



What are the Determinants for Presentation and Therapy Options for Rural Men with Prostate Cancer?

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What are the determinants for presentation and therapy options for rural men with prostate cancer?

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ABSTRACT

This paper reports on the findings of a study which sought to identify the determinants rural men use in deciding to attend health service providers for diagnosis of prostate cancer and the therapy regimes they choose following diagnosis. This is a significant study as little is known about how and why men decide they need to consult a health service provider for diagnosis of prostate cancer. Data collection involved focused interviews with men who have been diagnosed with prostate cancer as well key informants for example Director of the Cancer Council, Clinical Nurse Consultants. This study explicates how rural men make decisions about therapy and from whom they receive the information they use to make their decisions. Findings indicate that rural men do not recognise early symptoms of prostatic cancer. They are often not informed about prostate cancer and the possible complications resulting from therapy choices. They choose therapy options on the basis of a specialist medical practitioner's preference and retrospectively are not always happy with the limitations imposed on their decision making. The study provides useful information to health care providers when planning health promotion activities targeting men's health — in particular prostate cancer.

INTRODUCTION

One in three Australian men can expect to develop cancer in their.¹ Prostate cancer is the most common cancer in Australian males and the second most common cause of death.¹ It is extremely age dependent, being rare before the age of 50 but sharply rising to be the most common cancer in men from 55 years of age.

Prostate cancer has become the most common cancer in males with between 5000–6000 new cases diagnosed annually and a projection of incidence shows the largest increase of any cancer type.² The increase in prostate cancer is quite high at a national level and there is evidence from some States that it may be even higher when actual figures are available.¹ Data indicates that there was a dramatic rise in the incidence of prostate cancer to 1994 followed by a decline in incidence to 1997 with stabilisation thereafter. It is believed this upward trend is attributable to increased detection of the disease through investigations including prostate-specific antigen (PSA) testing (introduced around 1990).² Further it is argued that the decline in incidence rates from

1994 is attributable to a decline in the number of PSA tests conducted, thus reducing the number of reported cases.²

PROSTATE CANCER AWARENESS, EARLY DETECTION AND PREVENTION

It is well recognised that any strategy for cancer control in Australia should include secondary prevention through consumer awareness of signs and symptoms of the disease in combination with the early use of health.³ These strategies present significant challenges for the early detection of prostate cancer as there is increasing evidence suggesting that men feel constrained in acknowledging health problems, performing adaptive behaviours when faced with a health problem, or being involved in preventative health.^{4,5} McMurray contends men are the most infrequent users of health services and that consultation times with health service providers are longer than consultation times with women. She further believes that men may be underserved by health services where standardised consultation rates prevail.⁶

Therapy options

Options for the treatment of prostate cancer include radical prostatectomy, radiation therapy, cryosurgery or the option of non-intervention.^{3,7,8} Complications associated with radical prostatectomy and radiation therapy have been well documented and include bowel, urinary and erectile dysfunction.⁹ For elderly men with a life expectancy of ten years or less on diagnosis of prostate cancer, there is growing evidence for conservative treatment or “watchful waiting”.^{10,7} A Danish study concluded that elderly men (aged 75 years or over) are less likely to benefit from active treatment than are younger men.¹² Barnard cites a study by Ball et al (1981) which followed for a five year period, a group of men who suffered with mild prostate symptoms.⁸ One quarter of the men in the study after five years had improved, one half of the men involved in the same study symptoms remained the same and one quarter had gotten worse.

The influence of rurality on diagnosis and treatment

The health of rural communities has been the focus of much research in recent years, however rural men’s health has been neglected as an area of health research.⁶ For rural men early diagnosis and treatment of prostate cancer is further compounded through the tyranny of distance as they lack access to essential services, education and health.^{13,14,6,15} Studies by Humphreys et al and Strodl indicate that attitudes of rural people to health and the use of health care services vary significantly from those of their urban counterparts, with rural people being more self-reliant and independent even in the face of obvious ill health or disability.^{14,4}

Conclusion

There is little information available in the literature about the influence of rurality on presentation of men for diagnosis and the subsequent treatment of prostate cancer. How men decide on therapy options for the management of prostate cancer and how they gain information about the disease has not been well researched. In a study being undertaken by a New York-based company interviews are being conducted with men

who have been treated for prostate cancer.⁹ This study seeks to ascertain how men gain information about prostate cancer treatment options. This is a significant study however, the experience of rurality on choosing therapy options is not a significant aspect of this study.

