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Testing the Psychometric Properties of the Patient Reported Outcomes: Cancer (PRO-C) Instrument

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Purpose: Patient-reported outcomes are the gold standard in cancer care (Vahdat, Hamzehgardeshi, Somayeh, & Hamzehgardeshi, 2014). The Institute of Medicine (IOM) recommends that patient-reported outcomes are measured across six domains in order to evaluate the quality of care (The Institute of Medicine, 2001; Tzelepis, Rose, Swanson-Fisher, McHarg, Carey, & Paul, 2014). These domains embrace the following principles:

1. Respect for the values, preferences and expressed needs of patients;
2. Coordination and integration;
3. The provision of information, communication, and education;
4. Ensuring physical comfort;
5. The provision of emotional support and relieving fear and anxiety; and
6. Involving family and friends in care (The Institute of Medicine, 2001).

With the incidence of cancer diagnoses continuing to increase in Australia, (Australian Institute of Health and Welfare, 2017) and the high burden cancer poses on the Australian community (Australian Government, 2017), it is essential to understand cancer care is experienced in a dynamic context characterised by rapid changes in technology. Therefore a significant need existed for supportive care and models of service delivery that are increasingly devolving from inpatient to ambulatory and home-based care (Queensland Health, 2010). There is also an increasing expectation that cancer patients have the knowledge and skills to self-manage their care (Vahdat et al., 2014). While the cost- and resource-shifting entailed in such developments could benefit cancer services, it does not necessarily reduce patient burden or improve their quality of life. A recent systematic review (Tzelepis et al., 2014) indicated that despite espousing the IOM ideals of patient-reporting, cancer facilities do not routinely assess patient-reported outcomes to evaluate the quality of the care they provide in this rapidly changing environment. As a result, the IOM argues that patients are dissatisfied with care and that patient-reported outcomes should be routinely used to evaluate and thereby enhance the quality of care provided. This impedes health services’ ability to redesign care in response to the cancer patient and family need (Tzelepis et al., 2014). In this study, the Patient Reported Outcomes – Cancer measure was tested in a cohort of cancer patients in preparation for further testing in larger national studies. The measure is explicitly designed to meet IOM recommendations in cancer care, and is the first time nationally or internationally such a measure has been developed.

This study therefore had the potential to develop a novel instrument that accurately reflected patient’s perceptions of their cancer care experiences and the quality and continuity of care across and within service providers. The PRO-C aimed to achieve this by explicitly meeting the psychometric standards for reliability and validity whilst incorporating the six dimensions of care endorsed by the IOM (Institute of Medicine, 2001).

Methods: Face and content validity were established with 30 ambulatory cancer patients and 10 cancer clinicians in 2015. A sample of 430 ambulatory cancer patients was recruited in 2016. The PRO-C’s
promising psychometric properties, determined through exploratory factor analysis and by establishing construct, convergent and divergent validity, were then further explored. The PRO-C was modified according to these results in July 2017.

**Results:** Preliminary results indicated that the PRO-C assumptions underpinning the domain structure are sound with the six domain α’s ranging from 0.73 to 0.8, and that 24 of the 28 domain-specific items fit the hypothetical model well. The four items that did not load in the exploratory factor analysis are being revised after seeking further patient opinion. In addition, all 28 items have been modified to reduce the original 1-10 range of responses to 1-5, and to delete the ‘not applicable’ option. This was done to significantly improve the robustness of the instrument.

**Conclusion:** The PRO-C is the first instrument to measure patient-reported outcomes in the cancer chemotherapy setting according to IOM recommendations. The next step in PRO-C development is to confirm instrument reliability. This proposed study will establish, through confirmatory factor analysis, the psychometric properties of the PRO-C with typical ambulatory cancer patients treated in Brisbane, Australia. This procedure will indicate the instrument’s local relevance, and its potential to guide interventions in cancer service redesign, irrespective of service context. This will enable responsive, timely service redesign. If the PRO-C proves reliable, it could be digitized and linked to patient records. Our existing international cancer research partners and research partners in all states of Australia will be involved in the next phase of the PRO-C program after it is trialed in Brisbane.

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**Title:**
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**Keywords:**
psychometric, cancer and patient reported outcomes

**References:**


**Abstract Summary:**
The PRO-C is the first instrument to measure patient-reported outcomes in cancer according to IOM recommendations. It is flexible, with the capacity to measure outcomes irrespective of cancer type, cultural affiliation, cancer treatment received or the cancer service context. It could be digitised and linked to patient records.
Content Outline:

Introduction

Patient-reported outcomes in cancer care ideally capture health service performance in the following Institute of Medicine-endorsed domains¹:

1. Respect for patient values, preferences and needs.
2. Care coordination and integration.
3. Information provision, communication, and education.
4. Physical support.
5. Emotional comfort.
6. Involvement of significant others in care.

No existing patient-reported outcome instrument, however, measures all of these domains. Hence cancer services cannot accurately capture patients’ perceptions of the care they receive, nor develop and implement service improvements responsive to their feedback.

Body

The Patient-reported Outcomes-Cancer (PRO-C) instrument, explicitly based on Institute of Medicine recommendations, was developed in response to these concerns. The PRO-C’s face and content validity were established with 30 ambulatory cancer patients and 10 cancer clinicians in 2015. The PRO-C’s promising psychometric properties, determined through exploratory factor analysis and by establishing construct, convergent and divergent validity, were further explored in 430 ambulatory cancer patients in 2016. The PRO-C was modified according to these results in July 2017.

