SUBMISSION TO THE SENATE SELECT COMMITTEE ON MEN'S HEALTH

Submitted by:

The Department of Urology
Royal Melbourne Hospital
Level 3 Centre
Grattan St, Parkville, VIC 3050

The Royal Melbourne Hospital

Professor Anthony Costello
Head, Department of Urology
Urologist

&

Dr Addie Wootten
Clinical Psychologist
Department of Urology
&
Dr Heather Siddons
Clinical Psychologist
Department of Urology

Prostate Cancer in Australia in 2009

Cancer of the prostate (CaP) is the most common cancer diagnosis in Australia (excluding non-melanocytic skin cancer) with more than 18,000 new cases diagnosed each year [1]. New diagnoses of CaP have surpassed any other form of cancer, including breast cancer. Unlike other cancers, particularly breast cancer, there is no uniformity in care provision both for localised and for metastatic prostate cancer. The absence of clinical trial activity in prostate cancer hampers our activity to direct optimal therapy at all stages of prostate cancer.

We have no clear guide to optimal therapy for prostate cancer. A man with localized prostate cancer in Victoria in 2009 may be offered up to seven different treatment options for management of his disease. In non-metastatic prostate cancer, he could be offered active surveillance also known as watchful waiting, surgery by laparoscopic, robotic or open techniques, radiation therapy (external beam or brachytherapy implant), high intensity focused ultrasound, and cryoablation. This plethora of therapeutic options leads to confusion in the patient and partner, frequent paralysis in decision making, and decisional regret when adverse outcomes occur.

The major morbidities associated with treatment of localized prostate cancer include failed cancer control, incontinence of bladder and bowel, sexual dysfunction, and psychological trauma, and these are extant in all of the different prostate cancer treatment modalities. There is an absence of centralized data collection for outcome evaluation and collaboration between the major care providers in prostate cancer care across Australia is required. The multiplicity of urban and rural centres where prostate cancer treatment is given makes data acquisition difficult. A centralised data collection system would enable greater understanding of how effective prostate cancer treatment is in a curative sense by surgery, radiation, brachytherapy and other modalities. The development of a systematic and objective dataset on each patient should be obtained including – pre-treatment PSA, patient age, Gleason score, cancer stage, biopsy patterns, biopsy volume, continence status, sexual function, quality of life, and post treatment outcome assessment by PSA, continence, sexual function, quality of life, morbidity and mortality. This dataset would allow greater understanding of the disease and treatment process and outcomes and lead to increased consensus as to treatment of choice based on disease status.

Prostate cancer, unlike many other cancers, does not have clear guidelines available and the development of a database would inform the development of such enabling enhanced patient information and communication, increasing treatment outcomes and peace of mind for patients and their families.

The psychological impact of prostate cancer

While the incidence of CaP is growing, treatment of localised disease has become very effective and many patients are reportedly living with it rather than dying from it. However, with respect to localised CaP, all curative treatment interventions are known to incur considerable impact on quality of life (QoL), either temporarily or permanently. Survivorship issues in the prostate cancer population therefore poses unique challenges in terms of quality of life and the issues experienced by survivors

could be more accurately described as chronic illness type presentations. As such, in order to support these cancer survivors, the Victorian healthcare system must understand the needs of this population. Research in this domain now needs to focus on the ways in which patients can be supported by the healthcare system so as to minimize the impact of CaP on their well-being (Newton et al., 2006). There has been very little research examining psycho-social interventions for this group of cancer patients. Attention to the need for men's health initiatives is growing but urgently in need of further research. A recent review conducted by the Southern Metropolitan Integrated Cancer Service (SMICS) Genito-Urinary Group highlighted the lack of psycho-social support for men after treatment for prostate cancer as an area of high priority in southern metropolitan Victoria [2]. It is anticipated that other Victorian regions, if surveyed, would show similar findings. Furthermore, a recent NSW Cancer Council population-based study identified that more than 54% of prostate cancer patients expressed some form of unmet psychological need [3]. These studies highlight the need for improved psycho-social interventions for CaP patients. Despite the higher rate of diagnosis of CaP the care of prostate cancer patients is substantially lagging behind the level of care delivered to breast cancer patients.

