

Annotated Bibliography for ACCC's Prostate Cancer Programs

Developing Tools and Measuring Effectiveness in the Community Setting Project

PROSTATE CANCER CARE
SUPPORTIVE CARE SERVICES AND END OF LIFE CARE

Winter 2011



Chambers, S. K., R. U. Newton, et al. (2011). "**Living with prostate cancer: randomised controlled trial of a multimodal supportive care intervention for men with prostate cancer.**" *BMC Cancer* **11**: 317.

ABSTRACT: BACKGROUND: Prostate cancer is the most common male cancer in developed countries and diagnosis and treatment carries with it substantial morbidity and related unmet supportive care needs. These difficulties may be amplified by physical inactivity and obesity. We propose to apply a multimodal intervention approach that targets both unmet supportive care needs and physical activity. **METHODS/DESIGN:** A two arm randomised controlled trial will compare usual care to a multimodal supportive care intervention "Living with Prostate Cancer" that will combine self-management with tele-based group peer support. A series of previously validated and reliable self-report measures will be administered to men at four time points: baseline/recruitment (when men are approximately 3-6 months post-diagnosis) and at 3, 6, and 12 months after recruitment and intervention commencement. Social constraints, social support, self-efficacy, group cohesion and therapeutic alliance will be included as potential moderators/mediators of intervention effect. Primary outcomes are unmet supportive care needs and physical activity levels. Secondary outcomes are domain-specific and health-related quality of life (QoL); psychological distress; benefit finding; body mass index and waist circumference. Disease variables (e.g. cancer grade, stage) will be assessed through medical and cancer registry records. An economic evaluation will be conducted alongside the randomised trial. **DISCUSSION:** This study will address a critical but as yet unanswered research question: to identify a population-based way to reduce unmet supportive care needs; promote regular physical activity; and improve disease-specific and health-related QoL for prostate cancer survivors. The study will also determine the cost-effectiveness of the intervention. **TRIAL REGISTRATION:** ACTRN12611000392965.

Dy, S. M., S. M. Asch, et al. (2011). "**Quality of end-of-life care for patients with advanced cancer in an academic medical center.**" *J Palliat Med* **14**(4): 451-457.

PURPOSE: We assessed key aspects of the quality of end-of-life care using validated explicit process quality measures in an academic medical center (hospital and cancer center) before expanding to a broader palliative care initiative. **METHODS:** We evaluated 21 indicators most relevant to end-of-life care from the Cancer Quality-ASSIST supportive oncology indicator set for 238 patients with advanced/metastatic solid tumors who died between 2-15 months after diagnosis. These included outpatient and hospital indicators for cancer symptoms and information and care planning that met criteria for feasibility, reliability, and validity. We abstracted detailed information from medical records to specify the necessary data elements. **RESULTS:** Overall adherence was 53% (95% confidence interval [CI], 50%-56%); this varied widely among indicators. Adherence was highest for pain indicators; in particular, 97% of eligible subjects' hospitalizations had

documented screening for pain, and, after an outpatient pain medication was changed, 97% of patients had a pain assessment at the subsequent visit. For other symptoms, adherence ranged from 0% for documentation of life expectancy for patients starting parenteral or enteral nutrition to 87% for assessment of nausea or vomiting on hospital admission. For information and care planning, results ranged from 6% for documentation of ventilation preferences prior to intubation to 68% for documented communication of risks and benefits or prognosis prior to starting chemotherapy. **CONCLUSION:** In conclusion, Cancer Quality-ASSIST indicators are useful for practical quality assessment of cancer end-of-life care in an academic medical center. These results will serve as useful data for targeting areas for quality improvement and measuring progress.

Lindqvist, O. (2011). "Living with bodily changes in hormone-refractory prostate cancer." *Semin Oncol Nurs* 27(4): 309-316.

