were asked to rate how big a problem their function had been over the past four weeks. This was ranked on a five-point scale (no/ very small/ small/ moderate/ big problem).

Access to and use of sexual interventions

Two items from the ICHOM dataset assessing use of medications and devices for ED were included in the survey [20]. These were modified to avoid drug/trade names. An additional item on use of specialist services to help with sex life was included, "Have you used any specialist services to help with your sex life following your diagnosis of prostate cancer? (e.g. counselling, psychosexual clinics, psychology)".

Free text responses

Following the EPIC and sexual intervention questions, respondents were given the opportunity to add any additional comments in a free text box.

In addition, the survey contained questions relating to socio-demographics and treatments received. For the purposes of this study, we used self-reported information on age (where missing, supplemented by cancer registration records), presence of other long-term conditions (LTCs), type of treatment received (including monitoring), ethnicity, marital status, employment status, and sexuality.

Analysis

Quantitative analysis

The survey data were analysed descriptively, with chi-squared analyses used to investigate the characteristics of men offered intervention and those that found this helpful. Analyses were limited to men that reported they had poor/very poor sexual function and considered this a moderate/big problem, and who answered all three sexual intervention questions. Analyses were performed using Stata version 15.0 (StataCorp, TX, USA).

Free text analysis

Free text responses were transcribed verbatim and a thematic analysis was undertaken [21]. Three members of the research team (RW, LM, EW) read through all responses of men who reported that they had poor/very poor sexual function and considered this to be a moderate/big problem and categorised the comments as either relevant or not relevant to the topic of support for sexual dysfunction. Relevant comments were then independently coded by team members (LM, RW, EW) and a coding framework was constructed. The process of constructing the framework was both inductive and deductive [22]. Researchers coded all relevant free text comments using the framework. Codes were then collated and examined as a whole. Preliminary themes were constructed and refined and finalised following discussion.

Results

The study population

Overall, 35,823 men completed a survey (60.8%). Of these, 39.0% (13,978/35,823) men reported poor or very poor sexual function which they considered to be a moderate or big problem. These 13,978 men are the focus of this paper and their socio-demographic and clinical characteristics are presented in Table 1.

Survey findings

All three sexual intervention questions were answered by 13,589 (97.2%) men. Just under half (n=6,562, 48.3%) reported being offered any of the three interventions to support sexual wellbeing (Table 2). Men were most commonly offered medications (n=6,233; 45.9%), with smaller proportions offered devices (n=3,620; 26.6%) and specialist services (n=2,069; 15.2%) (see Figure 1). Many men (58.0%) were offered more than one intervention: 28.2% were offered medications and devices, and 23.7% were offered all three interventions. Other combinations were much less commonly offered (Supplementary Table 1).

The proportion of men offered any of the interventions decreased with age and as the number of other LTCs increased (Table 2). Around half of all married and separated/divorced men reported being offered any of the interventions, whereas fewer single (46.1%) and widowed (33.6%) men were offered an intervention (Table 2).

The proportion of men offered interventions varied considerably by treatment modality (Tables 2 and 3). Men treated with surgery alone were most likely to be offered an intervention (81.4%: Medications: 78.5%; Devices: 61.7%; Specialist services: 27.9%), followed by men treated with brachytherapy alone (65.1%: Medications: 63.5%; Devices 20.4%; Specialist services 14.4%). Men on other treatment pathways were much less likely to be offered any type of intervention (e.g. EBRT 34.9%, Monitoring 30%, ADT 22.4%).

Of those men offered an intervention, 71.9% (4,717/6,562) reported trying it. When offered, men were most likely to try medications (71.0%) and least likely to try specialist services (42.8%) (Figure 1). Just under half of the men who were offered and tried an intervention reported that it was helpful (n=2,296, 48.7%). Approximately half of the men who tried specialist services (n=469; 52.9%), or devices (n=1,049; 51.5%) found the intervention helpful, and 39.3% (n=1,741) of those who tried medication found it helpful (Figure 1).

Of those men who tried the interventions offered to them, there was variation across the treatment groups in how helpful they found them. Over 50% of the men treated with monitoring, surgery or brachytherapy reported finding intervention helpful. Men who received ADT alone were least likely to report finding intervention helpful (35%) (Table 3). The most common treatment modalities amongst men in our study were surgery alone (n=3,123) and combined EBRT & ADT (n=3,092). Over 80% of the surgical group were offered an intervention, and of those who tried the intervention, 37.2% found medication to be helpful, 55.3% found devices to be helpful and 53.3% found specialist services to be helpful. For men treated with EBRT & ADT, a much lower proportion (39.5%) were offered an intervention. Of those who tried the intervention, 37.2% found medication to be helpful, 33.1% found devices to be helpful and 55.6% found specialist services helpful.

Free text findings

28% (3,849) of men with poor sexual function, which they considered to be a moderate or big problem, provided free text responses following the EPIC-26 and sexual intervention questions in the survey. Of these, 597 (15.5%, or 4.2% of the total sample) comments were deemed relevant to providing insights into men's experiences of support, including medication and devices. Three main themes emerged from the analysis: Barriers to accessing support, Barriers to continuing use, and Drivers of sexual recovery (see Figure 2). Each of the themes and sub-themes are described below, with illustrative quotes for each theme presented in Supplementary Table 2.

