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The Praecox Program: Pilot testing of an online educational program to improve neonatal palliative care practice

Victoria J. Kain

School of Nursing & Midwifery, Griffith University, Australia

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ABSTRACT

The aim of this study was to develop and pilot test the first module of an educational program. Titled the Praecox Program its objective was to optimise palliative care to the neonate and their families through an evidence-knowledge-based education program for clinicians. The setting was a tertiary level hospital in South-east Queensland, Australia.

Pilot testing of this first module demonstrated that an educational intervention resulted in positive changes in both 'knowledge' and 'attitude' among participants. Feedback was also obtained from participants regarding opportunities to improve the module and desire to participate in future modules.

This pilot study supports the notion that evidence-knowledge-based education for neonatal palliative care has the potential to improve clinician confidence, through an increase in knowledge and positive attitudes toward neonatal palliative care delivery.

Introduction

The objective of this study was to develop and pilot test an approach to neonatal palliative care that utilises a consistent and evidence–knowledge-based approach.

Neonates have the highest death rate in the paediatric population (Kiman and Doumic, 2014) and prematurity is now the leading cause of neonatal death (Liu et al., 2012). Most of these deaths occur in neonatal units. These neonates may be identified in the following circumstances: 1. Antenatal diagnosis of a life limiting condition; 2. Neonates born at the margin of viability; 3. Neonates diagnosed with a life limiting condition at birth or in the early neonatal period; and 4. Neonates who deteriorate in the NICU and for whom palliative care is determined by the parents and primary care team as the best course of action (Kain and Wilkinson, 2013).

This Australian study developed and pilot tested the first of three modules (Module one) of a neonatal palliative care education program (the Praecox Program). The Praecox Program, undertaken by health care professionals working in the neonatal unit, included doctors, nurses, midwives, social workers and physiotherapists. The Program derives from the term '*Praecox*' being a Latin term meaning '*ripe before its time*' and '*premature*'.

Module one, reported here, was developed to address the principles of neonatal palliative care. The module was divided into four parts: Part one provided a definition of neonatal palliative care, and introduced palliative care principles and the Australian standards of palliative care; Part two explored the epidemiology of neonatal death; Part three explored palliative care services that may be available to neonates; and Part four discussed potential challenges in delivering neonatal palliative care.

Following the pilot testing of Module one, it is planned to develop the following modules which will provide evidence-based care on symptom management (Module two) and end-of-life care and care of the deceased neonate and family, including follow-up care (Module three). Undertaking the program in its entirety is expected to result in increased knowledge of neonatal palliative care, increased support of families, increased confidence in neonatal palliative care delivery, increased opportunities for advocacy, increased opportunities to increase quality of life for the neonate who is not expected to survive, and a more positive attitude to the role of palliative care for neonates. This pilot program provides an opportunity to develop a neonatal palliative care education intervention and evaluate its effectiveness.

Design

This pilot test was a randomised waitlist controlled trial with rolling enrolment. This design had the advantage of allowing everyone in the study to undertake the intervention (in this case,

E-mail address: v.kain@griffith.edu.au.

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after a two week wait list period). The research question for this study explored whether an evidence–knowledge-based educational program could enhance knowledge and attitudes towards neonatal palliative care delivery to neonates and their families.

Setting and participants

The participants for this study were a convenience sample of the multidisciplinary team at a tertiary level hospital in South-east Queensland, Australia who provide care to neonates who may not be expected to survive and their families. The research team conducted information sessions with the staff of the neonatal nurseries consisting of a brief presentation, access details to the electronic pre- and post-questionnaire, a copy of the Participant Information Form and details of how to access the online education package. Participants were also accessed via the hospital's email system.

Methods

Program development

The complete Module one content and the proposed content for Modules two and three underwent review by an expert panel. The panel included a neonatologist; a perinatal bereavement counsellor; an ethicist and linguist and three neonatal nurses with interest and expertise in this area of neonatal nursing. The proposed content was presented to the expert panel using a five-point Likert scale to determine the level of agreement to include each area of content. Only items reaching a mean score >3.0 were included in the program. Panel member's comments and suggestions were also taken into consideration.

The content was developed by the research team, and converted to video format by a digital software company. Using an online medium, participants were able to access pre and post questionnaires, and the intervention (a 40 min video [Module one]). Results were collected via an online portal and provided to the researchers in an anonymous format. The study site landing webpage had provision for participants to be tested in groups and for access to be limited by time intervals.

Participants logged onto the program website, and enrolled by creating a unique code (email address). Once logged in, the randomisation sequence was computer-generated with random block sizes using Mersenne Twister as a uniform random number generator (Echeverría and López-Vallejo, 2013). Subjects were randomised to commence Module one either immediately (the immediate intervention group) or after a 2-week wait list period (the wait list control group). The pilot study procedures are outlined in Table 1.

Table 1
Study procedures.