OBJECTIVES: To review the current knowledge on living with bodily changes in hormone refractory prostate cancer (HRPC), treatment options, and common symptoms, and suggestions for improving our understanding of the experience of HRPC. **DATA SOURCE:** Existing literature, research, and clinical experience. **CONCLUSION:** Alleviation of bodily problems and providing care for men with HRPC is of utmost importance. It is important to talk about their situation and everyday life before asking about expected changes and problems related to the disease and its treatments. **IMPLICATIONS FOR NURSING PRACTICE:** A preliminary framework is suggested for understanding the experience of HRPC from a nursing perspective. These results support an existing body of knowledge emphasizing the paramount importance of symptom alleviation, but indicate another motivation, that of freeing time, when time is so limited. The importance of dialogue between patients and health care providers is highlighted.

Yennurajalingam, S., B. Atkinson, et al. (2011). "The Impact of an Outpatient Palliative Care Consultation on Symptom Burden in Advanced Prostate Cancer Patients." *J Palliat Med*.

Abstract Objectives: There are limited studies characterizing cancer-related symptoms in outpatient advanced prostate cancer patients. The aim of this retrospective study was to describe the impact of an outpatient palliative care (PC) consultation on symptoms in patients with advanced prostate cancer. **Methods:** We retrospectively reviewed the medical records of 55 consecutive patients with advanced prostate cancer seen in our institution's outpatient PC center. Information regarding demographics, disease status, Edmonton Symptom Assessment System (ESAS) scores, Eastern Cooperative Oncology Group (ECOG) Performance Status, laboratory data, and pharmacological interventions were analyzed. **Results:** The median age of the study's patients was 66 years old, with 73% Caucasian ethnicity. All patients had metastatic disease and 96% had received prior cytotoxic chemotherapy. The most frequently occurring symptoms upon presentation were pain, fatigue, and drowsiness (>50%). Pain and fatigue were also the most severe symptoms, each having median ESAS scores of 7 (on a 0-10 scale). We instituted a median of 3 pharmacological interventions per patient, with a median of 15 days to follow-up assessment. At follow-up, patients reported significant symptom improvements in pain, drowsiness, fatigue, depression, sleep, sense of well-being, and anxiety. **Conclusions:** Based on our preliminary data, we

conclude that patients with advanced prostate cancer referred to PC experience severe and clinically significant symptoms. An outpatient PC consultation is associated with significant symptom improvement in this subset of a distressed population. Future prospective studies are warranted to further describe symptom burden and the role for outpatient PC for advanced prostate cancer patients.

Dy, S. M., K. A. Lorenz, et al. (2010). "**Cancer Quality-ASSIST supportive oncology quality indicator set: feasibility, reliability, and validity testing.**" Cancer **116**(13):3267-3275.

BACKGROUND: Although measuring the quality of symptom management and end-of-life care could help provide a basis for improving supportive care for advanced cancer, few quality indicators in this area have been rigorously developed or evaluated. **METHODS:** The authors conducted a pilot evaluation of a comprehensive set of 92 supportive oncology quality indicators, Cancer Quality-ASSIST, including outpatient and hospital indicators for symptoms commonly related to cancer and its treatment and information and care planning. They operationalized the indicators and developed an electronic abstraction tool and extensive guidelines and training materials. Quality assurance nurses abstracted the medical records for 356 advanced cancer patients in 2 settings: a Veterans Administration hospital and an academic hospital and cancer center. The authors evaluated the indicators' feasibility, inter-rater reliability, and validity. **RESULTS:** The authors successfully evaluated 78 indicators across the domains; results were similar in the 2 settings. They could not feasibly evaluate 3 indicators because of low prevalence; 22 indicators had significant inter-rater reliability issues, 9 had significant validity issues, and 3 had both reliability and validity issues, leaving a set of 41 indicators most promising for further testing and use in this population, with an overall kappa score of 0.85 for specified care. **CONCLUSIONS:** Of 92 Cancer Quality-ASSIST quality indicators for symptoms, treatment toxicity, and information and care planning, 41 were sufficiently feasible, reliable, and valid to be used for patients with advanced cancer in these settings. This set of indicators shows promise for describing key supportive care processes in advanced cancer.

