Patient-centred cancer care: a road less travelled

An investigation in Australian radiotherapy settings

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THESIS
Declarations

Statement of originality

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ABSTRACT

Cancer is a common health issue worldwide, with an estimated 30 million new diagnoses in the last five years. For over half of all newly diagnosed cancer patients, radiotherapy is recommended for cancer control or symptom relief. Despite the contribution that radiotherapy makes to extended survival of those diagnosed with cancer, this treatment is associated with a broad range of potential practical, physical and psychosocial impacts. To support patients dealing with this treatment burden, a holistic patient-centred approach to cancer care is needed. This thesis by publication reports on radiotherapy outpatients’ perceived experiences of cancer care, and the degree to which these experiences were responsive to their needs, values and preferences (i.e. patient-centred). The thesis introduction provides an overview of the burden of cancer worldwide and in Australia, and includes a review of the patient-centred cancer care literature, with a focus on radiotherapy settings. The five journal papers that comprise the thesis body report on findings from a cross-sectional study of cancer patients. Cancer patients were recruited from the radiotherapy treatment waiting rooms of four Australian metropolitan treatment centres during 2010. Radiotherapy outpatients’ perceptions of care were examined across three areas that resonate with the cancer care experience:

(1) Life expectancy disclosure (Papers One and Two)

(2) Psychosocial well-being and support preferences (Papers Three and Four)

(3) Quality of patient-centred care (Paper Five).

The thesis discussion provides an overview of the strengths and limitations of this work, and implications of this thesis for future research. The study that forms the basis
of this thesis is the first large Australian study in radiotherapy settings to assess cancer outpatients' preferences and experiences for patient-centred care. Study limitations include the restriction to English-speaking-cancer patients in metropolitan radiotherapy treatment centres, and the use of a cross-sectional design. Future research should move toward developing interventions that could be appropriate for improving patient-centred cancer care for patients receiving radiotherapy.
EXPLANATORY OVERVIEW

Cancer patients may experience profound physical and psychosocial consequences related to the diagnosis and treatment of cancer and its symptoms. Individual patients’ needs and preferences for cancer care vary. Holistic, patient-centred cancer care can be defined as an approach to care that is responsive to individual cancer patients’ needs, values and preferences. The publications included in this thesis make a significant contribution to describing perceptions of patient-centred care amongst cancer patients undergoing radiotherapy treatment. The findings reported in these papers suggest that subgroups of patients may be less likely to receive patient-centred cancer care.

This thesis by publication includes an introduction, five manuscripts and a general discussion providing implications and conclusions. The manuscripts included in this thesis report findings from a cross-sectional survey of cancer patients who were recruited from the radiotherapy treatment waiting rooms of four Australian metropolitan public hospital treatment centres during 2010. All five papers have been published.

The Introduction describes the burden of cancer in both the global and Australian contexts. The processes involved in cancer detection and treatment are described, with a focus on the primary cancer treatment modalities (i.e. surgery, chemotherapy and radiotherapy) and the shift towards delivery of cancer care on an outpatient basis. An overview of the potential practical, physical and psychosocial burden of outpatient radiotherapy is used to highlight the need for a holistic, patient-centred approach to cancer care. The literature assessing outpatients’ perceptions of patient-centred cancer care is reviewed. From this it is argued that there is a need to assess radiotherapy
outpatients’ experiences of cancer care, and explore the degree to which cancer care is responsive to patients’ preferences (i.e. is patient-centred).

An important component of high-quality patient-centred care is providing information and communication whilst being responsive to patients’ needs and preferences. Research should also be responsive to variations in patients’ needs and preferences, particularly when the research addresses sensitive topics. **Paper One** describes a patient-centred approach to conducting survey research into life expectancy communication preferences and experiences. Questions about life expectancy were acceptable to a majority (70%) of radiotherapy patients, as indicated by their completion of an optional life expectancy sub-section of the survey. However, respondents who were female, older, born in Asia and diagnosed with cancer types other than breast or prostate cancer had lower odds of completing this section of the survey. This suggests that survey questions about life expectancy are less acceptable to these respondent groups. Paper One is published in *Supportive Care in Cancer*.

**Paper Two** presents responses of patients who were willing to answer the survey questions about life expectancy in Paper One. The recommended patient-centred approach to life expectancy disclosure for cancer patients was compared with radiotherapy patients’ preferences and experiences of life expectancy disclosure. Agreement between patients’ preferences and experiences was poor. To move towards the recommended patient-centred approach to life expectancy disclosure, discussions about life expectancy need to be more responsive to patients’ preferences. Paper Two is published in *Psycho-oncology*.

**Paper Three** examines the likely prevalence of psychological distress amongst patients receiving radiotherapy treatment. The Hospital Anxiety and Depression Scale (HADS) was used with anxiety and depression classified by subscale threshold scores
of ≥11, and a total score of ≥15 to classify overall psychological distress. The likely presence of anxiety was found to be 15%, likely depression was 5.7% and likely psychological distress was 22%. Compared with breast cancer patients, prostate cancer patients had significantly lower odds of being likely cases of anxiety and overall psychological distress, and showed a trend towards lower odds of being likely cases of depression. When grouped together, respondents with other common cancer diagnoses (e.g. brain, colorectal, head and neck, and lung cancers, melanoma and non-Hodgkin’s lymphoma) had more than 3 times the odds of being likely cases of depression, compared with breast cancer patients. Paper Three is published in Supportive Care in Cancer.

Single-item assessment of patients’ self-perceived anxiety, depression levels and desire for professional support is explored in Paper Four. Patients’ perceptions of distress levels provide a stronger model of association with a desire to be offered professional support, compared with HADS classifications. The majority of cancer patients indicated that they would accept professional support if they were experiencing anxiety or depression. This paper suggests that a patient-centred approach to psychological screening and referral in the radiotherapy setting may increase the uptake of psychosocial services. The question of how to balance patients’ perceived need for psychosocial support services against limited psychosocial resources is discussed. Paper Four is published in Annals of Oncology.

In Paper Five, radiotherapy patients’ perceptions of patient-centred cancer care are presented. Respondents to a touch screen computer survey were asked to indicate whether better care across eight domains of patient-centred care would have greatly improved their well-being. Almost one-third of radiotherapy patients identified more than one domain where better care would have greatly improved their well-being. Over
20% of respondents endorsed “Information and communication about cancer and care” and “Emotional and spiritual support” as areas where better care would have improved their well-being. Migrants to Australia (compared with Australian-born respondents) and younger cancer patients (compared with older cancer patients) had higher odds of identifying multiple domains where better care would have greatly improved their wellbeing. Paper Five is published in BMJ Open.

The Discussion summarises the key thesis findings and outlines the potential implications of these findings for future research and provision of patient-centred care. The study that forms the basis of this thesis is the first large Australian study to assess cancer outpatients' preferences and experiences for patient-centred care in radiotherapy settings. Strengths of this study include a high consent rate and the combined use of validated and novel approaches to measuring patient outcomes and perceptions of patient-centred care. Study limitations include the restriction to English-speaking-cancer patients in metropolitan radiotherapy treatment centres, and the use of a cross-sectional design. Future research should move toward developing interventions that could be appropriate for improving patient-centred care for cancer patients receiving radiotherapy.