

Australian Research Centre
in Sex, Health and Society

Moving On

Mental Health, Resilience and Sexual
Recovery among Gay Men living with
Prostate Cancer

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**Australian Research Centre
in Sex, Health and Society**

Moving On

**Mental Health, Resilience and
Sexual Recovery among Gay Men
Living with Prostate Cancer**

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November 2015

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Main Messages

The *Moving On* Study report presents the findings of research concerning the experiences of Australian gay men following diagnosis and treatment for prostate cancer. The results of this study suggest a number of key considerations.

- The experience of gay men diagnosed with, and treated for, prostate cancer is different from that of heterosexual men, whose experiences currently dominate what is known about men's experiences of prostate cancer in the academic literature and among many health professionals.
- Sexuality and sexual identity play an important part for gay men at diagnosis and during the treatment of prostate cancer. Gay men experience forms of exclusion from the moment of diagnosis through successive practices of treatment, care and management. At times, gay men are compelled to conceal or manage information about their sexualities in clinical settings in ways that perpetuate a discursive silence regarding their experience.
- This discursive silence is further sustained in gay community health settings where prostate cancer does not feature as an important health issue in the way HIV/AIDS and sexual health do.
- This discursive silence also contributed to a problem in recruiting gay men, and especially gay male partners of gay men, for research on these issues. This potentially inhibits the research still needing to be done on the impact on prostate cancer in gay men.
- The mental health consequences of prostate cancer for gay men are best understood in relation to the ongoing threat the illness poses to gay men's sense of identity, and their relationships with other gay men and their gay community networks, demonstrating the particular significance of sexuality in understanding the effects of prostate cancer on gay men's mental health and well-being.
- Health care providers need greater awareness and training about the mental health and well-being issues faced by gay men with prostate cancer, in addition to a wider recognition and understanding of those aspects of sexual recovery that are different for gay men.
- The findings suggest that in order to support gay men with prostate cancer, substantial changes need to be made to the current processes of diagnosis, treatment and access to support to address gay men's unique needs.
- Systemic discrimination in the health system, supported by wider processes of social marginalisation, stigma and discrimination, further undermine the hard-won identities of gay men with prostate cancer.
- Gay men do bring resources to their own recovery from prostate cancer. These resources lie in the resilience developed by many gay men in coming to grips with their sexuality in the first place and in the resources available to this through their partners, their gay friends and the wider gay community.

Executive Summary

This report presents the findings of research concerning the experiences of Australian gay men following diagnosis of and treatment for prostate cancer. It focuses particularly on these men's experiences of the treatment side-effects of prostate cancer on sexuality and sexual relationships, and the implications of these for their mental health and well-being. The study aims to contribute to building the evidence base for the development of policy, programs and resources by those in the medical, health and community services professions to provide better support for gay men diagnosed with prostate cancer.

BACKGROUND

The prevalence of prostate cancer among gay men is unknown. A literature review and an audit of health education resources reveals very little research has been undertaken on gay men's needs for their mental and sexual health, and there is little specific health information to assist them or to inform the health services they utilise.^[1] Nor do we know much about their experiences of recovery and negotiation of mental and sexual health difficulties, and there is nothing available to assist their male partners as carers.

APPROACH

Using an interpretive case study methodology, this qualitative study included 35 in-depth interviews with gay men with prostate cancer, and six interviews with male partners of men with

prostate cancer. Mainstream prostate cancer services and organisations, gay men's health organisations and social networks, and the Internet were used to recruit research participants. The study provides a detailed account of these men's experiences of prostate cancer, and of the steps taken to recover a sexual life and identity following treatment.

RESULTS

The results of this study highlight a number of important findings. Most importantly, gay men have unique experiences of prostate cancer that have not been discussed or detailed in the scholarly literature, which largely focuses on heterosexual men in established relationships (i.e. marriage). In particular, the treatment of prostate cancer has long-lasting and detrimental effects on gay men's sexual practices, including effects on the sensation and experience of orgasm, and both insertive and receptive sexual practices.

The diagnosis of prostate cancer also has a profound effect on gay men's understandings of themselves in relation to ideas about aging and the aging body, which many find particularly distressing. Prostate cancer also affects gay men's relationships, placing pressure on sexual and relationship partners to adapt to the sexual effects experienced by men with prostate cancer. Prostate cancer also affects men's willingness to engage in new relationships, and raises specific concerns and anxieties related to disclosing

changes in sexual capacity and performance with new sexual partners. In reflecting on the impact of these changes, few men subscribed to the notion of 'survivorship' as a framework for making sense of and describing their experiences. Rather, prostate cancer was thought about as something one 'lives with', or 'moves on' from. This has practical implications for how men manage the physical, emotional and psychological impacts of prostate cancer, with many placing emphasis on individualised strategies of acceptance, perseverance and 'forgetting'. Such strategies were adopted in the absence of supportive psychological resources or sources of support in the health system. This extended to silences about gay sexual practices and relationships with clinicians, and the absence of specific information or networks providing tailored support.

Few men described clinical diagnoses of depression or anxiety. Where present, these were described as significantly harder to deal with than the cancer itself. However, distress and despair were commonly expressed emotions, specifically related to the shock of the cancer diagnosis, the effects of treatments on sexual life, relationships, body image and self-confidence, and the ongoing doubts about treatment decisions and possible cancer recurrence.

In terms of resilient responses to prostate cancer, a number of men emphasised the need to maintain a positive attitude in coping with prostate cancer, to accept the changes wrought by prostate cancer as a function of age, or as better than the alternative, i.e. death. Friends, family, and partners were described as sources of emotional and practical support. However, resilience was undermined by the absence of specific advice, information and guidance about treatment options and the consequences of prostate cancer for gay men, and their partners.

Participants also described gaps in support in gay community organisations, and the effects of a perceived emphasis on youth, health and sexual performance among gay men more broadly, which alienated them from previous sources of social support, identification and belonging.

IMPLICATIONS

The results of this study suggest a number of key implications. The first is that sexuality and sexual identity play important roles in determining the treatment outcomes of prostate cancer for gay men. While all men (regardless of sexual orientation) can be diagnosed with prostate cancer, the results of this study find that the experience of gay men diagnosed with, and treated for, prostate cancer is different from that of heterosexual men, whose experiences dominate the literature.

Secondly, the mental health consequences of prostate cancer for gay men are best understood in relation to the threat the illness poses to gay men's sense of identity, and their relationships to other gay men and a wider sense of belonging to a gay community. Only by taking these things into account can the effects of prostate cancer on sexual function, and gay men's mental health and well-being, be fully appreciated.

Thirdly, both mainstream and gay-specific health providers are not adequately addressing the unique needs of gay men with prostate cancer. This exacerbates the isolation and distress that many gay men living with prostate cancer experience. The results indicate that in order to provide better support to gay men with prostate cancer, substantial changes need to be made to the current processes of diagnosis, treatment, and the kinds of social support, information and advice

that are made available to them. It is not acceptable for any man experiencing the most common form of male cancer in Australia to go through this experience alone.

Introduction

In Australia, it is estimated that 17,250 new cases of prostate cancer will be diagnosed in 2015 and there will be an estimated 3,440 deaths from prostate cancer.^[2] Depending on age, prior sexual activity, and treatment success, 30–90% of men experience mild to severe sexual problems after prostate cancer treatments, e.g. erectile dysfunction, loss of ejaculatory capacity, incontinence.^{[2],[3]} The medical literature's focus on the sexual and emotional implications of prostate cancer treatment is concerned largely with clinical issues of 'sexual function', not with broader 'sexuality' issues involving physical, psychological, emotional, relational, social and cultural aspects of men's lives.

BACKGROUND

Men with prostate cancer are twice as likely to experience depression as other men.^[4] In one Australian study, 12% of men with prostate cancer had significant levels of anxiety and 16% experienced depression related to sexuality.^[5] In 2007, 36.7% of diagnoses occurred in men under 65, and younger men (who are more likely to be sexually active) are increasingly undergoing treatment as the age of diagnosis falls.^[6] Prostate cancer prevalence in gay men is unknown, as sexual orientation is not recorded. The FLEX study, an online international survey of prostate cancer and men's sexuality (n=558), found 15% of respondents were on antidepressants, and non-heterosexual men reported being more troubled by ejaculation problems than heterosexual men (32% vs 17%).^[7] Non-heterosexual men's Gleason scores (tumour grade) were also significantly

lower, suggesting earlier, possibly younger diagnosis. Gay men experience higher rates of depression than other men generally,^[8] and one US survey (n=92) found significantly lower Quality of Life (QoL) scores and worse mental health scores among gay men with prostate cancer compared with norms.^[9] Another study suggests that gay men have more sexual difficulties when taking certain hormonal treatments for prostate cancer.^[10]

There is considerable research on the impact of prostate cancer on men's sexuality and sense of masculinity and links to depression.^{[11],[12],[13],[14],[15]} Yet, this work has not explored these issues for gay men. Filiault et al. note the lack of detailed accounts of how gay men recover their mental and sexual health after prostate cancer treatment, how sexual practices change, and how a sense of self, personal relationships and social lives in the gay community might be affected.^[16] Such findings suggest a markedly different prostate cancer experience for gay men.^{[9],[17]} Existing qualitative studies focus on individual experiences.^{[16],[18],[19]} Others report on issues such as male couples both with prostate disease; and possible effects on gay sex.^{[20],[21]} Most recently, Lee et al. have explored the challenges to sexual practice, performance, relationships and the specific oncological and psychosocial needs for gay men with prostate cancer but do not link these issues to mental health and wellbeing.^[22]

Broad disparities in mental health between heterosexual and non-heterosexual populations have also led for calls to explore resilience as the flipside to such mental health

outcomes, with greater resilience being associated with better mental health and well-being.^{[23], [24], [25]} As Lyons argues,

knowledge of the circumstances or contexts in which lesbians and gay men display greater resilience can provide valuable information to shape therapeutic and public health strategies for building resilience and preventing and treating mental health problems.^[24]

Resilience refers to the degree to which an individual adapts positively to a challenge, bounces back from an adverse life event, or thrives in the face of adversity.^{[24], [25], [26]} Resilience among lesbian, gay, bisexual and transgender (hereafter, LGBT) populations has largely been explored as a function of minority stress, that is, as a function of stigma and prejudice related to sexual orientation.^[25] Social support, particularly from friends, role models, a sense of belonging or identification, and participation in a LGBT community have been shown to moderate identity-based stigma and discrimination.^[24]

Findings from the *Private Lives 2* study found that gay men reported a lower average score on resilience when compared with studies involving the general population.^{[25],[27]} Greater resilience was associated with being in a relationship, having gay friends, participating in LGBT community events, and seeking support from family or a relationship partner.^[24] Importantly, concealing one's identity was associated with lower resilience, which was also associated with lower social support, and less help-seeking behaviour. Older men were also found to be less resilient which the authors suggest is related to the negative attitudes toward homosexuality these men faced coming out.^[27] Lyons concludes that

social support and identity concealment need to be addressed when seeking to build resilience in gay men.^[24] This concept of minority stress becomes quite important in understanding the mental health and well-being outcomes for gay men diagnosed with, and treated for prostate cancer.