PURPOSE

This paper reports on the findings of a study which sought to identify the determinants rural men use in deciding to attend health service providers for diagnosis of prostate cancer and the therapy regimes they choose following diagnosis. In addition, the study aims to identify from whom men diagnosed with prostate cancer obtain information.

METHODOLOGY

This is a descriptive study which used ontological hermeneutics as the methodological approach. This mode of inquiry allows the researcher to dialogue with participants about a phenomena of mutual interest. The researcher seeks to subjectively understand the lived experience men have, when diagnosed with prostate cancer in order to comprehend what initiates the seeking of a diagnosis and/or treatment and how rural men progress to making choices about therapy.¹⁶ In order to capture the essence of what rural men experience their own words are used when ever possible in discussing the emergent themes.

DATA COLLECTION

In order to gain an understanding of how men diagnosed with prostate cancer choose therapy options advertisements were placed in a local free newspaper, and men involved in a cancer support group in a rural town in NSW were invited to participate in the study. The men were asked to consent to an interview, which was audiotape recorded and which lasted for approximately one (1) hour. Men included in the study had been diagnosed with prostate cancer within the last five years, were English speaking and ranged in age from 57–78 years.

Eleven males, John, Jim, Steve, Ron, Tim, Phil, David, Sam, Miles, Charles and Tony who had been diagnosed with prostate cancer within the last five years agreed to participate in the study (pseudonyms have been used to protect the participants identity). An in depth interview was conducted with each participant at a venue agreed upon by the interviewer/s and the participant. A focus interview schedule was used to elicit the participant's recollections on:

- ◆ What factors resulted in them presenting to health care providers for diagnosis of prostate cancer?
- ◆ What information was given to them about prostate cancer including treatment options and by whom?

- ◆ How did they make a decision/s on therapy options after being diagnosed with prostate cancer and what factors influenced these decisions?

DATA ANALYSIS

The qualitative data (from the face-to-face interviews) were transcribed verbatim with all identifying information such as people's names, geographical location and health services replaced with pseudonym names to protect the identity of participants, and others. A content analysis was undertaken to identify key themes from the data. The themes were developed from words, phrases and passages within the texts which expressed the essence of meanings the men attributed to their experience of being diagnosed, and subsequently choosing therapy options for prostate cancer.

FINDINGS

Four major themes were identified from the research:

- ◆ being diagnosed;
- ◆ losing control;
- ◆ taking control; and
- ◆ sharing the story to benefit others.

Being diagnosed

Being invincible

The research findings indicate that rural men in this study are reluctant to accept that they are susceptible to an illness such as prostate cancer. They relate the acceptance and verbalisation of ill health to others as a sign of weakness. Phil indicates that he recognised symptoms but was reluctant to visit the doctor because he felt it was inconsequential. He states

It was, ah, about what ... three, five — five years ago since I first had symptoms, and um then I didn't go to the doctor until probably, it'd be six years ago since I had the first symptoms and I didn't go to the doctor till about three years ago.

For some men, this lack of ability to discuss their diagnosis started with their father or a close relative including siblings. For example, Phil states his father suffered from prostate cancer and lived with the symptoms of metastatic disease but did not share his illness with his family:

... some of the family have been there and lived, and stayed with them on holidays and so forth, they realised that he had problems of some sort but Dad would never tell anybody, he'd never talk to anybody about it.

Miles declares that he became aware of prostatic disease "... in 1989 when my brother died, of prostate cancer ..."

The participants in this study not only expressed a reluctance to talk about their illness, they also stated that they were either unaware of prostate cancer as a health risk, or they had a level of awareness usually associated with a family history of prostatic disease but did not believe they were at risk.

John has a family history of prostatic and colon cancer. He indicated that while he was aware of his father's condition he believed, prior to having a routine physical examination performed by his local general practitioner and being diagnosed with an enlarged prostate, that he was unlikely to develop cancer:

...But of course I was at the age in those days when it seemed remote and so you know unlikely that I'd have the same problems, that I didn't really take it in very much.