Prostate Cancer and QoL:

It is well-known that the treatment of prostate cancer with prostatectomy or radiotherapy can often result in residual symptoms post-treatment (Kao et al., 2000; Lubeck et al., 1999). These may include sexual, urinary and bowel dysfunction (Lubeck et al., 1999; Nguyen, Pollack, & Zagars, 1998; Schwartz, Bunner, Bearer, & Severson, 2002) with changes often occurring up to two years post-treatment (Litwin, Melmed, & Nakazon, 2001; Wootten et al, 2007a). Coping with these residual symptoms can be very difficult for the patient (Gray, Fitch, Phillips, Labrecque, & Klotz, 1999) and has been found to significantly impact on the patient's quality of life (Bokhour, Clark, Inui, Silliman, & Talcott, 2001; Wootten et al., 2007b). The body of research examining the quality of life and psychosocial consequences of prostate cancer is growing (Weber & Sherwill-Navarro, 2005).

Psycho-social implications of prostate cancer have been documented. Depression is at least two to three times more common in patients with cancer (Fisch, 2004), with general psychological disorders (including depression and anxiety) estimated at 25-47% (Keller, et al., 2004; Trask, 2004; Wootten et al., 2007b). It is also noted that depressive symptoms are believed to be under diagnosed and under-reported among cancer patients (Eller et al., 2006). Suicide in older men with prostate cancer has also been reported; one study has reported that older men with prostate cancer were more than four times more likely to complete suicide than an age a gender matched cohort without prostate cancer (Llorente et al., 2005).

To date, quality of life research has generally focussed on the physical impact of treatments on prostate cancer patients. However, research investigating the impact of prostate cancer treatment on psychological well-being is increasing (Blank & Bellizzi, 2006; Couper et al., 2006; Eller, et al., 2006; Hervouet, et al., 2005; Korfage et al., 2006; Wootten et al., 2007b). The results of these studies have revealed that among those who have had prostate cancer treatment, the prevalence of mood disorders (i.e. anxiety, depression, adjustment disorders) ranges from 9-24% (Couper et al.; Frick et al., 2007; Hervouet et al.; Pirl et al., 2002). The results from other studies suggest that physical side effects of prostate cancer treatment (such as incontinence and sexual dysfunction) are associated with anxiety and depression

(Eller et al.). While the long-term psychological outcomes have been less researched, one study has shown that these patients experience increased mood disturbance compared to geriatric norms, even up to two or more years post treatment (Wootten et al.). This suggests that the outcomes of prostate cancer and its treatment can be quite long-term and can therefore have ongoing consequences for not only physical well-being but also mental health.

Ahmad, Musil, Zauszniewski, and Resnick (2005) have proposed that the health care of patients treated for localised prostate cancer should take a more holistic approach. Rather than focusing on treating the initial stages of the disease, Ahmad et al. (2005) concluded that health care services should focus on the longer term survival issues of the prostate cancer patient and target all aspects of health, including the QoL of the patient (Ahmad et al., 2005).

Patient-reported needs:

One large population based Australian study of 1,067 men diagnosed with prostate cancer between 200-2001 in NSW surveyed patients between 3 and 12 months after diagnosis (Smith et al., 2007). This study found that 74% of men reported some form of unmet need in relation to their prostate cancer diagnosis. Fifty-four percent of men reporting poor health stated that they had unmet needs in relation to their health and the rate rose to 74% in men under the age of 50 years. Men reported a range of areas of unmet support needs. The most commonly reported area of unmet support need was in the psychological support domain where 54% of men expressed that they felt some level of unmet psychological support need (Smith et al., 2007). Sexuality was reported by 47% of men as an area where they had some level of need for assistance or support and more than 20% of men reported a moderate to high need for the "uncertainty for the future" domain. The authors of this study strongly recommended improved access to the spectrum of supportive care services for prostate cancer patients, including nursing specialists, psychological counselling, peer support groups and consumer information (Smith et al., 2007).