A recent Australian audit noted the limited health information available for gay men specifically, as almost all the resources and training on depression, sexuality and prostate cancer assume universal heterosexuality.^[1] This, combined with the poor evidence on gay men with prostate cancer noted above, suggests that new research in this population is urgently needed.

Aims

This study concerns the experiences of Australian gay men diagnosed with, and treated for prostate cancer. It focuses on the treatment consequences of prostate cancer for these men's sexuality, their experiences of mental health and wellbeing in relation to sexuality issues, and their resilience in adapting to changes in sexual life after treatment. The study sought to answer the following six research questions:

- (1) What are gay men's experiences of prostate cancer diagnosis and treatment, particularly as these relate to mental and sexual health and wellbeing?
- (2) How might depression, anxiety and sexuality interact, e.g. does poor sexual recovery lead to depression, or the reverse?
- (3) How do bodily changes wrought by prostate cancer inform sexual relationships, individual sense of self and identity?
- (4) How do gay men adapt to changes in sexual function and recover a sexual life after prostate cancer? What activities or technologies (e.g. Viagra) are used? How might sexual practice and expectations have changed?

- (5) How do the partners of gay men experience their journey as carers and supporters?
- (6) What assistance and/or support were and are received from medical and health professionals? What other resources were and are utilised (e.g. support groups, online resources etc.)?

The study's findings have a dual purpose. The first is to demonstrate the gaps in the provision of medical and health services for gay men with prostate cancer. The second is to provide a basis for the development of new public health responses to the mental and sexual health consequences of prostate cancer treatment through the expansion of our understanding of sexuality and well-being issues faced by gay men living with prostate cancer.

Approach

To investigate the experiences of gay men with prostate cancer and their partners in overcoming, or accepting, the physical, sexual and psychological challenges posed by prostate cancer diagnosis and treatment, this study undertook a qualitative approach. Past research into gay men's experiences of prostate cancer has been heavily focused on quantifying medical measures (e.g. degree of 'sexual dysfunction', level of 'sexual bother').^{[15],[29]}

This approach, while valuable, is unable to capture the complexities of gay men's individual and shared experiences of prostate cancer, including the ways in which they might negotiate sexuality and sexual relationships during and after treatment. Similarly, quality of life (QoL) scales measure and compare patients, but they fail to capture men's deeply personal and ongoing experiences.^[30] Anxiety, depression and QoL measures are limited in their ability to grasp the 'more nuanced, individual consequences of cancer'.^[31] A qualitative approach provides a more appropriate methodology to begin to explore these individual experiences.

and sexual identity play in shaping gay men's experiences of prostate cancer, and to determine future pathways for successful treatment and rehabilitation concerning their mental and social well-being.

The study sought reflective, in-depth accounts of experiences and processes of mental health and sexual recovery at personal, relational and social/community levels, and to explore details of research participants' interactions with medical and health professionals and support services. At the outset of this project, a Reference Group was formed with 11 experts in the field of cancer, prostate cancer, men's health and gay community organisations to aid in the development of the research design, interview schedule and the dissemination of the research findings. Research ethics approval was also sought from the gay community partner agencies in this study, ACON (formerly the AIDS Council of NSW), and the Victorian AIDS Council/Gay Men's Health Centre, following approval from La Trobe University's research ethics committee.

DESIGN

This study used an Interpretive Case Study method, a qualitative approach that seeks an 'intensive, holistic description and analysis of a single entity, phenomenon or social unit'.^[32] We used this approach to explore the role sexuality

As there are no prevalence data for gay men with prostate cancer, the study utilised a purposive approach to sampling with recruitment based on a set of particular characteristics.^[33] There were six major criteria for gay men with prostate cancer to be eligible to participate in the study, outlined in **Table 1** on the following page.

TABLE 1: Eligibility Criteria

Criteria	Eligibility	Reasoning
<i>Sexual identity</i>	Identify as a gay man	The issues faced by bisexual men are likely to be different from those faced by gay men and were therefore not included in this study.
<i>Sexually active</i>	Sexually active before treatment and motivated to recover a sexual life after treatment.	Men needed to have been sexually active before treatment, and interested in recovering a sexual life after treatment, so as to evaluate what effects prostate cancer has had on their sexualities
<i>Confirmed diagnosis and treatment</i>	Had a confirmed diagnosis (not 'watchful waiting') and had undergone treatment	Men needed to have undergone treatment for prostate cancer to determine what lasting effects there were on their sexual well-being post-prostate cancer.
<i>Language</i>	Spoke fluent English	For clear and coherent communication between the researcher and the interviewee
<i>Recovery Period</i>	At least six months after final treatment	To allow some time for sexual recovery
<i>Age range</i>	Between 40 and 65 years of age	(1) prostate cancer diagnosis is rare under the age of 40, but is increasingly occurring in the 40s (2) this cohort of men is more likely to be sexually active than those >65 at the time of diagnosis

Originally, men were sought only in the age range of 40 to 65 years. However, it proved difficult to attract sufficient participants with this criterion, and the age-range was expanded to include men under 40 and above 65. One man who was in the watchful waiting period was also interviewed. Recruitment criteria for partners of men with prostate cancer were less prescriptive. Men who had been with a male partner at the time at which that partner had been diagnosed and/or treated for prostate cancer were sought for an interview.

RECRUITMENT

Participants were recruited using an advertisement (see Appendix 2) sent through prostate cancer and gay men's health services. These included advertising through the Prostate Cancer Foundation of Australia support group network, advertising in gay community media in Sydney and the Gay Men's Health Centre, through gay men's medical services, and through prostate cancer community websites such as the US-based MaleCare.

Social media was also used with advertising on Facebook and Gaydar. The lead investigator also appeared on two radio shows on JOYFM (the LGBTI community FM station) in Melbourne to promote the project. Recruitment was initially focused on Sydney and Melbourne as these cities have large gay communities, and nascent prostate cancer health initiatives, and it was thought that they would provide the strongest recruitment possibilities. Recruitment initially proved tricky as some prospective participants were reluctant to contact the researchers directly. Consequently, the research team created and linked a WordPress website where participants

were presented with basic information about the study, and were provided with a field where they could leave their contact information to participate in the study. Once they left their contact information, the project research officer would contact the potential participant, determine eligibility, and set up a meeting time. This format contributed to the online recruitment success.

Table 2 highlights the details of the recruitment process. Seventy-seven percent of those who contacted the researchers for more information about the project participated in an interview. Facebook (46%) and Gaydar (17%) proved to be the most effective sources of recruitment, followed by partner referral (15%).

TABLE 2: Recruitment Breakdown

Sample N=41		
Recruitment		
Recruited	53	NA
Interviewed	41	77%
Interviews Completed		
In Person	13	32%
Via Phone	28	68%
Recruitment Strategy**		
Facebook	19	46%
Gaydar	7	17%
Community Organisations	3	7%
Support Groups	4	10%
Media	2	5%
Partner Referrals	6	15%

*This is calculated by dividing the number of interviews conducted by those recruited.

**These percentages exclude potential participants who were deemed ineligible or who ultimately chose not to participate in the project

THE SAMPLE

The sample comprised 35 gay men with prostate cancer, and six male partners. This sample size is typical for in-depth qualitative studies with reasonably homogeneous participant populations.^[34] **Table 3** highlights the demographic characteristics of the participants with prostate cancer interviewed in this project.

TABLE 3: Demographic characteristics of men with prostate cancer

Sample N=35		
Age Range		
40-50	3	9%
51-55	8	23%
56-60	7	20%
61-65	5	14%
66-70	9	26%
70+	3	9%
Geographic Location		
VIC	7	20%
NSW	13	37%
QLD	7	20%
NT	2	6%
WA	2	6%
TAS	3	9%
SA	1	3%
Relationship Status		
In relationship	8	23%
Single	26	74%
Widowed	1	3%
Treatment (more than one treatment)		
Prostatectomy	24	69%
Radiation	10	29%
Hormone Therapy	3	9%
TURP	2	6%
Proton Therapy	1	3%
Active Surveillance	1	3%
Years Since Treatment		
<1 year	5	14%
1 year	3	9%
2 years	4	11%
3 years	9	26%
4 years	5	14%
5 years	6	6%
6+ years	3	9%
HIV Status		
Yes	4	11%
No	31	89%

Most of the men with prostate cancer interviewed resided in Victoria, New South Wales or Queensland (77%), and had undergone prostatectomy (69%). Five men had been in recovery for less than 12 months, 16 had been in recovery for less than three years, while a further 14 men had been in recovery more than three years. Most men were single (74%), and HIV negative (89%). Age ranges varied, but most men were between 51-55 (23%), 56-60 (20%) and 66-70 (26%). The majority of participants were of Anglo-Australian background.

Table 4 highlights the demographic characteristics of the partners interviewed. Despite the advertising campaign and extended calls for participation, only six men were recruited as partners to participate in the project. We speculate that the reason for this may be that gay men have not regularly been invited to see themselves or participate in research as ‘partners’ and/or ‘caregivers’—roles that are usually gendered feminine in popular and conventional health discourse, and particularly in prostate cancer health education materials.^[1] The subsequent lack of discursive space for gay male partners may mean that such men did not see their experience as relevant to the present study.

TABLE 1: Demographic characteristics of partners of men with prostate cancer

Sample N=6		
Age Range		
18-30	1	17%
31-39	1	17%
40-50	1	17%
51-55	2	33%
56-60	0	0%
61-65	0	0%
66-70	1	17%
70+	0	0%
Geographic Location		
VIC	1	17%
NSW	3	50%
QLD	1	17%
NT	0	0%
WA	0	0%
TAS	1	17%
Partner Status		
Current	5	83%
Ex	1	17%

DATA COLLECTION

Data collection involved the use of telephone and face-to-face interviewing. As most of our participants (80%) were located outside Victoria, telephone interviews (see **Table 2**) constituted the bulk of the interviews (68%). Interviews typically lasted an hour to an hour-and-a-half and were audio-recorded.

A semi-structured interview schedule was designed, focusing on the following domains: mental health; body practices and embodiment; relationships; changes to sexual practice; technology use (e.g. Viagra); experiences of medical and health professionals on sexuality issues; and gay community. A ‘progressive

focusing' approach was used in interviews, a method that allows researchers an iterative and reflective way to consolidate issues, to open space for unexpected topics, and to reach 'saturation of categories' efficiently—the moment when few new data are forthcoming and fieldwork can begin to wind down.^{[35], [36]}

ANALYSIS

Interviews were audio-recorded and then transcribed by a commercial transcription service after signing of a confidentiality agreement. The transcriptions were then verified for accuracy by the research team. Analysis was guided by the principles of critical grounded theory.^[37] Each transcript was read and re-read by the research team and several team meetings were held to discuss initial impressions of the data, and possible strategies for analysis. These discussions formed the basis for the development of a coding schedule.

