

How can healthcare services support LGBTQ+ patients with prostate cancer?

As one of the coordinators of a peer support group for LGBTQ+ people and their partners who have been affected by prostate cancer, Dave Wardell discusses measures that could be implemented to help clinicians better understand and support this group.

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The author of this article helps to run a support group for lesbian, gay, bisexual, transgender and queer-identifying (LGBTQ+) people affected by prostate cancer. This comment piece highlights some of the concerns and problems encountered by members of this group, based on the author's experience.

It is important to note the inclusion of lesbian and transgender people in this support group, as transgender women and non-binary people can also develop prostate cancer. However, the author is not qualified to represent the experiences of transgender women or non-binary people in this piece, and there is a lack of relevant academic work to support this discussion. Consequently, the present article will be limited to discussion of gay, bisexual and queer communities (henceforth referred to as 'the community'), acknowledging that research is needed to explore to experiences of transgender women and non-binary people with prostate cancer. Unless otherwise cited, all quotes and opinions are from conversations, discussions and disclosures made in the support group, with the consent of the group members.

Profile of the support group

The support group has just celebrated its eighth year of operation, running monthly meetings for individuals at all stages of the disease, from initial diagnosis to palliative care. There are around 40 active members, with meetings held both in person and online (via Zoom) to allow those who cannot attend in person (because of health or distance) to participate. Members are predominantly gay men, but bisexual and heterosexual men are also welcome, as are trans women with prostate cancer. Partners of those with prostate cancer can also attend. Most members are between 50 and 70 years of age, although the current age range of the group is between 40 and 90 years. Members of the group are undergoing various treatments, including surgery, radiotherapy and hormone treatments, as well as active surveillance. None of the current group members are undergoing brachytherapy, although some recently diagnosed members are considering that option.

The support group originated in Manchester, with most members being from the north west of England, but there are regular members who also attend from Ireland, London, Scotland and even the United States of America and Thailand. UK-based members are seen across a wide range of NHS trusts, including those serving Blackpool, Bradford, Calderdale, Edinburgh, Leeds, Liverpool, London, Manchester, Preston and Sheffield.

Challenges encountered by support group members

In the 8 years that the support group has run, some common themes have arisen in group discussions and personal disclosures. Some are specific to the type of treatment the patient is receiving, but many are universal for this group. One of the major challenges encountered by these patients is feeling lost when choosing which treatment to have. Most of the support group have been diagnosed somewhere between the localised and locally advanced stages of prostate cancer (T2a to T3b). For these stages of cancer, the two treatment models commonly offered are radiation therapy (usually with hormone treatment) or radical surgery (with a possible follow-up course of radiation therapy and hormone treatment). The

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outcomes for both treatments are similar and as neither is clinically ‘better’ the choice is usually given to the patient. However, this can be a source of severe stress for the patient, especially when it is presented as a personal choice, with no real support or education given regarding the consequences of each option, particularly with issues relating to sexual function (Ashcroft, 2021).

Concerns about how this choice may affect urinary and faecal continence are also common. Urinary incontinence is common during the initial stages after surgery but, although some patients will become fully continent again, sometimes this never returns, or patients may experience incontinence again in later years.

Concerns regarding how treatment will affect sexual function are also common, with group members often experiencing a lack of representation of the LGBTQ+ community in medical advice and materials. Leaflets and questionnaires on this topic are usually heteronormative and often focus only on issues relating to penetrative sex. For example, the International Index Of Erectile Function, the standard questionnaire on erectile function, focuses heavily on penetration (Ashcroft, 2021). Furthermore, group members were not always told that the length and girth of the penis can be reduced, and may even be permanently damaged, by treatment (especially surgical intervention), particularly if erections cannot be maintained soon after treatment (Kirby et al, 2014). Similarly, many did not receive any information on penile pumps or why their use is important. Others found that climacturia (orgasm-associated incontinence) was not mentioned at all before surgery; if it occurred after the procedure, the only advice received was to use a condom, with no discussion of how sex becomes ‘leaky’ (Mykoniatis et al, 2021). There was also a lack of discussion around how anal sex can be affected by treatment, either for the insertive or receptive partner, and when it is safe for the receptive partner to resume this. Other negative experiences reported by group members included:

- Loss of libido from hormone treatment, which may never come back
- Shortening of the penis by 2–4cm as an effect of surgery, permanently changing the individual’s experience of erections (this was a unanimous experience among all group members who had undergone treatment for prostate cancer)
- Changes and difficulties in experiencing orgasms after treatment
- A sense that erectile dysfunction clinics quickly give up on patients and have to be pushed into offering further treatments if Viagra does not work.

Overall, many group members have reported feeling emasculated, whether from loss of libido, loss of function, reduction in penis size or a combination of these factors, during or after their treatment for prostate cancer.