Inadequate patient and spouse knowledge has also been implicated in poorprostate cancer outcomes and increased distress experienced by the patient andspouse. A recent study found that inadequacies in patient and spouse knowledge andawareness of prostate cancer contributed to delayed contact, shock at diagnosis,preferences regarding decision making, health judgements and patient coping(Docherty, Brothwell, Symons, 2007). This study highlighted the commonmisunderstandings and misinformation about prostate cancer in the wider community.The findings of this study indicated an apparent lack of awareness of treatmentoptions or side-effects and a reliance on general practitioner (GP) assistance,highlighting the need for consistent information and support provision. The authors ofthis study recommended the involvement of a PCLN across a number of domains: (1)assistance in the assessment of patient preferences; (2) response to inadequateknowledge and (3) to engage and involve the patient in their care (Docherty et al.,2007).

Clinical Impressions

- There are significant stigma/shame barriers in terms of men accessing support
    - Psycho-social care is still often seen as unacceptable for many men and

more education needs to be given to inform the general population that it is ok for men to need support. Support seeking needs to be normalised.

- Men often feel marginalised and this is often a great source of distress
- Men do not know how, where or when to access support and it is often the partner who initiates contact with a psychologist.
- Specialist training in how to work clinically with men would be beneficial for psychologists and other support providers working in this area.

Recommendations

A review of the research literature as well as our own clinical practice indicates that the care of prostate cancer patients needs to be improved. Both patients with localised disease and those with advanced disease report a range of ongoing psycho-social problems; sometimes for many years. Prostate cancer can have a widespread impact on patient quality of life as well as a significant impact on the patient's partner and family.

As such the following recommendations are made:

1. *Consistent and unbiased information to all men and their families:*
    a. Patients need to be able to routinely access credible and consistent information. The treatment decision making process for localised disease is difficult for almost every patient. Without credible information provided to patients they are left to sift through the often questionable information available on the internet, further raising anxiety levels. With no clear consensus on which treatment option is the best for localised prostate cancer within the medical community patients need support and guidance in this decision making process.
    b. We highly recommend financial support of a national information pack being distributed to each man diagnosed with prostate cancer that provides clear and consistent information, without bias, about the treatment options available and the support services that can be accessed.
        i. The Prostate Cancer Foundation of Australia have been working on such a project and are well placed to deliver such a service to patients.
2. *Access to appropriate support services*
    a. Medical management of prostate cancer patients has come a long way in recent years and survival rates are now excellent. However, management of ongoing physical complications, such as erectile dysfunction, urinary incontinence, and bowel dysfunction and subsequent mood disturbance is not being effectively managed. Patients require ongoing support from specialists. The current state of the healthcare system in Australia does not allow for easy access of these specialist services. Therefore we recommend that an increase in services is required across the following areas:
        i. Prostate cancer **nursing**
            1. Ongoing medical care can be monitored and supported by a specialist nurse
        ii. Specialist prostate cancer specific **physiotherapy** services

1. Speed of recovery can be enhanced through access of physiotherapy services; particularly in relation to pelvic floor.

iii. Specialist prostate cancer specific **clinical psychology** services

1. To assess and treat a range of emotional sequelae associated with a diagnosis of cancer, coping with residual symptoms, relationship difficulties associated with prostate cancer and management of anxiety and depression.

iv. Specialist prostate cancer specific **exercise physiology** services

1. Research has indicated that early exercise intervention can improve a range of physiological, social and emotional responses as a result of being treated for advanced prostate cancer with androgen deprivation therapy.

3. *Increased awareness raising*

a. National education and awareness raising campaigns highlighting the facts of prostate cancer. Often men feel marginalised by their disease an unaware of the number of other men dealing with similar issues. There is also a misconception that prostate cancer is an old man's disease and this myth needs to be expunged. In order to get men to take responsibility for their own health we need to get a conversation going about prostate cancer, we need men to start talking to each other about the issues around prostate cancer.

References

Ahmad, M. M., Musil, C. M., Zauszniewski, J. A., & Resnick, M. I. (2005). Prostate cancer: Appraisal, coping, and health status. *Journal of Gerontological Nursing, 31*, 34-43.

American Cancer Society. (2005). *Cancer facts and figures 2005*. Atlanta: American Cancer Society

Australian Institute of Health and Welfare. (2007). *Cancer in Australia; an overview 2006.* Canberra, ACT: Australasian Association of Cancer Registries.