Individual case studies analysing each interview were developed in parallel with the development of the coding schedule. Transcripts were then imported into the data analysis software NVIVO for coding. An initial stage of open-coding involved the analysis of statements, turns of phrase and specific words for underlying patterns of meaning that were shared across the data set. Unusual and unique examples were also explicitly coded to ensure attention to the diversity of participants' experiences and sense-making. Analytical and descriptive notes relating to individual comments and thematic codes were made as analysis progressed. In relation to the research aims and the interview schedule, open codes were subsequently thematically organised

producing a number of broad subject areas for writing up as findings. The themes identified in the analysis are as follows: health seeking behaviour; sexual life; mental health; relationships; and, coping. Each of these themes comprises a series of nodes and sub-nodes, containing elements of transcripts that speak to that theme. For example, the theme 'sexual life' consists of a number of nodes, including: lifespan desire for sex; erection problems; penis size; and, anxieties about sex after treatment. Summaries of these are presented in the following section of this report.

Results

The findings of this study highlight the significance of sexuality and sexual identity for gay men living with prostate cancer and its impact on their mental health and their sexual and social well-being. A number of distinct themes emerged from this research project that directly or indirectly relate to gay men's mental health post-prostate cancer treatment. These themes focus on:

- (1) the impact of prostate cancer on gay men's sexual practices;
- (2) coping with aging and prostate cancer;
- (3) negotiating relationships and accessing sources of social support;
- (4) the fear of recurrence and rejection of 'survivorship';
- (5) navigating the health system;
- (6) the experience of depression and anxiety; and
- (7) the potential for building resilience.

The presentation of findings on these themes will be followed by a Discussion section outlining the implications of the study's findings.

Impact on Sexual Practices

The treatments for prostate cancer have significant side-effects primarily related to sexual function and urinary and/or rectal continence. The consequences of these side-effects were of profound concern for the men interviewed, extending far beyond their framing in biomedical terms as erectile dysfunction and incontinence. Participants described changes in their sexual function, their impact on their sexual practice, sexual role, body image, partner relationships, the formation of new sexual relationships, and their relationships with gay men and the gay community more broadly. Related to each of these, we found evidence of distress, despair, isolation, anger and resignation among participants. We begin with a discussion of sexual performance.

SEXUAL PERFORMANCE

Participants were asked specific questions on how prostate cancer had affected their sex lives, and how they felt about these changes. For many, sex was closely connected to a sense of self and to what was valuable and pleasurable in life.

Well, sex was a really important and enjoyable part of my life and I rarely have sex anymore. So I've lost something that was really significant and important to me, and not just recreationally, but really as a part of my identity I guess. (participant 2, age 55)

In describing that sense of significant loss, participant 2 reported that, in retrospect, he had

probably also experienced depression during treatment as a consequence:

...was I depressed through treatment? I'd say yes I was. But I wasn't being treated for depression at any time.

The loss of a source of pleasure and identity noted by participant 2 was reported by a number of participants, and was particularly the case for younger men, and those whose sense of identity and life was organised around being gay and sexually active. Participant 7, age 58, who had started treatment for depression in the two months before the interview, described his feelings about his sexual life:

Well, basically, my desire for sex has only diminished since the surgery. You know, I've been sexually active all my life, but you can't be sexually active after what I've gone through 'cause it's physically impossible. So therein lies the, the, the mental issues come, come through now, so I'm actually having counselling and going to a clinical psychologist at the moment to, to work through the, the mental issues. 'Cause, when you're very fit and sexually active and enjoying that part of your life, when it's taken from you it's like, you know, having an amputation, really. And you have to come to terms with it very, very quickly.

While participants described similar experiences in adapting to changes in their sexual function, not all spoke of these changes as loss or despair. Several men spoke about the necessity of trying to

find the positive side to these changes. As participant 17, age 67, said:

But no, when I look today, the only real problem I have is, is the fact that I can't perform sexually. But the fact that I do get some sexual satisfaction with the men that I do meet, then I think to myself, 'Well that's a positive'. And the fact that I can have them as, as friends as well as sex partners, that's sort of a plus.

Other men also decided to focus on the pleasures of physical intimacy with a partner, rather than on sexual performance per se. Others saw the loss of sexual life as just something to accept:

Well, okay, if it [an erection] happens, it happens, and, if there's still sexual activity after the event, well that's a bonus. If there isn't, well, you know, you have to accept what happens in your life (participant 30, age 63).

The description of a loss of sexual capacity as an 'amputation' speaks to the depth of impact of prostate cancer on this man's sense of self. Prostate cancer impacts not just physically on the body, but also upon a man's image of himself as fit and active. The loss of sexual function is more deeply felt than at the level of erection strength and sexual performance. Here, the metaphor of amputation strongly registers a self that is not whole.

ANAL RECEPTIVE / INSERTIVE PREFERENCE

Research has argued that gay men might adapt to sexual difficulties created by prostate cancer treatments better than other men due to the perceived sexual openness of gay men and gay community more generally. However, this advantage can be offset by having less-stable relationships, which may change as a result of prostate cancer, whereas heterosexual men are thought to have more stable partner support.

A prominent sexual change we observed of gay men with post-prostate cancer erectile difficulties was to change from being the insertive partner (penetrating) to being the receptive partner (penetrated) in anal intercourse. We should note that anal intercourse is not the most commonly practised sex act undertaken by gay men, as might be commonly thought (mutual masturbation and oral sex are more frequently practised).

A number of men described adapting to an exclusively receptive role in anal sex in response to the effects of treatment on their capacity to sustain an erection. For example, participant 17 described:

...my sex life has changed almost totally from, well, getting down to the nitty-gritty, from being a top [insertive] to now being more a bottom [receptive].

Participant 23, age 61, had the same experience, saying:

I'm a receiver where before I was a giver, a top. And so now I have to resort to that...

The word 'resort' reveals that this change in role is not a simple swap, indicating that adapting one's sexual preference is not straightforward, nor without regret.

Other men described giving up on being receptive in sexual encounters, where treatment consequences affect a man's capacity to engage in receptive anal intercourse. As the prostate is a point of pleasure during anal sex, its removal can result in the loss of pleasure. If radiation was a part of the treatment procedure, the patient might experience rectal bleeding and sensitivity that could make anal penetration difficult:

As someone who's been a dedicated bottom all of his life, I can tell you that being a bottom after prostate surgery isn't nearly as good as being a bottom before and, when you add in the complications of radiotherapy, and I've, 'cause I've had moderately severe radiation proctitis, it just becomes almost impossible and not always pleasant (participant 2, age 55)

This loss was greatest for those men who had lost the ability to be the insertive partner because of erectile problems and were also not able to be receptive as a result of treatment complications.

This also had consequences for men's partners, as participant 9, age 67, noted:

So, although in our sexual relationship, I was always the active partner and [partner's name] was passive, so [partner's name] was not really inclined to, to, to screw me even if I was able to let him. But I would have liked to have

tried. But it's just too painful there. I have a lot of pain anally as well, so that's not an option for us to explore. So generally, when we have sex now, it's generally oral sex and, and mutual masturbation.

Participant 9 was only able to sustain a semi-erection while taking Levitra, and was deeply disappointed that he could not perform as the insertive penetrative or receptive partner.

Some men indicated that they believed there was a causal link between anal sex and prostate cancer—an added layer of worry and, for some men, a source of shame related to the stigma that still attaches to being gay, even today. There is no evidence of such a link but this worry was, for some, part of searching for an explanation for why they had been affected by prostate cancer:

But we also made fairly extensive use of vibrators for, for, anal vibrators. And I have wondered at times whether that might have been – there might have been some link between that usage and the, the diagnosis of prostate cancer? I, I don't know whether that's been looked at. If, if there is a link, then that was a consequence of, you know, something which I chose to do. (participant 3, age 59)

For gay men, changes to sexual practice and role in response to prostate cancer treatment side-effects extended beyond the absence of erection as 'erectile dysfunction' to include a wider set of psychological, categorical and relational issues that contribute to confusion and loss for many.

out of your cock. It just, it just really is a bit of a let-down. That's another thing I'd feel embarrassed about if I was gonna have sex with somebody.

EJACULATION

Removing the prostate and seminal vesicles takes away a man's ability to ejaculate. In the psychological treatment of prostate cancer patients, Mitteldorf notes that heterosexual men treated for prostate cancer do miss the sensation of ejaculation during orgasm, while their wives do not mention any loss.^[29] In contrast, as Mitteldorf suggests, it is possible that gay men and their partners might miss the sight and experience of ejaculation.^[29] Among the men we interviewed, ejaculation was regarded as the visible expression of a satisfactory sexual event. Participant 17, age 64, was not alone in noting:

I always used to enjoy the actual ejaculation.

Other men spoke of their disappointment at the loss of ejaculation:

If I ever watch a porn [film], I'm fascinated with it, watching it now. So like especially when someone reaches ejaculation. Like I think, 'Oh shit!' that's, that's the biggest part I look at now I think. I don't know why. 'Cause I can't do it. And, I don't know ... it's just, when you look at it. I don't know why. (participant 27, 48)

Participant 20, age 54, described the perceived effect of this loss on potential sexual partners:

But it's not a fantastic orgasm either 'cause, you know, you're just not seeing cum come

The loss of ejaculation is not only the absence of physical sensation, which in itself is a 'let down', but also a source of potential self-consciousness, which changes men's sexual and relational outlooks. These men described not just the loss of physical sensation that accompanies the loss of ejaculation, but also the visual and symbolic significance of ejaculation as an expression of a satisfactory sexual encounter with another man. Furthermore, as participant 20 implies, the absence of ejaculation can lead to embarrassment at the failure to perform sexually.

ORGASM

A possible silver lining for some men who experience treatment for prostate cancer is a change in the strength of their orgasm. Following surgery, some men reported prolonged and more intense orgasms, such as participant 6, a physically very active man of 66 who used injections to gain a strong erection:

And, strangely enough, I still have amazing orgasms and sometimes they'll last up to a minute and, you know, sometimes I almost bloody pass out they're so intense. But if I'm fucking or something, well I can just keep on fucking, you know. Once I get my breath back, I can, I can just keep going, which is absolutely sensational. So that sort of, you know, counteracts, you know, the loss of ejaculation.

For other men, the experience of the orgasm is diminished by the lack of ejaculate, but as participant 9, age 67, explained:

If my eyes were closed, I wouldn't know it was any different 'cause sometimes, if, if I'm having oral sex with [partner] and I have an orgasm, I'll actually say to him, you know, 'Is there any semen there?' because it just feels the same. It's strange. It just feels as good as, as if there was semen there.

This was not the case for all the men interviewed. Participant 26 was unusual among our participants in that he was having more sex with more people than before his surgery. However, he was now only able to orgasm by manual self-stimulation:

Like, arousal's still the same and everything. [But] It's like, you know, I really can only achieve orgasm through masturbation now.

Most participants reported frustration with the length of time it took to achieve orgasm. Others persisted, in the knowledge that trying to achieve orgasm was the best way to sustain the physical capacity for erection:

I masturbate with difficulty because, without the erection – but I masturbate probably two or three times a week. (participant 8, age 67)

For those participants not able to have an erection, orgasm was still possible with a flaccid penis. Participant 28, age 53 took a while to gain back his erection after surgery, but was surprised when he learned that he could have an orgasm without an erection:

And that was something I didn't know. It was the first surgeon who told me that. He said, 'Of course, you can orgasm without an erection.' I was like, 'Oh really?' And sure enough you can.

