

Facilitating needs-based care of people with progressive cancer: Evaluation of a palliative care needs assessment intervention

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This thesis contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text.

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The research described in this thesis was conducted within the framework of a larger program of work involving six discrete phases. A national multi-disciplinary team, including a palliative care physician, a general practitioner, nurses, two statisticians, an oncologist, a psychiatrist and behavioural scientists from our research group assisted in this work. My thesis supervisors were three members from this team.

The first two phases involved a large national qualitative study undertaken to explore perceptions of palliative care and issues surrounding referral in the Australian health care system; as well as a national survey identifying current referral patterns. In Phase 3, the *Palliative Care Needs Assessment Guidelines* were developed to provide advice and information for health professionals about the various physical and psychosocial issues affecting people with cancer and their caregivers. While I was involved in the development of the *Guidelines*, this did not form part of the work contained in this thesis.

This PhD work begins with the development and validation of the Needs Assessment Tool: Progressive Disease - Cancer (NAT: PD-C) (Chapter 4 and 5), which aimed to complement the *Guidelines* and assist health professionals in identifying the level and type of needs being experienced. I was responsible for drafting up each version of the NAT: PD-C with input from the multi-disciplinary advisory group; developing study protocols and materials, preparing ethics applications, recruiting participants and assisting with focus groups, liaising with clinical services, collecting and analysing data and drafting the manuscript. All authors contributed to the final manuscripts.

Study 3 (Chapter 6, 7 & 8) make up Phase 4 of the wider program. I developed the protocol with input from the multi-disciplinary team. I was responsible for implementing the protocol, supervising research staff, liaising with site investigators and overseeing data collection, analysing data (with assistance from statisticians on the advisory team) and writing up the outcomes of this work in the included chapters.

The final two phases of the program do not form part of this PhD. They involved the national dissemination of the *Guidelines* and NAT: PD-C and the generalisation of these resources to a heart failure population.

I hereby certify that the work embodied in this thesis has been done in collaboration with other researchers. I have included below a statement clearly outlining the extent of collaboration, with whom and under what auspices.

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LIST OF ABBREVIATIONS

SPCS	Specialist palliative care service
WHO	World Health Organization
PCA	Palliative Care Australia
NAT: PD-C	Needs Assessment Tool: Progressive Disease – Cancer
PC-NAT	Palliative Care Needs Assessment Tool
GP	General Practitioner
UK	United Kingdom
USA	United States of America
NHPCO	National Hospice and Palliative Care Organization (USA)
NHS	National Health Service (UK)
NCPC	National Council for Palliative Care (UK)
NHIF	National Health Insurance Fund (Hungary)
ABS	Australian Bureau of Statistics
SES	Socio-economic status
ATSI	Aboriginal and Torres Strait Islander
CALD	Culturally and linguistically diverse
LLI	Life-limiting illness
PCOC	Palliative Care Outcomes Collaboration
CATI	Computer-assisted telephone interview
SAS	Statistical Analysis Software
NSAP	National Standards Assessment Program
RACGP	Royal Australian College of General Practitioners
RCNA	Royal College of Nursing Australia
ACRRM	Australian College of Rural and Remote Medicine

SYNOPSIS

There is an expectation that palliative care will be available to all people suffering from life-limiting illnesses such as cancer. However, a disparity exists between this perception and current experiences in end-of-life care. It has been recommended that palliative care be provided according to the individual needs of the patient, caregiver and family, so that the type and level of care provided, as well as the setting in which it is delivered, are dependent on the complexity and severity of individual needs, rather than prognosis or diagnosis. This dissertation examines a strategy to facilitate this needs-based approach to the delivery of palliative care to people with advanced cancer in Australia. The overall aim of this research was to develop and examine the feasibility and efficacy of an intervention to assist in the allocation of palliative care resources according to need, within the context of the population of people with advanced cancer.

