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Assessing and Addressing Research-practice Gaps in Practitioners
Provision of Decision Support for Terminally-ill ^{Cancer} patients Considering
the Place of their End-of-life Care: Design and Evaluation of a
Multi-Faceted Educational Intervention

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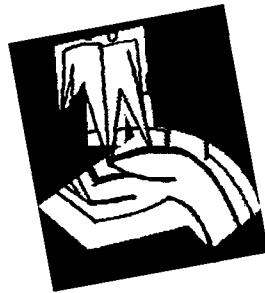
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**Assessing and Addressing Research-Practice Gaps in Practitioners' Provision
of Decision Support for Terminally- Ill Cancer Patients Considering the Place of
their End-of-life Care: Design and Evaluation of a Multi-Faceted Educational
Intervention**



Mary Ann Murray

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Faculty of Graduate and Postdoctoral Studies
in partial fulfillment of the requirements for the
PhD degree in Nursing

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University of Ottawa

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*Ones' destination is never a place but rather
a new way of looking at things*

Henry Miller

Assessing and Addressing Research-Practice Gaps in Practitioners' Provision of Decision Support for Terminally- Ill Patients Considering the Place of their End-of-life Care: Design and Evaluation of a Multi-Faceted Educational Intervention

Abstract

Background

A paradox exists between preferred place of end-of-life care (home/hospice) and actual place of care (hospital). Patients often need help with decision making yet practitioners generally lack skills in providing quality decision support.

Purpose

To evaluate an intervention designed to address barriers to providing decision support for place of end-of-life care. Objectives were to:

1. describe nurses' perceptions of factors that affect their provision of decision support; and
2. design and evaluate the efficacy of an educational intervention for strengthening the quality of practitioners' decision support.

Design and Methods

1. Systematic review: Synthesis of primary research studies investigating factors influencing place-of-care.
2. Needs assessment: Semi-structured interviews with 22 nurses.
3. Randomized trial: Comparison of intervention and control groups on the quality of decision support provided to simulated patients considering place of care before and after training.

Setting of the Needs Assessment and Randomized Trial: Ontario palliative and oncology practice settings.

Results

1. *Systematic Review:* Of 735 papers identified, 39 papers (33 studies) met inclusion criteria. Factors related to the illness, the individual and the care and social environment influence place of end-of-life care for cancer patients. Commonly identified factors were patient preference, social supports and health care resources. Stated preference, care-giver presence and contact patterns with health care services influence place of end-of-life cancer care.
2. *Needs assessment:* Nurses held favourable attitudes towards providing decision support for place-of-care at end-of-life. Nurses considered decision support an important part of patient-centred care yet identified a lack of skills, confidence and tools as barriers.
3. *Randomized control trial:* The before-after changes in the quality of decision support were greater ($p < 0.0001$) in the intervention group (mean change 3.75, 95%CI: 2.46, 5.03) compared to the control group (mean change -0.667, 95% CI: -1.57, 0.24).

Conclusions

Numerous determinants influence terminal cancer patients' decision making about place of care. Nurses believe they have a role in providing decision support, but lack skills, confidence and tools. These barriers can be addressed with an educational program and a patient decision aid.

Broad implementation of the intervention may improve end-of-life care planning. Full implementation of the intervention requires examination of broad system perspectives.

Trial registration: NCT00614003

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So many people have generously shared their expertise, experience, time and insights over the past four years. I am very grateful to the nurses, other health care professionals and the organizations who partnered with me to make this study a reality. You have my heartfelt admiration and respect for your efforts and skills in making important differences in the lives of patients and their families every day.

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2. "Where the Dying Live: A Systematic Review of Determinants of Place of End-of-Life Cancer Care," by Mary Ann Murray, RN, MScN, CON(C), GNC(C), CHPCN(C), Valerie Fiset, RN, MScN, Sandra Young, RN, CHPCN(C), and Jennifer Kryworuchko, RN, BScN, 2009. <i>Oncology Nursing Forum</i> , 36(1), pp. 6977. Copyright 2009 by the Oncology Nursing Society. Reprinted with permission.	

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List of Abbreviations

AHRQ	Agency for Healthcare Research and Quality
ALC	Alternate level of care
CPR	Cardio-pulmonary resuscitation
DSAT10	Brief Decision Support Analysis Tool
EOL	End-of-Life
ESAS	Edmonton Symptom Assessment Scale
IPDAS	International Patient Decision Aid Standards
ODSF	Ottawa Decision Support Framework
PtDA	Patient Decision Aid(s)
POC	Place of Care
PPS	Palliative Performance Scale
RCT	Randomized Control Trial
SCOHS	Sisters of Charity Health Services
SDM	Shared Decision Making
SUPPORT	Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatment
TPB	Theory of Planned Behavior
UK	United Kingdom
US	United States
WHO	World Health Organization

SECTION 1

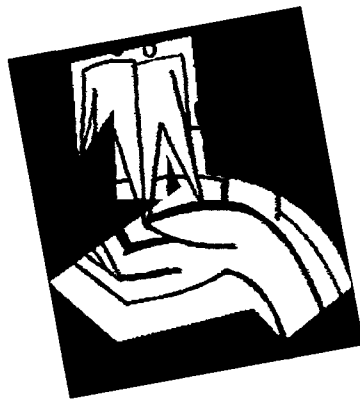
PROBLEM IDENTIFICATION

The research-practice gap impacting practitioners' provision of decision support for patients considering the place of end-of-life care is outlined in this section



Chapter 1

Overview and Organization of Thesis



Chapter 1 presents an overview of the thesis and a description of the organization of the thesis elements.

Overview

Many patients do not receive optimal care (Grol et al., 2005). Estimates suggest that 30-45% of patients do not receive proven, effective treatments and 20-25% receive care that is not needed or that is potentially harmful (Grol et al., 2005; McGlynn, 2003; Schuster, McGlynn & Brook, 1998). A research-practice gap can occur between the generation of knowledge about effective ways to improve patient care and the instrumental use of that knowledge. Indeed, research findings cannot improve patient outcomes until practitioners have adopted them into practice (Ward, Grimshaw & Eccles, 2006). This manuscript-based thesis aimed to examine and to address a research-practice gap related to supporting patients considering place of end-of-life care decisions.

Different aspects of this research-practice gap were examined in a series of interrelated studies. The studies were designed sequentially so that findings generated information for further exploration and testing in the subsequent studies. The overarching framework for this research project was guided by the Knowledge-to-Action process (Graham et al., 2006).

The Knowledge-to-Action process, based on an analysis of 31 planned action theories, is an organic process designed to guide the implementation of evidence into practice (Graham et al, 2006; Tetroe, 2007). Consistent with expectations for continuing professional development and life-long-learning, the knowledge-to-action process recognizes the interactive relationship between research and practice (College of Nurses of Ontario, 2002). Within the knowledge-to-action process knowledge creation and integration happens as stakeholders exchange, apply and refine knowledge.

The Knowledge-to-Action process begins with recognition of a problem followed by synthesis of evidence relevant to the problem. Problem-related knowledge is then adapted to the local context and barriers to knowledge use identified. Next, interventions are designed

and implemented to overcome barriers. Finally, knowledge use is monitored, outcomes evaluated and strategies to sustain knowledge use are identified. Elements of the knowledge-to-action process most relevant to this research project included: problem identification; review and selection of current knowledge; assessment of barriers to knowledge use; adaptation of knowledge to local context; and selecting, tailoring and implementing an intervention to address barriers (Table 1.1). The remaining phases of the Knowledge-to-Action framework (monitoring of knowledge use; evaluating outcomes; reassessing barriers and enablers for ongoing sustainable knowledge use) were beyond the scope of this research project.

The theoretical stance anchoring this research project lies within the philosophical paradigm of contemporary empiricism (Weiss, 1995). In this view, there is no contention that universal laws govern health and health behaviour. Rather, there is an assumption that reasonable predictions are possible that can help nurses predict patient responses to health and illness and how nursing care can influence these responses in beneficial ways (Weiss, 1995).

Decisions about place of end-of-life care provided the context for each of the interrelated studies included in this thesis. However each study varied in several ways: research question, research method and stage in the knowledge-to-action cycle (Table 1.1). This combination of perspectives and methods facilitated a fuller examination of factors contributing to the quality of decision support regarding place of end-of-life care. The use of a mixed methods approach was selected to counteract the biases associated with single method studies so that collectively, the findings could support a more robust conclusion than a single source of data (McEvoy & Richards, 2006; Tashakkori & Teddlie, 2003).