Conclusion

The next step in the instrument’s development is to confirm instrument reliability. This proposed study will establish, through confirmatory factor analysis, the psychometric properties of the PRO-C with typical ambulatory patients treated at a tertiary hospital. This procedure will indicate the instrument’s local relevance, and its potential to guide interventions in the relevant service redesign, irrespective of service context.

First Primary Presenting Author

Primary Presenting Author
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Professional Experience: 2016 - Senior Lecturer, School of Nursing and Midwifery, Griffith University. This role includes undertaking research in cancer care, teaching, course and/or program coordination and curriculum development at both undergraduate and postgraduate levels in the School of Nursing and Midwifery and contribute to the development of nursing and/or midwifery knowledge through research and scholarship. 2013 –2016 Lecturer, Queensland University of Technology. 2015 -2017 Other Achievements: Developed National and International Research collaborations for Health Services research. Chair Global Network Contacts Task Force, Governance Committee STTI. Elected member International Governance Committee STTI. Chief Investigator research grants for studies in cancer care. Chief investigator for and completed research studies on self - management and chronic disease.
Published in and reviewed for Scopus accepted journals.

Author Summary: Dr Carol Reid has many years of research and teaching experience and is currently a Senior Lecturer with Griffith University's School of Nursing & Midwifery. She has made contributions to the field of knowledge regarding Self-Management of Chronic Diseases and Health Services research. Dr Reid is currently testing a psychometric measure relating to patient-reported outcomes in cancer care. This research is complementary to previous research she has undertaken to increase understanding of effective patient outcomes.

Second Author
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Professional Experience: 2017: Current projects include an intra-chemotherapy exercise program to prevent peripheral neuropathy; an intervention to alleviate chemotherapy-induced nausea; a post-chemotherapy physical activity program to modify peripheral neuropathy; and an amino acid intervention to mitigate the impact of cancer anorexia and cachexia syndrome. Professional distinctions and memberships: Associate Editor, European Journal of Oncology Nursing, since March 2017. Invited Distinguished Fellow, Chinese University of Hong Kong, July 2016. Executive Committee Member, Exercise Oncology Group, Clinical Oncology Society of Australia, since November 2015. Organising Committee member, Annual Scientific Meeting (for 2016), Clinical Oncology Society of Australia, August 2015-November 2016. Expert Panel Member, Online Geriatric Oncology Education Resource for Nurses, Peter MacCallum Cancer Institute. From March 2014. Editorial Board Member, Journal of Clinical Nursing, since November 2014. Committee Member, SIOG Nursing and Allied Health Group, International Society of Geriatric Oncology. From March 2014. QUT Vice Chancellor's Performance Award in November, 2012.

Author Summary: I have developed a cumulative and multidisciplinary program of research in cancer care. As Chair of Cancer Nursing, Princess Alexandra Hospital, Brisbane, my program explored the assessment, prevention and management of the short- and long-term toxicities of cancer therapy. My program philosophy is that cancer patients, both during and after treatment, are often willing to embrace the lifestyle changes that could enhance their well being and reduce the chronic disease risks associated with cancer therapies.

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Professional Experience: Over the past 15 years to 2017, I have established a nationally and internationally recognized program of research in behavioral oncology. This research relies on my experience in psychological and epidemiological methods and theory, and has focused on two main behavioral oncology research areas: i) Cancer prevention/early detection, and ii) Supportive care in cancer.

Author Summary: My background as a psychologist/behavioral therapist, as well as extensive postgraduate training in epidemiological research methods and clinical trials enables me to conduct translational research that combines epidemiological/behavioral research methods and derives new clinical applications of these. The aim of my research is to implement evidence-based interventions for the prevention/early detection of cancer, and to improve supportive care for cancer patients.
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**Professional Experience:** 2017 Biostatistician, Institute of Health and Biomedical Innovation Role and Responsibilities include: Designing and undertaking statistical analysis Providing statistical training Reviewing and contributing to publications Contributing to grants. 2012-2015 Biostatistician /Database manager Statistician, University of Queensland. Roles and responsibilities: Responsible for harmonization of 20 international women’s datasets, including database design and management. High quality presentation of results using SAS, STATA Contributing to publications. 2010-12 Biostatistician Queensland Institute of Medical Research (RBWH). Roles and responsibilities : Providing statistical consulting for the Royal Brisbane and Women’s Hospital (RBWH) Designing and undertaking statistical analysis Providing statistical training Reviewing and contributing to publications Contributing to grants. 2005-10 Biostatistician Queensland University of Technology Roles and responsibilities : Casual lecturing and tutoring in statistics Course coordination at postgraduate level. Responsible for training tutors. Class management. Lecturing to large classes.

**Author Summary:** Lee was accredited as a Graduate Statistician in 2008 and established herself as a consulting biostatistician at the Royal Brisbane and Women’s Hospital, which was followed by a biostatistician/data management role at The University of Queensland. Her current position at the Queensland University of Technology involves teaching and collaborating with researchers in statistical methodology. In 2016, Lee received accreditation as a senior statistician from the Statistical Society of Australia (AStat).