Others, like participant 12, were constrained by more conventional ideas about masculinity and erection. Participant 12 was not able to have an erection at the time of the interview due to receiving hormone therapy for the cancer, and was surprised to be asked about whether he was able to orgasm without an erection:

No. That would turn me into a chick then wouldn't it? Fully!

Participants 12 already felt feminised by the hormone treatment—unsurprisingly, when it is termed 'castration' by medical professionals.

Taken together, the findings on gay men's sexual lives after prostate cancer treatment indicate there is more to sexual recovery than loss of erectile capacity, experiences of erectile dysfunction, and the bother of loss of ejaculation. Issues of gay sex are also important for these men and their partners. These once sexually active men now struggle with bodies that no longer function as they once did. Also, they now must negotiate a premature sense of aging and it is to this issue we now turn.

Coping with Aging and Prostate Cancer

Chambers et al. found that cultural ideas about youth, masculinity and virility are more powerful in shaping heterosexual men's experiences of prostate cancer than actual chronological age.^[38] However, these authors did not include gay men in their study, but speculated that these dynamics might be worse for them.^[38]

I still considered myself as okay, well, you know, I'm over 55 but I can probably get away with thinking I'm 50 or whatever. But once you've had surgery, it reinforces that you are in that age group because you keep getting told by the doctors you are in that age group, and they keep referring to the fact that you are in that age group. So I now consider myself as a senior citizen, which I would never have considered a couple of years ago. And it's not pleasant, especially in the gay scene, to think of yourself as a senior citizen.

'SENIOR' CITIZENS

Prostate cancer was viewed by a number of men as a turning point in their lives, often being their first experience of a serious illness. For some men, the experience of cancer brought with it feelings of becoming old, but a narrative about aging also facilitated a greater acceptance and adaptation to the sexual side-effects caused by prostate cancer treatments. A loss of sexual capacity was expected in older age. As participant 25, age 65, said:

I was 64 when it was done so, you know, I was getting to the stage where it was, 'Thank you. Thanks for the memories.'

Other men found this moment distressing. Participant 30, age 63, saw himself as 'getting old' as a consequence of the cancer, and participant 7, age 58, explained:

I see myself now as an old gay man because it really makes you think about your age. Before I was diagnosed with prostate cancer,

Importantly, as participant 7 indicates, the experience of one's age is also shaped by cultural narratives and social relations. The discourses of health professionals contribute to the constitution of prostate cancer as an 'old man's disease'. Many men, irrespective of sexual identity, might feel the same in these circumstances. However, for gay men, this sudden aging conflicts with the ways in which the 'gay scene' invites gay men to think about and see themselves.

A number of men described the way in which prostate cancer, the treatment side-effects on sexuality noted above, and the changed appearance of the body (e.g. loss of muscle, surgery scars, etc.) had changed their engagement with the gay scene. As participant 23, age 61, noted:

If I tell them it's prostate cancer, then they think you're too old.

There is more to this than annoyance. When discussing what he would like to change about his post-prostate cancer situation, participant 21, age 61 said:

Probably the sexual function, but mainly the aging process! Stop it! I'd love to stop it because, and I mean, I speak to my friends who are around the same age and we've all got the same opinion. You know, there is no positive in growing older. Not really. There's no real positives. I mean a \$2.50 travel card per day, you know, or cheap movies - big bloody deal, you know. When you feel the aches and pains, and you're starting to slow down, and you see the body changing, you know, that's when I like to put the brakes on.

novelty person on the prostate ward 'cause they're all in their seventies, you know. I literally shut the door on the ward for three days and didn't, didn't go out of my room. So it was like, 'This will depress the fuck out of me'. So, it'd be like a nursing home, you know. So I think, and obviously I think, if there was somebody who was 70 on a ward full of young guys, they'd be a bit like, you know, isolated.

The shock of experiencing a disease associated, in actuality and symbolically, with older age had led participant 26 to work on trying to reverse the physical side-effects of prostate cancer through bodybuilding and testosterone supplements.

This frustration is not just a narrow notion of changed sexual engagement, e.g. the loss of the sex to be had; it is also about changed social engagement in the scene where sexuality, in all its aspects, is a defining characteristic of membership of that community. Ussher et al. call this loss of engagement, both sexual and social, 'sexual disqualification'.^[44]

These responses reflect the tensions many gay men find difficult to reconcile between the ways in which prostate cancer is regarded as a disease associated with aging, and the sexual lives they have been living and the social worlds in which they live as gay men.

Wassersug et al. have also found that gay men tend to be diagnosed at an earlier age, which compounds this potential age/sexuality nexus.^[7] Younger men in the sample were clearly distressed by the age-related problems of prostate cancer. Participant 26, age 42, had the following to say:

I think it would probably help to distinguish between the age groups 'cause I think, you know, luckily, when I went into the hospital...I managed to get a private room. But I wouldn't have loved to have been in a room with four old men. You know, people are coming to look at me as the kind of

Negotiating Relationships and Accessing Sources of Social Support

Friendship has been shown to be profoundly important in the lives of gay men who may be estranged from or less reliant on their natal family than other men, and are less likely to have families (as we commonly understand them) of their own.^[39] Significantly, only one in four of the men interviewed was partnered, indicating a further key difference with the majority of similar research on the effects of prostate cancer treatment which focuses almost exclusively on men in heterosexual marriages.^[40] These factors have implications for where men might turn when diagnosed with prostate cancer and the forms of resilience that it might be possible to demonstrate, or, from the perspective of community and health services, foster.

FRIENDSHIPS

Consistent with HIV and AIDS research, which has indicated that gay men turn to friends rather than family for support, many of the men in this study also prioritised friends as key sources of care.^{[49], [50]} Reflecting on his experience of treatment, participant 10, age 60, explained:

I wouldn't say I was depressed; I just felt unhappy with myself. That didn't last very long. My friends are really good, you know. Put me back to earth and, you know, I just got on with life.

Similarly, participant 20, age 54, said:

I've got this great circle of friends and we have lots of fun together, and lots of laughs...so that side of things always helps lift your spirits.

Friends and sometimes family provided sources of emotional support that were helping participant 5, age 66, cope with prostate cancer:

I think emotionally I'm, well I think I'm okay but, and, as I say, I've got enough friends and family to support me.

Besides friends and family, partners were also a very important source of support, as participant 20 explained:

My social support was, I have to say, is, is critically important because, without a partner, I think there would have been very lonely and difficult thing to do. And I have to say it's probably the one thing that's kept me out of falling into depression about the whole thing.

Those participants in ongoing, long-term partnerships said that their relationship was one of the most important things that supported them during the prostate cancer experience. Among all the participants there was only one who said he had an unsupportive partner, but

this was due to the partner's unrelated addiction problems. However, not all men had the same forms of support. Participant 11's (age 52) circumstances are a good example of this:

Because a lot of people, we all have friends but, when, when something like this happens, you find a lot of your friends vaporise. Like either, we don't have family. We're not, we're gay men. We don't, like up here in [Town's name]... we know, and the same with [City's name], we know plenty of gay guys who have been, who are in their 40s, 50s, have been married, they've got children, they've got grandchildren. I've always been a gay guy. I don't have any children. I don't have a support network. I've got my partner and that's it.

Those sources of support that may be taken for granted for heterosexual men are not necessarily available to gay men, especially those living in regional areas, or those without partners. We know from studies in HIV and AIDS that there is a link between social support and quality of life for gay men.^[51] In terms of prostate cancer, younger gay men might still have their parents, but later in life fewer close family members remain, unless a man has children of his own or close siblings. Quite a few men did not have partners, friends or family they could rely on for support.

RELATIONSHIPS

The types of intimate relationships experienced by the men in this study were extremely varied, ranging from those with conventional monogamous arrangements approximating heterosexual marriages, partnerships with open

(non-monogamous) agreements, 'fuckbuddy' arrangements with friends, and actively dating, to single men interested in relationships and casual partners, and those without any sexual or relationship activity. Each of these raised complex issues for men experiencing treatment for cancer or living with the treatment side-effects.

As mentioned, many men described how prostate cancer made them feel older, which they perceived as in conflict with the dominant messages about youth in the gay community. This was reflected in the ways the men spoke about the prospect of meeting new partners. As participant 5 lamented:

But it's just the fact that, you know, it's a young man's world these days and young men only want young men - they don't want older.

This also implies that some older gay men prefer younger men. Several participants also described the emphasis on sex in the gay community and the pressure and expectation this created in terms of their own sexual function. Participant 20 believed this is why he struggled to meet new partners after his relationship broke up:

I think I have to say that sex in the gay community seems to be taken to a much higher level of prominence than elsewhere, and I found, particularly when I broke up with my partner, I completely lost all confidence around that.

Participant 5 described similar ways his confidence had been affected by the cancer treatment:

Finding partners is not really difficult. It's feeling inhibited and the fact that lack of confidence... if I try to venture into a new partner[ship], that's where I start to feel a bit inhibited, a bit, oh ... What's the word? I can't just quite think of it but I feel a bit inferior sort of thing.

All of the men interviewed were very candid about changes to their sexual function. It may be that the emphasis on disclosure of HIV status in sexual encounters with new partners as an HIV prevention strategy means that our participants similarly described the importance of disclosing the sexual consequences of their cancer treatment as a way of managing expectations. For instance, participant 6, age 66 described the use of injections in preparation for sex with a new partner:

I'm not ashamed of it or worried about it - but it just, you know, I like to be honest and up-front... I say, 'Look, I had prostate cancer. I'm all fine but I just don't ejaculate.'

Participant 3, age 59, said:

But how much do you reveal on a first date I suppose? It's kind of that question. I guess I've just kind of gone with the flow a bit, to an extent, and just thought, 'Well, you know, there's no point hiding this.'

Paradoxically, despite the generally accepted advantages of disclosure, participants were actually divided between those prepared to disclose, those who preferred not to talk about the cancer with new partners, others who said they did not know how to talk about it, and others who preferred to talk about it only after a sexual encounter had begun. Other

participants described avoiding sexual encounters since treatment due to embarrassment and shame.

While disclosure may ameliorate the pressure of a sexual situation in which a man may not be able to perform unaided, some men felt that disclosure may prohibit the development of a more serious relationship with a new sexual partner. As participant 8 explained:

I mean it's like you've gotta have somebody fall in love with you and fall in love with, without having any sort of sexual thing - tricky under any circumstances and whatever your sexual orientation is - and not, and say, 'Well we're not gonna have sex'. And then you go, 'Okay, well now that you love me I can tell you that we won't be able to do the following things'. I mean it's putting another pressure on a partner.

New sexual relationships raise new challenges leading to feelings of uncertainty and inferiority, and in some cases inhibiting the pursuit of new sexual relationships at all. Several single men described avoiding casual sex for the very reason that it could lead to judgment and embarrassment about sexual performance, and described pursuing an established romantic partnership with an understanding partner as one way to counter this situation. Participant 13, age 52, was one of the men who moved towards favouring long-term relationships:

I would be less-inclined for something completely random the way it wouldn't have bothered me in the past because I can't produce the same physical immediacy that I could have in the past. So I would be more inclined to some greater physical intimacy or

relationship type stability. Yeah. That would have been my focus previously.