Grant, M. and V. Sun (2010). "**Advances in quality of life at the end of life.**" Semin Oncol Nurs **26**(1): 26-35.

OBJECTIVES: To provide an overview of the developments in promoting quality of life (QOL) at the end of life (EOL) in oncology settings, to describe implications for clinical care for cancer patients at the EOL, and to address the continuing challenges for assessing QOL at the EOL. **DATA SOURCES:** Published articles, clinical guidelines, and web resources. **CONCLUSION:** QOL continues to be an important aspect of patient care at the EOL. Nursing has made substantial contributions to the literature on QOL at the EOL through instrument development, clinical care priorities, and research. **IMPLICATIONS FOR NURSING PRACTICE:** Oncology nurses practicing in clinical and research settings must be aware of the importance of QOL assessment for terminally ill cancer patients, be informed about the process of selecting relevant QOL measures for the EOL, and apply current knowledge to quality cancer care.

Lebret, T., P. Coloby, et al. (2010). "**Educational tool-kit on diet and exercise: survey of prostate cancer patients about to receive androgen deprivation therapy.**" *Urology* **76**(6): 1434-1439.

OBJECTIVES: To test a tool-kit designed to improve well-being in patients with prostate cancer. Lifestyle changes might lessen the metabolic, cardiovascular, and osseous side effects of androgen deprivation therapy (ADT) in prostate cancer patients. **METHODS:** Urologists supplied 10 consecutive patients initiating ADT with a tool-kit (information brochure, practical guidance on diet and exercise, recipe booklet, and lifestyle diary). The urologists completed a total 4 questionnaires, at study initiation, one at the patients' first and second visits, and one at study completion. **RESULTS:** Overall, 91 urologists completed all questionnaires; 585 patients (median age, 75 years) were seen at the first visit, and 511 patients at the second. Patient response rate to the first questionnaire was 62% and 56% to the second. After the first visit, 82% of respondents reported being very glad or glad to receive the kit; among those having read the practical guidance (301/362), 57% had started implementation and 36% intended to do so. After the second visit, 76% were satisfied with the tool-kit and 84% were implementing guidance. Clinician satisfaction rate was 82%: benefits were improved patient dialogue (62%), follow-up (55%), and better explanation of side effects (51%). Only 14 clinicians were not pleased by the tool kit. Their main criticisms (too long, tedious, not tailored to individual needs) matched those of patients. **CONCLUSIONS:** Written detailed guidance on diet and physical exercise for patients about to receive ADT met a genuine need and was well perceived by both clinicians and patients. Implementation rate was high. However, content should be adapted to patient age and disease stage.

McNiff, K. K., M. N. Neuss, et al. (2008). "**Measuring supportive care in medical oncology practice: lessons learned from the quality oncology practice initiative.**" *J Clin Oncol* **26**(23): 3832-3837.

We provide a brief review of the use of quality measures to assess supportive care in the medical oncology office. Specifically, we discuss the development and implementation of supportive care measures in the Quality Oncology Practice Initiative (QOPI), a voluntary quality measurement and improvement program of the American Society of Clinical Oncology. QOPI has demonstrated that medical oncologists voluntarily engage in self-assessment and often select measures related to supportive care for measurement and improvement. Results to date have demonstrated that there is room for improvement in this domain. Because supportive care measures appropriate for use through structured chart review in the outpatient oncology setting are not generally available in the published literature, measures have been developed and tested through the program. Additional measures are in development for implementation in QOPI in 2008.

Lindqvist, O., A. Widmark, et al. (2006). "**Reclaiming wellness--living with bodily problems, as narrated by men with advanced prostate cancer.**" Cancer Nurs 29(4): 327-337.

