

**GAY MEN AND THEIR EXPERIENCES IN PROSTATE
CANCER DIAGNOSES, TREATMENT, CARE AND
SUPPORT:
ISSUES IN NEED OF NEW APPROACHES**

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& Society



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Introduction

Question

- Might there be differences in gay and straight men's experiences of prostate cancer?

Focus

- The part played by sexual identity and sexuality in living with PCa

Purposes

- Assess the scope of prostate cancer, its diagnosis, treatment and consequences, and what these might mean for gay men and other men who have sex with men.
- Position sexuality at the centre of PCa as a field



MOVING ON
Gay Men and Prostate Cancer
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**IN A RELATIONSHIP WITH
SOMEONE WHO HAS
PROSTATE CANCER?
OR BEEN TREATED
YOURSELF?**

RESEARCHERS AT LA TROBE
UNIVERSITY WOULD
LIKE TO HEAR FROM YOU.

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Framing the issue

Who are gay men and other men who have sex with men (MSM)?

- **Australian Study of Health & Relationships #2, 2012-13**
 - ❑ N=20,094 adult men and women
 - ❑ 3.2% of men identified as gay/bi
 - ❑ 6.5% reported having homosexual experience, and have more lifetime and recent partners than women
- **SSASH** - National 5-yearly survey of Australian secondary students and sexual health:
 - ❑ young men having sex with men rose over last 3 surveys to 11.9% in the 5th survey

Framing the Issue (cont.)

What is the prevalence of prostate cancer among gay men?



One answer -

Among men of different sexual orientations, gay men had significantly higher prevalence of cancer survivorship, about 8% or almost double the prevalence of heterosexual or bisexual men ($P < .0001$). For male cancer survivors, we found gay men to have a significantly younger age of diagnosis (mean age, 41 years) compared with other sexual orientation groups ... However, gay men reported a significantly lower rate of prostate cancer, with 5%, or about 1/3 of the prevalence in other men. Both gay and bisexual men reported a greater prevalence of other cancers. (Boehmer et al., 2011)

Prostate cancer in Australia

Australia

>3,000 deaths
>18,000 new cases
this year
~150 deaths among
gay men each year
~1,000 cases among
gay men each year
>13,000 gay men
living with PCa by
2017

NZ

>300 deaths
~3,000 cases
>20 deaths among gay
men each year
~160 cases among gay
men each year

- Māori men diagnosed
with more advanced
disease; and poorer
survival rates ($p=0.004$)

Prostate cancer among gay men

- **Prostate Cancer Foundation of Australia 2013 Annual Community Survey**
 - N = 1,243
 - 13% respondents with prostate cancer identified as non-heterosexual
- **Private Lives 2 (ARCSHS)**
 - Gay men 40+ 2.1% with prostate cancer
- **LifeTimes (ARCSHS)**
 - Gay men 1.6% overall
 - 60+ it was 9.5% with prostate cancer

What do we know for certain?

- (1) known differences
- (2) connection to HIV infection
- (3) gay relationships
- (4) consequences for sexuality
- (5) mental health
- (6) health services and support

Known differences for gay men living with prostate cancer

- 2010-2011 International online survey (N=558)
 - 32% non-heterosexual men vs 17% heterosexual troubled by loss of ejaculation
 - Lower Gleason scores
- Hart et al., (2014) - USA
 - Worse quality of life (QoL) scores, but better sexual functioning scores
- Lee et al. (2015) – Canada
 - sexual dysfunction ↑ = sexual QoL ↓

Known differences for gay men living with prostate cancer (cont.)

- Ussher et al. (2016) – Australia
 - Lower QoL and masculine self esteem , higher distress and ejaculatory concern; BUT higher sexual functioning confidence
- Allensworth Davies (2012) – USA
 - Gay men reported more stigma, lower masculine self esteem and more treatment regret
 - Stigma in homosexuality affects QoL outcomes
 - This points to broader social issues intersecting with PCa for gay men

HIV infection

- PLHIV on effective ARTs living longer, but more prone to ailments of old age
- Crum et al., (2002) – USA
 - US Navy study found higher rates of prostate cancer among HIV-positive men
- Lowe et al., (2013) – Australia
 - Only 6% of men in PCFA survey were HIV positive
- Marcus et al. (2014) – USA
 - HIV+ men lower incidence of PCa, even with higher levels of screening
- So what do we really know?

