



## Clinical Methods

## Establishing research in a palliative care clinical setting: Perceived barriers and implemented strategies

Tracey Bullen, DCP/MSc<sup>a,\*</sup>, Kate Maher, MNurs(NursPrac), RN<sup>b</sup>, John P. Rosenberg, PhD, RN, MACN<sup>a</sup>, Bradley Smith, PGCert, RN<sup>b</sup><sup>a</sup> Calvary Centre for Palliative Care Research, Australian Catholic University, ACT, Australia<sup>b</sup> Clare Holland House Calvary Health Care ACT, ACT, Australia

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## ABSTRACT

There are many challenges in developing research projects in research-naïve clinical settings, especially palliative care where resistance to participate in research has been identified. These challenges to the implementation of research are common in nursing practice and are associated with attitudes towards research participation, and some lack of understanding of research as a process to improve clinical practice. This is despite the professional nursing requirement to conduct research into issues that influence palliative care practice. The purpose of this paper is to describe the process of implementing a clinical research project in collaboration with the clinicians of a palliative care community team and to reflect on the strategies implemented to overcome the challenges involved. The challenges presented here demonstrate the importance of proactively implementing engagement strategies from the inception of a research project in a clinical setting.

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## 1. Introduction

The aim of academic research centres located in clinical settings is to generate robust research projects that address clinically relevant problems. When integrating research into clinical practice is introduced, it presents many opportunities for the conduct of meaningful research. However, implementing research into a research naïve clinical setting also presents a number of challenges. As a discipline of health care, palliative and end-of-life care has only relatively recently begun to effectively integrate research into its clinical practice. The challenges in conducting research with clinicians as recruiters are common across nursing but can be amplified when working with vulnerable populations. In the context of this paper, palliative care is defined as specialist care for individuals with progressive terminal disease (Gysels, Evans, & Higginson, 2012).

The role of the research centre team was to use their experience of research to facilitate the implementation of the first collaborative research project between the research centre (a collaboration between a health care service and an Australian university) and a community palliative care team to ensure that the project was both scientifically robust and clinically relevant. This article focuses on the

challenges in one ongoing study. The study examined the impact on patient outcomes of providing emergency medication kits [EMK] to home-dwelling palliative care patients, and assessed the influence of this medication provision on carers' self-confidence to provide care. The purpose of this article is to describe the research issues and barriers experienced by the investigating team in developing and implementing a research project and to discuss the strategies that were developed in response to these challenges.

## 2. Background

The challenges of conducting research with vulnerable populations, such as those receiving palliative care, have been widely discussed (Wohleber, McKittrick, & Davis, 2011). These challenges can range from ethical and clinical issues to systemic or professional challenges. Over the course of their illness, palliative care patients can experience rapid deterioration, fluctuation in symptoms and psychosocial distress, which can strongly influence their willingness and ability to participate in research studies, even following an agreement to take part (Addington-Hall, 2002). The issue of providing consent has generated a debate regarding the conduct of research (Duke & Bennett, 2010). However, there is an ethical imperative to develop evidence-based methods that optimise nursing and medical care for patients who can no longer speak for themselves (Karlavish, 2003). It is crucial during the research development phase to address concerns regarding the risk of coercion for research participation, in order to maintain high research standards and obtain Human Research Ethics Committee [HREC] clearance (Duke & Bennett, 2010). Concerns

\* Corresponding author at: Calvary Centre for Palliative Care Research, Australian Catholic University, Clare Holland House, 5 Menindee Drive, Barton ACT 2600, Australia. Tel.: +61 2 6264 7300.

E-mail addresses: [tracey.bullen@acu.edu.au](mailto:tracey.bullen@acu.edu.au) (T. Bullen), [kate.maher@calvary-act.com.au](mailto:kate.maher@calvary-act.com.au) (K. Maher), [john.rosenberg@acu.edu.au](mailto:john.rosenberg@acu.edu.au) (J.P. Rosenberg), [bradley.smith@calvary-act.com.au](mailto:bradley.smith@calvary-act.com.au) (B. Smith).

regarding coercion are frequently the source of 'gate keeping' by nursing staff, as the decision not to inform patients about opportunities to participate in research is seen by some as a protective act (Addington-Hall, 2002). Conducting research with patients receiving palliative care can also present a number of systemic challenges. These challenges can vary depending upon the location in which care is provided, such as the acute setting of hospitals, hospices, residential aged care facilities, and in the community.

