
Research

An Evaluation of a Specialist Nursing Role for Men with Prostate Cancer

Suzanne Boxhall
Melissa Dougherty

The purpose of this study was to evaluate a specialist prostate nursing service in a metropolitan public hospital setting servicing a large war veteran population. The service was originally delivered as a component of the Prostate Health Improvement Project, a South Australian government funded initiative to improve decision-making processes for older men diagnosed with prostate disease. This initiative had been in place for 18 months at the time of this study. The urology medical staff members were responsible for initiating this program on the unit. Although the role was initially described as educational, a degree of independence and flexibility was given to the nurse throughout its evolution to address the needs of this group of men.

Suzanne Boxhall, BNg, RN, is a Research and Specialist Prostate Nurse, Repatriation General Hospital, Daw Park, Australia.

Melissa Dougherty, BA, is a Project Officer, Clinical Epidemiology and Health Outcomes Unit, Flinders Medical Center, Bedford Park, Australia.

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The role of a specialist prostate nurse in the care of men with newly diagnosed prostate cancer has not been well documented. Therefore, the needs of men diagnosed with prostate cancer were individually assessed in this qualitative study. The nurse was an acceptable source of information, with time to listen and respond to the men's physical and psychosocial needs at diagnosis and throughout the continuum of care.

While recognizing that it could possibly mirror the role of the Australian breast care nurse as described in Horden (2000), this was not used as a model. Rather it evolved in response to men's needs as they arose. Therefore, an evaluation from the perspective of the consumers of the service was sought.

Purpose

This qualitative study was developed to identify aspects of nursing care that were valued by men through classification of transcribed audio material.

Review of Literature

There is a plethora of knowledge in the medical literature about prostate cancer regarding etiology, diagnostic methods, treatments, their effectiveness and morbidities, and quality of life issues. However, it has only been in recent years that the needs of newly diagnosed Australian men have been articulated to health care providers.

Australian state cancer councils, nurses, and researchers have all drawn attention to the unmet needs of these men and their families (Girgis, 2000; Lumsden,

1997; Pinnock, O'Brien, & Marshall, 1998; Steginga et al., 2001). International nursing research also reflects similar experiences for men elsewhere. These concerns are related to insufficient or confusing information, especially during decision-making processes and the practical management of treatment side effects (Asbury, Findlay, Reynolds, & McKeracher, 1998; Girgis, 2000; Fitch, Gray, Franssen, & Johnson, 2000; Helgesen et al., 2000; Higgins, 2000; Jakobsson, Hallberg, & Loven, 2000; Krizek, Roberts, Ragan, Ferrara, & Lord, 1999). It has been suggested that patients may sometimes be reluctant to bother their doctors about personal quality of life issues (Lumsden, 1997) and less likely to attend support groups (Moore & Estey, 1999) even though 31% experience psychological distress following diagnosis (O'Rourke & Germino, 1998). Gray, Fitch, Phillips, Labrecque, and Klotz (1999) referred to the impact on spouses and Davison and Degner (1997) demonstrated that information provided to men through decision-making processes led to lower levels of anxiety.

Table 1.
Mr. PHIP Series

- ◆ Prostate Cancer: Should I be Tested?
- ◆ Prostate Cancer: Interpreting the PSA Test
- ◆ Prostate Cancer: After Diagnosis
- ◆ Prostate Cancer: Recurrence after Treatment
- ◆ Prostate Cancer: Hormone Treatment
- ◆ Prostate Cancer: Useful Resources and Glossary

Note: Available through the Web site: www.prostatehealth.org.au

Australian men are now asserting their consumer rights through an association of support groups and are using the media, government submissions, and professional forums as the Australian Collaboration for Prostate Health to draw attention to the disparity between prostate and breast cancer resource allocation.