In contrast, several men in relationships at the time of diagnosis described how their subsequent inability to perform sexually had led to the negotiation of an open (non-monogamous) relationship. Participant 32, age 58, was not able to achieve a satisfactory erection and described the serious emotional strain of these difficulties on his relationship. He had insisted that his partner have sex with other men:

The relationship is still fine. I feel that I'm letting him down a bit 'cause he was also very sexually active prior to me being inactive... it's a monogamous relationship, to the degree that, if he feels like having sex with somebody else, I, I don't object... I think at times he's quite disappointed but he's very understanding.

The ways in which gay men's sexual and relationship lives may be affected by prostate cancer are as varied as the forms of sexual and intimate relationships that gay men form. Importantly, however, we wish to emphasise that none of the men was unaffected in thinking through the implications of his cancer treatment for forming or maintaining a relationship.

The Fear of Recurrence and Rejection of ‘Survivorship’

Participants reported experiencing a shocked or dazed feeling after diagnosis, and several questioned whether this feeling and the anxiety at the prospect of having cancer had led them to make hasty decisions about treatment options, given the diversity of treatments available, and varying outcomes on sexual function and continence.

FEAR OF RECURRENCE

Participant 15, age 51, in speaking about the diagnosis, said:

I think it was more just the shock of everything that was happening. Open surgery and everything afterwards.

These thoughts were heightened for those whose outcomes after treatment were less than promised or anticipated. Indeed, for some men, doubts about treatment decisions made at the time of diagnosis were the source of ongoing anxiety, doubt and anger.

The sudden changes brought about by diagnosis included very specific consequences for men’s relationships with their partners, and on the way they thought about their futures. As participant 20, age 54, said:

But, yeah, I know I was in a relationship at the time and it was a big impact on us. Yeah. So, you get scared, obviously. Extremely uncertain of the future and, yeah, and, ‘Why, why me?’

One of the frequently reported fears men diagnosed with prostate cancer have is of the cancer recurring.^{[41], [52]} As Torbit et al. found, worse physical symptoms lead to higher fear of recurrence, but that better self-efficacy and satisfaction with the treatment mitigated that fear.^[41] In this study, some men acknowledged the possibility of recurrence:

When you’re told you’ve got cancer, you may have it removed and think you’re okay. You still have in the back of your head that you have cancer and you may still get the secondary growth. So the whole perspective of long-term planning and that, that all goes out the window. And my approach now is, every day – make it wonderful. (participant 35, age 60)

Mortality loomed large for many of these men, an extension of the imposition of aging that prostate cancer, an ‘old man’s disease’, brought with it. Even for those men who had been told they had been ‘cured’, perceptions about the future had fundamentally shifted. As participant 25, age 65, said:

According to my specialist, they got everything so there’s nothing there to worry

about, but it still sits in the back of my mind, you know, ‘Is there another, is there another little piece that’s gonna flare up?’

In contrast, for some men, the experience of prostate cancer often meant living in such a way as to avoid thinking about the cancer, including not thinking about or planning for the future. As participant 17, age 67, said:

But, no, I, I don’t sort of worry about it or, or anything else like that. I, I figure that, if it’s, if it comes back somewhere else well, that’s life Doris, get over it!

It is not always that simple, as participant 35, age 60, explained:

Of course you always have that [fear of cancer] because, when I saw him, the surgeon, first visit post-op, so first visit as an out-patient, I asked him very clearly about how much cancer there was and the margins, and the spread. And he clearly said to me there’s no evidence that it’s spread into local areas like the bladder, bowel, bones. And I said to him, ‘So I can now say I’m cured?’ and he said, ‘Oh no. We never say you’re cured.’ And I said to him, ‘I know because if I get a secondary and you’ve told me I’m, I’m cured, I’ll sue you.’ So he said, ‘True.’ And he said, ‘Five, 10 per cent risk you might get a secondary.’

experience of prostate cancer in that way appeared incommensurable with the way many of the participants described coping with the uncertainties created following diagnosis and treatment for prostate cancer. These participants were at different stages of recovery, and prevailing ideas about what constitutes cancer ‘survivorship’ for health professionals resonated differently with each man. However, many revealed ambivalence toward the notion of survivorship. For example, participant 26, age 42, said:

I’ve never thought of it like that actually. I just think of it as a hideous kind of experience that’s gone. Like, you know, you’ve got through. I don’t really, no. I don’t really see myself as that really. Although, you know, people probably might say that. Like quite reasonably would say that. I don’t, no, I don’t see myself as a survivor.

The dominant impression given by the participants was of a desire to ‘move on’. As participant 29, age 54, said:

No. It’s not really surviving. It’s just something I had to deal with and something that had to happen. Yeah. So it’s gone now.

Participant 30 made a similar point:

I just feel as though that this is something that I’ve had and I’ve got over it, and now I don’t have to think about that anymore, and I can just sort of keep ploughing on.

REJECTION OF SURVIVORSHIP

Whereas discourses of survivorship are common in accounts of most cancers, framing the

Among these men there was no identification with narratives of having overcome or survived cancer; nor a sense in which prostate cancer might serve as a site of social or political

meaning or support. Rather, many men interviewed described the experience of prostate cancer as one of isolation, loss and despair, from which they would prefer to move on, rather than dwell on the negative consequences or the championing of better outcomes for themselves or other men. In other words, 'moving on' meant not so much leaving the cancer behind, or successfully adapting to a new set of sexual and relational circumstances created by the sexual and physical side-effects of treatment, but simply avoiding thinking any more about it.

Participant 20, age 54, gave more tangible reasons than most to detail this liminal state, as he was at the time of interview in treatment for advanced prostate cancer:

Like my test results were really good up, good up until just last week and then you get, then you get some negative ones, and it sort of knocks you back again, yeah. I'm, I am a little bit scared about what's gonna happen if all these drugs don't work 'cause I'm on the last lot that you can really use. So, at the moment, the chemo's working really well on the tumour, on the prostate tumours and the lymph nodes but it's not working on the bone cancer.

Moving on, or not thinking about prostate cancer, was not an option for participant 20; he is 'living with prostate cancer' in a very direct, daily, and ongoing way. All these men must deal with the side-effects of treatment and the consequences for their daily sexual and social lives. This can be better described as 'living with prostate cancer', not surviving it.

Navigating the Health System

The men in this study spoke at length about their experiences with the health system, from regular testing, diagnosis, biopsies, surgery and recovery. In this section, we will discuss three main themes. The first is the initial reaction to cancer. The second is the importance of the relationship men described with their specialists. Third is the unique circumstances of being a gay man navigating prostate cancer as a medical and health field.

DIAGNOSIS

Participant 7, age 58, clearly described the initial feelings most men may experience when diagnosed with cancer, indicating how some men might be led to make quick, rash decision, or to believe so in retrospect:

It was a bit difficult to hear that I had cancer 'cause cancer obviously is the big C-word and you don't tend to think what degree I've got cancer. My immediate thought was, 'I want the cancer out,' but the thinking is, the support group told me and the medical people, and especially the urologist, is, 'Hang on. Don't jump the gun. We need to think this through because we need to do plenty of tests.' But, you know, as a patient sitting there and you've been told that you've got cancer and you need surgery, you just want it out.

Participant 29, age 54, described the similar mental impact of the cancer diagnosis, emphasising the 'alien' character of cancer:

To know that inside your body there's these little cells just breeding away. That would, no. I'd rather just, once I found out I had it, I just wanted it out. I wanted it gone.

The language these men used to describe cancer and their desire to see it removed as soon as possible was common, with many participants describing the immediate preservation of life as outweighing other considerations about the consequences of the confusing array of treatment options and sequelae. As participant 12, age 50, described:

Well sexual drive, getting an erection, was something I was sort of conscious of but didn't table at that point, 'cause I had a bigger concern [that] being cancer.

Unfortunately, not raising these concerns at the outset might lead to larger dissatisfaction once the cancer is taken care of. Once the cancer is under control, sexual dissatisfaction and frustration can become the most important negative influences in a man's life.

When asked if he had concerns about side-effects, participant 29 said:

No. I'd rather get rid of the, get rid of the cancer.

Participant 31, age 58, summed up this fear of cancer when he talked about his biggest concern when he was diagnosed:

That it was cancer and that it would spread, and you can die from it.

Participant 35, age 60, said:

Mind you, when someone says ‘cancer’, because we live in the society and cancer’s got those awful, you know, beliefs and views around it, it’s still a bit of a shock. When I was told I had cancer, and that was on the biopsies, I clearly made the decision, you know, within a second, that I would have it removed.

This urgency to be rid of the cancer might spur some men to make decisions that might be regarded as an error in judgement with hindsight.

Despite the seriousness of a cancer diagnosis, and the strong emotional reactions that it can prompt, including the ways in which important considerations about treatment side-effects might be diminished in the face of the shock of cancer itself, two of the men in this study reported that they were informed that they had cancer over the telephone. Participant 28, age 53, explained:

What I did find interesting, though, was when they told me I had cancer. They did it over the phone and, you know in all HIV testing, you’ve always had to go in because, you know, you might not cope with it or something like that. So it was quite a surprise to me when he [specialist] said, ‘Oh hello, it’s so and so on the phone. The tests have come back and you’ve got cancer’. It’s like ... I thought, ‘On the phone? You didn’t even get me back in.’

THE SPECIALIST

Many of the men praised their specialists for a well-managed experience. Unfortunately, others did not. As participant 30, age 63, noted, there is an implicit trust in the medical system that can often lead to patients not asking more questions, or making hasty decisions:

You know, I trust the people that I go to and they’re trained in what they do. And just like the oncologist that I went to was considered one of the best and so I sort of went, ‘Well he’s done all that training and he’s one of the best so that’s ... what he says I do’.

Unfortunately, when a specialist overpromises on recovery results, there is much disappointment, as participant 24, age 68, explained:

He [the specialist] was talking all affirmative. So he said, ‘Give me two months,’ I think it was. ‘You’ll be right. You’ll be on the go.’ Or was it six months? Something. Anyhow, you’d be all right. But it didn’t. Nothing’s ever—it was a failure I reckon this operation.

For some gay men, such as participant 18, age 54, previous experience with HIV and AIDS as a public health issue has provided him with a unique perspective on trust in the medical system:

In terms I think of having watched the evolution of treatments and the improvements [of HIV]. Having seen the medical profession as the enemy at the beginning of the epidemic, you know, gives

me a certain perspective when I'm dealing ... you know, I'm, 'You're not God sitting on the other side of the desk telling me what I need to do. And, in two years' time, you're gonna be telling me something different to what you're telling me today.' And to know doctors don't have all the answers and treatments can improve. So yeah, I think having lived through that whole changing scenario gives me a different perspective to doctors.

The comparison with HIV cannot be greater than when it comes to issues of sexuality. Several men noted reluctance on the part of some health practitioners to talk about sexual consequences of prostate cancer:

He [the doctor] seems to have this thought that what you don't know won't hurt you. (participant 17, age 67)

A few participants were not informed about some of the basic consequences of prostate cancer surgery. Participant 2, age 55, said:

The biggest thing I didn't expect and the surgeon didn't mention it until well after he'd consented me and I was in hospital, it was the night before surgery and he said, just as he walked out of the room, 'Oh, and, by the way, you'll lose a couple of inches of your penis 'cause I've got a, you know, taking out your prostate and I've gotta re-join the plumbing.' And, of course, it made perfect sense but nobody told me. And that was kind of the icing on the cake. And I thought, on top of everything else ... So that was the biggest surprise.

