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Heteronormativity and prostate cancer: a discussion paper.

Daniel Kelly, Sarah Fry, Dikaios Sakellariou, Sofia Vougioukalou

Abstract:

Aims and objectives: To discuss the role that heteronormative assumptions play in prostate cancer care and how these may be addressed.

Background: Evidence exists to support the case that LGBT cancer patients are less likely to report poor health or self-disclose sexual orientation. Gender-specific cancers, such as prostate cancer, evoke particular needs in terms of supportive care. These may include advice about side-effect management, treatment choices and social and emotional issues. In this paper we discuss and problematize the heteronormative discourse and culture that exists around this cancer. We argue that situation may act as a barrier to effective supportive care for gay men.

Design: Theoretical exploration of heteronormativity against the clinical context of prostate cancer.

Methods: Scan of relevant evidence combined with discussion.

Results: The paper posits a number of questions around heteronormativity in relation to cancer information provision, supportive care and sexuality and disability more generally. Whilst assumptions regarding sexual orientation should be avoided in clinical encounters, this may be difficult when heteronormativity dominates. Existing research supports the ascertain that patient experience.

Conclusion: Sexual orientation and relational models of care should be promoted at the start of cancer treatment in an appropriate manner. This can assist in reducing the risks of embarrassment or offence to patients or professionals. Service providers should also remain aware of potential bias in the provision of information or supportive care resources to men who do not identify as exclusively heterosexual.

Relevance to clinical practice: Awareness of heteronormative assumptions in clinical practice can be useful for health professionals engaged in prostate cancer care. This can prevent embarrassment for patients and ensure a more equitable provision of support; including men who do not identify as heterosexual.

Keywords: sexuality, heteronormativity, cancer, nursing, prostate cancer, inequality, supportive care.

Relevance to clinical practice:

- Clinical practice is shaped by time pressures and provision of care that is directed towards the majority. These can lead to assumptions about the sexual preferences of cancer patients. When heteronormative assumptions dominate this can lead to embarrassment and inequality in provision of support to men who are gay or bisexual.
- Cancer service providers should be aware of the culture that exists in their organisations and monitor the extent to which heteronormative assumptions are challenged in order to promote diversity and equality.

Introduction

Prostate cancer is now the second most frequently diagnosed cancer worldwide. However, in more developed countries deaths from prostate cancer are decreasing, as a result of improved treatment and better detection (Torre et al, 2015). Increased survival from, or with, prostate cancer introduces new challenges now being addressed under the umbrella term cancer survivorship; a phase of care concerned with supporting the chronic side-effects of cancer treatment (Collela and Gejerman, 2013). In this article, we question the dominance of heteronormative assumptions and invite a more open debate about whether cancer services meet the needs of all, rather than the heterosexual majority.

Heteronormativity and prostate cancer

The incidence of prostate cancer is increasing and it is inevitable that a proportion of homosexual and bisexual men will be diagnosed in their lifetime. There is concern that for some of these men prostate cancer may present particular challenges relating to sexual function (often due to side effects of treatment rather than the cancer itself), but also because of the heteronormative bias in clinical settings (Asencio et al, 2009). Some men consider impotence because of treatment as an inevitable and even acceptable side-effect, whereas others may associate impotence with their identity as men (Chapple & Ziebland, 2002). For men who do not identify as heterosexual, there are particular issues to consider. One of the most pertinent is the role that heteronormativity plays in shaping service provision.

Heteronormativity has been defined as 'the hegemonic discursive and nondiscursive normative idealization of heterosexuality' (Hird, 2004, p.27). It rests on several assumptions about human sexuality including binary opposites of male/female sexual roles stemming from a heterosexual stance. Thus, medical culture may mirror heteronormative discourses by failing to challenge assumptions about information needs connected with prostate cancer (information usually created by, and directed at, men who identify as heterosexual). Heteronormative assumptions can also be more widely pervasive and influence others such as prostate cancer charities, advocacy organisations or research funders.

Until very recent times (from the 1960's on in the UK) there was a reluctance to view gay men as equal to heterosexual men (Herek, 2000). Although attitudes are changing, sexual acts between men who have sex with other men remain taboo in some circles (McDonagh et al, 2014). This may be reflected in clinical practice, particularly through subtle yet powerful reinforcements such as the heteronormative language used in scales to measure quality of life or sexual dysfunction (McDonagh et al, 2014) or during specific communication tasks such as assessment of sexual functioning which reinforce vaginal penetration (Carr, 2007).

