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Gay men's experiences of sexual changes after prostate cancer treatment—a qualitative study in Sweden

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ABSTRACT

Background: The needs of gay men after prostate cancer treatment are becoming visible. This patient group reports a more negative impact of treatment than heterosexual men. Yet, gay men's experiences of post-treatment sexual changes are still little explored. This study aims to determine specific concerns of gay men's post-treatment sexual practices.

Methods: A qualitative study design was deployed using semi-structured interviews as data. Participants were purposefully sampled through advertisements and the snowball method. Eleven self-identifying gay men aged 58–81 years and treated for prostate cancer participated in interviews during 2016–2017. The interviews were transcribed, coded and thematically analysed.

Results: The analysis highlights sexual changes in relation to the physical body, identity and relations. Problematic physical changes included loss of ejaculate and erectile dysfunction. Some respondents reported continued pleasure from anal stimulation and were uncertain about the role of the prostate. These physical changes prompted reflections on age and (dis)ability. Relationship status also impacted perception of physical changes, with temporary sexual contacts demanding more of the men in terms of erection and ejaculations.

Conclusions: Gay prostate cancer survivors' narratives about sexual changes circle around similar bodily changes as heterosexual men's, such as erectile problems and weaker orgasms. The loss of ejaculate was experienced as more debilitating for gay men. Men who had anal sex were concerned about penetration difficulties as well as sensations of anal stimulation. Additional studies are required to better understand the role of the prostate among a diversity of men, regardless of sexuality.

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Introduction

Sexual changes in relation to prostate cancer treatment are well documented. Studies have reported changes in erectile function, orgasm, ejaculation, libido and the effects of climacturia on sexuality [1–3]. Much of this knowledge is built on generalized experiences of men, often older, married and heterosexual [4]. However, there is reason to believe that certain patient groups, such as younger men, single or non-heterosexual men can have specific, unique, contingent experiences and needs which are important to articulate [4], not least related to the assumed access to a care-giving partner throughout the treatment and recovery process [5,6].

There is a growing body of international studies which discuss sexual changes in connection with prostate cancer and its treatment for gay men. Studies have shown that gay men, compared to heterosexual men, report lower health-related quality-of-life across a range of dimensions, including sexual indicators and psychological distress [7–9]. Synthesis of qualitative studies, part of which analysed gay men's experiences of

prostate cancer, highlighted processes of self-stigmatization and changed sexual practices that differ from the main body of literature [4]. It is also emphasized that sexual changes and concerns, such as erectile problems or a loss of libido, may lead to feelings of exclusion from sexual communities [10].

The current study builds on this body of research, aiming to determine specific concerns of gay men's post-treatment sexual practices in a Swedish context. In line with previous work in the field [11], we understand sexual changes as embodied, relational and part of men's identities. We believe these perspectives highlight important areas for designing better care and rehabilitation programmes for what others have called the 'hidden population' in prostate cancer care [12].

Materials and methods

Design

This study builds on a qualitative design and attempts to study human experience through analysis of narratives of

Table 1. Background characteristics of the 11 informants.

Background characteristics (<i>n</i> = 11)	<i>n</i>
Age (median, range in years)	72 (58–81)
University level education	9
Born in Sweden	10
Relationship status	
Single	3
Partner, cohabiting (female)	7 (1)
Partner, L.A.T.	1
Treatment	
Surgery (nerve sparing)	7 (4)
Radiation (+ hormone treatment)	3 (3)
Surgery and radiation	1
Time since	
Surgery (range in years)	0.5–6
Radiation (range in years)	8–15

that experience. The study analyses variations and the production of meaning from experiences, creating an ‘interpretive portrayal’ [13]. In this understanding of qualitative research, the reader, not the researchers, may judge the generalizability of our findings to other contexts or patients groups [14].