Similarly, participants 20 and 21 reported that they were not explicitly informed that they would not be able to ejaculate after surgery.

When I was having a [previous] TURP procedure, I wasn't even told right 'til the last minute, when I was getting done, that, you know, my ejaculation could go backwards, for example, into your bladder. There was no even, they didn't, I guess their thoughts were of you don't really have a choice. (participant 20, age 54)

I s'pose one thing that came up much later that I hadn't realised was that, when you take the prostate out and you, you didn't come anymore, there was no more ejaculation, and I hadn't realised that. (participant 21, age 61)

In a comprehensive summation, participant 2 described his feelings about the treatment he thought he should have received from his specialist:

I think it's inexcusable that no-one can really tell you anything... I think that there needs to be a baseline to at least be able to explore with the person in front of you what kind of extra support, assistance, advice, information they might need and then be able to match them to what's available. I think, but, and I think that starts from diagnosis, so I think that probably takes you back to urologists. And I think urologists and radiation oncologists are central in this. They're gonna be the people that everyone will consult with so I think they're kind of at the centre of the system that I would be designing and implementing to make sure that people are getting matched to the information they need.

The literature notes that many patients at these moments of diagnosis are so confused and disoriented that much that health professionals might say may not be taken in or ‘heard’ accurately.^[42] That is understandable, but the persistence of this idea of not being informed, particularly about sexuality side-effects such as shortened penile length, loss of ejaculation, consequences for anal intercourse, does resonate with the more general and acknowledged neglect of sexual issues in cancer primary care.^{[42],[43]} Given that gay men also report health professionals and services as not really aware of, or tuned into the particular issues gay men face in prostate cancer discussed earlier, there is good reason to believe that men may not be being fully informed by health professionals; we just do not know how frequently this occurs.

A UNIQUELY GAY PREDICAMENT

As other research has found, gay men tend to be diagnosed at an earlier age.^[7] One of the possible reasons for this might be the more regular HIV and STI testing regimes gay men follow. When gay men go for their regular HIV/STI tests, it is possible that their primary health medical practitioners are exploring other aspects of their health. Participant 28, age 53, provided a good example of this:

‘Cause that’s what I did. I was going in for an HIV test and I said, ‘Do my PSA as well’.

However, one of the first obstacles many gay men face in consulting with specialists and other healthcare professionals about prostate cancer involves the decision on whether or not to disclose information about their sexuality. Quite a few men

interviewed had not seen the need for disclosure. Participant 21, age 61, said:

He never asked, I never said.

There may be other reasons for not disclosing, as Participant 19, age 61, suggested:

I just felt like I don’t think they need to know. If I lived in a bigger town, it might have been different but, when I’m in a small community, I’d rather people didn’t know.

Participant 2, age 55, worried about embarrassing his surgeon, despite the fact he had specific questions about the consequences of the surgery for his sexual life:

I didn’t think there was anything useful in embarrassing or making my surgeon feel uncomfortable before the operation. I wanted him to be focused on the technical job. But there was nowhere to go to get, ‘How is this for gay men?’ You know, ‘What do you experience? What’s it like? Who do you talk to?’ There was nothing. And, and I did spend a lot of time looking online for resources and information, apart from Male Care and that little sort of monograph.

When there is no disclosure, assumptions about heterosexuality can mean other issues about sexuality and cancer cannot be canvassed.

Another assumption can be that the patient is not sexually active, as participant 4, age 67, explained:

I don't think it would have mattered what I was, yeah, they weren't very interested. But the one that gave me the diagnosis, I got quite frustrated with him and I actually said to him, 'Well perhaps, unlike yourself, I am still quite sexually active,' and I said I wasn't prepared to forfeit that!

Participant 9, age 67, described his experience in the public health system where a medical practitioner made a similar assumption:

And there's one doctor who, he had a sheet in front of him and he had to ask me all these questions. And it was about pain and pain management. And then he came to this other section, and I couldn't see the form. He was just reading it out to me. And he said, 'Are you married?' And I said, 'No.' He said, 'We can skip that section', and he went onto the next section. So the whole section I think was about sexuality. This bloke just thought, 'Well, he's not married so he's not having sex', and I didn't really feel that I wanted to say that I'm having regular sex with a male partner. I mean, I perhaps should have, but you're in a very unpowerful position there. You're frightened. You're in pain. You're dependent on this person, you know, managing your symptoms and stuff.

Participant 9 clearly explains the calculations gay men make in weighing up whether or not to raise questions about their sexuality or reveal their sexual identity. Those men who had partners to support them in the process were more likely to be open about their sexuality, as participant 35, age 60, said:

But my partner was visiting me regularly and the surgeon knew I was gay. My partner went to pre-op interviews, you know, appointments and that with me.

Not only do gay men encounter obstacles in the hospital system, but the broader prostate cancer support system can be problematic. It is not always possible for gay men to find a suitable support group. Participant 11, age 52, described his encounter with such a group:

I'm a gay guy. I went to a prostate cancer support group here where, like my father, 75-year-old men with their wives to talk about intimate things. [If you were to talk about gay sex] You'd be shot.

Participant 8, age 67, also tried his local gay community organisations for support, but with no luck. The focus for gay community organisations has long been largely on HIV. There have been efforts of late to broaden this support base, but it is a work in progress.^[44] He said:

I couldn't find anybody everywhere in the gay movement who was the least bit interested in the fact that I had prostate cancer, there were no support groups, there was nothing... and there's also no literature on it, and they were just like, 'Oh look, I'm sorry. We're busy dealing with AIDS. We haven't got time with that'.

Relations between health professionals and patients, especially good communication, are vital to the successful treatment of, and recovery from, prostate cancer. Disclosure of gay men's sexuality is central to improving these relations and guaranteeing that best treatment decisions are taken, and both parties know what is in store, and can work, fully informed, toward achieving the best outcome.

The Experience of Depression and Anxiety

All men living with prostate cancer can also experience depression and anxiety as a consequence; not all do, but it is a serious concern in the literature.^[45] The possibility of depression after prostate cancer diagnosis treatment is heightened by earlier experiences of depression.^[45] We asked specific questions about gay men's experiences of anxiety and depression, prior to, during and after diagnosis and treatment for prostate cancer.

Relatively few men described being clinically diagnosed with anxiety or depression during treatment, although many described an emotional and psychological turmoil wrought by a cancer diagnosis and the side-effects of treatment. In keeping with the fact that it is the treatment side-effects of prostate cancer with which these men mostly described experiencing difficulty (particularly as these affect sexuality), depression and anxiety were most pronounced in the months and years immediately after treatment.

This is unsurprising: as the threat of the cancer recedes, men will slowly learn about the extent to which their sexuality has been affected.^[3] It may take more than 12 months before those who have received a prostatectomy gain a clear picture of the extent to which they may regain capacity to achieve an erection. In contrast, men who have been treated with radiation therapy may experience diminishing sexual function as time from treatment progresses.^[3]

Several men described becoming depressed during the recovery stage when things were not returning to 'normal' (usually meaning a pre-prostate cancer state, or as promised by the relevant specialist.^[46] For several men, life was characterised as 'before' and 'after' treatment:

I don't enjoy life as much as I used to.
(participant 9, age 67)

Men also noted a focus on the physical effects of treatment initially, with the psychological dimensions of those changes left for later in the process of recovery. As participant 15, age 51, said:

...everything was very physical and mechanical but there was no support psychologically afterwards.

Other men described frustration with being told their problem was depression, feeling that they were not being listened to by their specialists. Participant 5, age 66, recalled an experience with his urologist, who insisted that he was depressed, while participant 5 insisted that

...the problem wasn't between my ears, it was between my legs. And he sort of discounted that as much to say, you know, 'I know best', sort of thing. And I never ever felt confidence with him as an urologist.

Instead of medication for depression, participant 5 found relief from his distress in the provision of a sling fitted to his bladder to solve his incontinence. Among those men who reported a previous clinical diagnosis of depression, the effects of the physical illness and treatment of prostate cancer were viewed as less profound than the depression itself. As participant 14, age 67, said:

I don't consider it anything like the problem the depression's been... If I only had the prostate cancer and the diabetes, I wouldn't have a thing to worry about. It's the depression is the worst by far. Ten times worse than tackling these other two.

Other men who described being depressed similarly resisted the notion that their depression was related to their prostate cancer in any simple or straightforward way; rather, they emphasised the impact of their illness on partners and family, and the contribution of other sources of conflict or difficulty in their lives to which the cancer added further burden:

There's other issues with me personally. Family and, yeah ... it wasn't just because of the prostate cancer, it was a combination of four or five things. (participant 7, age 58)

It is clear that prostate cancer has profound effects that cause major life disruptions, and that these have mental health implications. As participant 7 said:

But, yeah, there's a lot of, lot of anxiety, which manifested in chest pain and shortness of breath, and not sleeping, and, you know, everything snowballs and then you, you get to a point where you, well, I was

in hospital for a couple of days just to try and calm down. And then I thought I was having heart attacks but they kept running tests, and they kept saying, 'It's not your heart, it's not your heart'. And then I went to heart stress tests, you know, and running machines, and all that sort of thing, so I, I volunteered to do as much testing as possible but it all came back to stress and anxiety.

This can become quite serious. For instance, participant 27, age 48, described his suicide attempt a year after his surgery:

...when things weren't properly working like erections and that type of thing, and like the sex wasn't there... I had a sleeping tablet and then I went and had a few more, and then just something like that happened, and the next thing I know I could hear some people talking and the next thing, I woke up and I was in hospital.

However, as already noted, relatively few men in the sample had been diagnosed with depression or anxiety following treatment for prostate cancer, despite the obvious distress many men experienced.

While we expected to find more men discussing an experience of depression following treatment for prostate cancer, men were reluctant to categorise their experiences in those terms. Some men had embarked on counselling during the process of being treated for prostate cancer:

I only went through the, about 10 weeks of counselling during the time when I was trying to deal with the cancer (participant 20, age 54)

However, the majority of participants had not. Indeed, some were defensive at the suggestion that anything they experienced could be related to depression and cultivated a 'no nonsense' attitude to the idea that prostate cancer might have an impact on their mental health. When participant 17, age 67, was asked if he had been treated for depression or anxiety, he said, somewhat ambiguously:

Not, not been treated. I'm one of these people that, I can't be over-sympathetic with a lot of people. Get over it Doris!

Participant 10, age 60, similarly refused the label of depression to describe his unhappiness:

I wouldn't say depressed. I just felt unhappy with myself. That didn't last very long. My friends are really good, you know. Put me back to earth and, you know, I just got on with life.

Asked if he was ever treated for depression or anxiety, participant 11, age 52, said:

Oh God, no, no... I was never depressed!