Averill, P. M., Novy, D. M., Nelson, D.V., Berry, L. A., (1996). Correlates of depression in chronic pain patients: a comprehensive examination. *Pain, 65* :93-100

Becze E. (2007). New therapies for advanced prostate cancer: the nurse as part of the multidisciplinary team. *ONS Connect. 22(8 Suppl):* 47-8.

Blank, T. O. & Bellizzi, K. M., (2006). After prostate cancer: Predictors of well-being among long-term prostate cancer survivors. *Cancer, 106*, 2128-2135.

Bokhour, B. G., Clark, J. A., Inui, T. S., Silliman, R. A., & Talcott, J. A. (2001). Sexuality after treatment for early prostate cancer: Exploring the meanings of

erectile dysfunction. *Journal of General International Medicine, 16*, 649-655.
Boxhall, S., Dougherty, M., (2003). An evaluation of a specialist nursing role for men with prostate cancer. *Urologic Nursing, 23(2)*, 148-152.
Bradley, C. J., Neumark, D., Luo, Z., Bednarek, H., Schenk, M., (2005). Employment outcomes of men treated for prostate cancer. *Journal of the National Cancer Institute, 97*, 958-965.
Bradley, C. J., Neumark, D., Luo, Z., Schenk, M., (2007). Employment and cancer: Findings from a longitudinal study of breast and prostate cancer survivors. *Cancer Investigation, 25*, 47-54.
Bradley, C. J., Oberst, K., & Schenk, M., (2006). Absenteeism from work: The experience of employed breast and prostate cancer patients in the months following diagnosis. *Psycho-Oncology, 15*, 739-747.
Bultmann, U., Rugulies, R., Lund, T., Christensen, K. B., Labriola, M., Burr, H., (2006). Depressive symptoms and the risk of long-term sickness absence: a prospective study among 4747 employees in Denmark. *Social Psychiatry & Psychiatric Epidemiology. 41*:875-80.
Clark, J. A., Wray, N., Brody, B., Ashton, C., Giesler, B., & Watkins, H. (1997). Dimensions of quality of life expressed by men treated for metastatic prostate cancer. *Social Science and Medicine, 45*, 1299-1309.
Couper, J., Bloch, S. A. L., Ducehsne, G., Macvean M., Kissane, D., (2006). The psychosocial impact of prostate cancer on patients and their partners. *MJA, 185*, 428-432.
Eller, L. S., Lev, E. L., Gejermen, G., Colella J., Esposito, M., Lanteri, V., et al., (2006). Prospective study of quality of life of patients receiving treatment for prostate cancer. *Nursing Research, 55*, S28-S36.
Fisch, M., (2004). Treatment of depression in cancer. *Journal of the National Cancer Institute Monographs, 32*, 105-111.
Frick, E., Tyroller, M., Panzer, M., (2007). Anxiety, depression and quality of life of cancer patients undergoing radiation therapy: A cross sectional study in a community hospital outpatient centre. *European Journal of Cancer Care, 16*, 130-136.
Gerber, L. H. (2001). Cancer rehabilitation into the future. *Cancer, 92*, 975-979.
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*, 130-135.
Gudbergsson, S. B., Fossa, S. D., Borgeraas, E. and Dahl, A. A., (2006). A comparative study of living conditions in cancer patients who have returned to work after curative treatment. *Support Care Cancer, 14*, 1020-1029.
Hervouet, S., Savard, J., Simard, S. B., Ivers, H., Laverdiere, J., Vigneault, E., et al., (2005). Psychological functioning associated with prostate cancer: Cross sectional comparison of patients treated with radiotherapy, brachytherapy or surgery. *Journal of Pain and Symptom Management, 30*, 474-484.
Kao, T. C., Cruess, D. F., Garner, D., Foley, J., Seay, T., Friedrichs, P., et al. (2000). Multicentre patient self-reporting questionnaire on impotence, incontinence and stricture after radical prostatectomy. *Journal of Urology, 163*, 858-958.
Keller, M., Sommerfeldt, C., Fischer, C., Knnight, L., Riesbeck, M., Lowe, B., et al., (2004). Recognition of distress and psychiatric morbidity in cancer patients: A multi-method approach. *Annals of Oncology, 15*, 1243-1249.
Korfage, I. J., Essink-Bot, M., Janssens, A., Schroder, F. H., de Koning, H. J., (2006). Anxiety and depression after prostate cancer disgnosis and treatment: 5-year