Table 1.1: Organization of Thesis

Stage in Knowledge to Action Cycle	Thesis Section	Chapter	Related Manuscript	Manuscript Objective	Method	Manuscript Status
Problem identification	1	Chapter 1: Overview & organization of thesis Chapter 2: Problem description, potential solution, purpose & conceptual frameworks	N/A	N/A	N/A	N/A
Review & select current knowledge	2	Chapter 3: Current knowledge of determinants of place of end-of-life care Chapter 4: Current knowledge of decision support related to end-of-life	Where Dying Cancer Patients Live: A Systematic Review of Determinants of Place of End-of-Life Care N/A	To describe the determinants of place of end-of-life care for terminally ill cancer patients. N/A	Systematic Review N/A	Oncology Nurses Forum Published N/A
Adapt knowledge to local context	3	Chapter 5: Research proposal including methods & procedures	Efficacy of a training intervention on the quality of practitioners' decision support for patients deciding about place of care at the end-of-life: A randomized control trial: Study protocol	Study protocol	N/A	BMC Palliative Care Published
Assess barriers to knowledge use	4	Chapter 6: Nurses views on patient decision support for place of end-of-life care	Nurses Perceptions of Factors Influencing the Patient Decision Support around Place of Care at the End-of-life	To describe nurses' perceptions of factors (attitudes; perceived social pressures; perceived control) that affect their provision of decision support regarding place of end-of-life care.	Qualitative analysis of an interview guided survey	American Journal of Hospice and Palliative Medicine (in press)

Stage in Knowledge to Action Cycle	Thesis Section	Chapter	Related Manuscript	Manuscript Objective	Method	Manuscript Status
Select, tailor & implement intervention	5	Chapter 7: Intervention tools	N/A	N/A	NA	N/A
		Chapter 8: Implementation and evaluation of a multi-faceted intervention	Efficacy of an evidence-based educational intervention to strengthen practitioners' decision support skills for place of end-of-life care: A randomized control trial	To design and evaluate the acceptability and efficacy of a multifaceted educational intervention in strengthening the quality of practitioners' decision support skills regarding place of end-of-life care.	Randomized control trial	<i>Psychology</i> Under review
		Chapter 9: Integrated discussion & conclusions Chapter 10: Contributions	N/A	N/A	N/A	N/A

Organization of Thesis

The thesis is organized in six sections (Table 1.1). Section 1 outlines the research-practice gap impacting decision support for place of end-of-life care. Chapter 1 situates the philosophical stance anchoring this research inquiry and provides a broad overview of the thesis. In Chapter 2 the problem is described: a potential solution proposed. The purpose and objectives are then defined and the conceptual underpinnings of the thesis are presented.

Section 2 presents a review of the literature with particular attention to what is known about place of end-of-life care and patient decision support. Chapter 3 focuses on results of a systematic review of the literature that details factors that influence place of end-of-life care for patients with cancer. Chapter 4 highlights relevant literature related to patient decision support, particularly in the context of end-of-life care.

Section 3 describes how knowledge synthesized from the literature was adapted to local conditions. Specifically, Chapter 5 describes the methods and procedures of the research study designed to optimize decision support for place of end-of-life care.

Section 4 focuses on assessing barriers to providing decision support for place of end-of-life care. Chapter 6 presents findings from a needs assessment designed to elicit nurses' perceptions of factors that influence decision support in the context of end-of-life place of care.

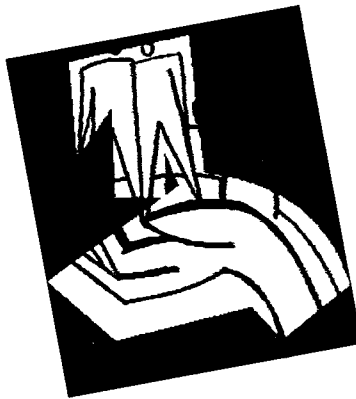
Section 5 details the selection and implementation and evaluation of a knowledge transfer strategy. Chapter 7 describes tools developed in response to barriers identified in the needs assessment. In Chapter 8 results of evaluation of a knowledge transfer strategy to address barriers are presented. Chapter 9 extends the analysis through an integrated discussion focusing on the results, lessons learned and contribution of this work to the science and knowledge of nursing. As well, implications for research, practice, education and health policy are highlighted and key conclusions presented. Finally, in Chapter 10 the contributions of collaborators are described.

Section 6 completes the thesis with references and related appendices.

In summary, this manuscript-based thesis contains four papers with additional chapters. The papers in Chapters 3, 5, and 6 have been accepted for publication in peer reviewed journals. The paper in Chapter 7 has been prepared for submission to a peer reviewed journal.

Chapter 2

Description of Problem



Chapter 2 presents an overview of the problem, proposes a potential solution and describes the conceptual frameworks guiding the design of specific interventions.

Problem Description

Cancer patients have several options for place of end-of-life care due to reorganization of health care services, improved understanding of illness trajectories, equipment portability, pharmacology advances, and consumer expectations. Place of care has various meanings to patients and families and is more than a particular geographic location (Andrews et al., 2005). Options can include hospice, private residence, long term care facility, homeless shelter, and hospital. For patients with good symptom control, instrumental support, and a predictable course of illness, decisions regarding place of care are often based on values, expectations and contact with health care practitioners and services (Gomes & Higginson, 2006; McCall & Rice, 2005; Murray et al., 2003; Thomas et al., 2005).

Typically end-of-life decisions, such as where to receive care, are highly values-sensitive. The best choice depends on how patients value advantages and disadvantages associated with potential options (O'Connor, et al., 2003a; Wennberg, 2002). When considering options patients often experience decisional conflict (personal uncertainty). Personal uncertainty stems not only from the inherent difficulty of the choice, but also from other modifiable factors such as knowledge deficits, lack of clarity about what matters most, and inadequate support (O'Connor et al., 2003b).

Unresolved decisional conflict leads to decisional delay or reversal, dissatisfaction, regret, and blaming the provider for bad outcomes (Gattellari & Ward, 2005; Sun, 2004). Failure to take patient preferences into account can result in missed opportunities, decreased quality of life, unwelcome interventions, and increased risk for complicated bereavement for survivors (Addington-Hall & Karlsen, 2000; Costantini et al., 2000; Murray et al., 2003; Singer

et al., 1999). Patients facing values-sensitive decisions frequently need decision support to help resolve their decisional conflict (Bunn et al., 2006).

Strong evidence, from systematic reviews, confirms that decision support interventions such as patient decision aids (PtDAs) and decision coaching can reduce decisional conflict and increase the likelihood that decisions are informed and based on personal values (Coulter & Ellins, 2007; O'Connor et al., 2007a). However, practitioners may avoid raising uncomfortable topics and often lack skills and confidence in helping patients in non-directive ways (Chang et al., 2000; Higginson & Romer, 2000; Murray et al., 2004a; Zhukovsky et al., 2000). Furthermore, timely discussions about what lies ahead are important for improving the quality of care for dying patients (Workman, 2007).

Variations in where patients receive care as death approaches have been described both in Canada and the United States (Canadian Institute of Health Information, 2007; Pritchard et al., 1998; Wennberg et al., 2008). While variations may indicate differences in the availability and organization of local social and health care services there are likely practitioner factors which shape end-of-life discussions and influence decision making for place of end-of-life care. For instance, there is evidence that decision support practices can be strengthened by enhancing practitioners' knowledge and attitudes about communication and decision support (Archer et al., 2005; Coulter, 2005; Saunders, 2000; World Health Organization, 2004a). However, research is needed to determine effective strategies to implement decision support interventions into palliative care practice. Specifically, there is a need for systematic examination of the needs and barriers to the effective implementation of decision support with identification of interventions to help practitioners overcome those barriers. While a few studies have empirically examined the impact of an educational intervention on the quality of decision support provided by practitioners none have been undertaken in palliative care (Legare et al., 2006a; Stacey et al., 2006b).

Potential Solution

Patients and families want practitioners to listen to their perspectives and preferences and standard palliative practice calls for patient inclusion in care planning (Coulter, 2005; Last Acts Palliative Care Task Force, 2002; WHO, 2006). Most patients with advanced cancer want information and to participate in decision making (Gaston & Mitchell, 2005). Although patients want to discuss end-of-life issues, their preferences for participating in decision making varies and is difficult to predict (Arora & McHorney, 2000; Heyland et al., 2003; Voltz et al., 1998). Unlike many discrete time-bounded decisions, such as whether or not to have surgery, place of care decisions depend on patients' ongoing interpretations of their social circumstances, illness situation and the impact of symptoms on their quality of life. Thus ongoing monitoring for decisional conflict with opportunities for revisiting the decision in response to new information or changing circumstances is integral to end-of-life decision support.

Findings from a systematic review indicate that training practitioners in patient-centered approaches is an effective strategy for increasing patients' understanding of the evidence and implications (Trevena et al., 2006). For example, decision coaching by nurses has helped to foster an informed use of resources and avoid the over-use of interventions that patients don't value in urology and in women's health care (Archer et al., 2005; Kennedy et al., 2002).