Methodology

A nurse was made available (0.4 full-time equivalent) during outpatient urology clinics. The qualifications required for this position were a bachelor of nursing degree with a clinical knowledge of urology practice, an interest in research, and the expertise to produce educational materials. The position is currently held at a clinical nurse level, which usually requires a minimum 3 years postgraduate experience in the area of specialty. The nurse, who worked in collaboration with the existing continence nurse advisers, educated herself about continence issues. Other knowledge was accumulated through self-education with the support and access to the unit urologists

Appropriate study patients were identified through medical referral or the institutional prostate cancer database. An introductory card was available to urologists to give to patients at diagnosis. Initial contact was made either by the nurse in a consulting room or by phone within 14 days. A verbal invitation was issued to men to consider the nurse as another available resource willing to address concerns about any aspect of their

current or future care. In recognition of many men's difficulty with the notion of "support," they were invited to view the nurse in a "service" role. Since there was a wide variance in the needs of men, the nurse sought to provide information at the time and level appropriate to each person. Library resources were offered to all men and peer support made available to those who might benefit.

The core component of education at diagnosis was to ensure each man understood the nature of grade and stage of his cancer, and consequently the reasons for his treatment options. Prior to the men consenting for surgery, the nurse reviewed the common side effects of urinary, bowel, and erectile injury, and potential changes from hormone therapy. These side effects were explained in the context of basic anatomy and physiology and at the level of each man's need. Practical information was provided before and after surgery and radiotherapy.

An urologist and a research scientist prepared written educational materials, with contributions from consumers, continence and urology nurses, and the state Cancer Council. Consumer feedback suggested that men preferred information delivered in stages. The state of South Australia funded the research and development of educational resources for men with prostate cancer in the form of information sheets. These information sheets, known as the Prostate Health Improvement Program (Mr. PHIP) package, were distributed to general prac-

tioners and urologists. See Table 1 for the titles of the information sheets in the series.

Sample

One hundred and five consecutive men were identified in the outpatient clinics who were diagnosed with prostate cancer or were seeking second opinions during the previous 12 months. Forty-four of these men were then excluded. The exclusion criteria included: (a) living more than 80 km radius from the hospital (12 men), (b) those who had clearly expressed that they had no needs or wished to "forget all about it all" (10), (c) those who had sought a second medical opinion only with no clinical followup at the hospital (9), (d) those who had major physical or cognitive impairment (9), (e) were not contactable (1), (f) had social constraints (1), or (g) had died since diagnosis (2).

The remaining 61 men were mailed invitations to attend a discussion group seeking their opinions on the role of the specialist nurse. Of those men invited, 30 participated in the study. The breakdown of the responses were as follows:

- Attended discussion group: 30 (49%).
- No reply received: 10 (no followup done) (16%).
- Replied but declined (no reasons given): 8 (13%).
- Declined due to physical impairment/ill health: 11 (18%).
- On vacation: 2 (3%).

A choice was given of day or evening sessions, with free parking or transport reimbursement. Additionally, the study participants were assured that no member of their clinical team would listen to the recordings. Four focus group discussions were convened in a nonurologic venue and facilitated by an experienced psychology researcher. Length of sessions were between 60 to 90 minutes. Institutional ethics approval was obtained and participants gave consent for the audiotaping of the discussions.

Analysis

The audiotapes were transcribed and checked by the facilitator. Individual statements were then categorized into themes and analysis was made and checked by two persons. Semi-structured prepared questions were introduced to prompt discussion. See Table 2 for a list of the prepared questions. Nonverbal acknowledgments were not recorded nor were indistinct unison agreements on audiotape. Since data were collected on the basis of group discussions and not questionnaires, not all men made statements on every issue.

Results

The main themes discussed were: (a) referral patterns, (b) information provision, (c) approachability and role of the nurse, (d) accessibility, and (e) satisfaction with supportive services associated with prostate cancer management.

Referral patterns. Doctor: 19 (63%); nurse initiative through phone or letter: 4 (13%); other men: 1 (3%); education sheets (nurse contact details included): 2 (6%); had not needed service: 1 (3%); three subjects did not respond.

Information provision. All 30 men in the sample had received Mr. PHIP information sheets which were rated highly even though one person felt the information was all "frightening" (3%). Other information and resources sought by men reflected their varied needs. Only a small number had borrowed extra prostate nursing resources 4 (6%) and 2 (6%) had used the Internet.

The nurse complemented medical care particularly by increasing men's understanding of disease processes. "I would have been a bit at sea without the information she gave me."

