



# Do women have a role in early detection of prostate cancer?

## Lessons from a qualitative study

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### BACKGROUND

Prostate cancer is the most common internal cancer in Australian men; more than 3000 men die annually from it. Public awareness of prostate cancer is an important factor in early detection and treatment. Women are known to act as 'health managers' for their families and may have a role to play in early detection.

### OBJECTIVE

To describe community perceptions of prostate cancer and identify information needs within the Australian context.

### METHOD

A qualitative study using focus group and individual interviews with 44 community volunteers, 18 men with recent diagnosis of prostate cancer and nine of their wives/partners (n=71).

### DISCUSSION

Men in the community are poorly informed about prostate cancer, prefer to ignore (male) health issues, and expect their general practitioners to provide authoritative advice on testing for prostate cancer. While women are also poorly informed, they are keen to change the prevailing situation of silence and lack of information in the community, and need to be included in public education campaigns.

**Prostate cancer is the most common internal cancer in Australian men, with over 11 000 new cases diagnosed in 2001 – some 5000 (44.5%) of these cases are in men under 70 years of age.<sup>1</sup> More than 3000 Australian men die from prostate cancer annually. International research indicates poor public awareness of prostate cancer and related issues.<sup>2,3</sup> Australian research suggests a similar lack of knowledge about prostate cancer and male urological health generally.<sup>4,5</sup> Combined with poor access to general practitioner and urological services, public ignorance typically results in delayed diagnosis and increased mortality. Although this situation is common in remote areas of Australia, it also prevails in the more populated regions north of Sydney in New South Wales (such as Hunter and New England) where the incidence of prostate cancer is lower but where mortality is higher than in NSW as a whole.<sup>6</sup>**

Although prostate cancer affects only men, it is becoming evident that women also need to be informed about it. It is known that women act as family 'health managers' for their partners and children.<sup>7,8</sup> In the context of prostate cancer diagnosis, the spouse often acts as information seeker, support person and advocate.<sup>9</sup> Women also seek out

other women whose husbands have been diagnosed with prostate cancer in order to learn from their experiences.<sup>10,11</sup> Women may hold the key to changing men's behaviour in relation to early detection of prostate cancer.<sup>12</sup>

### Method

The main aims of this qualitative study were to describe perceptions of prostate cancer as a personal experience, to explore how prevailing community perceptions and attitudes are sustained, and to identify implications for health education campaigns about prostate cancer within the Australian context.

Community participants without personal experience of prostate cancer were recruited through media releases and poster displays in the Hunter and New England areas of NSW. Men with recent diagnosis of prostate cancer and their partners were recruited via a regional oncology service.

Seventy-one people were interviewed between October 2004 and March 2005. This involved 58 individual, semistructured interviews lasting 30–100 minutes, and two focus groups lasting 75–95 minutes. Maximal variability sampling (designed to avoid biased conclusions based on a narrow sampling frame) was used so that the sample included men and women from a range of age groups, educational,

ethnic and social backgrounds. Data saturation (with analytical categories clearly supported and no new categories being identifiable in data from later interviews) determined the final sample size. Age and gender characteristics of the participants are summarised in *Table 1*.

All interviews were transcribed verbatim and resulting texts analysed using a thematic approach. The project was approved by the relevant university and area health service human research ethics committees, and carried out in accordance with approved protocols.

## Results

### Community awareness

Most community participants revealed minimal knowledge about the prostate and prostate cancer. Many men did not appreciate the difference between benign hypertrophy of the prostate and prostate cancer. Some confused prostate cancer and testicular cancer, others prostate and bowel cancer. Most assumed that prostate cancer was a disease of old men, and many accepted misinformation as fact, commonly citing myths such as 'men never die from prostate cancer' and that metastatic tumours are not prostate but bone or liver cancer, that prostate cancer may simply 'go away' without treatment, and that absence of bleeding and pain indicate absence of prostate cancer.

In the words of a 50 year old patient diagnosed 6 months earlier:

'I think men are just so stubborn about [not] talking about the issue. Most men, like myself, I didn't even understand the male reproductive system, until I had to decide which pieces were going to be taken away, and that's the truth of it.'

### Community attitudes

The strongest theme to emerge about men's attitudes was one of awkward silence concerning anything to do with the prostate. Men are embarrassed and reluctant to raise the issue with others, including their GPs. Older men attributed this attitude to their upbringing, although university educated younger men seemed just as reluctant to challenge social expectations:

'Women will talk about their health problems but men don't tend to. I think there is still that stigma that if you do, you are a bit of a wuss, you are a girl's blouse, that sort of thing... I think it's ingrained in our culture' (male, 32 years).

Men do not generally discuss their health concerns. Men who reported having regular medical check ups sought reassurance during research interviews that their actions were not unreasonable or in some way unmanly. The more common attitude is to maintain a veneer of toughness and avoid health checks:

'It's a blokey thing to think to yourself, well, I am healthy, if it's not affecting me, why bother with it? If it's not broke, don't try to fix it – don't touch it. Blokes tend to put it aside, try to ignore it, or pretend it's not there until such time as they absolutely have to do something about it' (male, 57 years).

However reluctantly they may discuss it, most of the men we interviewed were aware that beneath the veneer of toughness lie ignorance and fear. It was the women in the study who talked about the fear they see in the men close to them:

'I remember when my dad was diagnosed [with prostate cancer]. I actually tried to encourage a few of my older male friends to get tested... and they just weren't interested. They would rather

not know... I guess for us [women] it's having Pap tests, you get used to it and it's okay. But males are so scared, just going there' (female, 42 years).

