

## Original Article

**Cite this article:** Kinnaird W and Stewart-Lord A. (2021) A qualitative study exploring men's experience of sexual dysfunction as a result of radiotherapy and androgen deprivation therapy to treat prostate cancer. *Journal of Radiotherapy in Practice* 20: 39–42. doi: [10.1017/S1460396920000059](https://doi.org/10.1017/S1460396920000059)

Received: 14 November 2019  
Revised: 16 January 2020  
Accepted: 19 January 2020  
First published online: 17 February 2020


### Key words:

erectile dysfunction; masculinity; oncology; quality of life; sexual health

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# A qualitative study exploring men's experience of sexual dysfunction as a result of radiotherapy and androgen deprivation therapy to treat prostate cancer

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## Abstract

**Aim:** Sexual dysfunction is a common side effect of external beam radiotherapy (EBRT) and androgen deprivation therapy (ADT) to treat prostate cancer. Men are likely to experience erectile dysfunction, low libido, ejaculatory problems and penile shortening. This qualitative study explored men's perceptions of sexual dysfunction, including factors such as self-perception, relationships and information and support needs.

**Methods:** Semi-structured interviews were carried out with  $n = 8$  men living 18–30 months after EBRT ± ADT. The interviews were transcribed and thematic analysis was carried out.

**Results:** All men experienced sexual dysfunction following treatment. The main themes arising were: (i) priorities—sexual issues were not a priority when making treatment decisions, (ii) information and support—men described a lack of information and support about sexual dysfunction and (iii) impact—sexual dysfunction impacted on their self-perception and relationships.

**Findings:** Men undergoing EBRT/ADT for prostate cancer may be affected by post-treatment changes in sexual function in a range of ways. This study suggests that they would benefit from early and wide-ranging information and support on sexual dysfunction, even if they do not consider it as a priority. Candid discussions about self-perception and relationships, as well as physical changes, may equip them to cope with post-treatment changes.

## Introduction

Prostate cancer is the commonest cancer in men in the United Kingdom with more than 47,000 cases diagnosed each year.<sup>1</sup> Improved treatments have seen 10-year survival rates rise from around 25% in the 1970s to around 84% today.<sup>1</sup> It means record numbers of men are living through and beyond cancer and dealing with the side effects of treatment. Sexual dysfunction is one of the most significant long-term side effects for prostate cancer patients.<sup>2,3</sup> Between 62 and 85% of men treated with radiotherapy (RT) experience erectile dysfunction.<sup>4,5</sup> Five years after treatment, two-thirds of patients treated with RT report being unable to achieve an erection sufficient for intercourse.<sup>6</sup> Other problems include ejaculatory dysfunction, penile shortening and changes in sensation.<sup>7,8</sup> Problems are often compounded by neo/adjuvant androgen deprivation therapy (ADT), which is also associated with low libido and sexual dysfunction. Less than 20% of men undergoing ADT maintain any sexual activity.<sup>4</sup>

Reviews of interventions for sexual dysfunction have assessed a range of mechanical and pharmacological aids, including vacuum erectile pumps, implants and prostheses as well as phosphodiesterase—5 inhibitors (PDE5i). A Cochrane Review found that PDE5 inhibitors were the only intervention with evidence of effectiveness.<sup>4</sup> Recommendations for the management of erectile dysfunction after RT were set out in UK guidelines in 2014<sup>9</sup> suggesting erectile dysfunction was generally under-diagnosed and under-treated. This could suggest many men who undergo external beam radiotherapy (EBRT) and/or ADT for prostate cancer have to adjust to life with chronic sexual dysfunction. The guidelines recommend early intervention after EBRT/ADT to maximise chances of sexual rehabilitation.<sup>9</sup> However, success rates for interventions have remained relatively low.<sup>7</sup> This has led to an increasing interest in survivorship and the psychosocial impact of side effects.

In more recent years, sexual dysfunction research has focused more on perceptions and experience. Men have described the negative impact sexual dysfunction has had on their self-perception and self-esteem.<sup>10,11</sup> Some said it had a greater impact on them than any other side effect of prostate cancer treatment.<sup>12</sup> It often went beyond the ability to have erections and into the realms of personal relationships and the ways in which they saw themselves.<sup>11</sup> Sexual problems caused high levels of distress, anxiety, anger, frustration and depression.<sup>13</sup>

Evidence has shown those who are properly informed of the consequence of treatment go on to make the best emotional recovery.<sup>14</sup> Early information and support may help men prepare for and accept post-treatment changes in their sexual function.<sup>10</sup> The National Institute for Clinical Excellence recommends men and their partners are given the chance to discuss psychosocial problems before and after treatment.<sup>15</sup> However, a recent report found most men were not offered helpful intervention or support and improvements that were required.<sup>16</sup>

Further investigation is needed into the men's perceptions of sexual dysfunction caused by EBRT and ADT and how it impacts on their life. A better understanding of their experience could help inform service improvements.

## Methods

This phenomenological study utilised semi-structured interviews with participants recruited at a hospital in the south of England. Approval was granted by the hospital and University Research Ethics Committee (UREC 15/A/82).