Becoming aware

Prior to diagnosis participants believed they were asymptomatic. When asked to comment on why they presented to a health care provider and were subsequently diagnosed with prostate cancer, in retrospect they were able to identify symptoms including a weakened stream when passing urine and episodes of being unable to pass urine when desired. Sam states:

Well I had no idea of what was wrong, but I just got up one morning and went to the toilet, as per usual. Oh, over the years there'd, oh, never had any troubles, just, plenty of pressure and no troubles at all. Um, anyway, half way through the process, oh, the tap turned off, for about as long as you click your fingers. No pain, no nothing. And, um, and it stopped off for about that long, and then it started again. And ever after that it was half to two-thirds the normal flow ...'

Most of the participants retrospectively identified nocturia and poor stream as early signs of prostatic disease. Charles recalls:

Well, towards the end of 1996 I went to the doctor complaining about running to the toilet, too regularly. Getting up 4 and 5 times a night...

Jim recounts

Well, the problem first was I, uh, urinate particularly at night time, it was sort of coming in waves, a bit and then a bit more....

Some of the participants indicated that they were alerted to nocturia as being symptomatic because their partners complained of having their sleep disturbed. One participant said his wife complained about being woken in the night by his need to pass urine and told him to see the doctor. Phil reports that he subconsciously he recognised symptoms, and chose to ignore the warning signs. He states;

...(I) sort of couldn't pass urine, um, freely. Uh, but that wasn't happening all the time, that was spasmodic and I just thought that, probably, in the back of my mind there was just something psychological or whatever.

The majority of the participants in the study could recognise symptoms indicative of prostatic disease retrospectively. Most of the participants did not initiate a consultation specifically to discuss the symptoms of nocturia and weakened stream with a health care professional, usually a general practitioner. Diagnosis was made as a result of presentation to a general practitioner for other health issues. Participants experienced

episodes of what can be described as a lack of control over the illness and the treatment options offered to them.

Losing control

When confronted with the reality of being diagnosed with prostate cancer the participants experienced a sense of having lost the battle for survival and of having no choices with regard to treatment or non-treatment options. These feelings were described as “being afraid”, having to leave their town for treatment, feeling they had not choice in the treatment options offered by the medical profession and losing their masculinity from the complications or side-effects of the treatment.

Being afraid

Steve was referred to a specialist medical practitioner (Urologist) following a routine medical examination. He stated:

... he, [the urologist,] rang me up on the Boxing Day night it was, told me that uh, you know, the results had come back and I had prostate cancer, [and I had to]) have my testicles removed. That sat me back on my heels a bit.

Phil suggests he

... didn't want to listen probably. And that's why I think I would say Uh the problem with man, men ah they don't want to know. They don't want to face up to the fact that them um they've got to go to the doctor about their private life, sort of thing. Yes. And Uh it's no good being a he-man about because you've just gotta face up to it and get something done and be checked.

All of the participants were referred to a specialist medical practitioner, either a general surgeon or a urologist, for further therapy.

Being referred to specialist medical practitioners for therapy

Participants reported that they were not appropriately informed about prostate cancer by the general practitioner and/or specialist however they agreed that some information was provided. The data indicates that participants often chose a therapy option which was initiated before they were given information or actively sought information because they trusted the expert opinion of the attending specialist. Sam remembers he was sent to hospital to have exploratory surgery. On discharge he was given instructions by “... the specialist to take two pills a day for a month and come back and have it tested again”.

Information provided on possible complications resulting from therapy were not well explained. Phil recalls seeing a urologist following radiographic investigations to confirm prostate cancer. He suggests that the urologist talked with him about treatment regimes which were available

... either with um ray treatment or (I could) have the radical prostatectomy.

While therapy options were discussed with the specialist medical practitioner, the choice of therapy was determined by the consultant's preferences, rather than being an informed choice of the participants in this study

During this stressful time for all of these rural men, the stress was compounded by the need to travel to gain access to therapy. The distances travelled varied from 300 kilometres to 2000 kilometres (round trip).