Some participants found that the nurse provided a guide through the information. "Everybody is different and what they write in a pamphlet is just a general part of it. I think you need a

Table 2.
Semistructured Questions

Prompts used included:

1. How did you first come to hear about the nurse?
2. How accessible and approachable did you find the nurse?
3. How did men feel about speaking to a female nurse when discussing issues around a male-specific disease?
4. Would written information alone be adequate for your needs?
5. Was the timing of information given appropriate?
6. In retrospect would you have liked less or more information from the nurse?
7. Were any books or videos borrowed helpful?
8. What other resources did you use?
9. Did you ever feel that you couldn't access the right information for your personal needs?
10. Which areas of your care would you have liked more information and support but didn't feel you were able to get from your doctor or nurse?
11. How did you rate the continence supports available at the hospital?

person that guides you, specially before an operation, things like that."

Nursing intervention was seen as particularly helpful around the time of diagnosis and before treatment decisions: 22 (73%). "(The nurse) certainly breaks down that barrier when you first hear." "...calming you down after being 'thumped on the head' that you have cancer, and....quite useful was a lead up to making a decision." "You are sitting across the table and the guy says you have cancer, just like that."

One person (3%) expressed unmet needs and these related to dietary information.

Approachability/Role of the nurse. The most valued element of the nursing role was the time afforded them: 15 (50%). "You need everything explained, and they are not flustered if you rang a few times." "She is doing specific things and not doing lots of other things, she is not trying to do us and then go down to a surgery." "She will spend a fair bit of time talking with you and there may be three or four things on your mind that are worrying you, but you are not going to come out with those things all at once, you talk around the topic

and eventually you get around to the things that are starting to worry you." "...she always gives you all the attention in the world."

Both practical and emotional support was rated highly by men: 24 (80%). "Just being broken with the news was too much. It wasn't really information overload but just the information you got tended to be bad rather than good." "She keeps the stress out for us."

"There was something that I wasn't too sure about, so I rang her, and put she me on the right track. That is what she has done all the time, allayed any fears and explained things in layman's language."

Continence support was valued greatly by those who had needed it: 3 (10%). "It might not seem as important when it comes to comparing to the chopping, but believe you and me it is."

Men believed that a nurse's time was more cost effective than a specialist, particularly when dealing with side effects or incidental questions or concerns about their care. Nursing knowledge was perceived to be practical and able to fill gaps left by doctors working with time constraints: 4 (13%). "...his fingers

are very valuable, he needs somebody else to do the other part.” “...specialists who are very specialized....I don't seem to get the right answer that I want. Perhaps it is because I am not asking him the right question, but he is not helping me to ask the right question.” “You don't just have cancer do you? You have incontinence and erection problems and everything else. It is not just like having a wart taken off your hand, you have side effects you have to handle.” “I have just had radiotherapy and had some bowel trouble — it is the sort of thing you can discuss with a nurse — simple things like how to keep your body going and that sort of thing.”

However, men felt confident about referral to medical opinion when it was appropriate: 10 (33%). “I see her role as being a support role, not an initial consultation.” “...mine was symptomatic stuff....she would check with (the urologist) and get back to me and she did. Absolutely proper to me.”

In view of the intimate nature of sexual, continence, and relationship issues surrounding prostate cancer, the female gender of the nurse was considered not to be a problem. Twenty-eight men (96%) considered it not to be a disadvantage. Nurses were presumed to be comfortable discussing intimate issues. The factors deemed most important were the nurse's experience and knowledge. “I don't care what age, what gender, so long as the knowledge is there.” “Experience matters though and young people don't have it as much.” “They have to be qualified to be able to talk.”

The nurse's manner was rated as very important and all who had used the service felt well satisfied with this aspect of their care: 21 (70%). “...we have been treated by people who are genuinely interested in our disease and to me that is absolutely paramount.”

Accessibility. The accessibility of the part-time nurse was also deemed important by partici-

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pants: 16 (53%). “...could you get on the phone and ring up (the urologist) and say I want to see you? I don't think you would, would you?” “When you are going through it, everything worries you and you want a response straight away.”

Four men (13%) who had delays in contacting the nurse through the use of an answering machine felt it to be a problem. But they acknowledged that other continence/urology nurses were available for urgent problems. The reliability of any information from others was considered to be very important. “...fortunately I have not really needed to call on her, but it is very reassuring to know that you have got a person who is capable.”

