

Electronic Advance Care Planning in Community: Nurses' role

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Abstract— Advance care planning implementation occurs across the world using different legislative frameworks, different language to describe both the process and the outcome, and different models to develop these plans. Many countries are in the process of developing personally controlled electronic health records. Including advance care plans as part of this record is proposed in Australia. The eACP in Community project aims to develop a model that will engage community dwelling older adults with chronic life-limiting illnesses in the process of advance care planning that is person-centred, evidence-based and has a focus of dignity of life. A systematic review was conducted to identify models of advance care planning and to examine the nurses' role. A realist review comprising metasynthesis of 8 qualitative studies and 9 quantitative studies informed the Dignity of Life Advance Care Planning Inventory Model. The DOLAC Model proposes a formal role for nurses in the consultation and development of the advance care plan as well as assisting with the relevant legal requirements for documentation. The medico-legal framework around advance care plan development needs to be understood by nurses around the world to better inform end-of-life care planning and practice. The DOLAC Model offers guidance to curriculum developers and policy makers to enable nurses to expand their scope of practice to include all aspects of advance care plan development.

Keywords- Nursing model of advance care planning, elderly, community dwelling, chronic illness, electronic record

INTRODUCTION

Models of advance care planning for older adults living in the community vary around the world. Developed countries like Australia, the United Kingdom, the United States, Canada and Japan have legislative frameworks around end-of-life decision-making which enable a person's wishes to be enacted if appropriate [1-7]. In Australia these frameworks are not consistent across all jurisdictions. Registration of the relevant documents is not mandatory or consistent between

jurisdictions [5, 8]. Advance care plan documents can be as simple as ensuring that a legal power of attorney, or enduring guardian has been appointed in the event of mental incapacity to extensive end of life care plans that incorporate a person's values and beliefs as well as their health and social care choices[7]. Research has shown that knowing a person's end of life wishes is not a simple process for most health agencies; recommendations have been repeatedly made to incorporate this information in the electronic medical record to make it more readily accessible at the point of care [3, 8]. Although there has been documented societal and government support for advance care planning, the uptake, in Australia has been limited [2, 5]. This study aimed to identify the role of nurses and or nursing in the evidence-based models for electronic advance care planning for community dwelling older adults.

METHODS

A systematic review of the published and grey literature was conducted between January and July 2012. An electronic database PICO search using MESH terms and key word searches of the following 8 databases was conducted : Cochrane, PubMed, Embase, ProQuest, CINAHL, Psychinfo, Google & Google Scholar.

Figure 1

PICO:	Search No:	Search terms:
Population:	S1	Advanced and Chronic and Illness or Terminal and Care or Life-Limiting and Illness
	S2	Old and Elderly
	S3	Chronic and Illness or Heart failure or Diabetes or Kidney failure or Renal Failure or COPD or Dementia or Cancer
	S4	Life-limiting illness and/or chronic illness or death or dying or morbidity or mortality or terminal
	S5	Community and dwelling or Primary health and/or Care or Outpatients or Primary Care
	S6	# 1-5
Intervention:	S7	Advance and/or Care and/or Directives or Health and Directives or Advance Care Plan or End-of-Life or Electronic Care Plan or Enduring Power of Attorney or Conservative Therapy
	S8	Health and Professional or Doctor or Physician or GP or Primary Health Care or Outpatients and Clinic or Nurse
	S9	#7-9
Comparison:	S10	Model and/or Care or Organisations or Administration
Outcome:	S11	Bereavement or Satisfaction or Anxiety or Support or Stress and Care

Inclusion criteria were all studies in English that described model development or model testing for advance care planning and electronic record sharing for community dwelling older adults. Exclusion criteria included narrative reviews, models of advance care planning in residential aged care facilities or acute care facilities and papers that proposed models but did not test them. A scoping search was conducted to establish the appropriateness of the search terms and to identify index papers. The scoping search revealed that there were no articles that included electronic health records in the title and the search was broadened to incorporate all of the studies that reported models of advance care planning and community dwelling older adults. These search terms, see figure 1 were combined to identify the relevant papers. The role of nurses and nursing was distilled from the models identified.

RESULTS

One hundred and twenty five titles were identified that met the inclusion criteria. Duplicates were removed. Seventy one abstracts were retrieved and reviewed identifying 18 studies that met the inclusion criteria for full text analysis. Of the 18 studies full text articles, 8 qualitative studies and 9 quantitative studies were reviewed. One study was excluded as it was an opinion piece. Of those studies only two studies included nurses or nursing in the model. One study was conducted in Japan which used nurses to deliver the intervention and the other study was conducted in the United States which used trained nurse facilitators.