Purposeful sampling was used to select participants who had completed EBRT 18–24 months previously and were in follow-up care. This time frame that was chosen as the initial treatment phase was completed and it would be expected that acute side effects had begun to stabilise.<sup>17</sup> Patients were identified by the principle investigator through the hospital record and verify system.

Inclusion criteria: men over 18 years of age; diagnosis of prostate cancer; external beam radiotherapy;  $\pm$  androgen deprivation therapy; EBRT prescription 74 Gy/37#. Men who received other first-line treatment, such as prostatectomy, brachytherapy or high-intensity focused ultrasound, were excluded.

As a phenomenological study, the key factor in sampling was to identify men who had the relevant experience. A sampling pool of 21 men was initially identified, and invitation letters and participant information sheets were sent; however, only  $n = 6$  responses were received. A second batch of letters was sent to another ten men. To identify sufficient numbers, it was necessary to include men who were up to 30 months on from completing EBRT. It was found that this would not compromise the integrity of the study because sexual dysfunction remained an issue for men for many years after the treatment. This led to four more responses, resulting in a total of  $n = 10$  participants. The principle researcher conducted face-to-face interviews on hospital premises. One participant did not attend their interview and could subsequently not be contacted. Another was excluded when it emerged during interview that he had other first-line treatment.

A semi-structured interview schedule was designed with the aid of literature.<sup>18</sup> Semi-structured interviews were chosen to allow participants to give their own insights that were not based solely on pre-conceived questions.

Interviews were transcribed verbatim, by an independent transcriber, with each participant being given an identifier P1-P8. A six-step thematic analysis as outlined by Braun and Clarke was used to analyse the data.<sup>19</sup> Passages in the transcripts were coded manually and reviewed for emerging initial themes. Codes and themes were agreed with the second researcher. A process of repeated condensation, refinement and review was carried out to identify robust themes. The final stage of the analysis involved drawing themes into a coherent and logical argument with the aid of literature. Credibility and trustworthiness were achieved by showing coherence, systematic research conduct, convincing interpretation and accounting for the researcher role.<sup>20</sup>

## Results

A total of  $n = 8$  participants were recruited with an average age of 74 years. All participants had completed EBRT 18–30 months previously and  $n = 6$  participants were still receiving ADT.

The three main themes identified through thematic analysis of the data were

- (i) Priorities—sexual issues were not perceived to be a priority when making treatment decisions
- (ii) Information and support—men described unmet information/support needs relating to sexual dysfunction
- (iii) Impact—sexual side effects had a wide-ranging impact on their self-perception and relationships

The first theme focused on the priorities of participants when they made treatment decisions. Participants described a strong focus on survival when deciding which path to follow. All said the desire to be cured outweighed all other factors, including sexual dysfunction. They described how other considerations were secondary when making treatment decisions. Sexual dysfunction was ignored or deliberately pushed aside as they perceived it to be unimportant when compared with survival.

'The treatment was more important than anything else'. (P4)

'I talked very seriously to myself and said, almost as a mantra: "It doesn't matter, it's much more important that you live"'. (P5)

'I mean I just really didn't want to even kind of hear any more about [treatment for sexual dysfunction] at that point'. (P7)

'The most important thing was to get the thing knocked on the head... I think the sexual... was not a priority... I think if we had done it earlier on I'd have thought it was a bit periphery... compared to what I was really worried about'. (P8)

'It's like taking medicine—it might taste terrible but it's for your own good'. (P3)

Some said their views changed after treatment and the onset of side effects. They described how they came to realise that survival was not the only consideration when undergoing cancer treatment. They felt they were not prepared for what was to come.

'Hindsight's always 20–20 isn't it... I don't think it would have changed my view about what to do in terms of treatment but it might have just prepared me better for what happened'. (P6)

'I think that most people they don't really understand the full effects of prostate cancer... It's dealing with the aftermath which is your main hurdle'. (P2)

The second theme focused on the information and support participants received about sexual side effects during the treatment pathway. Most said they were not told enough or given an unrealistic picture. While some described being given comprehensive and accurate information, others described being surprised and shocked by the onset of problems. The participants also reported inconsistency in offers of interventions or support with managing problems. For some, there was a perception that offers of rehabilitation were overly optimistic.

'I don't think [sexual side effects] were discussed as a specific problem'. (P1)

'This is the first time I've had the opportunity to really talk, err, to discuss it with anybody in any depth. Even [doctor] has never discussed my sex life'. (P2)

'It came out the blue really. It was just something I discovered myself'. (P3)

'I think it was something that could have been done better. Really, this sort of hit me as a bit of a shock... I was warned that I would have side effects... but with hindsight I wasn't given a bleak enough picture about it, you know, it was glossed over rather'. (P6)

'I don't think there were any particular discussions about side effects at all... I think they probably looked at me and thought to themselves well he probably doesn't have sex [laughs]'. (P8)

The third theme focused on participants' perceptions and experience of sexual dysfunction. All the participants had experienced erectile dysfunction and loss of libido, and most were keen for sexual rehabilitation. Some had been deeply affected by the post-treatment changes in ways that went beyond the loss of sexual function. They described how it affected the mechanics of sexual function, but there was a greater emphasis on how it impacted on their self-image and the nature of their intimate relationships.