Practitioners, such as nurses, through their trusted and frequent interactions with patients and families are well positioned to elicit and explore decisional needs and sources of decisional conflict (College of Nurses of Ontario, 1999). Practitioners can then coach patients with information, values clarification, support and links to resources. While a key challenge is the need to strengthen palliative care nurses' decision support skills, targeted educational interventions have been shown to markedly improve the quality of decision support skills of nurses for other clinical problems (Murray et al., 2004a; Stacey, 2005). As well, cancer

related PtDAs are effective in improving patients' knowledge without increasing anxiety (O'Brien et al., 2009). Thus an intervention that combines a place of care PtDA with targeted education could help nurses to strengthen their capacity for providing decision support for place of end-of-life care.

Given patients' preference to die at home and documented variations in place of end-of-life care further investigation of ways to help practitioners' be better able to meet patients' decision making needs are needed (Canadian Institute of Health Information, 2007). A first step involves the systematic examination of practitioners' needs and perceived barriers to providing decision support and then evaluating the efficacy of practical strategies and tools designed to help address those needs and mitigate the barriers prior to large scale effectiveness trials (Campbell et al., 2000; Thomas et al., 1999; Walker et al., 2003).

Purpose

The aim of this dissertation was to examine and to address a research-practice gap between optimal decision support for cancer patients considering place of end-of-life care and usual approaches aimed at supporting patients decision making. Specific objectives were to:

1. describe the determinants of place of end-of-life care for terminally ill cancer patients
2. describe nurses' perceptions of factors (attitudes; perceived social pressures; perceived control) that affect their provision of decision support regarding place of end-of-life care; and
3. design and evaluate the acceptability and efficacy of a multifaceted educational intervention in strengthening the quality of practitioners' decision support skills regarding place of end-of-life care.

Conceptual Frameworks

Two frameworks were used to expand upon constructs embedded in Graham's (2006) Knowledge-to-Action framework. The Theory of Planned Behaviour (TPB) guided the assessment of nurses' perceived barriers to knowledge use and the design and evaluation of strategies to address these barriers (Ajzen, 1991). The Ottawa Decision Support Framework (ODSF) was used to design and evaluate the intervention for improving nurses' decision support skills (O'Connor et al, 1998). The TPB (Legare F et al., 2003; Limbert & Lamb, 2002; Walker et al., 2003; Walker et al., 2004) and the ODSF (Fiset et al., 2000; Murray et al., 2003; Stacey et al., 2002) are relevant to nursing and have performed well in numerous health-related studies.

Briefly, the TPB asserts that behaviour is predicated on intentions, which are influenced by the person's attitude toward the behaviour, perceived social norms surrounding the behaviour and perceived control over the behaviour in question (Ajzen, 1991). In the case of decision support, nurses' provision of decision support is influenced by their intentions. In turn their intentions are influenced by their: a) attitudes such as their beliefs about the likely outcome of providing/ not providing decision support plus their evaluation of these outcomes; b) perceptions of others about their role in providing decision support; and c) whether they feel they have any control over providing decision support interventions.

While the TPB guided exploration of practitioners' use of decision support, the ODSF was used to improve decision support itself (O'Connor et al., 1998). The ODSF proposes that decisional needs [uncertainty, knowledge, values clarity, support, personal characteristics] strongly influence the quality of decisions patients make and that practitioners can improve the quality of those decisions by providing decision support to address decisional needs [clarify decisional needs, provide facts/probabilities, clarify values, support/guide deliberation, monitor/facilitate progress in decision making] (O'Connor). The ODSF has been used in

multiple studies to identify patients' decision making needs: to guide the development of decision support tools and to strengthen practitioners' knowledge and skills in decision support (Legare et al., 2006; Murray et al., 2003; O'Connor et al., 1999; Stacey et al., 2006b). Practitioner-identified factors associated with practice change: utility, strong evidence basis and flexibility to acknowledge the individuality of patients fit well with the ODSF (Limbert & Lamb, 2002).

SECTION 2

REVIEW OF CURRENT RELATED LITERATURE

A review of the literature with particular attention of what is currently known about place of end-of-life care and patient decision support is outlined in this section



Chapter 3

Current Knowledge of Determinants of Place of End-of-life Care



**Where Dying Cancer Patients Live: A Systematic Review of Determinants of Place of
End-of-Life Care
(Manuscript 1)**

Note: Formatted for the journal: Oncology Nurses Forum

Abstract:**Purpose/Objectives:**

To describe the determinants of place of end-of-life care for terminally ill cancer patients.

Data Sources:

A systematic literature review of primary research studies (January 1997 to January 2007) was undertaken. Studies that investigated place of care or identified place of end-of-life care in relation to outcomes were submitted to screening, critical quality appraisal and bibliographic mapping.

Data Synthesis: Of the 735 papers identified 39 papers representing 33 studies met inclusion criteria. Two main research designs emerged; 1) large scale epidemiological reports and 2) smaller descriptive studies. Findings suggest that factors related to the disease, the individual and the care and social environment influence place of end-of-life care for cancer patients. Social supports, health care inputs and patient preference were the most important.

Conclusions:

Most terminal cancer patients prefer home palliation yet die in an institution. The reasons for this paradox are complex with various determinants influencing place of care decisions.

Implications for Nursing:

Findings may help to inform evidence-based interventions to assist patients and families facing place of end-of-life care decisions. A clearer understanding of factors that influence place of care for patients with cancer could help to inform health care policy and guide needs based modifications of the health care system.

Key Points

- Stated preference, care-giver presence and contact patterns with health care services influences place of end-of-life cancer care
- Home versus hospital as the preferred site for terminal care may not capture the multiple determinants affecting place of end-of-life care
- Timely communication and attention to the unique circumstances of each patient are required to help patients facing decisions for end-of-life place of care
- Quality decisions for place of end-of-life care are characterized by informed patients who have knowledge of options, the possible advantages and disadvantages related to those options and are congruent with patient's values about what matters most among the possible consequences associated with the options.

Where the Dying Live: A Systematic Review of Determinants of Place of End-of-Life Cancer Care

Background

Cancer is the second leading cause of death in the United States and in Canada. Almost 1.5 million Americans will receive a cancer diagnosis in 2007 and despite increased survivorship more than 1,500 people will die every day of cancer in the US; Canadian men have a lifetime cancer risk of 44 percent; Canadian women a 38 percent risk (American Cancer Society [ACS], 2007; National Cancer Institute of Canada [NCIC], 2005). In Canada an estimated 29 percent of men and 24 percent of women will die from their disease (NCIC). Most will receive end-of-life care in an institution despite a preference for home palliation (Cantwell et al., 2000; Murray, O'Connor, Fiset & Viola, 2003; Stajduhar & Davies, 2005; Steinhauser et al. 2000). This perplexing paradox has not been well explained. Dissonance between preferred and actual place of end-of-life care for cancer patients warrants systematic investigation of influencing factors.

Understanding factors impacting end-of-life place of care is an underdeveloped field of inquiry and limits the provision of comprehensive, holistic palliative care (Gomes & Higginson, 2006; Higginson & Sen-Gupta, 2000; Last Acts Palliative Care Task Force, 2002; Romanov, 2000). Strengthening awareness of the practical, social, and psychological considerations affecting place of terminal cancer care would assist practitioners and health care leaders to develop relevant, responsive, evidence-based interventions to better meet the needs of terminally ill cancer patients and their families. At a health systems level, an enhanced understanding of the factors linked to place of terminal cancer care may also help to inform policy and resource allocation decisions.

An important starting place is to establish what is known about the determinants of place of end-of-life care for cancer patients. A number of narrative reviews regarding place of end-of-life care have been published (Grande, Addington-Hall & Todd, 1998; Tang, 2000;

Thomas, 2005). However, limited information regarding the quality of the studies included, scope of the review and potential selection bias limits the utility and generalizability of these reviews. One systematic review (Gomes & Higginson, 2006), encompassing a 31 year span [1971-2002], has examined studies in cancer and non-cancer populations. Given that no systematic review we encountered exclusively focused on cancer patients and that the shelf life for systematic reviews directly relevant to clinical practice is relatively short (Shojania, Sampson, Ansari, & Duce, 2007) a systematic review was conducted to identify what factors, under what circumstances, are associated with place of care for terminally ill adult cancer patients. To reflect the current context of end-of-life care the review focused on publications from 1997-2007. To provide insight about current state of knowledge development related to end-of-life place of care, preliminary bibliometric analysis was also undertaken

Methods

Theoretical model for study and analysis

Gomes (2006) has modeled a network of influencing factors related to place of end-of-life care. In the model, variations in place of death are explained by interactions between three primary factors: 1) illness factors, 2) individual factors, and 3) environmental factors. The model offers a practical means of mapping of a broad set of determinants to a variety of places of care and was used to guide data abstraction, analysis and presentation of results.

Searching the literature

Meta-study and analysis techniques described by Egger and colleagues (1998; 2001) provided the general review methodology. A recognized search strategy from the Centre for Reviews and Dissemination (1998) was used to identify reports that either investigated place of end-of-life care or identified place of end-of-life care in relation to outcomes relevant to end-of-life care for cancer patients. Specific inclusion criteria are described in Table 1.