Having to travel to access therapy

Charles stated:

So, that's the only problem that I have with it, that I've got to travel down there.

The participants acknowledged that they were aware of outreach services provided in the rural town in which they reside, by two visiting urologists. However, the waiting lists for appointments are extensive to see the consultants locally. They therefore chose to travel where they could access services quickly, rather than wait for up to months for treatment.

It is apparent, therefore that for these men, the options available regarding the choice of consultant, geographical location of health facilities if therapy is required and the mode of therapy chosen were further limited by the costs, financial and emotional, associated with the need to travel to access services. For example, John was unwilling to be away from his home and property and chose a therapy options available in Sydney only. He says

... and I had to wait two months for them to get the seeds from America, and worst aspect was the cost of the treatment ... \$16 500, plus your hospital costs.... So I had to pay for it all. Which was quite a drain...

Despite the fact that all participants had consulted both a general practitioner and a medical specialist, they all were distressed that they had not been adequately prepared for the complications/side-effects of treatment — including incontinence and impotence. These men saw this as a loss of masculinity.

Loss of masculinity

Phil indicates that he was provided with information on possible complications/side effects but that the discussion pre-therapy was limited and misleading. Phil stated:

Ah yes (complications were discussed). Not a ... not as such a big problem but as they just said "well that can be taken care of". Sometimes I get a bit down about it but never mind.

Participants found it difficult to discuss incontinence and impotence. Participants spoke of impotence in passing as a problem. David was grateful to have his partner present when discussing therapy options with the specialist. He explains

...I think wives should know. Because the, particularly if a man has surgery, the impotence which probably follows, is of considerable, what shall we say,...

As the interviews progressed and the participants felt more at ease these issues were raised. For some participants unresolved grief about the loss of their masculinity as they perceived it was discussed. Charles believes

... you don't need other people telling you all the horrors that are going to happen to you. And, and that is a problem. Impotence is a problem. And that's my biggest problem. Um, I'm healthy and well and, but I'm impotent. And that's the major downside of the operation. And, it's still a downside of radiotherapy or any other part of, of prostate cancer.

Whilst the men noted that they had not been prepared by the medical practitioners for the complications/side-effects of their illness, in most cases they began to take control prior to undertaking treatment.

Taking control

Once a health professional's advice was sought diagnosis was determined on either the participant's insistence that something was medically wrong or the attending general practitioner's initiation of diagnostic investigations including rectal digital examination, radiographic imaging or laboratory testing. Some of the men in this study were willing to question the advice and treatment options given by either the general practitioner or the medical specialist. This, taking control of the situation, was evident in their demanding to be heard, being involved and informed of the diagnosis and having the right to choose their treatment options in an informed way.

Demanding to be heard, being diagnosed and choosing therapy

Charles presented to his general practitioner distressed because he was experiencing nocturia and weakened stream. He asked for investigations to be initiated because he had talked with a friend who was diagnosed with prostate cancer. Charles believed that he was experiencing similar symptoms to his friend. He was worried that he also had prostate cancer and wanted confirmation to allay his fears or initiate therapy immediately. Charles reports that the general practitioner did not diagnose prostate cancer at this time, nor did the medical practitioner initiate any tests to confirm that the signs and symptoms experienced by Charles were prostate cancer. As a result, Charles was misdiagnosed and treated for a condition he did not have for two and a half years. Finally, in desperation he presented to his general practitioner and demanded that specific investigations for prostate cancer be initiated:

So, anyway, I persisted for the next two and one-half years, with the GP, and finally thumped on his desk and said "Look, there is something wrong. I've got to find out what it is".

Most of the participants suggested that following diagnosis or after treatment, they actively sought information because they were not satisfied with the information provided and/or were not aware, nor prepared for the complications resulting from therapy.

Seeking information

Steve asserts that he actively sought information prior to choosing therapy from sources including the Internet, national newspapers, lifestyle magazines and the television. He explains that the procedure he chose was not explained to him but he was offered the choice of choosing one of two therapy options. John also accessed information from the Internet. He explains;

Yes I um got a lot of information on the Internet, from America, people who'd had this treatment and various other treatments, and I found the worst aspect about it was trying to make up one's mind which way to go.