Gay relationships

- O'Shaughnessy et al. (2013) – UK
 - 29 studies (4 on gay men)\
 - PCa impact on 'personal relationships, body image, social interactions and sense of masculinity'
- Taylor Ford et al. (2013) – impact on body image
- Particular issue for gay men (Duncan 2010)

Gay relationships (cont.)

- Filiault et al. (2008) – Australia
 - little research on gay men's sense of self and relationships
 - Santillo and Lowe (2005) – USA
 - 28% chance of PCa in a gay relationship
 - 3% chance both partners diagnosed
- '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.'(20)

Gay relationships (cont.)

The relationship is still fine. I, I feel that, 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. (32)

Gay relationships (cont.)

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. (3)

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. (6)

Gay relationships (cont.)

- 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, 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. (5)

Gay relationships (cont.)

Yeah. I, I see myself now as an old gay man because it really makes you think of your — think about your age... And it's not pleasant, especially in the gay scene, to think of yourself as a senior citizen. So yeah, you just battle on, you know. (7)

If I tell them it's prostate cancer, then they think you're too old. (23)

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'. (25)

Gay relationships (cont.)

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 forties, fifties, 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.
(11)

Sex and sexuality

The spirit is willing but the body fails to respond.

I have been completely unable to have any form of sex since my operation.

I have no erections. [I have] desire but nothing there.

Often get very depressed about my ED and sometimes want to shoot myself and end my life...

Sex and sexuality (cont.)

Well, basically, my desire for sex has only diminished since the surgery... So therein lies 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.

(7)

Sex and sexuality (cont.)

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

Sex and sexuality (cont.)

It is hard work to get and maintain erection. Most times must take Viagra or Cialis. About 20% of the time must use pump even after taking pills. IT IS NOT THE SAME...Loss of ejaculation makes the feeling so different. (41)

We use a pump for therapy to maintain the blood flow to penile tissue and with rings when we want penetrative sex which now is 90% successful. (155)

Three years ago I had a penile implant installed. One with a pump. Works fine. I miss the feeling of getting an erection — but the rest is just fine. Particularly when the alternative was total impotence and a shrinking penis. (267)

Use injections or VED (vacuum erection devices) and drugs to get enough of an erection for intercourse. Works OK if a bit comical. (13)

I am not my penis!

- Focus on sense of masculinity as only erections and penetration
- 20% all men have had anal sex (ASHR2)
- Gay and str8 men with PCa changing anal sex practices
- Most gay men are versatile – modal changes
- Anal sex requites firmer erections

I am not my penis (cont.)!

What of non-penetrative sex practices?

- Masturbation?
- Oral sex?

Prostate cancer as a medical and health field way behind in its understanding of sex and sexuality, cf. HIV/AIDS

Mental health

Not one kind of experience:

- The problem wasn't between my ears; it was between my legs. (5)
- I don't consider it anything like the problem the depression's been. (14)
- I just sort of think that I'd rather throw myself into work and try and forget about my gayness and my sexual problems, and try and look at other things. (7)

Mental health (cont.)

- I had depression. That was years ago. It's over 26 years ago (24)
- I only went through about 10 weeks of counselling during the time when I was trying to deal with the cancer. (20)
- I'm one of these people that, I can't be over-sympathetic with a lot of people. Get over it, Doris! (17)
- ...when things weren't properly working and like erections and that type of things, 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 I woke up and I was in hospital.

Health services & resources

- ARCSHS PCa resources audit for PCFA (2011)
- ARCSHS focus group study for PCFA (2012)
- PCFA / ARCSHS Monograph on Gay and Bisexual men (2013)
- PCFA Resources for gay/bisexual men (2014)

Professional/patient interaction

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.

Professional/patient interaction

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.

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. (4)

Professional/patient interaction

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.

Last word

I think it's inexcusable that no-one can really tell you anything. I think that's not acceptable. And you, sort of, like, go to your GP as a woman, and your GP not having any comprehension of what issues might be for women...!

I think that there needs to be a baseline [about gay men's issues] 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.

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