



Understanding Gay Men's Experiences of Prostate Cancer: Making Visible the Concerns of an Invisible Population in Health Services Research

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Men and Prostate Cancer

- Most common cancer in Australian men (1 in 11 incidence) (AIHW 2002)
- Peak incidence 60-84 years (AIHW 2002)
- Three main treatment courses:
 - Radical prostatectomy
 - Radiation therapy
 - “Watchful waiting”



Treatment and Side-Effects

- Incontinence
- Gastrointestinal
- Erectile dysfunction
- Impotency
- “All forms of treatment for this cancer cause serious sexual problems for men” (Katz 2005, 977)



Treatment and Side-Effects

- Psychological:

- Depression (Galbraith et al 2005; Harden et al 2002)

- Relationship difficulties (Couper et al 2006; Harden et al 2002)

- Threatened sense of masculinity (Broom 2004; Fergus, Gray & Fitch 2002; Wall & Kristjanson 2005)

- Hegemonic masculinity and sexual prowess

Relationships and PCA

These factors impact partners and patients!

- Quality of life and marital satisfaction linked to health status (Galbraith et al 2005)
- Depression and anxiety (Couper et al 2006)
- Including partners in care process may help (Couper et al 2006; Harden et al 2002)

Gay Men and PCA

- **Gay couples: 28% chance** (Santillo & Lowe 2005)
- **Little research record** (Smith et al 2007)
- **Unique concerns** (Smith et al 2007):
 - Prostate as pleasure site (e.g. Underwood 2003)
 - Painful/impossible anal sex (Blank 2005; Martinez 2005)
 - Polyamorous/open relationships (Signorile 1997)
 - Ambiguous role of gay carers (Blank 2005; McCann & Wadsworth 1992)

Gay Men and Health Care

- Heteronormative attitudes:
 - GPs do not know sexual orientation of pts. (Lee 2000)
 - Embarrassment/lack of communication about sexual health (Cant & Taket 2007; Hinchliff, Gott, & Galena, 2005)
 - Lack of training (Hinchliff, Gott, & Galena, 2005)
 - Lack of devoted research (Cant & Taket 2007; Lee 2000)

False assumption: Gay men do not experience a range of health issues

Disempowerment in the health care system



Twice and Thrice Hidden: Older Gay Men

- Heteronormative research record (Harrison 2006; Hughes 2006)
- Difficulty in accessing older gay men ;
“hidden treasures” (Morris 2006)
- GLBTQI research record and youth (Hughes 2006; Lo 2006)
- Thrice hidden: Older gay men with prostate cancer

Research Methods

- Ethics approval from University of South Australia and Royal Adelaide Hospital
- Focus groups and individual interviews
 - Gay men with PCA
 - Partners of gay men with PCA
 - Health care providers (in July 2007)
- Audiorecorded and transcribed
- Inductive, thematic analysis with inter-rater comparison of themes

Recruitment

- Convenience Sampling
 - Local support group for gay men with cancer
 - Local GLBTQI newspaper article
 - Local cancer council
- Snowball sampling
- Over six months of recruitment and dozens of phone calls later:
 - Two patients
 - One partner

An extremely difficult population to access ...

It's Just Not the Same: Gay Sex and PCA

“To me, the prostate gland is a sort of major part of the male sexual experience.” (patient, 56 years)

- Substantial changes in sex drive:
 - Patients ...

“Your libido is gone. You know, wasn't as, like, revved up as it used to be, but it um ... even masturbation is like not possible post-operatively, at the moment.” (patient, 51 years)

It's Just Not the Same: Gay Sex and PCA

- And partners noticed changes:

“I noticed that [partner] wasn’t initiating intimacy. I was initiating intimacy, but he wasn’t picking up on those cues. And I got really angry about that, although I didn’t express it at the time. Although one day I did. I said “What’s going on? Don’t you like being intimate with me any more? I’m starting to feel ugly, I’m feeling rejected.” And he said it’s not that, he’s just lost his libido.” [partner, 45 years old)

Information Disconnect: Gay Sex and PCA

- Not gay specific ...

“Certainly [partner’s] doctor did give him information, primarily about symptoms and what to expect, but it didn’t give that specialized information about being gay and how does that impact on relationships.” [Partner, 45 years old]

“But I mean that’s a very, in some ways, that could be a very conservative heterosexual assumption about, you know, how you have sex. Because a lot of gay men don’t have that kind of um, intimate kind of sexual contact. That sometimes it’s more like meeting in saunas or things like that, or beats, or something like that, where um, an erection is kind of like a very important part of the whole kind of social ritual.” (patient, 51 years)

They Should Have Known: Anger Toward Health Providers

- Disingenuous

“To me again that’s a big issue with the way information is provided, it’s so disingenuous, it doesn’t, it sort of like says things ... You know everybody’s sort of coy about it.” (patient, 56 years)

“It is sort of very Victorian in the way they talk about these things.” (patient, 51 years)

They Should Have Known: Anger Toward Health Providers

- Homophobic/heteronormative

“I mean they don’t ask you are you heterosexual or are you homosexual. No one kind of referred to my sexuality directly at all.” (patient, 56 years)

*“I suppose I see a hospital as a sort heterosexual kind of place.”
(patient, 51 years)*

“You fear, you’re frightened of the judgmental attitude of the doctor. You’re frightened that he might not have your best interest at heart. Better to be silent about it all, and not create waves.” (partner, 45 years)



Commentary

- Anger toward health care system ...

“Facing the medical institution, there is a sense of bias, a sense of discrimination, a sense of a lack of opportunity to be ourselves.” (partner, 45 years)

Reason behind difficulty in recruitment?

Have we alienated this population?

What can be done?



Commentary

- Need for training on gay issues
- Need for sensitivity toward sexuality
- Need for accessible, gay-specific information
- Need for gay-specific health care venues/providers



Looking Ahead

- Focus group with health care providers
- Creation of gay-specific pamphlets and information
- Continue recruitment for patients and partners

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