Having advanced prostate cancer means living with considerable bodily problems, a living we know little about. Thus, the aim of this study was to illuminate meanings of living with bodily problems, as narrated by men with advanced metastasized hormone refractory prostate cancer. Eighteen participants were interviewed, and the text was analyzed using a phenomenological-hermeneutic approach. Findings show that meanings of living with bodily problems are to live in cyclical movements between experiencing wellness and experiencing illness. New, or changed, bodily problems mean losing wellness and experiences of being ill. Understanding and, to some extent, being in control of bodily problems, make it possible to reclaim wellness and to experience oneself as being well. Findings also show that pain and fatigue are the most prominent problems and that they have different meanings. Pain being a threat of dying in agony, whereas fatigue is more of an emissary of death. Reclaiming wellness versus adaptation and enduring versus suffering deriving from 2 different perspectives, the inside or life world perspective and the outside or professional perspective, are questions discussed in the article. One clinical implication for nursing is the risk of obstructing the patients' possibility of reclaiming wellness by focusing on symptoms and disease.

Gore, J. L., T. Krupski, et al. (2005). "**Mental health of low income uninsured men with prostate cancer.**" J Urol 173(4): 1323-1326.

PURPOSE: We evaluated mental health outcomes in a cohort of low income, uninsured men with prostate cancer and identified factors that influence mental health. **MATERIALS AND METHODS:** We performed a retrospective cohort study of 277 subjects enrolled in a program that provides free care to men with prostate cancer who have an annual income of no more than 200% of the federal poverty level. We compared scores on the 5-item RAND Mental Health Inventory (MHI-5) to those in individuals with other chronic diseases. We also examined the relationship between MHI-5 scores and validated measures of general and disease specific health related quality of life. Disease specific quality of life included measures of distress related to urinary, sexual and bowel habits. Multivariate analyses were performed to evaluate factors associated with mental health score. **RESULTS:** Most men studied were Hispanic (51.6%) and had at most a high school education (85.9%). Mean MHI-5 score +/- SD was 68 +/- 23 on a 100-point scale, significantly worse than cohorts of men with diabetes, congestive heart failure and chronic pulmonary disease. Hispanic ethnicity, urinary bother and bowel bother were negatively associated with mental health. Spirituality and physical functioning were positively associated with mental health. **CONCLUSIONS:** Economically disadvantaged men with prostate cancer report worse mental health than people with other chronic diseases. Patients especially at risk are those with significant urinary or bowel distress, poor physical health, low spirituality and Hispanic ethnicity.

Katz, D., T. M. Koppie, et al. (2002). "Sociodemographic characteristics and health related quality of life in men attending prostate cancer support groups." *J Urol* 168(5): 2092-2096.

PURPOSE: Prostate cancer can be associated with anxiety, depression and fears of recurrence and side effects of treatment. Support groups may help meet the needs of patients with cancer by providing treatment information and emotional support. We describe men in prostate cancer support groups and compare them to a national registry. **METHODS AND METHODS:** Men attending prostate cancer support groups in the San Francisco Bay area completed a questionnaire including sociodemographic and clinical characteristics, health related quality of life items, satisfaction with treatment, relief of prostate cancer symptoms and bother from perceived side effects of treatment. Patients in support groups were compared to men enrolled in a national prostate cancer registry (Cancer of the Prostate Strategic Urological Research Endeavor). **RESULTS:** Men attending support groups had higher annual income and education levels, lower median serum prostate specific antigen and higher cancer grades than men in Cancer of the Prostate Strategic Urological Research Endeavor. Clinical stage was comparable for the 2 groups. Men in support groups were satisfied with treatment and alleviation from symptoms. Adjusting for ethnicity, marital status, age and type of treatment, sexual function scores were higher in men who attended support groups ($p = 0.001$). There was no statistically significant difference in bowel and urinary function between groups, although urinary function approached statistical significance at $p = 0.05$. Sexual and bowel bother scores indicated less bother for men in support groups ($p < \text{or} = 0.025$). **CONCLUSIONS:** Men enrolled in support groups have unique sociodemographic characteristics. Their health related quality of life appears to be better than that of other men with prostate cancer. Whether this is related to support group participation is not known. Additional studies are required to determine whether routine support group participation improves outcomes in men with prostate cancer.