Materials

The study was approved before its initiation by the regional ethical review board in Linköping, Sweden (no. 2016/167-31). We interviewed 11 gay men, with a focus on their experiences of sexual changes after treatment for prostate cancer (see Table 1). Inclusion criteria were that the men self-identified as gay and had been treated for prostate cancer. The men were recruited by means of purposeful sampling through advertisements in different networks, such as R.F.S.L. (a Swedish organization for L.G.B.T.-people’s equal rights in society) and Prostatacancerförbundet (the Swedish national patient organization for prostate cancer patients). As recruitment was difficult and there are no patient groups or support groups who actively include this patient group in Sweden (a problem in other national contexts, as well, see Capistrant et al. [5]), we also used a snowball method. Each informant was asked to suggest other possible interview candidates through their personal networks, which provided eight of the informants. After 11 interviews we stopped sampling. We judged this to be an adequate number with regard to (i) the material’s detailed richness, (ii) the diversity of experiences and perspectives and (iii) our collective previous experiences in the area of prostate cancer and bodily changes [15].

During 2016–2017, nine informants were interviewed by the first author in their homes, while two were interviewed in a hospital setting. All of the men gave written, informed consent. The interviews were semi-structured using an interview guide, thematically structured around cancer and care, bodily and sexual changes and support. The interviews lasted between 30–90 min, were digitally recorded and transcribed verbatim.

Analysis

The transcribed interviews were coded and analysed through thematic analysis [16]. The coding process was mainly

inductive, staying close to the material, but with our scholarly backgrounds as analytical starting points. We have our backgrounds in sexual medicine (first author) and medical sociology (second and third author). Our analysis consisted of three steps. First, the first and second author conducted individual initial line-by-line coding. Second, the individual codes from both authors were collapsed into sub-themes. During that process, possible themes were articulated and reviewed, using analytical tools such as a mind map and moving codes or sub-themes between different documents where they clustered into possible themes. Third, we, together with the third author, defined and refined three main themes in the material which showed different aspects of the sexual changes: physical changes, identity, and relationships. These themes were understood through theoretical insights from medical sociology that specifically study how the body and subject are intertwined, understood, and also impacted by medical diagnosis and treatments [17–19].

Results

The current analysis shows that the prostate cancer treatment’s physical impact on the body changed the men’s understanding of their sexual abilities and desires in varying degrees, yet in ways which were both explained by their ageing bodies and at times precipitated by particular relationship constellations. We identified three particular themes in the material: (1) changes to the physical body; (2) elements related to a perceived sense of identity that incorporated sexuality and age; and (3) issues precipitated from relationships and relational practices. In the Discussion, we will address ways in which these changes and concerns are particular to gay men.

Physical changes

This theme refers to the men’s descriptions of the way their experiences of the body during sex changed after treatment. We identified three main areas of concern: changed orgasms; loss of ejaculation; and erectile problems.

There was a wide variation in their experiences of orgasms, where some men described a weaker feeling of orgasm and others described the opposite, a more intense feeling. For example, one of the men noted: ‘now I am able to have a female orgasm, and that can be, I noticed afterwards, longer and more expanded’. The prostate as an erotic zone was discussed in the interviews. One of the men spoke about his prostate as a point of pleasure when he received anal penetration, which now, after the operation, was gone. However, other men felt that, during anal sex, the feeling in the entire anal canal or the outer edge of the anus was the source of their pleasure and was the same as before the operation.

More than half of the informants expressed a feeling of loss from the lack of ejaculation post-treatment. This loss stemmed both from not being able to deliver ejaculate during the sex act, i.e. they could not perform as they had done prior to treatment, and a loss of the symbolism of

ejaculation, the proof that sexual pleasure had been achieved. 'Even if you are not trying to make a baby, there is a symbolic meaning in the semen [...] and I hadn't really understood that before, that it would be sort of empty without the semen'. One of the informants also explained how he drew comfort in being able to use lubricant as a surrogate, underlining the physical, tangible importance of the ejaculate.

Dominant in the material were also stories about *erectile problems*, as one finds in general literature about (assumed heterosexual) prostate cancer survivors [1,20]. In our study, erectile dysfunction became apparent in discussions about sex with other people. Many of the men spoke about how the penis felt 'completely gone', 'cut off', indicating the individual's experience of the non-erect penis is important. As one man put it, using what is perhaps a particularly Scandinavian metaphor: 'It's like having a dead herring hanging between my legs'.

Identity

This theme, *identity*, captures how changes related to social identity help the men make sense of their physical changes.