Previous palliative related reviews have found that descriptive, exploratory,

observational studies and or large scale epidemiologic reports form the bulk of the identified reports (Finley et al.; Franks et al., 2000; Goodwin et al,2002; Higginson & Sen-Gupta, 2000; Thomas, 2005). Typically attrition, recruitment challenges, ethical concerns, and sample selection bias limit the utility or appropriateness of randomized control trials with this patient population (Ahlnér-Elmqvist, Jordhoy, Jannert, Fayers & Kaasa, 2004; Goodwin et al.; Higginson & Sen-Gupta). Therefore, a broad range of evidence was sought and study design not used as a selection criteria.

Four bibliographic databases (Medline, EMBASE, CINAHL, PsychInfo) were searched using the OVID interface from January 1997- January 2007. Key search terms were synonyms for place of care or place of death or placement; hospice or home or hospital or nursing home or institution or residence; dying or terminal or terminally ill or palliative or palliative care; terminal illness or cancer or oncology or neoplasm; demographic factors.

Given that place of end-of-life care inquiry is diffusely distributed across broad topic areas such as patient perceived burden, quality of life, health services, and symptom management, traditional search protocols were supplemented as described by Greenhalgh (2005). Specifically, we used snowball sampling by scrutinizing indexes of journals that contributed the most publications in the electronic search (*Palliative Medicine, Journal of Palliative Care, Cancer Nursing*) and scanned reference lists of retrieved papers. As well, we asked experts to recommend relevant papers while we remained attentive to the possibility of serendipitous findings when searching as part of other related research. Grey literature which generally consists of unpublished and unindexed reports that have not been peer reviewed (GreyNet, 2004) were not included given Cooks' (2001) findings of the minimal contributive value of grey literature to reviews.

Data extraction and quality assessment

Papers were independently screened at three levels (titles, abstracts, full text). Ambiguous citations were retained for further review with disagreements resolved by

consensus. MAM extracted the data; VF and SY assessed the extractions for accuracy of the data extraction process. Reports of a single study were logged as a single entity for data extraction. Two reviewers independently evaluated studies for validity, methodological rigor and relevance to the review foci.

Papers selected for full text review underwent quality assessment and content abstraction. Content was abstracted to a standardized tool used in previous systematic reviews (Joanna Briggs Institute, 2004). Critical quality appraisals were conducted independently by two reviewers using previously published quality assessment tools apropos to specific study designs (Fain, 2004; Goodwin et al, 2002; Joanna Briggs Institute). Quality assessment scores were compared and consensus reached.

Meta-analysis was not attempted due to heterogeneity among study designs, outcome measures and findings. Rather, the included reports' findings were thematically synthesized and mapped to Variations in Place of Care Model (Gomes, 2006). Basic bibliometric analysis was undertaken to identify the state of knowledge development around place of end-of-life cancer care. Publication counts, authorship frequency and dissemination patterns were examined.

Findings

Characteristics of eligible studies

Our search revealed 735 potentially relevant reports. Most were identified via electronic search (94%) with a further 45 reports added from hand searching and referral from colleagues. The final sample included 39 reports reflecting 33 different studies. Figure 1 details the flow of the review process.

The included studies represent over 35 million patients in 15 countries; mostly from Canada, USA and the UK. There was considerable heterogeneity in study characteristics like design, population, sample size and reported outcome measures. All studies had some

weakness; most commonly: selection bias, reliance on administrative data, use of non-validated measures and attrition of participants. Quality appraisal varied considerably (quality scores 45% - 93%). The most frequent gaps were in failing to state a guiding conceptual / theoretical framework or the presence of ethics approval for the study. Descriptive studies such as *retrospective reviews, surveys and smaller descriptive studies involving terminally ill patients, families and or care practitioners* were the most prevalent followed by larger scale epidemiological reports. Two systematic reviews were identified and one cluster randomized trial. Table 2 details the study designs of included reports.

Home was the most common reference point for studies. Several studies dichotomized location of care as home versus non-home. Hospital was the most frequently identified non-home location, followed by hospice and nursing home.

Factors Related to Place of End-of-life Care

Environmental factors were the most frequently identified determinants for place of care, followed by individual factors and illness factors. Home, as place of care, was commonly related to personal characteristics, availability and intensity of home care and community based services, caregiver factors and preferences. Non-home location of care related to cancer diagnosis and symptom intensity, age, gender and health care system factors. Specific results from the included studies are mapped to the Variations in Place of Care Model (2006) in Figure 2 (Home), Figure 3 (Non-Home) Figure 4 (Hospital), Figure 5 (Hospice) and Figure 6 (Nursing Home).

Environmental Factors

Variables within the health care system were the most influential and consistently reported determinants. Characteristics of health delivery systems affected place of care, particularly community based care. Social support emerged strongly as a consideration for home as end-of-life place of care. The importance and connections to informal caregivers was striking for home and slightly less so for non-home locations and geographical impacts

were variable.

Individual Factors

Views of patients and caregivers emerged as an important determinant. However, a wide range of social determinants mitigated place of care for both patients and caregivers. The same factor could either enhance or hamper place of care decisions depending on patient characteristics and circumstances. Overall, the evidence pointed to the need for individualizing place of care discussions based on patient preferences and context.

Illness factors.

A wide range of illness related factors impact place of care for patients nearing the end-of-life. Overall health, functional status and complexity of care needs were common considerations for end-of-life care patients in the included studies.

Mapping the Evolution of the Field from 1997-2007

Medline followed by EMBASE and CINAHL yielded the most electronic citations. Included reports were published in 19 different journals. Attention to place of end-of-life care was recent: 34/39 (87%) of reports were published in the past five years (2002-2007). The most prolific year was 2005 (10 publications). There was an average 3.76 authors per paper. Six authors had authorship on three or more of the included reports with one author having authorship on five. Within the data-set palliative care journals were the most frequent publication venue (Table 3). The discipline of the first author was not specified in 25 reports and the most common affiliation of first authors was reported as a University. First authors were more likely to come from the United Kingdom, followed by USA and Scandinavia (Table 4).

Discussion

The evidence informing this review comes from several different countries, cultures, and clinical settings confirming that place of end-of-life care is a common concern. Overall,

findings from the review reinforce that individual, contextual and practical considerations shape how people deal with place of care and how health care systems respond. Findings from this review have major policy implications for decision makers interested in reforming end-of-life care for cancer patients and for practitioners in their daily practice.

Patient-centered, co-ordinated care is pivotal to quality of end-of-life care (Bircumshaw, 1998). Findings suggest that illness factors and characteristics of the health care system rather than patient preferences and needs often drive place of care decisions. Patient preferences have been linked to psychological and social health as much as to physical health (Sherbourne, Strum & Wells, 1999). Thus, truly patient centered end-of-life care planning needs to incorporate strategies to elicit patient preferences in a timely and effective manner.

Delays in identifying transition points in goals of care such as a changing focus from curative to supportive approaches can limit patients' opportunities to benefit from such approaches. Prognostic uncertainty, funding issues, lack of relevant expertise and boundary issues between practitioners and services have been identified as particularly troublesome (Addington-Hall et al. 1998). In response, several researchers (Fins et al, 1998; Lynn, 2005), policy makers (Romanov, 2000; WHO, 2000; 2004; 2006) and professional organizations (Institute of Medicine, 2001; Canadian Strategy on Palliative and End-of-life Care Working Group, 2005) advocate models that combine life-prolonging care with palliative approaches. Typically, within these models, disease modifying approaches that focus on quality of life and respect for patient autonomy and choice begin at diagnosis and continue throughout the illness trajectory.

As cancer is increasingly considered a chronic condition, principles from chronic condition management models (Wagner et al., 2005), which acknowledge the patient as an expert in their situation and emphasize practitioner and patient partnership, may be more conducive to meeting the needs and preferences of patients and families around place of care at end-of-

life (Murray, 2007). This philosophy is supported by the improvement in well-being, physician/patient communication, and reduction in social limitations and health service utilization shown in a randomized control trial when a chronic condition management approach was used with patients with a diagnosis of stroke, arthritis, heart or lung disease (Lorig et al., 1999).

Findings also reinforce that place of end-of-life care emerges from a complex set of relations and preparations that occur when living with terminal cancer. Arrangements and characteristics of health care services emerged as an important influence on place of care. The importance of social and health system factors is consistent with other reviews of place of end-of-life care, not specific to cancer (Gomes & Higginson, 2006; Higginson & Sen-Gupta, 2000). Other studies confirm that patients consider trust in their health care team, avoidance of unwanted life support, effective communication, continuity of care, having time with loved ones and life completion to be the most important elements of quality end-of-life care (Heyland et al., 2005; Heyland et al., 2006; Singer, Martin & Kelner, 1999). Given the pressure to strengthen the links between evidence, policy and practice decision makers may find these findings helpful in planning health systems that are responsive to patient preference, circumstances and needs.