The study by Matsui (2010) was a non-randomized quasi-experimental study of 112 participants allocated into 2 groups to understand participant's acceptance of advance care planning. Intervention group members were recruited from 2 senior citizen centres; controls were recruited from 4 other centres in the same region. All participants were aged >65years. The intervention group received a 90 minute educational program to discuss life sustaining treatments at their end-of-life, the control group received an information hand out. The intervention consisted of viewing a video, listening to a lecture from a nurse with the information hand out and participating in a 10 member group discussion run by the nurse. Participants were surveyed pre and post intervention with a one month follow up to identify changes in attitudes towards life sustaining treatments and advance care planning. Wilcoxon rank sum was used to analyse changes in attitudes towards advance care planning and McNemar's test was used to examine the effect of the program on each group. The findings show that there was a significant positive change in attitude between pre and follow up surveys towards advance care planning in the intervention group and a significant increase in the number of intervention group members who had end-of-life care discussions with physicians and/or family members at follow up 20.4% to 38.9% ($p=0.031$). There was a

greater acceptance of the program in the intervention group compared with the control. The author noted a limitation of the study being the absence of distributing advance directive documents to the participants. [4]

The pilot study by Schwarz et al (2002) was a randomized control trial of 61 participants, recruited from 2 geriatrician practices and an independent living centre and randomized using blinded envelopes. The aim was to conduct a prospective study of one element, the facilitated interview, of the successful community wide program 'Respecting Choices' on the effectiveness of improving participants' knowledge of legal and practical aspects of advance care planning, and agreement between health care providers and participants on participants' wishes for end-of-life care. The intervention consisted of a structured interview and information giving session lasting approximately 1 hour with a nurse facilitator, which was documented using a checklist and included the completion of an advance care plan. The control group received standard care and 'Health Care Proxy' form to take home and complete. Participants were surveyed at baseline and at 2 months post intervention, health care agents were surveyed only at 2 months post intervention. Participants completed a 9 item knowledge questionnaire adapted from the original study with an α reliability co-efficient of 0.78. Participant treatment preferences were assessed using a validated tool, the modified Emanuel and Emanuel Medical Directive. Agreement between the participant and their health care agent was measured using an adaption of the Medical Directive questionnaire administered to the health care agent. Paired t tests were used to measure change over time in participants' and health care agents' knowledge about advance care planning. Agreement between the participant regarding their wishes and the health care agent's understanding of those wishes was calculated using t tests. Results of t tests were converted to a measure of effect size (ES) using Cohen's formula. The findings show a small increase in knowledge in the intervention group compared to the control ($ES=0.22$). There was a medium increase in agreement between the groups. The intervention group had a 76% overall agreement and the control group had a 55% overall agreement, ($ES=0.43$). [9]

DISCUSSION

Legislation differs between countries and even within states of countries regarding advance care planning. In addition there are differing terms used to describe both the process and the documents such as Advance Care Directives, Advance Care Plans [5, 6, 10]. Within legislative frameworks, the completion of Advance Care Plans is commonly by lawyers with medical staff often noted as the key health professional in the discussion [5-7].

From the empirical studies reviewed from this systematic review, the role of nurses in advance care planning is portrayed as being that of the provider of education around

advance care planning prior to the patient having a discussion with a medical practitioner and the collection and documentation of advance care plans information for the medical record. In the two studies that investigated the effectiveness of nurse facilitators both reported a significant effect on advance care plan discussions with family members and physicians.

Recommendations from the National Framework documents from Australia, Canada and the United Kingdom (UK), promote a clear role for nurses in advance care planning [5-7, 11]. The UK and Canada have recognised the unique position of nurses as patient advocates being in constant close relationships with patients and their families at the end of life. They have developed core common competencies for advance care planning for nurses as part of the health and social care staff group [6, 12]. The United Kingdom's National Health Service (NHS) is leading the way with published competencies for advance care planning. The NHS (2008, p.10) state that "All Health and Social Care staff should be open to any discussion which may be instigated by an individual and know how to respond" [13]. The 5 dimensions that comprise these End of Life Core Competences (2012, p. 4) include communication skills, assessment and care planning, symptom management, comfort and well being; and advance care planning [12]. Knowledge and skills outlined in the advance care planning core competencies (2012, p.11) include knowledge of the legal framework of advance care planning and mental capacity; assessment skills in the timing of conversations; sensitiveness around the conversations of people's preferred wishes and care, and communication skills around conversations with patient's families and health workers [12].