Several of the men spoke about the changes in their bodies after their prostate treatments by identifying themselves as older, in line with previous work on prostate cancer and ageing among gay men [11]. They discussed specific changes in their bodily functions as if it would have changed and become different anyway, regardless of their cancer diagnosis and treatment. If anything, they said that the treatment merely sped up the process of changing with age. Physical changes became not 'sudden' and 'problematic', but rather, part of the 'natural' ageing process. As one man said, 'It is a bit of an exertion to make [intercourse] happen in the best possible way, actually. Not when you are 25 or 28, but when you are over 60 so ... you just have to accept that. Everyone gets older'. In this way, men who used the trope of ageing as an explanation are normalizing their pathologized body.

However, we also identified two completely different types of narratives about how the bodily changes impacted the men's thoughts about their identities. For some men, they saw their new bodily practices as an example of how they were now disabled and less capable. One man spoke about himself as unattractive to potential partners because he was 'handicapped'. Loss of ejaculation was compared with being an amputee by another informant. This man also reflected over how he now perceived his role as giving pleasure by receiving penetration. Yet, for another man in our sample, physical side-effects of hormone treatment had made life easier in a heteronormative world. For this man, the loss of libido had made it easier for him to combine his social status as a man married to a woman with his self-identified homosexuality: 'I feel like I have had a mini vacation [...] because I live the life I live, gay and married to a woman, and I have the life I want to have'. This informant was concerned that his desires would return if he terminated his hormone treatment—again leaving him torn between

wanting to live his life together with his wife and having sexual desires for other men.

Relationships

This theme describes how physical changes impacted the men in relation to others. We use the term 'relationships' as a gloss, but want to emphasize that we use this term to mean interactions with others, not necessarily within formalized partnerships.

The inability to achieve an erection was spoken about as an impetus to developing or strengthening existing practices aimed at physical closeness and emotional intimacy. Some of the men spoke about their own and their partner's needs for caring and intimacy and in relation to these discussed how physical contact through hugs, kisses and caressing was important, as was their emotional support of each other. Such intimacy was often described by men as present in more stable relationships. As discussed above, impotence could become a handicap in the men's search for temporary, short-term or spontaneous sexual interactions, either as a single person or outside of an existing relationship. This was particularly poignant in their discussion of erectile dysfunction pharmaceuticals. 'The spontaneity is gone. It is as if you have to schedule your sex life. To go out and try to pull someone, that would simply not work'. Yet, the lack of ejaculate also became a potential problem in the light of trying to attract new sexual partners. 'It is about being attractive on the market in some way, and about being able to come with something [ejaculate]. So of course it can be a little more difficult then'.

In these cases, the erectile problems and the loss of ejaculate become problems when experienced (or imagined) through sexual relations with others. This may seem self-evident, but it is important to consider: the physical body and its changes are experienced by the individual, but within a social context and in relational interactions with others. Very little did the men speak of physical changes in terms of their own (loss of) pleasure; this only surfaced concerning orgasm and anal stimulation post-treatment.

Discussion

While some of our findings may apply to any men with prostate cancer, others may highlight particular concerns for gay men.

One particular finding was the relative importance of *ejaculate*. In over half of the interviews, men spoke about the ejaculate as an important aspect of their sexual pleasure, as a material manifestation of their masculine sexual performance and pleasure. Semen became something that was both a symbol of their masculinity, proof of their pleasure and a material deliverable to their partner(s)—not always within a relationship. This is in line with other studies among gay men [9,21], but contrasts an earlier study we conducted with heterosexual men, which showed that the loss of ejaculate was less of a concern [22].

Another finding was that the experiences of changes to the physical body were precipitated and formed in the context of relationships and that the particular details of *relationship practices* influenced how negatively the men perceived the changes. Earlier studies among gay men also pointed at relationship difficulties and the fear of exclusion and loneliness [10,11]. Some of the interviewees spoke about the market. For these men, the idea of spontaneity and the sexual marketplace as a single, gay man, and looking for new contacts (e.g. cottaging and cruising) were particularly impacted by the treatment side-effects.