Many studies used home as the primary reference point. Our findings suggest that place of care is less important than how patients' experience care. It is difficult to model the complexities and interconnections between determinants of place of end-of-life cancer care. Our approach was to abstract the details, make a number of simplifications and hope the resulting low-resolution model would capture the essence of the underlying dynamics. Further qualitative studies may provide additional insights yet will not capture the tension between what happens at the level of the individual and what is transferable to other patients and situations.

A quality end-of-life decision is consistent with an informed patient's values and preferences, is acted upon and results from shared decision making where patients a) are involved in the process, b) informed of options and the uncertainty of outcomes, c) participate in the actual decision to the extent desired, and d) are satisfied with the process (Levy & Curtis, 2006; Murray et al., 2004). Given this definition, place of care is not a measure of a quality decision. One should therefore be cautious about holding home death as the gold standard. Privileging one location over another may disregard the multiplicity of factors considered by patients, create unrealistic expectations, and not serve patients or health service planning well. As practitioners, we need to be mindful that we are thinking in terms of therapeutic rather than geographic landscapes.

Another finding underscores that preferences matter. Several studies highlighted that stating and sharing preferences with others influenced spending ones' last days in a preferred place. When patients and carers acknowledge the possibility of death and discuss options in an open sensitive manner the chances of dying in a preferred location increase. While patients are frequently thinking about place of end-of-life care (Voltz, Akabayashia, Reese & Hans-Martin, 1998) practitioners may avoid raising the topic (Chang, Hwang, Feueman & Kasimis, 2000; Higginson Romer, 2000; Zhulovsky, Abdullah, Ricardson & Walsh, 2000), feel unprepared to engage in palliative conversations (Doherty, Miles & Brandon, 2007), and often lack skills and confidence in helping patients in non-directive ways (Murray et al., 2004). Moreover, families and practitioners' often misjudge patients' wishes regarding end-of-life care (Ditto et al., 2001; Miura et al., 2006). Thus, advance care planning discussions should include a range of goals considered important to patients. As well, opportunities for skills development and practice in conversations about death and dying should be included in professional pre and post licensure education programming (Epstein & Street, 2007; Fitch, 2007).

Preliminary bibliometrics were conducted. Analysis of publication patterns, frequency, and author contribution citation can provide a proxy measure of how knowledge is developed and disseminated within and outside a field of study (Estabrooks, Winther & Derkson, 2004). The bibliometric analysis showed that studies were predominantly published in palliative care journals (Table 2). Given that few patients at end-of-life receive specialty palliative care this has implications for knowledge exchange (Carstairs & Beaudoin, 2000). Gaining access to a wider audience of health care professionals is necessary to ensure that emerging strategies to address end-of-life place of care are relevant and meaningful. Knowledge translation encompasses both knowledge creation and application. Using planned action theories and frameworks and proven knowledge transfer strategies could foster a broader understanding of the determinants of place of end-of-life cancer care and the subsequent implications.

Limitations

Completeness of the literature search, language limitations, inconsistencies in terminology and idiosyncrasies in database indexing influenced the final data set and ultimately limit the review. Diversity of study designs and outcome measures makes it impossible to synthesise findings with meta-analysis techniques or to fully capture the impact of individual determinants on place of end-of-life care. However, efforts to conduct a transparent, comprehensive review characterized by careful searching, multiple levels of critical appraisal, reviewer reflexivity and implementation of quality control mechanisms to minimize bias and error represents a useful contribution to our knowledge about determinants of place of end-of-life cancer care.

Conclusion

Home, as a place of end-of-life care, is often preferred. However, the presence of care-givers and contact patterns with health care services influences place of end-of-life cancer care. Our findings suggest that home versus hospital as the preferred site for terminal

care may not capture the multiple determinants affecting place of end-of-life care. The review contributes to the discourse about the current state of the evidence, how the published evidence is disseminated and the salient methodological implications that impact our knowledge related to place of end-of-life cancer care. This review strengthens our understanding of place of end-of-life cancer care and may lead to the identification of best practices to meet the needs of those who entrust us with their care; the ultimate 'raison d'être' of palliative care research and praxis.

Tables and Figures

Table 1: Inclusion Criteria

- Primary, published research (qualitative and quantitative)
- Cancer diagnosis with cancer related cause of death
- Reported outcomes include factors which impact place of terminal care
- Factors impacting place of terminal care stated by the authors or appear from the published data to be an important element of the study findings
- Study data collected January 1997- January 2007
- English/ French language

Table 2: Publication Location of Included Reports

Journal Category	Journal Type	Frequency (n)
Specialty Journals (n=25)	Palliative Journals	15
	Oncology Journals	6
	Symptom Specific Journals	5
General Medicine/Nursing Journals (n=14)	Medicine	7
	Non-specific	5
	Nursing	1