'I don't feel one hundred per cent a man because I'm not able to have that function in my life. I know I feel inadequate sometimes... We had a fantastic sex life and now that's non-existent'. (P2)

'I mean if there was something that could get it back working then fair enough... I miss the intimacy and that side of it'. (P4)

'We had a good sex life before and that's... that's vanished now, you know it's... not the end of the world but it's disappointing'. (P1)

'I feared the impact it was gonna have on my relationship... it was going to change our relationship, it was gonna end or introduce a whole new dynamic'. (P7)

Just one participant, who had lost his wife to cancer, said he was resigned to living with sexual dysfunction and had no desire for rehabilitation.

'It's not the end of the world as far as we're concerned. If I suppose I was thirty years younger it would be a different story'. (P8)

## Discussion

Sexual dysfunction is a potentially distressing side effect of EBRT and ADT to treat prostate cancer.<sup>1,9</sup> Quantitative studies have highlighted the incidence of the problem but have not characterised men's perceptions of post-treatment changes. This phenomenological study was designed to give a better understanding of men's experience of sexual dysfunction. In particular, the intention was to explore participant's experience of the treatment pathway, and whether they were prepared for changes to their sexual lives.

The interview format allowed participants to speak in-depth about the effect of treatment-induced changes. Participants went beyond discussions about the mechanical differences caused by RT and ADT to talk about self-perception and relationships. The impact went beyond physical differences to a deeper psychosocial meaning involving their perceptions of themselves and their relationships with partners. The findings were in line with other studies that have described how sexual dysfunction has undermined masculinity and the concept of what it means 'to be a man'.<sup>10,11,21</sup>

In this study, participants gave a wide interpretation of treatment side effects. When asked about post-treatment changes, they put greater emphasis on emotions, relationships and self-image than physical changes. The participants understood the sexual side effects of RT and ADT to be psychosocial as well as physical. This could have implications for healthcare professionals providing pre- and post-treatment information and support. In order to properly prepare patients for sexual side effects and support them in follow-up, they may need to look beyond a focus on physical changes.

Concentrating on preparing people for physical changes alone could potentially overlook much wider issues.

This broad perception of side effects may partly explain why some men felt they were not given appropriate information and support. A focus on physical symptoms may have been insufficient preparation for psychosocial changes. Some felt the discussions were inadequate or inaccurate. It should be emphasised that this study focused on participant's perceptions of discussions, and it was not an objective analysis of discussions. However, the findings were consistent with literature, showing sexual concerns may not be properly discussed in clinic settings.<sup>3,22,23</sup> These studies found important information was not well communicated. Discussion focused narrowly on 'cure', leaving men unprepared for long-term changes in quality of life.

This focus on 'cure' may also contribute to men's perception of not being properly prepared for sexual side effects. Most thought sexual function was less important when making treatment decisions and they were prepared to sacrifice it for overall survival. Some described being single-minded, saying cure was 'more important than anything else'. The focus on survival may have distracted them from considering the full impact of sexual dysfunction. It may also have given healthcare professionals the impression they were unconcerned about sexual side effects. There was then a risk that the subject did not properly inform the decision-making process. Previous studies have demonstrated survival is the core questions for most patients when choosing a treatment path.<sup>24</sup> Patients are prepared to endure sexual side effects to gain survival benefits.<sup>25</sup>

UK experts have raised similar concerns about engaging patients in discussions about sexual side effects.<sup>9</sup> Guidelines for treating sexual dysfunction after EBRT/ADT said that the benefits of early engagement were not always obvious to patients whose libido was affected by ADT. They said it was essential that health professionals communicated the risks of sexual dysfunction clearly to these men to ensure they had the best possible chance of rehabilitation and adjustment. Other research has demonstrated patients who felt informed reported less distress at side effects and more overall satisfaction with care.<sup>12,14</sup>

## Limitations

As a qualitative study with a small sample, the results of this study are not generalisable. The low response rate may have introduced some selection bias among those willing to speak on a sensitive issue. The interviews required participants to discuss events several years earlier, so there may have been some recall bias. The study was based on men at one point in the treatment pathway and results may be different at other stages.

## Conclusions

This study suggests men undergoing EBRT and ADT for prostate cancer may benefit from early and wide-ranging information and support on sexual dysfunction, even if they do not consider it a priority. Candid discussions about self-perception and relationships, as well as physical changes, may equip them to cope with post-treatment changes. The participants in this study did not perceive sexual dysfunction to be a priority when making treatment decisions. However, many later felt they would have benefitted if they had been better informed about the consequences of treatment. Participants were deeply affected by the post-treatment changes in ways that went beyond the loss of sexual function. These

findings may be useful to those involved in the provision of information and support. Further study is needed to look at the type of information and support needed and the best methods of communication.

**Acknowledgements.** None.

**Financial Support.** This research received no specific grant from any funding agency, commercial or not-for-profit sectors.

**Sources of Support.** None.

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