follow-up. *British Journal of Cancer, 94*, 1093-1098.
Llorente. M. D., Burke, M., Gregory, G. R., Bosworth, H. B., Grambow, S. C., Horner, R. D., Golden, A., & Olsen, E. J., (2005). Prostate Cancer: A significant risk factor for late-life suicide. *The American Journal of Geriatric Psychiatry, 13*(3); 195-201.
Litwin, M. S., Melmed, G. Y., & Nakazon, T. (2001). Life after radical prostatectomy: A longitudinal study. *The Journal of Urology, 166*, 587-492.
Lubeck, D. P., Litwin, M. S., Henning, J. M., Stoddard, M. L., Flanders, S. C., & Carroll, P. R. (1999). Changes in the health related quality of life in the first year after treatment for prostate cancer: Results from CaPSURE. *Urology, 53*, 180-186.
Nguyen, L. N., Pollack, A., & Zagars, G. K. (1998). Late effects after radiotherapy for prostate cancer in a randomised dose-response study: Results of a self-assessment questionnaire. *Urology, 51*, 991-997.
Pirl, W., Siegel, G., Goode, M., Smith, M., (2002). Depression in men receiving androgen deprivation therapy for prostate cancer: A pilot study. *Psycho-Oncology, 11*, 518-523.
Ruta, D. A., Garratt, A. M., Leng, M., Russel, I. T., & MacDonald, L. M. (1994). A new approach to the measurement of quality of life: The patient generated index. *Medical Care, 32*, 1109-1126.
Schwartz, K., Bunner, S., Bearer, R., & Severson, R. K. (2002). Complications from treatment for prostate carcinoma among men in the Detroit area. *Cancer, 95*, 82-89.
Shields, M., (2006). Stress and depression in the employed population. *Health Reports. 17*:11-29
Smith, D. P., Supramaniam, R., King, M. T., Ward, J., Berry, M., Armstrong, B. K., (2007). Age, health, and education determine supportive care needs of men younger than 70 years with prostate cancer. *Journal of Clinical Oncology. 25* (18);2560-6.
Sultan, R., Slova, D., Thiel, B. & Lepor, H., (2006).Time to return to work and physical activity following open radical retropubic prostatectomy. *Journal of Urology, 176*, 1420-1423.
Tarnhuvud, M., Wandel, C., Willman, A., (2007). Nursing interventions to improve the health of men with prostate cancer undergoing radiotherapy: A review. *European journal of oncology nursing, 11*, 328-339.
Tarrant, C., Sinfield, P., Agarwal, S., & Baker, R., (2008). Is seeing a specialist nurse associated with positive experiences of care? The role and value of specialist nurses in prostate cancer care. *BMC health services research 8*, 65.
Trask, P., (2004). Assessment of depression in cancer patients. *Journal of the National Cancer Institute Monographs, 32*, 80-92.
Visser, A., Van Andel, G., Willems, P., Voogt, E., Dijkstra, A., Rovers, P., et al. (2003). Changes in health-related quality of life of men with prostate cancer 3 months after diagnosis: The role of psychosocial factors and comparison with benign prostate hyperplasia patients. *Patient Education and Counselling, 49*, 225-232.
Weber, B. A., & Sherwill-Navarro, P. (2005). Psychosocial consequences of prostate cancer: 30 years of research. *Geriatric Nursing, 26*, 166-175.
Wootten, A. C., Burney, S., Frydenberg, M., Foroudi, F., Ng, K. T., & Coleman, G. (2007a). Long-term experience of residual symptoms following treatment for localised prostate cancer: An Australian sample. *Asia Pacific Journal of*

Clinical Oncology, 3, 189-196.
Wootten, A. C., Burney, S., Foroudi, F., Frydenberg, M., Coleman, G., & Ng, K. T. (2007b). Psychological adjustment of survivors of localised prostate cancer: investigating the role of dyadic adjustment, cognitive appraisal and coping style. *Psycho-Oncology, 16(11);* 994-1002.