An example of such an assumption can be seen in the methods for assessment of erectile dysfunction after prostate cancer treatment. It is well documented that the outcomes of such treatments can include problems with sexual functioning, such as erectile dysfunction, penile shrinkage and loss of libido (Blank, 2005; Asencio et al, 2009), as well as potential damage to the pelvic floor causing urinary and faecal incontinence (often as a result of surgical intervention and radiotherapy). Discussions about sexual dysfunction after prostate cancer treatment commonly focus on the assessment of erectile (dys)function, however, based on the assumption the penis should be erect enough to achieve and maintain vaginal penetration; which fails to recognise a group of men for whom vaginal penetration may not be a concern. For sexually active gay men, oral

or anal penetration may be more concerning when sexual activity is assessed, and for men who are anally receptive concerns will centre more on the late effects of radiotherapy on the bowel, including abdominal pain, dietary advice or diarrhoea management (Blank, 2005).

Since the introduction of Viagra in 1998 conversations about erectile dysfunction have become part of normative speech in prostate practice (Incrocci, 2011), however conversations about oral sex or anal penetration remain more taboo in everyday clinical discourse. The difficulty clinicians may face in asking men who have sex with men (MSM) about their sexuality is often reflected in the relationships gay or bisexual men establish with their healthcare professionals (Blank, 2005). Gay and bisexual men may feel they need to tread carefully with heterosexually-orientated clinicians, with the associated worry of experiencing subtle or overt homophobia. These fears may, in turn, evoke feelings of isolation and embarrassment that can be implicated in late presentation of cancer symptoms (Jowett and Peel, 2009). The impact of heteronormativity, therefore, goes beyond attitudes and can play an important role in how MSM feel about presenting to a healthcare professional with symptoms. Expert nurses have a crucial role to play in challenging negative stereotypes and spearheading practice that promotes equality and diversity in cancer care.

The professional response

The remit of the Clinical Nurse Specialist, Advanced Practitioner or Consultant Nurse roles has expanded greatly over the last thirty years and now more commonly involves the giving of a prostate cancer diagnosis and ongoing psychosocial support (Tarrant et al 2008). This is happening because their remit is to support the patient and their family and, in the UK context, because of the requirement for each cancer patient to be assigned a key worker at diagnosis. However, confirming a cancer diagnosis can evoke anxiety for the nurse about communicating with sensitivity but also with authority so that the patient has confidence feels secure. This is a skill which takes some time to master, as does a conversation with a patient about sexual dysfunction. There is evidence that such conversations may not take place- even in consultations involving prostate cancer patients (Forbat et al 2012). In this study, consultations between doctors and patients were observed, comparative studies are now needed to establish whether nurses are able to address psychosexual concerns more effectively.

However, in busy clinical situations it may surprise or sometimes embarrasses men when sex is mentioned suddenly during a consultation. It is reasonable to suggest that maturity and experience will be required on the part of the nurse to choose the best time to move the conversation on from initial embarrassment to uncover how the man really feels about their cancer, sexual recovery or adjustment to a new reality that incorporates some degree of sexual dysfunction.

It is also reasonable to assume that most professionals are not homophobic; instead they may feel that it is safer to discuss erectile dysfunction in the context of vaginal penetration, particularly because there will be clear guidelines regarding onward referral for the patient and the treatment options that can be offered, when required.

For the wider cancer care community there is a need to understanding the wider context for gay and bisexual men and opportunities need to be given to nurses to explore and challenge any preconceptions they may hold about men who have sex with other men.

This process could start by involving nurses with the gay and bisexual community to become better informed about lifestyle choices, including sexual activity, so that a conversation can be had at diagnosis about which aspect of treatment is going to affect men the most, and where and when the best support can be offered. Gay professionals themselves have contributed to this change process by adding their own views to the literature (Cornell 2005).

Gay men are only one of the groups whose sexual lives may be treated with some degree of taboo by health providers. Disabled people may face similar prejudice and it is important to consider the wider impact on these groups in order to compare inequalities in different contexts.

Who is allowed to be sexual?

Despite recognition of the needs and rights of disabled people¹ and people living with illness to sexuality, many healthcare professionals report reluctance to address sexuality (Esmail, Darry, Walter, and Knupp 2010). Much of this reluctance can be traced to social discourses that limit the right to sexuality to an idealized young, heterosexual, able-bodied male and subsequently deny the sexuality of those who do not fit in this model (Tepper 2000).