These men tended to emphasise traditional masculine traits such as emotional restraint and stoicism in the face of illness, and saw depression as a state of being that was distant from them:

I don't know what depression feels like... And that's not in my DNA. I've never been like that. (participant 12, age 50)

However, some of those who emphatically denied any depression and anxiety later mentioned instances where they either sought

professional help or confessed to feeling some form of anxiety or depression. For example, participant 12, who mentioned that he believed depression and anxiety were not in his DNA, had consulted a psychologist before and after his surgery. He described the purpose of the consultation before the surgery as an opportunity to process the significance of the cancer diagnosis and prepare himself for the unexpected. In the months after the surgery, he returned to the psychologist to seek reassurance on whether he had made the right decision.

The gay men in this study revealed a range of mental health side-effects to their diagnosis and treatment. Not all suffered from depression, and if they did it was not always deep or enduring. Some sought help; others did not. However, when we add the findings from this study, noted earlier, on experiences of marginalisation, exacerbated by the lack of information on gay sexuality, and the discrimination by some health professionals and systems, there is a distinct possibility that mental health and well-being consequences for a gay man living with prostate cancer are more complex and potentially worse.

The Potential for Building Resilience

Resilience may consist in anything that mitigates the impact of stress on health and well-being.^[25] Following Meyer, resilience among LGBT populations may be conceived in relation to *minority stress*. As is evident, experiences of marginalisation and silence in the diagnosis and treatment of prostate cancer indicate that these men experience unique forms of stress. Here, we explore some of the ways in which these men managed and responded to those forms of stress.

The manner in which some men saw themselves as agents actively managing prostate cancer was one strategy for coping. Participant 8, age 67, exemplifies this:

It's a question of how you approach the cancer and how you are going to deal with it. And, if you've got a, I mean I used to sit there in some waiting rooms waiting for the, getting the hormone injections and I'd see these people. And they'd all decided they were dead... And I'd look at them and I'd think, 'My God, you're about 10 years younger than me. I mean what the hell's...'. So I think it's got to do with, completely to do with, with how you approach the disease myself.

Deciding how to feel about the situation helped some of the men in thinking about their sexuality as well. Even though participant 5, age 66, was not able to perform sexually, he described how he did not allow that to affect his life negatively:

I think emotionally I'm, well, I think I'm okay but, as I say, I've got enough friends and family to support me. And the gay men I do know are both good sexually and good friends. If I really stop and think about it, I've got far more plusses in my life than I have negatives, you know.

It is important to note the social and sexual role played by gay friends here.

Participant 12, age 50, who was undergoing hormone therapy to slow the advance of bone cancer following an earlier prostatectomy, said in response to a question about his quality of life:

With not getting an erection? It's a fact. It's frustrating. It does my head in. But what do I do? On a personal side, I'm very happy with my life, my job. Yeah. I have goals and set to achieve them.

Alleviating the stress of prostate cancer lies not only in returning bodily functions back to a perceived normality, as far as is possible, but also in addressing a broader idea of mental health and well-being throughout the process. Participant 31, age 58, for other reasons, had access to mental health support, which prepared him for the process:

I have depression and anxiety for which I have medication and therapy. That is related largely to some sexual abuse stuff that

happened when I was younger. However, I'd, I'd also say I talked with my psychologist and my psychiatrist about the, emotionally preparing myself both for the operation and after.

Such preparation is a wise strategy, but thinking about such preparation as treatment decisions are made and before treatment is rare. This suggests that adding mental health issues to an assessment of treatment options should be added to the clinical consultations that precede treatment itself.

For other men, knowing what was happening was important:

Well, knowledge is my first thing. I wanna know everything. I want to, I want the stats on all options and, you know, I get a certain reassurance if I could see tables. Every possible scenario all nicely tabulated for me and I can plot myself. 'Okay, that's where I sit'. That would be my first coping method to just quantify the problem. (participant 18, age 54)

This desire for knowledge and information is not specific to gay men and has been noted in the literature, sometimes regarded as a masculine trait (although we are sure women want to be well informed about their illnesses and treatments). What is different for many gay men is their level of health literacy as a result of thirty years of the HIV epidemic.^[26] That has focused many gay men's attention firmly on their health and their sexual health in particular.

Other gay men living with prostate cancer are sources of support:

I go to nude yoga [Melbourne men-only classes] so it's fairly hard to go to nude, nude yoga when you're incontinent. So I spoke to my, to both of my instructors and sort of explained the situation, and they said, 'Look, this is not a problem. You can still come along. You can wear your undies. You can wear your pad. As long as you feel comfortable with it all'... I had their support, and then, as soon as I became dry and things like that, then they were the first ones to sort of say, 'I was really pleased to see that, you know, you're starting to work, you don't have to do it all anymore' and stuff like that. So I feel as though, through the process, I've had really good support. (participant 30, age 63).

Indeed, for participant 30, a fellow yoga class member was directly of help:

I think probably by meeting a fellow that I go to yoga with who had the procedure done 10 years ago and, when he found out that I'd had mine done, we had sort of a, we went for coffee and we sort of talked for a couple of hours. And he put me at ease a lot about his body and what had happened to it, and how it would heal.

Some men seek out alternative therapies:

Alternative therapies that complemented what I was doing with the medical profession would have been very helpful ... And even now the medical doctors have said I've done really well considering what state I was in, yeah. Mostly diet-related but there's also a couple of therapies in Germany that, where they do it under heat and they're the ones I was most interested in, and I actually went across to Germany and had, I've had two lots

of the treatments over there. (participant 20, age 54)

Men also talked about taking responsibility for themselves:

I've gotta just apply myself. I go swimming in the mornings, most mornings. Try and eat healthy. Try not to drink during the week. But that's a choice, isn't it? They are the choices I make. If I really am serious about it, I would do that blitz on it. But, you know, life balance. (participant 12, age 50)

Some men noted that they were not the kind of person to suffer emotionally from a challenge, and described 'taking things a day at a time'. There was an attitude of pragmatism, optimism, acceptance and realism. Getting over prostate cancer, and accepting it as a fact of life, was in one way, a motto. As participant 6, age 66, said:

And I tell that to a lot of people, you know. Get up. If you're feeling crook and sorry for yourself, bloody get up, get dressed and go out, get out and enjoy yourself.

Participant 3, age 59, summed it up nicely:

But I think there, I think there's kind of a, I won't call it 'mental toughness' necessarily and I don't really like the word 'resilience' either but I think there's a, I have a capacity to ... to just, 'Okay, what's, what's the issue? What do I need to know about it? What do I need to do to get through this?' It's kind of, I think that's kind of how I managed all that.

We would also note here the difficulties gay men have in dealing with specific post-

treatment sexual problems, in negotiating the health system (discussed earlier). These add to the circumstances that might dent even the strongest person, but many men in the study revealed determination to move on:

And, and so with, in my case, you know, yes, it was disappointing. Yes, I'm, I wish things had have been different and, yes, I wish I could do other things, and all that kind of thing, but I can't so that's all there is to it. Get over it! And, and if, and if men are in a relationship whether they're straight or, or not, you know, there's no point being miserable about it 'cause you only make everybody around you miserable as well. That's my view on it. (participant 17, age 67)

Recognising what gay men, particularly in the age group most affected by prostate cancer, bring to the experience of prostate cancer diagnosis and treatment is useful to recognise and utilise. Coming to grips with a sexuality not regarded as 'normal', being gay in a homophobic world, living through the HIV epidemic, and managing a life on the margins produced its own kind of resilience, something that, if recognised and understood, can be better brought to bear on the process of recovery

Discussion

We set out in this study to investigate the experiences of Australian gay men as they are diagnosed with, treated for and recover from prostate cancer. When the first author started research on this issue nearly eight years ago, he asked a leading men's health organisation in Australia if there could be differences in gay men's experiences of prostate cancer. He was told 'No, after all, they are men too'. That might have been a 'politically correct' response, and nice to hear. But, it was wrong. Subsequent research by this team and colleagues in a number of studies here in Australia, Canada and the USA, cited in this report, have now revealed small but significantly different clinical outcome differences for gay men. Similarly, a number of studies (also cited in this report) have now found worse quality of life outcomes and effects on sexual practice for gay (and bisexual) men living with prostate cancer.

Now, in this report, we have added to that body of evidence new findings on specific sexuality consequences, experiences of health systems, more detail on mental health consequences, and a broader understanding of gay men living with prostate cancer not just as individual patient experiences but as social experiences embedded in the sexual and social world of gay community.

Central to the findings of this study is the significance of sexuality and sexual identity for gay men living with prostate cancer and the impact of diagnosis and treatment on their sexual and social well-being. A number of distinct themes emerged from this study that

directly or indirectly relate also to gay men's mental health post-prostate cancer treatment. First, sexuality and sexual identity play an important part at diagnosis and throughout the treatment of prostate cancer, and the experience of gay men is different from that of heterosexual men, whose experiences dominate in the literature.

Secondly, the mental health consequences of prostate cancer for gay men are best understood in relation not just to depression, anxiety and fear of recurrence, but also to the ongoing threat the illness poses to gay men's sense of identity and their relationships with other gay men and their gay community networks. This demonstrates the particular significance of sexuality in understanding the effects of prostate cancer on gay men's mental health and well-being. These are individual, relational and social effects, not simply the experiences of the individual man.

Thirdly, both mainstream and gay-specific health providers are currently not adequately addressing the unique needs of gay men living with prostate cancer. The experiences of gay men can be, at best, marginalising and unsupportive and, at worst, discriminatory. In sum, our findings strongly suggest that, in order to improve the support for gay men living with prostate cancer, substantial changes need to be made to the current processes of diagnosis, treatment and access to support to address their unique experiences and needs.

There are seven themes explored in this report. Here we summarise their findings. The first is the impact of prostate cancer on sexual practice. The findings indicate that loss of erectile capacity, varied experiences of erectile dysfunction, and the bother of loss of ejaculation are serious for these men, but they are not the only consequences of treatment. Beyond these issues common to most men, for gay men there are further issues related to anal intercourse, in terms of loss of pleasure, difficulties in negotiation of sexual role for themselves and their partners, and finding a psychological and relational path through the dent in their sexual identity as gay men, and as once sexually active men struggling with bodies that no longer function as they once did.

The second theme focused on coping with aging and prostate cancer. On this issue, participants described difficulties reconciling the ways in which prostate cancer is imagined as a disease associated with aging, with the sexual lives and the social worlds in which they have been living as gay men. These men are negotiating a premature sense of aging, a condition which is not simply an inevitable experience of the disease itself, but which leads to the probability of a distinct and valued social world starting to close down early.

In the third theme, we reported on men's experiences of negotiating relationships and accessing social support. It is now clear that the ways in which gay men's sexual and relationship lives may be affected by prostate cancer are as varied as the forms of sexual and intimate relationships that gay men form. Importantly, however, it is also clear that none of the men we interviewed was unaffected in thinking through the implications of his cancer treatment for forming or maintaining a relationship. This

issue of negotiating sexual and emotional relationships, whether primary, casual or combinations of both, becomes more complicated when the future of life after prostate cancer diagnosis and treatment are considered. Conceiving of a future that includes sex and intimacy becomes the focus of men's attention after the immediate urgency of obtaining treatment has passed.