Figure 1: Flow of Identified Studies through Review

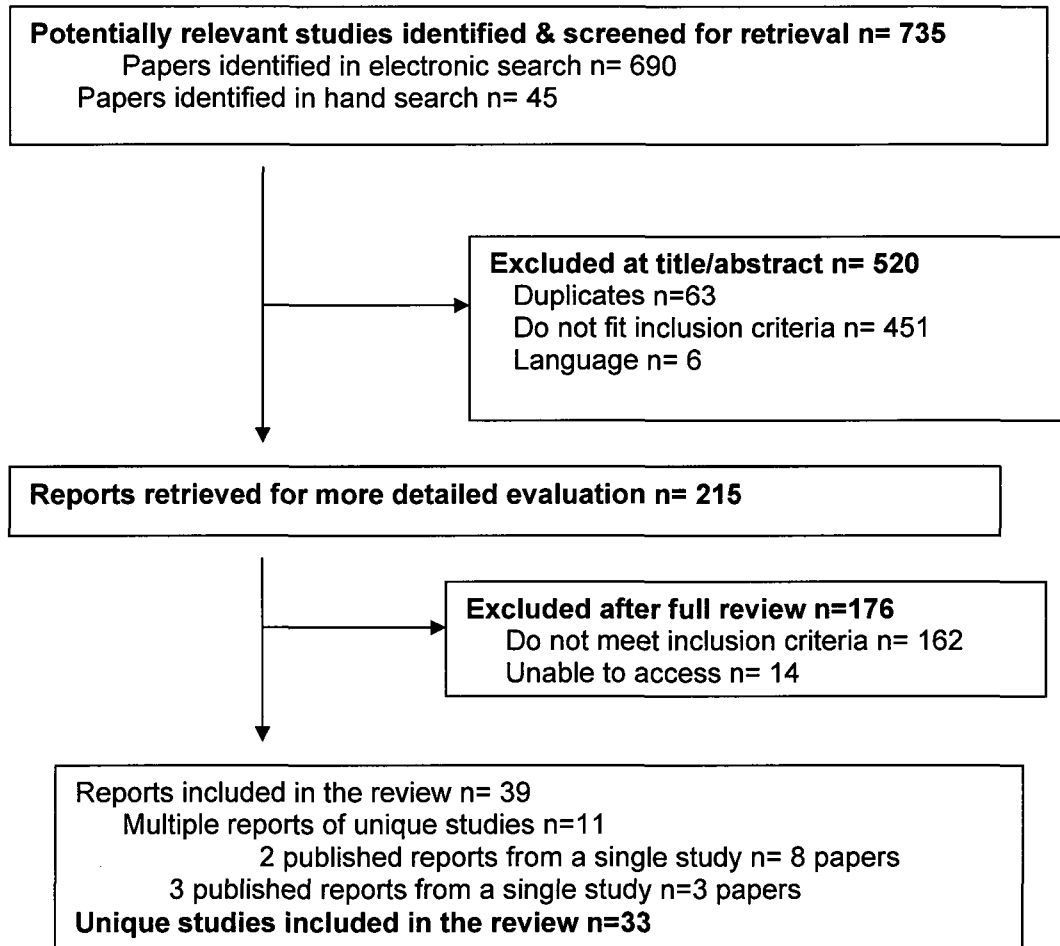


Figure 2: Factors related to Home as place of care at end-of-life

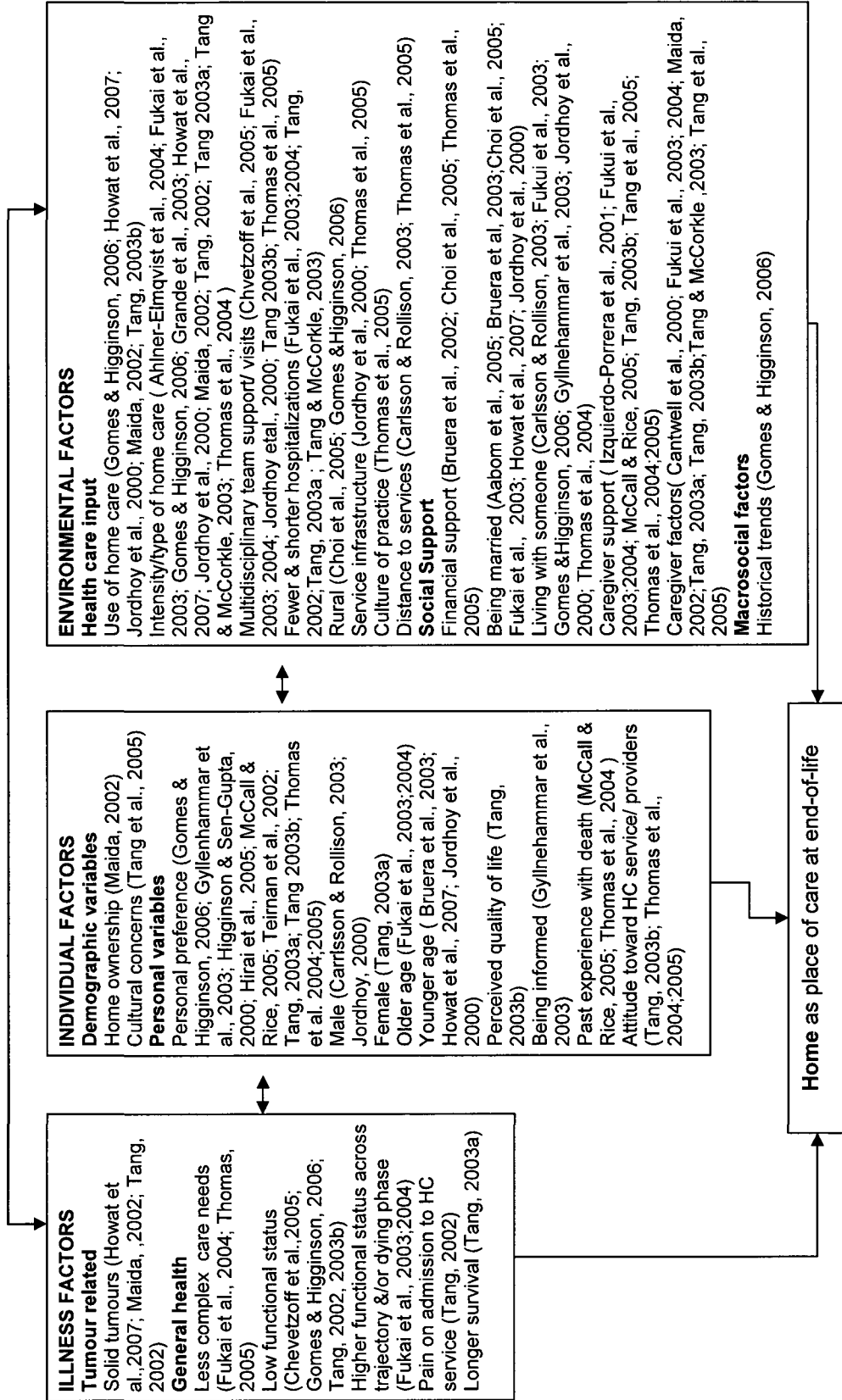


Figure 3: Factors related to Non-Home venues as place of care at end-of-life

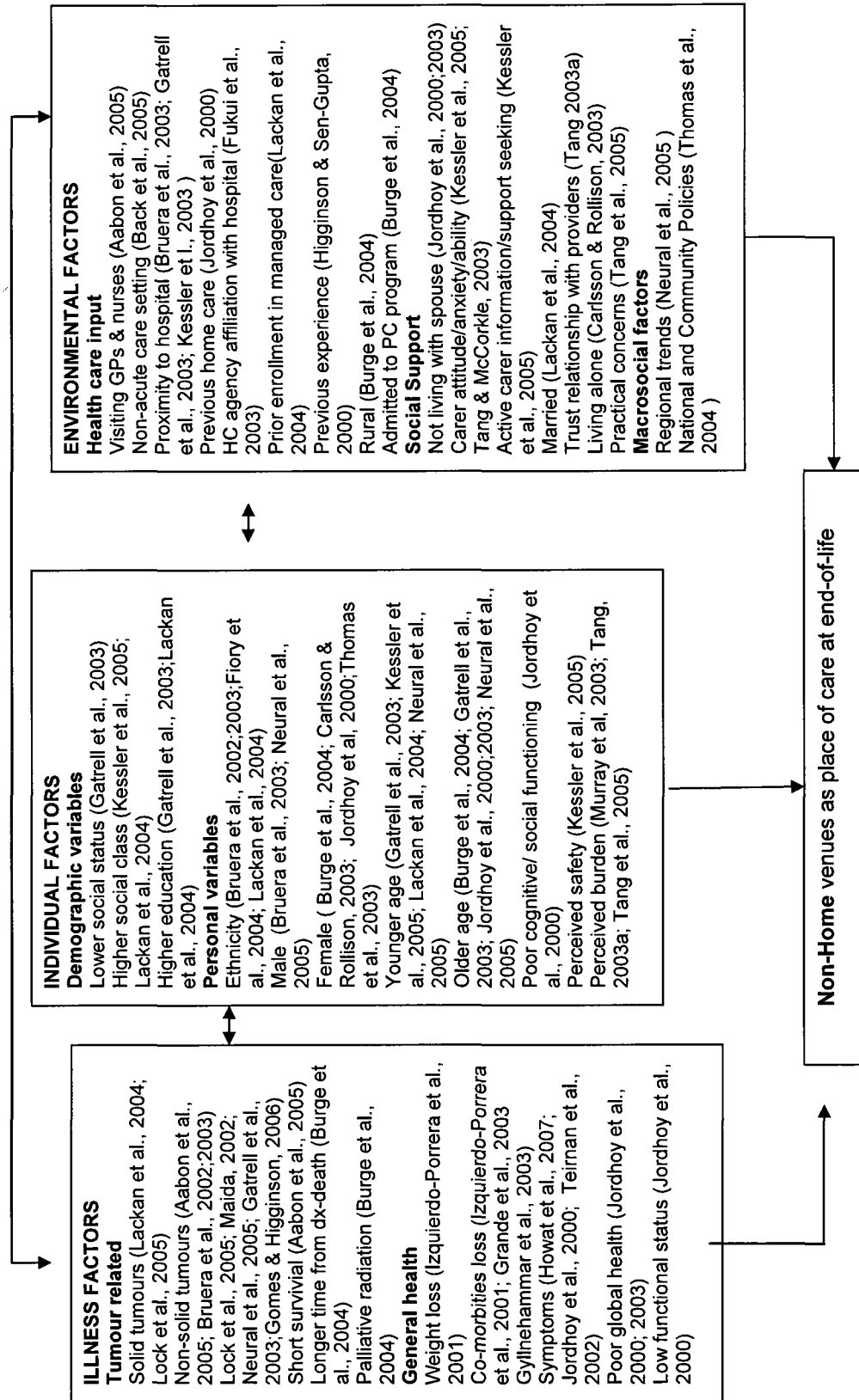
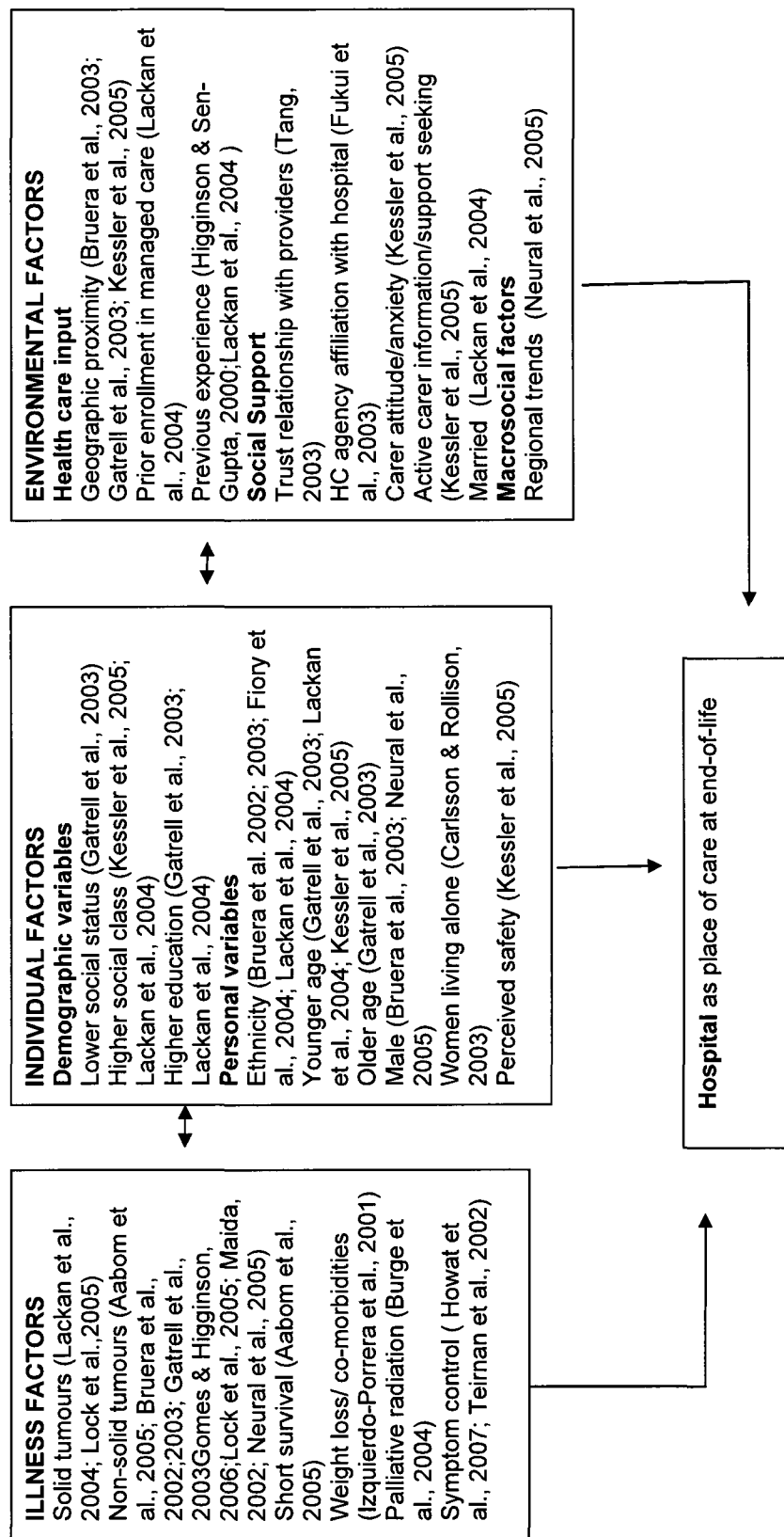
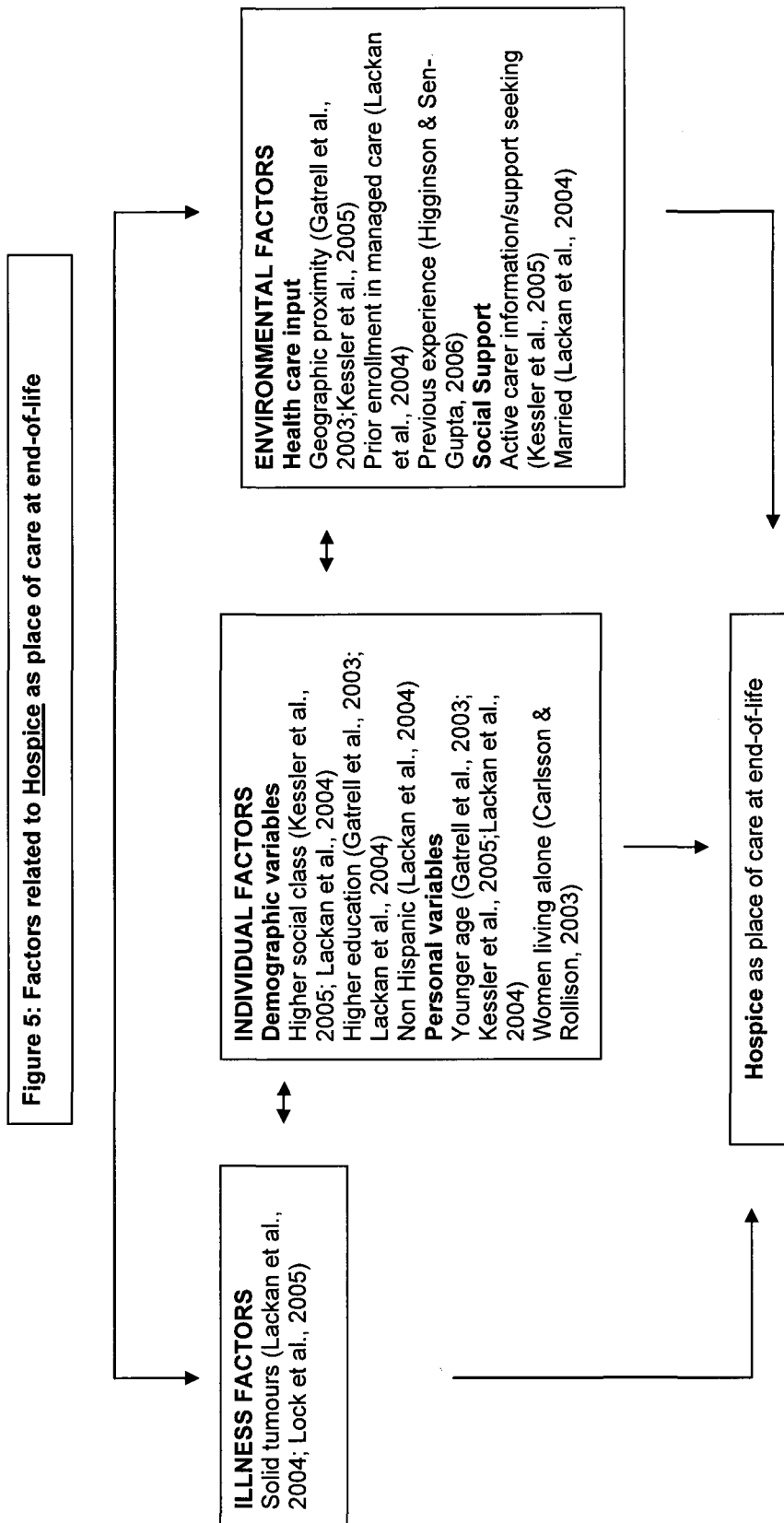
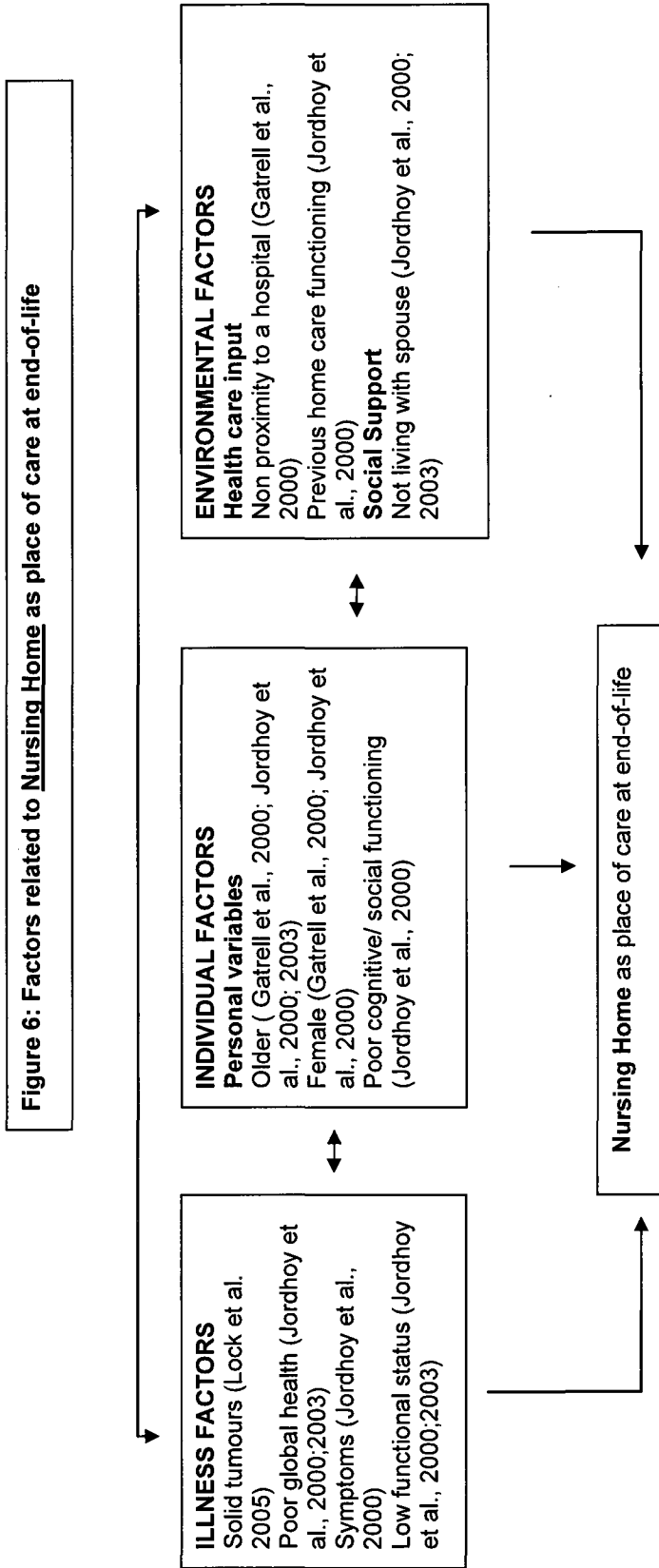


Figure 4: Factors related to Hospital as place of care at end-of-life







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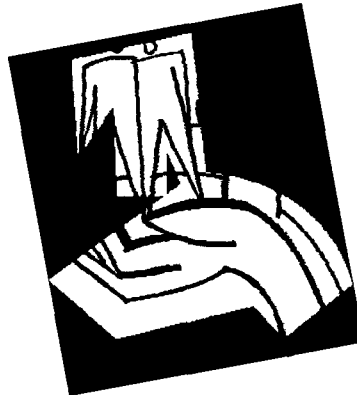
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Chapter 4

Current Knowledge of Decision Support related to Place of End-of-life Care



Chapter 4 presents a summary of our current state of knowledge related to patient decision making needs and decision support in the context of place of end-of-life care.