Despite the challenges of conducting palliative care research, participation in the conduct of research into issues identified in nursing practice form part of the key competencies for registered nurses (Australian Nursing Federation, 2006). The engagement of Australian Registered Nurses with research is also clearly articulated in the National Competency Standards for the Registered Nurse (2005). Moreover, Palliative Care Nurses Australia Inc. endorses competency standards in palliative care specialist nursing, promoting the conduct of high quality research which identifies and addresses gaps in clinical knowledge (Canning, Yates, & Rosenberg, 2005).

Recent literature discussing the challenges to conducting research and associated strategies to manage these issues in palliative care has primarily focused upon barriers to recruitment to such studies (Abernethy et al., 2010; Fischer, Burgener, Kavanaugh, Ryan, & Keenan, 2011). However, challenges to project development and staff engagement in research have received less attention within palliative care. Therefore, there is a strong case for conducting research and evaluating research processes within community specialist palliative care services.

### 2.1. Research transitions: Utilisation to participation

Nurses generally hold positive attitudes towards utilising existing research. One of the key determinants of utilising research is being engaged as a nurse within a clinical specialty (see Squires, Estabrooks, Gustavsson, & Wallin, 2011 for review). However, transitioning from utilising research to developing and participating in clinical research practice appears to present a number of attitudinal barriers; these appear amplified within the palliative care sector. Kirsh et al. (2004) found the majority of palliative care staff reported having insufficient time to dedicate to clinical research despite a desire to recruit patients directly and being supportive in principle of conducting palliative care research. It appears conducting clinical research to inform nursing practice is not viewed as "core business" (Higgins et al., 2010, pg 175), as it is seen to detract from a patient care focus. This is despite evidence that researching practice change improves patient outcomes (Higgins et al., 2010) which may consequently decrease workload demands in the medium to longer term.

## 3. Method

This article utilises the EMK project as a case study to explore and reflect upon the experiences of the investigators involved during the first year of the project's development. Each of the investigators reported written observations of the challenges which arose and counter strategies that were implemented in developing the research project (see Fig. 1) from an initial idea into a comprehensive proposal. These written narratives were examined for recurring thematic patterns; member checking was conducted in the analysis to refine and validate the findings.

### 3.1. Case study: The EMK Study

The intervention comprised altering clinical practice in how medications were made accessible to home-dwelling palliative care patients. The aim of the EMK study was to evaluate the impact of this practice change upon symptom management and carers' self



Fig. 1. Study implementation challenges and strategies.

confidence in performing the caregiving role. The setting was a community based specialist palliative care service.

Newly admitted patient–caregiver dyads to the community palliative care service were recruited to the trial. Patients and caregivers were supplied with an emergency medication kit containing a medication diary and medicines that are frequently used to address common symptoms that can arise unexpectedly, such as pain or breathlessness. Caregivers were asked to complete a questionnaire at admission, 3 and 6 months post recruitment to determine the impact of the intervention on their perceptions of self efficacy to provide care.

## 4. Key challenges and strategies

There were numerous stakeholders whom the research investigators perceived could influence the outcome of the EMK project as their practical support was crucial to facilitate the project's implementation. These included policy makers, pharmacy staff and management of clinical departments. In a clinical setting unfamiliar with the conduct of research, negotiation of the EMK project's design and operationalisation required focussed and sustained collaboration between these key stakeholders and the research team. Whilst this facilitated better understanding of research processes, it increased the duration of the preparatory phase of the project beyond expectations.

### 4.1. Professional challenge 1: Resistance by some clinical staff to participate in research

An ongoing issue in the project's development was opposition by some clinical staff to participate in research that assessed practice change. This resistance appeared to be brought about by a number of factors. Firstly, negative attitudes towards research held by dominant individuals within the team were evident, influencing less-decided team members about the value of the project. This attitude became rapidly evident following communication to the clinical team that this assessment of practice change would be conducted as a research project rather than a quality improvement exercise. This was initially surprising to the research centre investigators given that the idea for this project originated within the clinical team. It is understood that

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