In dealing with the future, an important fourth theme emerged concerning the fear of cancer recurrence, which also highlighted a discomfort with the idea of cancer 'survivorship' among these men. Moving on and/or not thinking about prostate cancer were the most common strategies for coping with the fear of recurrence, yet men lived with the consequences of prostate cancer in very direct, daily and ongoing ways. Whether men minimise the energy they put into thinking about prostate cancer or inhabit a liminal psychological state with cancer as a palpable presence, all men must deal with the side-effects of treatment and the consequences for their daily sexual and social lives. This can be better described as 'living with prostate cancer', not surviving it. Living with prostate cancer is an existential space, a comportment in social life, and a daily practice consisting in all the above, whether fear, preoccupation, or defiance.

Gay men in Australia have for the last thirty years been living in communities focused on notion of 'living with HIV' was adopted as a way to refuse ideas of 'sufferers', 'victims' or 'survivors', which were often accompanied by the stigmatising of those infected with the virus. Adopting this phrase was both a political strategy and a collective determination to fight the virus together in every way. The phrase 'living with', therefore, has a special salience for

gay men that those other phrases, including survivor, do not and will never have so long as HIV is present in our world. That said, strategies and programs that frame the experience of prostate cancer as survivorship may gain more traction among gay men if these men experienced a sense belonging to the fields of prostate cancer medical and health practice and programs that support non-gay men.

The fifth theme examined how gay men navigate the health system from the moment they are diagnosed with prostate cancer. Relations between health professionals and patients, especially good communication, are vital to the successful treatment of, and recovery from, prostate cancer. Gay men experience forms of exclusion from the moment of diagnosis, e.g. being assumed to be heterosexual, through successive practices of treatment, care and management. Disclosure of gay men's sexuality is central to improving these relations and guaranteeing that best treatment decisions are taken, and both parties know what is in store, and can work, fully informed, toward achieving the best outcome.

Yet, sometimes, gay men are compelled to conceal or manage information about their sexualities in clinical settings in ways that perpetuate a discursive silence regarding their experience. There is a need for significant change here in many health professionals' current practice. Fortunately, things are changing a little. There are now gay men's support groups, and the gay community organisations are trying to broaden their scope to include things other than HIV and AIDS. Health professionals are also seeking more information on LGBT health, and an evidence base is slowly developing that can better inform

their practice. We hope this research report will contribute to those continuing developments.

The penultimate theme explored gay men's experience of depression and anxiety. We know that gay men are more likely to experience both 12-month and lifetime depression than other men.^{[27],[47]} This may lead to a greater possibility of an experience of depression (and/or anxiety) for gay men undergoing treatment for, and recovering from, prostate cancer. The potential intersection of these suggests that health professionals should be aware of, and plan for, a greater possibility of occurrence from the start of treatment for gay men. The gay men in this study revealed a range of mental health side-effects of their diagnosis and treatment. Not all suffered from depression, and if they did it was not always deep or enduring. Some sought help; others did not.

It is also known that mental health for all LGBT people can be worsened by experiences of stigma and discrimination.^{[24],[25],[47]} Meyer's concept of minority stress in relation to sexual minorities offers a powerful conceptualisation of the social determinants of LGBT mental health.^[25] Therefore, when we add the findings from this study on experiences of marginalisation, exacerbated by the lack of information on gay sexuality, and the discrimination by some health professionals and systems noted earlier, there is a distinct possibility that mental health consequences for gay men living with prostate cancer are more complex and potentially worse. This requires some rethinking about positioning mental health more centrally in the framing of appropriate treatment for, and recovery from, prostate cancer.

However, our findings also suggest a more social approach to thinking about mental health and well-being might be needed for gay men, as the implications of diagnosis and treatment on these men's identities as men living in gay communities are unique to them. Damage to that gay identity can begin the moment a gay man enters a clinic, debating whether to 'come out' as gay and bring his partner, when he asks questions about gay sex, and/or encounters a system and a medical field that is, at best, heterosexist and, at worst, sometimes homophobic. Understanding the mental health consequence for gay men living with prostate cancer needs a reconfiguration, beyond depression and anxiety only, to accommodate all these aspects and determinants of mental health and well-being.

Gay men do bring significant resources to this process at individual, interpersonal and social levels. This is the focus of our last and seventh theme. Mental toughness and self-reliance were the dominant strategies of coping identified. Further, emotional openness and hope or optimism were not present in the way Kwon imagines them to be evidence of resilience in a minority stress model.^[23] Rather, most of these men expressed emotional regulation strategies that entailed not thinking about the future, because it was always shadowed by the prospect of the return of the cancer. Resilience for many of these men then entailed managing expectations of hope and optimism, underpinned by the ever-present threat of the cancer returning.

These strategies were often individualised and not strongly supported by the social worlds in which these men moved. Greater resilience among gay men has been shown to be associated with being in a relationship, having

gay friends, and participating in LGBT community events.^[24] Importantly, concealing one's identity was associated with lower resilience, which was also associated with lower social support, and less help-seeking behaviour. Thus, Lyons has argued that social support and identity concealment need to be addressed when seeking to build resilience in gay men.^[24] The findings of this current study would confirm this as an issue for gay men living with prostate cancer.

Many resources require an individual to access them so as to reap the benefits of 'community resilience'.^[25] Identification with a community is a prerequisite for being able to access and benefit from the supportive resources that might be found there. Further, it involves the institutions, social norms and values that sustain that community to provide resources that aid adaptation to stress. Structural inequalities in LGBT communities will mean that not all individuals in these communities will benefit equally from the compensatory benefits and support provided by identification with that group.^[25] Exclusions on the basis of race/ethnicity, class and gender will deprive some of community resilience. We note that the men in our study, most of whom are largely Anglo-Australian, middle-class, gay-identified men, experienced exclusion on the basis of age and 'sexual disqualification'.^[48]

Whilst aspects of community social support (such as friendship) were available and favourable to these men, there was little in the way of formal institutional information, advice or support, and few cultural narratives that appeared to validate these men's altered identities, particularly with regard to sexuality and aging. Instead, these men displayed a coping style termed 'individual-mastery',^[25] a

sense that they can only overcome obstacles based on their own internal resources.

Where evident, however, these resources come from the lived experience of being gay, living on the margins of a 'straight' world, and living with like others who have built modern gay communities, fought the HIV epidemic and dramatically changed the way LGBT people are dealt with in Australia over the last fifty years (its failure to date to recognise marriage equality notwithstanding). Friends, family, sexual partners and social networks constitute gay ways of living, somewhat akin to minority cultures in multicultural Australia. Recognising and acting with cultural sensitivity in multicultural Australia is now accepted as best practice; the same recognition and action need to be extended to gay men in the field of medical and health practice if we are to utilise the strengths and resources of gay men to assist them in managing their recovery and learning to live with prostate cancer.

FINAL COMMENTS

It is clear from this study and others noted earlier in this report that both mainstream and gay-specific health providers are currently not adequately addressing the unique needs of gay men living with prostate cancer. Systemic discrimination, intended or unintended, in the health system, supported by wider processes of social marginalisation, stigma and discrimination, further undermine the hard-won identities of gay men as they adjust to living with prostate cancer. Gay men also describe the isolation created by a gap in recognition of, and silence about, their experiences of illness by mainstream health organisations, as well as in

most of the support programs and health education resources available.

This discursive silence is sustained in gay community health settings where prostate cancer does not feature as an important health issue in the way HIV/AIDS and sexual health do. As noted earlier, this discursive silence also seems to contribute to a problem in recruiting gay men, and especially gay male partners of gay men, for research on these issues. This potentially inhibits the research still needing to be done on the impact on prostate cancer on gay men. It is clear that health professionals and support and care program providers need greater awareness and training about the issues faced by gay men with prostate cancer.

Finally, we reiterate the need to think about gay men's mental health and well-being in terms that do not focus just on the experience of depression and anxiety, and also recognise the social determinants and the specific relational and contextual factors that affect the social worlds of gay men living in their communities. Moreover, these social worlds provide resources for the resilience that gay men can bring to illness experiences and recovery. This is well documented in the gay communities' responses to the HIV epidemic. Those resources are, in principle, available to gay men living with prostate cancer and could be better brought into play by recognising these different circumstances in making needed changes in the current processes of diagnosis, treatment and access to support to address gay men's unique needs.

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Appendix 1: Recruitment Advertising



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Figure 1: Recruitment Advertisement

Appendix 2: Dissemination Outputs

Conferences:

- Dowsett, G.W. (2015). Psychosocial and sexual needs of gay/bi men and their partners. [Invited Plenary Address] *Oncology Social Work Australia 10th National Conference*. Sydney, 10-12 September.
- Dowsett, G.W. (2015). 'Panel discussion on "sex"' [invited member] *Oncology Social Work Australia 10th National Conference*. Sydney, 10-12 September.
- du Plooy, D.R., Dowsett, G.W., Duncan, D., & Prestage, G. (2015). Mental health, resilience and sexual recovery among gay men with prostate cancer. *Health in Difference. 9th National LGBTI Health Conference*. Canberra, 13-15 August.
- Dowsett, G.W. (2014). Sexual changes following prostate cancer experienced by gay men – a mixed method analysis. *International Academy of Sex Research. 40th Annual Meeting*. Dubrovnik, Croatia, 25-28 June.
- Dowsett, G. W. (2013). Gay and bisexual men living with prostate cancer: Same diagnosis and treatment; different issues and needs. Invited plenary address, panel presentation at *Inaugural Prostate Cancer Foundation of Australia National Support Group Leader Training Conference*. Melbourne, 19 May.

Industry Workshops

- Research dissemination workshop conducted in conjunction with the PCFA and UNSW. (2015, 22 May). Industry stakeholders present were: Movember, Prostate Cancer Foundation of Australia, Cancer Council, Andrology Australia, ACON, Victorian AIDS Council, Living

Positive Victoria, Representatives from PCa gay support groups.

- Cheron-Sauer, Maris-Claire & Dowsett, Gary (comp.) (2015) *Prostate Cancer and Gay and Bisexual Men: Social Science Research and Stakeholders – Report of a one-day workshop*, Sydney, NSW: Prostate Cancer Foundation of Australia, and Melbourne, VIC: Australian Research Centre in Sex, Health Society. [online publication] - http://www.latrobe.edu.au/__data/assets/pdf_file/0003/683535/PCFA_ARCSHS_GB_Social-Science-Report.pdf

Media Appearances:

- Dowsett, G. W. (2014). 'Moving on': Gay men and prostate cancer project. Hide and Seek Program. JoyFM Radio. 8 May. <http://joy.org.au/hideandseek/>
- Dowsett, G. W. (2013). 'Moving on': Gay men and prostate cancer project. Hide and Seek Program. JoyFM Radio. 4 December. <http://joy.org.au/hideandseek/>

Webinars

- Dowsett, G.W. (2015). 'Cancer: It's out of the closet –talking about the experiences of the LGBTI community with cancer.' [Invited Panellist] *Cancer Council NSW Webinar Series*. Sydney, March 25.
- Dowsett, G.W. (2015). 'Cancer & Men's issues – What is different for men?' [Invited Panellist] *Cancer Council NSW Webinar Series*. November March 25.

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