The symptom recognition and help-seeking experiences of men in Australia with testicular cancer: A qualitative study

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**Introduction**

- Testicular cancer affects approximately 550 men in Australia men each year (Andrology Australia, 2003).
- Advances in the treatment of testicular cancer over the last few decades have led to significant reductions in the mortality.
Introduction

- As a result of a meta-analysis, Moul (2007) suggested that treatment delays often occur.
- Most seek medical attention reasonably soon, but a significant minority do not.
- Health provider delays – misdiagnosis, delays in gaining appointments.

Reasons for delay:
- Lack of knowledge about testicular cancer
- Misattribution of symptoms to benign causes
- Mild symptoms that do not cause distress or interfere with day-to-day functioning
- Fear of being diagnosed with cancer
- Fear of appearing weak or unmanly
- Threat to masculinity of losing a testicle
Introduction

Factors facilitating help-seeking
- advice and encouragement to seek help given by friends or family members
- symptoms that interfere with day-to-day life

Further research
- to understand the differences between early and late help-seekers
- to determine the impact of individual, contextual and social determinants of help-seeking delays in testicular cancer.
- No Australian research
Aim of the research

- To analyse men’s accounts of their help-seeking experiences from the recognition of symptoms, to first medical contact and through to eventual treatment, to understand the factors that may help to promote early intervention
- A qualitative study

Participants

- 38 men were asked to participate in the study.
- 11 participants volunteered to take part (response rate of 29%).
- Participants ranged in age from 28-44 years ($M = 35.3$ yrs).
- Recruited from the patient lists of three specialist urologists in private practice in Melbourne, Australia
- Diagnosed and treated for testicular cancer in the 5 years prior to the commencement of the current study
Design

- Taped semi-structured telephone interviews
- Participants’ descriptions of:
  - early symptoms of their testicular cancer
  - duration of symptoms prior medical attention
  - factors influencing their decision about when to seek medical assistance
  - help-seeking experiences from first contact until the point of definite diagnosis and treatment for testicular cancer.

Data Analysis

- Interpretative phenomenological approach which aims to describe how participants experience a phenomenon
- a rich description that captures the essence of the lived experience of individuals concerning a particular issue
- Aim to produce a set of themes that characterise the phenomenon being explored
The Duration of Help-seeking Delay

- median = 4 weeks   mean= 15.8 weeks.
- Shortest period = 1 week.
- Longest = 18 months
- Substantially lower than the mean of 26 weeks described by Moul (2007) in his review of 21 studies.
- 64% of participants (n=7) had help-seeking delays of 4 weeks or less

Themes

1. **Something is Not Quite Right — The Discovery of Symptoms**

Participant 10 “Basically, I was doing what I call an adjustment, you know with your hands in your pockets and you just sort of move the testicles when they’re a bit tight or whatever and I just thought, that’s not right, which is very difficult to explain because if anyone asked me what does it feel like when you just feel your testicles, I can’t really tell them if you know what I mean.”
2. Let’s Just Wait and See — The Initial Monitoring of Symptoms

- Participant 10 “Being a male I initially thought I will go to bed and I’ll wake up and it will be gone.”
- Participant 8 “I wasn’t too fussed. I thought I’d just keep an eye on it and if it got any bigger or started experiencing any other symptoms, I’d get onto it straight away.”

- Participant 9 “I really wasn’t sure actually. I didn’t know what was wrong with me, I had a sensation that something was getting caught in my throat and I never would have guessed it was a tumour. I thought maybe I had something wrong with my lungs. You know I have never been a smoker or anything but maybe, I didn’t know, I thought there might be something similar to asthma that was going on with my lungs and that was why I was wheezing so much.”
Themes

3. Moving to Action — Exploring Differences Between Men’s Help-Seeking Behaviour

- Symptom severity
- Participant 3 “I was not one hundred percent sure if it was necessary and secondly, the busy lifestyle we have is probably you know . . . doesn’t force you to go and do that sort of thing also.”
- Participant 2 “And it was getting to the stage where I couldn’t really sleep properly with the back pain and I suppose then I figured I had to do something about it.”