Only two references (6%) were made to family members who had contact with the nurse, for one this was helpful, the other not.

Satisfaction with support services. When asked whether outside sources of support and information (cancer councils or central community shop front locations) would better meet their needs at diagnosis, there was a strong belief that these were best placed “inside” the system. Fourteen men (45%) related that care was given individually by someone who had access to their medical record, was part of the treatment team, and could readily communicate with doctors working in a busy public hospital. “She's got the inside running.” “I think it's terrific to be part of a team, rather than just a lot of individuals.”

Discussion

Nurses have always been involved in the care of men with prostate cancer. However, it has often been fragmented and only at points of medical intervention (assisting with tests, postopera-

tive care, specialist continence, erectile dysfunction clinics, and palliative care services). The role of a specialist prostate nurse in the care of men newly diagnosed with prostate cancer has not been well documented. A literature search revealed only three references to similar roles, one in Australia (Lumsden 1997) and two in the United Kingdom (Calman & Hine, 1995; Higgins, 2000). Another reference to a specialist prostate nurse was found in Sweden where routine reviews were done following treatment for prostate cancer (Helgesen et al., 2000).

These focus groups were the first opportunity to seek men's opinions and experiences with the specialist nurse. Given the unpredictability of daily workloads, the nurse also participated in flexible urology research projects. This enabled a fast response to the needs of men with prostate cancer when they arose. The lengths of the initial consultations ranged between 10 and 60 minutes and were tailored to the individual's need at the time. Most sessions were between 30 and 40 minutes. Although four men felt access to the nurse was limited by the part-time position, they were confident of alternative pathways to medical care. There was unanimous agreement that support services provided through a nurse, who worked as part of the clinical team, was beneficial. This finding is of relevance to both current and future prostate cancer services.

The nonreply rate (16%) of the invitations issued was significant, but no reasons were sought or reminders given after the initial mailing. This could include those men who may have felt they would not benefit from the nursing service.

Educational resources have

become more common and men were satisfied with the Mr. PHIP information brochures in current use. However, the men appreciated the opportunity for further discussion where they felt less constrained by time pressures. They also placed importance on expert knowledge. The nurse was always aware of the practice boundaries when counseling men through decision-making processes and was careful not to "give an opinion" even when often asked by men at this vulnerable time.

Men believed that the service was delivered in a manner and by a professional with whom they felt comfortable. Nursing experience, not gender, was more important to this group of men, even given the intimate issues surrounding this disease.

Clinical care included advice with problems with catheters at home, symptoms of infection, strictures, post-treatment depression, continence products, erectile dysfunction, allied health care resources, and domestic supports. The range of these functions was not totally reflected in these focus group discussions. There was a greater amount of "yarn swapping" than anticipated and time pressures may have discouraged the expression of unmet needs as they were discussed near the end of sessions. Viewed from the nurse's perspective, this role has evolved to additionally include liaison, counseling, advocacy, and research.

The small number of references to family contacts also does not reflect the amount of real time that the nurse spent with significant others. This was usually by phone or at an appointment following the initial consultation, with both parties present, or during a hospitalization. Partners were often the main source of support for these men, but they may also have their own needs and further research in this area may be warranted.

This research study sought men's responses to a service that

seeks to assist men during the stress of cancer diagnosis, treatment decision making, managing altered sexual function, bowel and urinary side effects, and the uncertainty that PSA monitoring brings to the years ahead.

Conclusion

This small sample of men who had access to a specialist nursing service found it to be useful in those areas where the literature suggested information and managing side effects were areas of unmet need. The nurse was seen to complement medical care in providing information, emotional support, and practical assistance with managing treatment side effects. Men believed that the service was delivered in a manner and by a professional with whom they felt comfortable. Expert knowledge was rated highly and communication was not hindered by the gender of the female nurse. Men believed that a nurse listened and responded to their physical and psychosocial needs at the time of diagnosis and throughout the continuum of care. ■