In some cases, the treatment options included complementary medicine. Some participants indicated that they actively sought alternatives to traditional medicine to maintain their levels of wellness and/or increase their natural immunity against cancer.

Using complementary medicine to improve wellness

Following radiation therapy Ron initiated a change in his lifestyle following a discussion with his urologist. Ron has maintained a high fibre and low cholesterol diet all his life. However he indicates that he was pleased the urologist suggested;

... some alternative treatment, which I was very, very pleased about. He advised me to take 100 mcg of Selenium daily. He also advised me to eat a lot of cooked tomatoes. Apparently they contain a substance, when they're cooked, called lycopenes, which is a natural cancer-fighting agent. To drink green tea, which I haven't got around to because I just don't like it.

The participants in this study felt it is important to share their experiences with other men. They live with the hope that by telling their stories, the communities' awareness of prostate cancer will be raised and men will be better informed about the disease.

Sharing the story to benefit others

Some of the participants sought support through formal structures such as cancer support groups while some felt these options were not appropriate for them. All participants accessed an informal support network of men with prostate cancer.

Sharing information

The participants shared information with other men. However, the sharing of information with other men only occurs if a cue is given and accepted that such information is required. Tim explains he was talking with a man while on holidays

... he had, uh, prostate cancer, and I'd only just been diagnosed with it, and he said "Don't have radiotherapy"...

The participants indicated that they were happy to share information and believed it necessary to tell other men to be vigilant and monitor their health status. Ron suggests that there is a dearth of literature available on prostate cancer. He further suggests

... Wherever you go there seems to be, ah, information on breast cancer. I don't begrudge this at all, I think it's a good thing, but, um, you very seldom do you find an article on prostate cancer. And, I'd like to see it, generally, spoken about more. I realise a lot of men are not game, or do not wish to discuss it, the problem, they prefer to keep it to themselves. And, I suppose, men are to blame to a degree in that they don't, they don't bother about it, but that's probably due to the lack of publicity regarding it.

CONCLUSION

This study has highlighted important issues related to how rural men seek diagnosis of prostate cancer and then choose therapy options. It is evident that the rural men in this study did not recognise early symptoms of prostatic disease. The data indicates that for some men when symptoms were recognised the medical practitioners from whom they sought treatment did not believe that the illness was prostate cancer and ultimately some of the participant rural men were forced to demand diagnostic tests be performed.

Men in this study were required to travel large distances to access specialist medical services: an issue well reported in the literature.^{15,17} The participants saw this as an extra financial and emotional burden which could have been avoided if timely treatment was available in their own town or a town close by. Further, it is apparent that when the participants presented to specialist medical practitioners options for therapy were limited by the practitioner's preferences and few participants were given sufficient information to make an informed choice about treatment.

Despite this, many participants in this study actively sought information either about therapy options, or having undertaken therapy about management of complications/side-effects of the therapy for prostate cancer because they believed the information provided to them was limited. Information was accessed from sources including the media and the Internet.

All participants expressed a desire to share their stories as a means of encouraging men to monitor their health and if diagnosed with prostate cancer to make choices based on adequate and current knowledge.

For health professionals working in rural areas, this study has important messages and therefore recommendations are made to improve the knowledge of rural men with regard to prostate cancer as well as to provide meaningful information about therapy options to men diagnosed with prostate cancer.

RECOMMENDATIONS

The study supports the need for the level of health promotion activity targeting men's health to be increased and that multimedia campaigns be used to raise awareness. It is further recommended that information be provided to men on how and where information may be obtained including Internet sites. It is further recommended that general practitioners and specialist medical practitioners be encouraged to discuss therapy options more openly with clients and refer men to specialist health practitioners to discuss coping with complications prior to the initiation of therapy.

For rural men coping with being diagnosed with prostate cancer and the need for therapy is often compounded by having to travel to another town for intervention and follow up medical care. It is recognised that specialist medical care in rural areas is a priority for the government. The recommendations of this research are that additional resourcing be made available to other health professionals who are in roles which support men when they are presented with a diagnosis requiring intervention and post-intervention therapy.

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