In the interviews, we used the term *prostate orgasm*, which in the literature is sometimes used to refer to the orgasm achieved through anal penetration [23]. However, this is a term which is seldom used clinically and does not generate any results in a search on PubMed as of January 2018. Yet, it is a term which flourishes in the public discourse. Still, the role of the prostate in pleasure during anal sex is unclear. Of particular note is that, despite our use of the term, this was a word that few of our informants related to and, of those informants which used anal stimulation, most had not reflected over the role of the prostate. In contrast to an earlier, smaller study by Hartman et al. [24], our informants who receive anal penetration said that it was as pleasurable after their operations as before.

Unexpected insights

The insight that a treatment's side-effects can mean different things to different people should seem obvious, in hindsight, but caught us off guard. For example, the loss of libido is generally presented as a negative side-effect of treatment. But, as the example of the gay man who was living in a heterosexual marriage (an agreement without sex) showed, the loss of libido is not always a *negative* side-effect.

Additionally, our study emphasizes the value of distinguishing between sexual identity and sexual practice when designing rehabilitation programmes. The same is true for urologists and other caregivers in their meeting with patients. A focus on sexual practices, that is, what the person actually does (having sex with other men, or practices like anal stimulation) could produce programmes for sexual rehabilitation which are more flexible than by using static identity terms such as gay or bisexual. Where this becomes particularly relevant is in a discussion about anal sex. The understanding that a 'prostate orgasm' exists is drawn from the wider social discourse, as the plethora of Internet pages explaining how to stimulate the prostate for pleasure and commercial sex toys to help achieve it attest to. This is relevant for heterosexual men as well as gay men. The prevalence of 'heterosexual' men reporting anal intercourse is documented and appears to be growing [25]. Thus, concerns about the impact prostate cancer treatment may have on anal stimulation does not necessarily only impact men who identify as gay.

Methodological considerations

We had difficulties finding informants for this study, despite the assumingly large number of men with prostate cancer in Sweden which self-identify as gay or bisexual. There are no patient groups or support groups which actively include this patient category, something one of our informants pointed out as well. Against that background, we see it as a strength of the study that we have been able to gather intimate narratives from 11 self-identifying gay men with experiences of different types of prostate cancer treatments in what is a relatively small country. When we make visible the experiences of some people, we simultaneously risk making invisible the experiences of others. We have in this analysis not addressed variations in informants' religion, age or physical abilities. A study from the U.S. showed that older L.G.B.T. people 'of colour' experience additional difficulties accessing healthcare [26], which speaks to the need for future studies with an intersectional perspective, including different categories of discrimination [27]. In fact, even as our study enrolled a small number of participants, the variation of concerns and experiences within our sample points to the danger of assuming all gay men have similar pre-treatment sexual lives and the same post-treatment concerns. This result should encourage future research to consider additional factors to predict and direct rehabilitation outcomes.

Conclusions

This study is the first in Sweden to examine gay men's experiences of sexual changes after treatment for prostate cancer. The study results emphasize the importance of physical changes, in particular erectile dysfunction and loss of ejaculation, and how these are connected to the men's identity and their social relations.

Our analysis shows areas of concern which should be attended to, in clinical practices and care guidelines, and within patient groups and support groups for men with prostate cancer. Previous work has described how men identifying as gay or bisexual experience lacking sexual communication in interactions with health professionals [28]. Although this was not our current study focus, in the men's narratives we could identify a lack of norm-critical questions or remarks from caregivers. Particularly given the knowledge that men identifying as gay or bisexual tend to display more negative indicators after prostate cancer treatment [8], we feel that our study has some specific insights for designing better care and sexual rehabilitation programmes for this patient group. These include support to deal with the loss of ejaculate and erectile dysfunction and provision of information about anal stimulation after treatment. Such support asks for professional sexual counselling rehabilitation in direct connection to treatment. Even if the national Swedish care programme for prostate cancer [29] emphasizes sexual rehabilitation, there are still few urology clinics in Sweden which can offer such professional support.

Future research about sexuality and prostate cancer should contain questions about sexual practice and go

beyond the norm of vaginal penetration in order to articulate the multiplicity and diversity of sexual practices.

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Disclosure statement

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