Themes

- Not attending GP for any other reason

Participant 8 “I’m not sure to be honest, but if I had a regular GP maybe I would have got onto it quicker.”
Themes

- Embarrassment about testicular examination

Participant 2 “And you know it’s kinda where it is as well. Like if you go to the doctor and you say I’ve got a tumour in my arm, or in my leg, or something like that, he’s gonna say OK, let’s have the look, but when it’s your groin and you’re 26 years old, the last thing you want to be doing is to be lying there with your trousers down, your legs spread and someone with their head stuck down there.”

Themes

- Lack of knowledge about symptoms

Participant 8 “Well again, not much changed and then I decided one day after coming out of the shower, I’d gone to the PC, typed in – I may have read something about someone or whatnot about testicular cancer – and I typed it in and ticked my cancer symptoms off and there it said that people who were born with undescended testes, there’s a prevalence of them having testicular cancer which unfortunately, I was born with that condition, although I was not advised or aware of the increase in prevalence for testicular cancer, and the penny dropped and that’s when I went straight to the hospital, got tested and got my specialist and got onto it straight away.”
Themes

- Threat to masculinity
  
  Participant 2 “It’s the old adage, and I suppose I’m guilty of it myself, you’re a real man depending on the size of your genitals, and you don’t want to think that there’s anything wrong down there, because you’re embarrassed about the whole thing. It might make you less of a man, and deep, deep down that’s possibly one of the things why you tend to hold off in the hope that it will go away and rectify itself.”

Themes

4. It’s Not Always From Lack of Trying — The Contribution of Provider Delay to Treatment Delay

- Shortest period = 1 week
- Longest period = 26 weeks.
- Slightly over a quarter of participants (n=3) experienced provider delays of 4 weeks or more. Main reason - Misdiagnosis
The Contribution of Provider Delay

Participant 4 “Actually yeah it probably started at the beginning of the year. I started getting a lot back pain and it progressively got worse and that’s when I decided to go and see a doctor about it… Then they referred me to a physiotherapist. And so I started doing back exercises and he was doing you know he was massaging my lower back and all that kind of thing… Maybe a few weeks when it felt the physio wasn’t helping and I started to feel I actually started to feel worse… Then I thought look I’ll go see another doctor. A different GP and he went and sent me to get some x-rays on my back. The x-rays came back and he said… I was born with a deformed spine and that pain will be there for the rest of my life and I just have to deal with it, basically….”

The Contribution of Provider Delay

So you know I left wondering this is ridiculous you know, what the hell is it you know, no one’s ever heard of this deformed spine business before - he gave it some name - I don’t know. So then for a couple more weeks I did live with it and it still got worse and worse where I started to lose my appetite. I started to get like indigestion and all that kind of thing. My health my declining, I just did not feel good at all… I couldn’t sleep at all. It was quite, quite painful. Then I went back to my original doctor and said look now I’ve got back pain, I’ve got stomach pain, I’ve lost my appetite, you know I don’t know what to do. And he said well go do some ultrasounds. So I went and got an ultrasound done on my abdomen area and that’s when they discovered a massive tumour
Discussion

- Barriers and facilitators to early help-seeking were broadly similar to those found in previous studies.

- Issues facing men with testicular cancer are similar across diverse cultural groups and in different health systems.

Discussion

- Findings highlight the level of individual variability in help-seeking behaviour.

- Help-seeking behaviour in testicular cancer may be influenced more by individual psychological factors or health beliefs than culturally determined masculinity norms.
Discussion

- Earlier intervention is partly dependent on doctors being better able to identify the different ways testicular cancer presents itself in patients.
- Difficult to achieve with such a low incidence condition.
- General practitioners are well placed to deliver health education messages that are designed to promote early intervention.

Limitations

- Low response rate – unknown how many men are in the various categories of response to testicular cancer.
- Estimates of time only – relied on participants’ memory.
Implications

- Use the themes to plan a larger representative research study of help-seeking in men who have had testicular cancer.
- May be other barriers in particular ethnic groups and in rural and remote areas of Australia.
- Public health campaigns – variability of help-seeking behaviour means that is not a “one size fits all” message.