Sexuality relates to how people behave, the choices they make, and to who and what they desire (Weeks 2002). Sexuality is often considered to be a deeply personal matter, unique to each individual. Historically, sexual desire has been seen as “natural and automatic and heterosexual and universal” (Gagnon and Parker 1995, p. 12), while sex has often been viewed as “a privilege of the white, heterosexual, young, single, non-disabled” (Tepper 2000, p.285) people. The perception of sexuality as a normative construct was problematized and ultimately deconstructed as a result of the social transformations of the 1970’s (e.g. the gay rights movement and the feminist movement).

For several years, understandings of disability and illness were influenced by the medical model. According to this model, the causes of illness and disability are located within the biological body (Stroman 2003). The social model of disability has reframed illness and disability as a dynamic relationship between people with an impairment or other health condition and their environment (Shakespeare & Watson, 2001; Stroman 2003). The social model of disability has helped relocate the emphasis from individual bodies to the social environment within people live (Stroman 2003). Similar perspectives can be seen in the context of gay men where the individual requirement for prostate cancer support eventually becomes a wider social concern about inequalities.

Nonetheless, persons who do not fit the able-bodied/heterosexual norm are often placed in invisible or marginalised spaces in the clinical arena, they are viewed as powerless people who need to be protected, or as simply asexual (Sakellariou 2006). Debates about sexuality are fundamentally debates about freedom of choice; they concern people’s ability to live the life they want to live- this does not stop when prostate cancer is diagnosed. The question we need to ask is what is permissible

¹ Our use of the term disabled people is informed by critical disability studies, and we use it with the explicit intent to draw attention to the fact that disability and illness are not personal characteristics, but the outcome of a process, through which a person becomes disabled.

and what is not? In the words of Weeks (2002, p113), “What can be said or performed by whom in what circumstances (...)”?

Sexuality is controlled through systems of gender and class, often functioning as a mirror of wider social attitudes towards difference. This can be shown, for example, through the ableism and heteronormativity that underpin institutions like marriage (although this is now changing in several countries), church, employment and health professions, as several studies from the last decade illustrate (Jackson 2000, Røndahl et al 2006, Weeks 2002).

The depiction of sexuality and cancer as exclusive identities supports a mono-dimensional depiction of men with prostate cancer as asexual service users who lack agency. When social behaviours and manifestations of sexuality are controlled by an intricate nexus of expectations and beliefs, sexuality can be understood as a state rather than a possibility, and people who do not fit into this ideal can be considered to be asexual (Sakellariou 1006; 2012). However, can we ever talk of *one correct* sexuality in the cancer clinic with confidence? Once again, the evidence would suggest that it is not a topic explored routinely- even in setting where men, who have been diagnosed with cancer, are being reviewed (Forbat et al 2012).

Male sexuality is commonly viewed as phallogentric, reinforcing the centrality of physical performance (Drench 1992, Shakespeare, 2000). This can cause feeling of inadequacy and even emasculation to men with prostate cancer. As Shuttleworth, Wedgwood and Wilson (2012, p.174) point out there is often a perception that “masculinity and disability are in conflict with each other because disability is associated with being dependent and helpless whereas masculinity is associated with being powerful and autonomous”. Sexuality, however, is not based only on this mechanistic view of penile strength and function (Milligan & Neufeldt 2001; Tepper 2000), but it can also be understood in terms of emotional closeness and also pleasure. While physical performance is one of the ways through which people can achieve sexual pleasure, pleasure can also be achieved through a variety of other, non performance-based, ways.

The problem of introducing sex into clinical settings is reinforced in several studies including the auto ethnographic *Teratologies*, by Stacey in 1997. This provided, amongst many other rich insights from an auto-ethnography of ovarian cancer, a Foucauldian interpretation of visual constructions of cancer. Both the culture and practice of medicine were altered when it became possible to map the internal body so precisely:

‘The clinical gaze, which is taken for granted in contemporary Western culture, is not the inevitable outcome of scientific progress or technological invention, but rather originated in a very specific medical culture in which the discourse of *visibility* became central. The clinic is a place primarily of vision and observation: doctors learn to see, to isolate, to recognise, to compare and thus to match (or not), to scrutinise and then to intervene’. (Stacey, 1997, p.55)

In prostate cancer, tumours are literally ‘opened up’ to scrutiny in the radiotherapy department through a combination of technologies such as computerised scans, X rays, tissue biopsies and blood

tests. Novel technologies are emerging constantly which allow images, and radiation therapy, to be panned and rotated in three dimensions similar to what occurs in geophysics and astronomy. Mathematical modelling can also be used to calculate the dosage of radiotherapy required to achieve maximum 'cell kill'.