References

- Asbury, F.D., Findlay, H., Reynolds, B., & McKeracher, K. (1998). A Canadian survey of cancer patients' experience: Are their needs being met? *Journal of Pain Symptom Management*, 16(5), 298-306.
- Calman, K., & Hine, D. (1995). *A policy framework for commissioning cancer services*. London: HMSO UK.
- Davison, J., & Degner, L. (1997). Empowerment of men newly diagnosed with prostate cancer. *Cancer Nursing*, 20(3), 187-196.
- Fitch, M., Gray, R., Franssen, E., & Johnson, B. (2000). Men's perspectives on the impact of prostate cancer: Implications for Oncology Nurses. *Oncology Nurse Forum*, 27(8), 1256-1263.
- Girgis, A. (2000, March 24). Psychosocial support guidelines for breast cancer — Relevance to men. *Cancer Forum*, 24, 1.
- Gray, R.E., Fitch, M.I., Phillips, C., Labrecque, M., & Klotz, L. (1999). Presurgery experiences of prostate cancer patients and their spouses. *Cancer Practice*, 7(3), 130-135.
- Helgesen, F., Andersson, S., Gustafsson, O., Ebeerhard, V., Goben, B., & Carnock, S. (2000). Follow-up of prostate cancer patients by on-demand contacts with a specialist nurse: A randomised study.

- Scandinavian Journal of Urology and Nephrology*, 34(1), 55-61.
- Higgins, D. (2000). The role of the cancer nurse specialist. *Professional Nurse*, 15(8), 539-543.
- Horden, A. (2000). The emerging role of the breast care nurse in Australia. *Cancer Nursing*, 23(2), 122-127.
- Jakobsson, L., Hallberg, I.R., & Loven, L. (2000). Experiences of micturition, indwelling catheter treatment and sexual life consequences in men with prostate cancer. *Journal of Advanced Nursing*, 31(1), 59-67.
- Krizek, C., Roberts, C., Ragan, R., Ferrara, J.J., & Lord, B. (1999.) Gender and cancer support group participation. *Cancer Practice*, 7(2), 86-92.
- Lumsden, G. (1997). Counselling prostate cancer patients. *Australian Nursing Journal*, 4(10), 24-25.
- Moore, K.N., & Estey, A. (1999). The early post-operative concerns of men after radical prostatectomy. *Journal of Advanced Nursing*, 29(5), 1121-1129.
- O'Rourke, M.E., & Germino, B.B. (1998). Prostate cancer treatment decisions: A focus group exploration. *Oncology Nurse Forum*, 25(1), 97-104.
- Pinnock, C., O'Brien, B., & Marshall, V. (1998). Older men's concerns about their urological health: A qualitative study. *Australian and New Zealand Public Health*, 22, 368-373.
- Steginga, S.K., Occhipinti, S., Dunn, J., Gardiner, R.A., Heathcote, P., & Yaxley, J. (2001). The supportive care needs of men with prostate cancer. *Psycho-oncology*, 10(1), 66-75.

Ethnic group - prostate cancer is more common amongst men of Afro-Caribbean and African descent. While the condition is relatively rare amongst men of Asian and South and Central American descent. Family history - having a close male relative - such as a brother, father or uncle - who had prostate cancer seems to increase the risk of you developing prostate cancer. Research also shows that having a close female relative who developed breast cancer may also increase the risk of you developing the condition. Diet - a diet high in dairy products and red meat has been linked to an increased risk of prostate cancer. There are several factors that you will need to take into account when deciding on your treatment. The specialist nursing workforce caring for men with prostate cancer in the UK Research report 2014. Commissioned by Prostate Cancer UK. 2. So access to a specialist nursing service depends on where you live. To get a greater understanding of these issues we will need further research. I hope that you find the report makes for interesting reading. Specialist nurse roles have been an informal part of the cancer nursing workforce for many years, with the first formal recognition provided in the Calman-Hine report (DH 1995). A number of drivers have influenced the number and extent of CNS role development over the past two decades including reduced availability of junior doctors, the EU working time directive and the introduction of waiting time targets (DH 1999, 2000). An evaluation of support of patients with prostate cancer during and beyond radiotherapy treatment. A local perspective on future provision. Journal of Radiotherapy in Practice, Vol. 14, Issue. Boxhall, S, Dougherty, M. An evaluation of a specialist nursing role for men with prostate cancer. Urol Nurs 2003; 23: 148-152. Canadian Cancer Society: Canadian Cancer Statistics.