Women tend to share personal experiences with each other and report a rich lore of knowledge gleaned from other women's stories. Consequently, women feel more confident asking questions and seeking information from GPs and other sources. Men, on the other hand, reported feeling unsure and intimidated, often waiting for their wives to identify a health problem or to urge them to visit a GP. While reluctant to present for a consultation, men nevertheless expected their GPs to broach the subject and provide them with relevant and authoritative advice on testing for prostate cancer.

This last point is of particular concern, as research participants also reported great variability in how their GPs acted in relation to early detection of prostate cancer – from providing information and initiating prostate specific antigen (PSA) and/or digital rectal examinations in men over 50 years of age, to failing to raise the issue or initiate tests, to those who actively discouraged 'asymptomatic' men from being tested.

### What have women got to do with it?

Women are interested and careful observers of their partner's health, noting even minor changes that men tend to ignore or may initially deny: feelings of tiredness, slow urination, or discomfort or pain on ejaculation. In such cases, it is often their partner's urging that leads men to seek medical consultation. Yet, given the asymptomatic nature of early prostate cancer<sup>13</sup> – a point on which the community is singularly uninformed – women's observations and urgings in this case are not particularly helpful.

**Table 1. Age distributions within the subsamples of the study**

	Community individuals (n=31)	Community focus groups (n=13)	Men with prostate cancer (n=18)	Wives/partners (n=9)	Total n=71 (100%)
Age range	19–74 years	21–80 years	50–77 years	18–76 years	
49 years or less	7 (23%)	6 (46%)	0	1 (11%)	14 (20%)
50–59 years	9 (29%)	5 (38%)	2 (11%)	2 (22%)	18 (25%)
60–69 years	13 (42%)	1 (8%)	9 (50%)	2 (22%)	25 (35%)
70+ years	2 (6%)	1 (8%)	7 (39%)	4 (45%)	14 (20%)
Median age	60 years	46 years	69 years	66 years	
Mean age	55 years	47 years	68 years	61.5 years	
Male/female	M 27, F 4	M 10, F 3	M 18	M 1, F 8	M 56, F 15

Women used the examples of cervical and breast cancer to illustrate how public education campaigns have informed and empowered women in relation to their own health. By contrast, wives of men with prostate cancer felt lost and sometimes angry that because of their husband's reluctance and their own lack of knowledge they could not 'nag wisely' and in a more timely way:

'We all know about breast cancer and having our Pap tests, but when it comes to men and the prostate, it's a different kettle of fish altogether... You know I had to push [husband] and he won't go to the doctor just on his own accord. I'll be honest, we fight about it... Until the nagging might wear him down, and off he goes. But gee whiz, it takes an awful lot... You only do it because you care about them, and you know there is something wrong. I think probably the wife might pick it up a bit earlier than they do. But that [prostate cancer] I didn't have a clue about' (female, 56 years).

The women we interviewed were clear that prostate cancer education campaigns need to target women as well as men. Women are not easily deterred by the embarrassing or uncomfortable nature of investigative procedures and they want a similarly pragmatic approach in public education campaigns. They want to see prominent men speaking out about prostate cancer and what men need to know and do. They want to be informed so that they can be involved in prevention and early diagnosis – not just as supporters and carers once the disease has taken its toll. More than anything, women want to grow old with their partners: they don't want them to die from something that could have been detected and treated earlier.

## Discussion

Our findings indicate that men prefer to ignore the issue of early detection tests for prostate cancer. In many cases they rely on their partner and GP to raise concerns and provide information, and expect their GP to initiate appropriate investigations. While debate on the relative merits of population screening and active treatment of prostate cancer continues,<sup>14</sup> men and their partner need clearer guidance from medical experts. Suggesting that the decision be left entirely to individual men,<sup>14</sup> particularly when

they are so poorly informed on the topic and reluctant to admit how little they know, and when early prostate cancer is so often asymptomatic,<sup>13</sup> seems the worst possible option. Emerging evidence suggests that prostate specific antigen (PSA) testing, combined with ready access to appropriate medical services, can contribute to reduction in mortality from prostate cancer.<sup>15–17</sup> The challenge is to distinguish between men who have an indolent form of prostate cancer that should be monitored but not overtreated, and those with aggressive disease that requires radical therapy. Active surveillance for the former can address the problem of overdiagnosis and unnecessary active treatment.<sup>18,19</sup> As with other diseases that affect our aging population, GPs can play a critical role in helping their patients make informed choices about being tested for prostate cancer.

Because of the lessons learned from screening for breast cancer, women know that early detection can provide greater treatment options and improve outcomes. In addition, women are aware that mammography screening has changed community perceptions of breast cancer and women diagnosed with it. Whatever the individual experience, the dominant narrative of breast cancer is one of hope, positive role models and collective optimism that if detected early enough, breast cancer is eminently treatable.

The dominant narrative of prostate cancer is very different. The prevailing silence conceals the extent of the problem and does nothing to dispel negative stereotypes and misconceptions. Women are adamant that this situation must change. They want to be educated so that they can inform and encourage men to be investigated appropriately. They do not want to live with the regret experienced by the partners of men with prostate cancer, who wish they had known more and acted sooner. Women are just as adamant that men's attitudes must change, and that men must learn to take greater responsibility for their own health.

Health education campaigns about prostate cancer need to recognise the key role that women see themselves playing in this area, and need to address women's as well as men's information needs.

Conflict of interest: none declared.

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