In such a culture there is a jarring with the emotional and private/sexual self and may go some way to explain the dominance and popularity of heteronormative discourses. To enter any other sphere of human sexuality may be seen as risky in such a scientific arena.

The impact of heteronormative inequality on prostate cancer care

The Inquiry into Inequalities in Cancer (All Party Parliamentary Group on Cancer's, 2009) reported that in the UK gay men have a greater incidence of anal cancer and cancers related to HIV/AIDS. However, we do not know whether there is also a difference in the incidence of prostate cancer between gay and bisexual men and the general population. Stonewall's survey of the health needs of gay and bisexual men, reported that 10% of gay and bisexual men of all ages have discussed prostate cancer with a healthcare provider, while 68 % of gay and bisexual men over the age of 50 have not discussed this issue. This is slightly lower compared to men in general (Prostate Cancer UK and Stonewall 2013: 8).

Gay men have reported that healthcare professionals do not always ask about sexual orientation in initial consultations, making an assumption of heterosexuality (Mitteldorf 2005). Furthermore, men with prostate cancer have reported not disclosing their sexual orientation to healthcare professionals due to a concern about negative reactions (Filiault et al 2008) or because they think the clinical relevance of their sexual orientation will be disregarded (Katz 2009). In the most recent Cancer Patient Experience Survey, respondents who identified as non-heterosexual, reported more negative experiences regarding communication, respect and dignity in relation to treatment, care and information within the National Health Service in the UK (Department of Health 2012). A survey on gay and bisexual men's health highlighted that 30% of gay and bisexual men who accessed health services in a period of one year have had a negative experience related to their sexuality (Stonewall 2013).

A small online focus group study lasting four weeks (Thomas et al 2013) confirmed the earlier points that emotional reactions to the diagnosis was closely linked with having access to information and support. Other factors that emerged included the role of sexual changes on sense of self, a re-evaluation of life and the need to find the most suitable health professional who could explore their current and ongoing needs. By doing so there was agreement that this improved the overall quality of care.

Critical illness not only presents patients with issues of finitude, but more importantly, it threatens the very foundation of time structuring by removing patients from life's comforting rhythms. Bryson argues that cancer survivorship is inextricable from surviving not only other serious medical traumas but also from surviving in a normative culture that has yet to accommodate diverse sexualities (Stacey and Bryson 2012). Even though normative ideals of masculinity still affect how Men understand their health and their risk of prostate cancer, the encounter with healthcare professionals needs to be able to accommodate diversity of expression and needs. The findings of Thomas et al (2013) and Forbat et al (2012) confirm this assertion.

Experiences of heteronormative discourse and practices can be particularly harmful to the psychological wellbeing of patients when disease affects reproductive organs and/or function. On

these occasions, patients have to adapt to the short-term side-effects of treatment as well as the long-term psychosocial effects on sexual function. Competent healthcare should be dependent upon a recognition that gender can have an impact on a person's wellbeing and failure to address those differences can accentuate existing health inequalities (Peate 2011), which is against existing national guidelines on health equity. The Cancer Reform Strategy (Department of Health 2009) discusses the requirement that every person affected by cancer should receive world-class services at each stage of the disease and its treatment. Despite this, there remain inequalities between different groups of people in terms of incidence, access to services and treatment, patient experience and outcomes (Boehmer et al 2011).

Participatory design approach (PDA) of support services for non-heterosexual men may offer one approach to ensure that personal experience can be used to challenge aspects of services that do not meet the needs of MSM (Al-Itejawi et al 2015). Such approaches employ a step-wise approach of focus groups on usability at the pre-conceptual, prototype and usability phase. The challenge facing health service researchers now is to recruit men to such studies and explore their needs in the face of the negative attitudes that may exist in some settings. However, doing so holds the promise of change.

Conclusion

It is important to close the gap in sexuality-based inequalities in cancer treatment. This will require the concerted effort of different organisations. Some of the strategies that are required include: networking between cancer and gay organisations to share good practice but also learn from negative experiences; developing resources for support groups; and developing resources (e.g. training materials) for health professionals, educating them about the importance of sexual orientation.

A first step in this process is to recognise the negative risks associated with heteronormative attitudes and to question the extent to which cancer services ignore the needs of those who do not identify as heterosexual. This paper has proposed the argument that change can be achieved by drawing on existing evidence, reviewing the experiences of gay men themselves and making comparisons with other marginalised groups who may also be at risk of inequity during cancer.

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