Theme 1: Barriers to accessing sexual care support

Barriers to accessing support to deal with erectile dysfunction were identified at the health service organisation level as well as the individual patient level.

i) Health service factors

Information provision and communication with health professionals

Men described unmet needs regarding erectile functioning and a desire for more information and support. Men often commented that health professionals had not initiated any discussion with them regarding sexual function following treatment or had failed to discuss potential medication or aids to help address sexual dysfunction. Some men indicated they believed sexual issues were not discussed because their doctors had made incorrect assumptions about their older age or, in a few cases, their sexual orientation. Comments indicated that in some cases health professionals had told men their sex lives would be over completely following treatment, with no indication that any further information or support for sexual functioning had been provided.

Inconsistencies between primary and secondary care

Many men described significant inconsistencies between what their consultants or specialist ED services advised and what their general practitioner (GP) had told them or was willing to prescribe. There were numerous instances reported about GPs reluctance to prescribe medication or aids which had been recommended by secondary care and requested by men.

Delays in support for sexual functioning - "Too little, too late"

Men reported significant delays in receiving medication or sexual aid after these had been ordered or prescribed, and long waiting lists following referral for sexual or couple counselling. This, in turn, sometimes led men to cease trying.

(ii) Patient factors

Some men described embarrassment and a reluctance to talk to health professionals about using sexual aids. Other men didn't want to try medication due to issues with comorbidities and concerns over polypharmacy. Some men discussed loss of libido due to treatment from PCa leading to a lack of motivation to try sexual aids. Others held negative views towards particular sexual aids, for example a dislike of mechanical options such as the vacuum pump or a phobia of injections which precluded these options. A few men noted concerns around the use of sexual aids potentially increasing the risk of cancer recurrence because of increased blood flow to the area.

Theme 2: Barriers to continuing use of sexual care support interventions

Amongst men who had tried erectile aids, many reported perceived problems or limitations. The most common problem reported was that men found the aids to be lacking or limited in effectiveness and so they stopped using them. Another issue was experiencing unpleasant side effects from using sexual aids or medications (e.g. headaches, pain etc.), which often became a barrier to further use. Men also reported finding sexual aids reduced the pleasure and the spontaneity of sex. Some men also described problems with getting adequate support 'troubleshooting' issues with medication or devices from health professionals. For those men who had found sexual aids to be effective, some described frustration with being unable to get an adequate supply to meet their needs due to manufacturer issues or funding constraints.

Theme 3: Drivers and facilitators of sexual recovery

Various 'drivers' that encouraged the use of sexual aids and appeared to promote their effectiveness were identified.

(i) Effectiveness of sexual aids/devices

Some men reported that sexual aids had been effective at helping them maintain erections good enough for sexual intercourse and noted the psychological benefits of being able to maintain a degree of sexual activity.

(ii) Health professional support

For men who had initiated the use of medications or devices ongoing support and encouragement from health professionals was important. Being offered a range of options by health professionals was identified as being helpful.

(iii) Motivation and persistence to gain sexual recovery

Patient-related drivers included men's willingness to proactively seek help and motivation to persist and try out different options. Some men noted the importance of maintaining some sexual function in the hope that even if penetration wasn't currently possible at that time it would return with time.

Some men who were unsatisfied with the sexual support received, did reach out to the private sector and consult the Internet. The Internet was used primarily for accessing medication and devices.

Discussion

This study, which has explored the experience of treatment and support for prostate-cancer related sexual dysfunction in a large, population-based sample of men in the UK, has highlighted significant shortcomings in the support provided to men. Just over half (52%) of all men who reported finding sexual dysfunction to be problematic were not offered support from the health system to deal with this. Of the men offered an intervention, 72% reported trying it and, of these, approximately half found the intervention helpful. Younger men, those post-radical surgery or brachytherapy, and men with no co-morbidities were most likely to be offered an intervention, most commonly in the form of medication. There was some variation by treatment modality in terms of how helpful men found interventions to be, with men treated with surgery, brachytherapy or monitoring most likely to find intervention helpful. Although referral to specialist services was not often offered, this was the intervention that the highest proportion of men reported as being helpful to them. Free-text responses revealed a range of healthcare service and patient barriers to accessing support, as well as barriers to continuing use. Support from healthcare professionals was an important driver of recovery of sexual functioning or wellbeing, alongside motivation and willingness on the part of the man to persist with trying different sexual aids/devices.