Gender, sexuality and prostate cancer

While most support group sessions keep a positive outlook, the condition and the side effects of treatment can have a considerable impact on members’ mental and physical health. Healthcare professionals may consider a patient’s sexuality or gender expression to be irrelevant to the treatment of a life-threatening disease (Ussher et al, 2022). However, prostate cancer directly affects sexual function, and this is of great significance to gay, bisexual and queer-identifying patients, who can experience severe psychological distress from the sexual side effects of treatment. This distress often relates to feeling a loss of manhood, a loss of sexual desire and a sense that one’s desirability has been removed (Ussher et al, 2017). This is especially felt by those who had discovered their sexual orientation later in life (Ussher et al, 2017; Ralph, 2021).

Group members also reported negative experiences with erectile dysfunction clinics; one member stated that it was seen entirely as a sexual function issue with no acknowledgement of the impact on self-esteem. Many found attitudes towards erectile dysfunction to be problematic in these clinics, with the false perception that men their age were no longer sexually active, or that erectile dysfunction was ‘normal’ at their age. These attitudes are particularly inaccurate for gay and bisexual men, who are typically sexually active for longer (Ussher et al, 2017).

Another common theme was the lack of attention given by healthcare professionals to penile rehabilitation in this patient group, and an absence of awareness about penile atrophy, which can occur if appropriate interventions are not introduced within a month of

treatment (Kirby et al, 2014). In the support group, the author and other organisers always ask members who have recently had treatment if they have ever used a vacuum pump or phosphodiesterase 5 inhibitors to treat erectile dysfunction; in almost every case, this has not occurred, and no one has discussed penile atrophy with the patients.

How can care be improved?

The common challenges and experiences of group members from across the UK, and even internationally, demonstrates that there are issues surrounding how gay, bisexual and queer-identifying people are supported during their prostate cancer treatment. Whether from lack of knowledge or embarrassment, healthcare professionals are not asking about their patient's sexuality—this may be coming from a well-intentioned desire to 'treat all patients the same' (Ussher et al, 2022). However, the impacts of prostate cancer treatment on gay and bisexual men are different, and potentially more severe, than for heterosexual men. Therefore, when explaining the clinical equivalence of radiotherapy or hormone treatment versus radical prostatectomy, it is important that healthcare professionals discuss the potential post-treatment effects on the patient's sexuality, sex life and self-esteem. Additionally, it is recommended that all patients are offered phosphodiesterase 5 inhibitors after surgery, at the catheter removal visit, and a vacuum erection device (pump) is introduced around 4 weeks after surgery, or when erections cease, with hormone treatment where necessary (Kirby et al, 2014).

There is now an accessible library of information for gay and bisexual men with prostate cancer and their partners, as well as materials for health professionals, including peer-reviewed research, available from Prostate Cancer UK (2022a, 2022b). However, healthcare professionals at all levels need to understand the different effects and experiences of prostate cancer on LGBTQ+ patients (Filiault et al, 2008), and to ask them about their sexuality so that information and support can be tailored accordingly (Ralph, 2021).

Author details

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References

- Ashcroft B. Experiences of LGBT people. Macmillan Cancer Support Booklet, no one overlooked. 2021. <https://tinyurl.com/53v7zhzj> (accessed 16 July 2022)
- Filiault SM, Drummond MJN, Smith JA. Gay men and prostate cancer: voicing the concerns of a hidden population. *J Men's Health*. 2008;5(4):327–332. <https://doi.org/10.1016/j.jomh.2008.08.005>
- Kirby MG, White ID, Butcher J et al. Development of UK recommendations on treatment for post-surgical erectile dysfunction. *Int J Clin Pract*. 2014;68(5):590–608. <https://doi.org/10.1111/ijcp.12338>
- Mykoniatis I, van Renterghem K, Sokolakis I et al. Climacturia: a comprehensive review assessing pathophysiology, prevalence, impact, and treatment options regarding the "leak of pleasure. *Int J Impot Res*. 2021;33(3):259–270. <https://doi.org/10.1038/s41443-020-0257-1>
- Prostate Cancer UK. Information for gay and bisexual men. 2022a. <https://prostatecanceruk.org/prostate-information/living-with-prostate-cancer/gay-and-bisexual-men> (accessed 6 October 2022)
- Prostate Cancer UK. For health professionals. 2022b. <https://prostatecanceruk.org/for-health-professionals> (accessed 6 October 2022)
- Ralph S. Developing UK guidance on how long men should abstain from receiving anal sex before, during and after interventions for prostate cancer. *Clin Oncol*. 2021;33(12):807–810. <https://doi.org/10.1016/j.clon.2021.07.010>
- Ussher JM, Perz J, Rose D et al. Threat of sexual disqualification: the consequences of erectile dysfunction and other sexual changes for gay and bisexual men with prostate cancer. *Arch Sex Behav*. 2017;46(7):2043–2057. <https://doi.org/10.1007/s10508-016-0728-0>
- Ussher JM, Power R, Perz J, Hawkey AJ, Allison K. LGBTQI inclusive cancer care: a discourse analytic study of health care professional, patient and carer perspectives. *Front Oncol*. 2022;12:832657. <https://doi.org/10.3389/fonc.2022.832657>