Chapter 1 describes how changes in attitudes towards death and dying, changes in demography and an increase in burden of diseases such as cancer have facilitated an increasing interest in the area of palliative care. The fundamental role that palliative care plays in caring for the dying and the benefits of this care for people with life-limiting illnesses, their caregivers and the system as a whole are outlined. Chapter 2 is a comprehensive review of the current literature describing the utilisation and referral patterns of specialist palliative care services, from an international perspective. Specifically, this chapter reviews international health system structures and funding, models of palliative care services and the personal and external factors that may influence service utilisation, in order to provide evidence for the inequitable and ill-timed delivery of care that is currently in use. In addition, the reasons for referral to specialist palliative care services, as well as the source and timing of referrals and the barriers to referral, are explored.

Chapter 3 outlines the alternative needs-based approach to the delivery of palliative care, outlining the importance and benefits of people receiving care according to the complexity and severity of their needs, independently of diagnosis or prognosis. The use of guidelines and referral pathways has been suggested as one way to determine who would benefit most from receiving palliative care; hence the Palliative Care Needs Assessment Guidelines were developed. The *Palliative Care Needs Assessment Guidelines* aim to provide advice to those caring for people with cancer and their families to ensure that they are offered the most appropriate care to meet

their specific needs. The various barriers to the uptake of guidelines are outlined, and the need for strategies to improve compliance with guidelines is acknowledged. The chapter outlines the benefits of using a needs assessment tool to improve compliance with guidelines, and this is accompanied by a review of available needs assessment tools for people with cancer and their caregivers to ascertain the suitability of these tools to complement the *Guidelines*.

The results of the review support the development of a new needs assessment tool to accompany the *Palliative Care Needs Assessment Guidelines*, and Chapters 4 and 5 outline the results of two preliminary validation studies conducted in the early stages of this PhD to assess the psychometric qualities of this new tool. Chapter 4 is a peer-reviewed published article describing the development and pilot testing of the Palliative Care Needs Assessment Tool (PC-NAT), which has since been renamed the Needs Assessment Tool: Progressive Disease - Cancer (NAT: PD-C). This pilot study was conducted in a simulated setting and aimed to test the PC-NAT for use by different health professionals who have contact with advanced cancer patients, in terms of its clarity, content, face validity, acceptability and inter-rater reliability. The study provides preliminary support for the psychometric properties of the tool including clarity, content validity, acceptability and inter-rater reliability. Chapter 5 describes a validation study to confirm the reliability, validity and acceptability of the NAT: PD-C in a clinical setting, in this case, a specialist palliative care service. The study offers further psychometric evidence for the NAT: PD-C and suggests that the NAT: PD-C is a highly acceptable and efficient tool that can be used by health professionals with a range of clinical expertise to identify patients' and their caregivers' levels of concern about physical and psychosocial aspects, thereby facilitating a better match of types and levels of services and resources to the types and levels of needs identified.

The need for further evaluation of the Palliative Care Needs Assessment Guidelines and NAT: PD-C to assess patients and their caregivers at multiple time points and determine the validity and responsiveness of the NAT: PD-C is acknowledged. Chapter 6 provides an outline of the methods adopted for this prospective, multi-site, multi-discipline longitudinal study. Recruitment sites and procedures, study participants and interview measures are described in this chapter, along with the proposed intervention and analyses. Chapter 7 is the first of two evaluation results chapters. This chapter describes the impact of using the Palliative Care Needs Assessment Guidelines and

NAT: PD-C on patient outcomes. The participant profile is described and any changes in the patients' unmet needs, depression, anxiety and quality of life that occurred as a result of the intervention are discussed. Chapter 8, the second evaluation results chapter, discusses the impact of the intervention on patient service use and referral patterns. Information on service utilisation was obtained from interviews, completed NAT: PD-Cs and audited medical records. This chapter also describes the suitability of the research design in terms of its strengths and weaknesses, as well as the implications of potential biases on the applicability and generalisability of the findings.

Finally, Chapter 9 examines the findings of the overall research in light of the original aims of the project. It also discusses strategies for ensuring the successful dissemination and implementation of the resources within clinical settings.