Strengths of this study include its size and the fact that it was conducted on an unselected population-based sample. The study achieved a good response rate (60.8%), however, as with all surveys the potential for non-response bias must be recognised. Furthermore, we do not have data on men’s sexual functioning or bother prior to the diagnosis of PCa, as men in the survey were 18-42 months post-diagnosis. Those men who experienced problematic sexual dysfunction in the initial post-diagnosis period but have either been successfully treated or no longer find this to be a problem are not represented in the findings. Sexual functioning difficulties vary according to treatment trajectories [9, 23]. For example, whilst some men in the sample who received radiotherapy treatment may just be beginning to experience erectile problems, those on ADT would have continuous challenges until they stopped treatment and possibly beyond [9]. It should also be noted that men in the survey were asked about their sexual function, and the extent to which poor sexual function was considered a problem. Men may have focussed responses on erectile dysfunction and there are other sexual problems which men may have experienced that were not specifically explored in this study. Analysis of men's free text responses has enhanced our understanding of their experiences of treatment and support for sexual dysfunction. It has, however, been suggested that those who are literate, have English as a first language, and have more negative experiences are more likely to complete free text boxes [24] . Nonetheless understanding men's negative experiences can be very helpful for future service development.

A few previous studies have also focussed on men's experiences of treatment and support for sexual dysfunction following a prostate cancer diagnosis. A recent UK survey conducted with a convenience sample of respondents found that a fifth of men were not offered any ED management, and a similar proportion were not satisfied with the way healthcare professionals addressed their concerns about ED. One quarter indicated they experienced difficulty or delays in accessing ED treatment [25]. Similar to our findings, a US study of 896 men 4-8 years after treatment for localised PCa found that approximately half of the sample were bothered by poor sexual function and, of these men, men treated with surgery were most likely to have tried an intervention (67%) compared to men receiving other forms of treatment [20]. A more recent US study found that 56% of patients (237/425) treated for localised PCa with surgery, EBRT or brachytherapy used an erectile aid at some point in the four years following diagnosis and treatment [26]. A Scandinavian study of 982 post-prostatectomy long-term survivors of PCa found 48% reported use of erectile aids, which significantly increased the proportion reporting sufficient erections [27]. Similar to our findings, previous qualitative studies have shown that men often report finding sexual aids artificial and that sex lacked spontaneity when using medication or aids [12]. Men also often reported oral medication to be ineffective [12, 28, 29]. Other papers have discussed men's rejection of sexual aids and their decision not to use them [12, 30].

Although the treatment-related sexual side effects of prostate cancer have long been known, our study clearly indicates that UK men are still not being adequately supported. Support is inconsistent and fragmented and there are a number of clear implications for practice. Regardless of age and treatment modality, the effect of different treatment options on sexual functioning should be discussed with men and their partners around the time of treatment decision-making to help men and their partners set realistic expectations of the impact on sexual functioning post-treatment. It appears that men in the UK treated surgically or with brachytherapy are considerably more likely to be offered intervention(s) and attention should be paid to other patient pathways, ensuring that all men, regardless of what treatment they receive, are offered the opportunity to discuss sexual dysfunction and have access to support and intervention. Timing is also important and men should be offered early and ongoing access to interventions soon after primary PCa treatment completion, along with encouragement to try available options and to persist [9]. Men / couples will vary as to when in the treatment pathway sexual function becomes a priority. In addition, recognising that men will have varying degrees of success regarding their sexual recovery [31] it would also be beneficial for health professionals to provide men with greater information and advice on ways of maintaining intimacy that may not involve penetration.

Our study has identified a range of barriers in the uptake of treatments by men, and health professionals could usefully discuss and challenge these barriers, including raising the topic with all men and establishing if they wish to discuss and signposting to further support if needed. Mehta and colleagues [32] found that patients and partners value both pre-treatment preparation for sexual recovery and support for sexual recovery for both after treatment, and that a web-based approach may help mitigate barriers to access to these support services. In a recent review, Faris and colleagues [33], also found educational intervention improved sexual function and satisfaction in men treated by radical prostatectomy

It is important to acknowledge the barriers that health professionals may have when discussing sexual health with men, and specific sexual care training may be needed for them to gain a full appreciation of the subject and feel confident in including this within their routine care [34-36]. Greater access to specialised psychosexual support for men and their partners is also needed to enable men to both work thorugh the 'loss' of their previous sex life and move on towards their new sexual normal.   There is also an urgent need for improved communication pathways (with standardised care) between secondary and primary care, and for greater clarity and equity over funding for sexual dysfunction treatments across the UK.

We believe that these findings should cause all leaders of the multi-disciplinary teams which care for PCa patients before, during and after major treatment interventions, to review their practice and training to ensure that patients are adequately informed of the risks and potential interventions for sexual dysfunction during and after treatment. Good written and internet-based advice does exist and needs to be more consistently drawn to patient's attention with the appropriate contact points for further discussions, and consideration of treatment options.

Ethical approval

The study received the following approvals: Newcastle & North Tyneside Research Ethics Committee (15/NE/0036), Confidentiality Advisory Group (15/CAG/0110), NHS Scotland Public Benefit and Privacy Panel (0516-0364) and NHS R&D approval from Wales, Scotland and Northern Ireland.

Data Sharing

The datasets generated and/or analysed during the current study are not available publicly, as eligible patients were informed at the time of the survey that their data would be stored securely and confidentially. The processes for accessing the data used are available from the corresponding author.

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