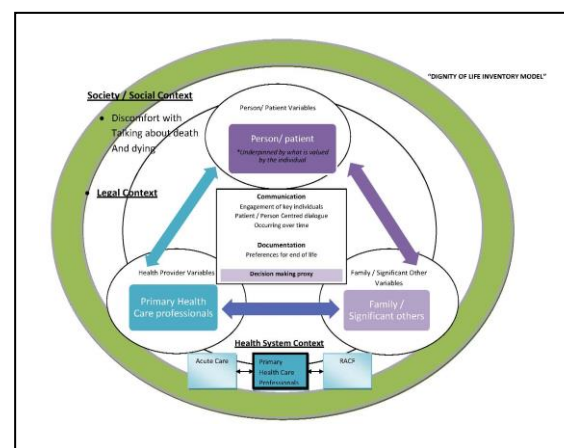
Nurses and allied health staff are key clinicians in the primary care setting especially in regard to elderly people with life-limiting chronic illness. Nurses are in the prime position for these conversations around dignity of life and providing support and advice for decisions for future care as function declines. The Australian National Framework for Advanced Care Directives (2011, p.30) states that an advance directive "should be written by the person to whom it relates". The Framework also proposed that nurses have an important role in providing information during care and identifying when health circumstances change warranting a review of the advance care plan [5]. The International Council of Nurses (ICN) Position Statement on Nurses role in providing care to dying patients and their families (2012) acknowledge there is still debate about the role of nurses in advance care planning. They recommend that nurses must know about legislation as it relates to end of life in their own countries [14].

Many countries are projecting large increases in their aged population. Therefore the capacity to provide care for this ageing population is also on many countries health care agendas. Our Dignity of Life Advance Care Inventory Model (DOLAC) poses that advance care planning discussions are

required across the continuum of care between primary health care, acute care and residential aged care. Research by Schiebel, et al (2012, p. 7) highlights the need for up-to-date information and timeliness of communication regarding advance care plans. This study found that 11 % of patients with initial Do Not Resuscitate (DNR) orders had them changed to full resuscitation during their hospital stay. Their research demonstrated that "these patients were of particularly high risk for being incorrectly designated DNR" thereby having "resuscitation efforts accidentally withheld". The use of an easily recognised and standard location in the electronic record for the most up to date order was shown to reduce the incidence of incorrect or outdated orders being implemented [3].

Current evidence suggest that there is a gap in people's preparation for end of life, with people more prepared to engage with issues of funeral arrangements and preparation of wills, rather than pre death issue such as advance care planning [2, 15, 16]. Strategies to address social norms and reluctance for discussing end-of-life issues are vital in any initiative to promote effective advance care planning. The Dignity of Life Advance Care Inventory Model recognises that the process of advance care planning is complex and is impacted by multiple variables. Research indicates that strategies that combine more than one element are more successful in engaging people in advance care planning [4, 16] and that multiple professionals should be involved, not just doctors. Nursing and allied health professionals have a key role in supporting people with advance care planning across the care continuum and at different stages in their life journey [9, 11, 17, 18]. The DOLAC Model takes a broad view. It does not just focus on the production of a document. It maps the key facilitators and barriers in the advance care planning process. It advocates an individualised, patient-centred approach, where discussions are founded on dignity and quality of life, as defined by the individual patient themselves. The DOLAC Model also promotes the early engagement in advance care planning, prior to the onset of acute or life threatening events, providing time for the exploration of personal care preferences and access to clinical information [4, 9, 11].

Figure 2



CONCLUSION

Nurses have a key role in primary health care, acute care and residential aged care supporting and advocating for their clients. Yet the empirical research on models of advance care plan development are described mostly from a medical (physician) perspective rather than a nursing perspective. Studies have shown that nurse's knowledge of Advance Care plans is lacking [19, 20]. Nurse leaders, educators and managers need to ensure that curriculum, policies, procedures, protected time and evaluation strategies are in place regarding nurses roles. The NHS (2008, p.51) recommend that consensus needs to be reached on the timing of discussions; who should be the initiator and the competencies and training needed by clinicians involved in this work [7]. The DOLAC Model provides a framework for person-centred advance care planning across the continuum that is founded on dignity of life.

ACKNOWLEDGMENT

The Rural Clinical School is funded by the Australian Government Department of Health and Ageing.

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