Current Knowledge of Decision Support Related to End-Of-Life Care

The literature review was guided by three components of the ODSF: 1) decision making needs, 2) decision support interventions; and 3) decision quality (O'Connor et al., 2002). Electronic databases (*Medline, CINAHL, PsychInfo, Embase*), table of contents of recently published journals, reference lists of included papers, referrals from colleagues and the Internet were used to identify relevant literature.

Decision Making Needs

Epidemiology of end-of-life place of care: Cancer is a global health problem (World Health Organization, 2004a). About 11 million people are living with cancer and about 7 million people die annually (International Agency for Research on Cancer, 2006). In the US, cancer is the second leading cause of death with an annual mortality rate of more than half a million. Presently, the lifetime risk for an American man to develop cancer is 1 in 2 and 1 in 3 for women (National Center for Health Statistics, 2004). Canadian estimates predict that cancer will be the leading cause of death by 2010 with about 44 percent of men and 38 percent of Canadian women developing cancer during their lifetime. Of those, about 29 percent of men and 24 percent of women will die (National Cancer Institute, 2005). Although recent cancer death rates have declined marginally, the current aging demographic means an increase in the overall prevalence of cancer with a consequent increase in the numbers of people requiring end-of-life care in the future (Edwards et al., 2005; Jemal et al., 2005).

Notwithstanding some reversal in the 20th century trend of hospital as the primary place of end-of- life care and an increasing proportion of deaths occurring in nursing homes, most dying cancer patients receive terminal care in an institution despite claiming that home is the preferred location (Bruera et al., 2003; Cantwell et al., 2000; Davison et al., 2001; Higginson et al., 1998; Higginson & Sen-Gupta, 2000; Hunt et al., 2001; Murray et al., 2003;

Stajduhar & Davies, 2005; Steinhauser et al., 2000a; World Health Organization, 2004b).

Currently, the proportion of those who die at home ranges from 28-47% in western countries (Burge et al., 2004; Cantwell et al., 2000; Hunt, 1997; Heyland et al., 2000; McWhinney et al., 1995). In the US, while most people over the age of 65 live at home over 50% die in hospital, and another 25% die in nursing homes (Flory et al., 2004; Introcaso & Lynn, 2002; Ribbe et al., 1997). In Canada the dying experience is largely hospital based (76%) (Heyland et al., 2000).

A trend analysis based on aggregated population data for England and Wales (1974-2003), predicts a 20% increase in institutional deaths by 2030 with fewer than 1 in 10 deaths occurring at home (Gomes & Higginson, 2008). Implications and costs at the macro-level health system originate at the micro-level in the individual decisions contemplated and made by patients and practitioners. Informed decision making around end-of-life place of care has the potential to help rationalize health care resources in ways that fit with patients' informed preferences and avoid costs associated with less desired options.

Current Context of Place of Care at End-of-life: Patients with advanced cancer consistently identify a preference for non-hospital end-of-life care (Higginson & Sen-Gupta, 2000; Karlsen & Addington-Hall, 1998; Tang & McCorkle, 2001; Townsend et al., 1990). However place of end-of-life care is often influenced by characteristics of local health care systems rather than patient preference (Pritchard et al., 1998; Murray et al., 2009a). In response, several reforms to enhance end-of-life care choices have been undertaken. In Canada, kin caregivers can apply for compassionate benefits; in the United Kingdom (UK) the National Health Service end-of-life program has received substantial funds (£12 million; 2003-6); and in the US the National Cancer Act (2002) aims to improve the quality of care for cancer patients. Despite these efforts a World Health Organization (WHO) (2006) palliative care report indicates that older persons continue to experience unmet needs related to place of care and communication of preferences.

Dying in the place of one's choice is an important element of the quality of dying and death (Patrick et al., 2001). Care setting affects the philosophy of care and has a direct impact on the quality of life and dying (Mezey et al., 2002; Siew, 2000). However, stating a preferred place of care may not adequately describe patients' ideas for best place of care (Murray et al., 2003).

Conflicting descriptions of best place of care exist. For some, home is a place of safety, normalcy, belonging, and perceived control (Gott et al., 2004; Murray et al., 2003; Tang, 2003). For others, home is not considered practical or desirable (Gatrell et al., 2003; Lee & Pang, 1998; Murray et al., 2003). Some patients consider institutional settings such as hospice, nursing home or community hospital as better options than home (Stajduhar et al., 2008). The nuance between preferred and best place of care underscores the importance of engaging patients to fully understand the factors influencing place of care decisions and their underlying decision-making needs (Murray et al., 2003).

Place of care appears to be an important ingredient in end-of-life care. Eliciting preferences may be a starting place to help patients reach informed decisions about what constitutes the best place of end-of-life care for them. Although much evidence supports home as the preferred place, this remains a superficial appraisal. More work needs to be done to better help patients differentiate between preferred and best locations of care based on their unique circumstances and values; in short helping patients to make quality decisions that are informed and consistent with what is most important to them.

Decision Support Interventions

Decision Support Tools: Terminally ill patients make health and personal care decisions in response to daily challenges and uncertainty. For instance, findings from a study which examined the context end-of-life decision making indicate that values, beliefs and experiences greatly shape patients' decision making (Gauthier & Swigart, 2003).

One line of research has focused on PtDAs, as a tool to prepare patients for decision making. PtDAs differ from traditional patient education materials by a) explicitly describing options; b) providing estimates of potential harms or benefits linked to options; c) clarifying values; and d) providing structured guidance in deliberation and communication (O'Connor et al., 1999; Whelan et al., 2001). In general, PtDAs are intended to complement decision support counseling. A multi-centre randomized control trial (n= 894 women) found that a PtDA used in conjunction with counseling by nurses improved patient satisfaction and reduced health care costs associated with the management of menorrhagia compared with standard care alone or compared to a PtDA alone (Kennedy et al., 2002).

One review of reviews and five systematic reviews have examined outcomes and limitations of PtDAs (Coulter & Ellins, 2007; Feldman-Stewart et al., 2006; O'Brien et al., 2009; O'Connor et al., 2003a; O'Connor et al., 2009; Whelan et al., 2001). Overall, PtDAs improved patient knowledge and understanding of their condition. A review of randomized control trials (n=55) found that PtDAs improved patients' decision quality and measures of feeling informed and clear about values (O'Connor et al., 2009). Relative to simpler PtDAs more detailed PtDAs showed greater congruence between patients' values and the chosen option. One review highlighted gaps in the completeness, balance and accuracy of information presented in the PtDAs which were evaluated (Feldman-Stewart et al., 2006). To address this, a recent international collaboration has established standards to assess the quality of PtDAs (Elwyn et al., 2006). Finally, a meta-analysis of cancer-related PtDAs found that patients' knowledge was improved without increasing anxiety, particularly in screening decisions (O'Brien et al., 2009). These reviews provide clear evidence that PtDAs are effective in helping patients consider options related to various health decisions.

However, while patients are generally satisfied with PtDAs and find them helpful PtDAs have not been widely adopted in clinical practice (Coulter & Ellins, 2007; Holmes-Rovner et al., 2007; Legare et al., 2008; O'Connor et al., 2007b). Suggestions for

implementing PtDAs include developing supportive infrastructures, reconfiguring reimbursement models and embedding PtDAs into processes of care (O'Connor et al., 2007b). As well, education needs of practitioners about how to access and use PtDAs requires attention (Legare et al., 2006b).

In looking for PtDAs specific to end-of-life care, a search of the A-Z Inventory of Patient Decision Aids maintained by the Ottawa Health Research Institute at the University of Ottawa (<http://decisionaid.ohri.ca/AZinvent.php>) revealed five end-of-life related PtDAs. Two were concerned with hydration and nutrition decisions, one related to preferences for CPR and mechanical ventilation, one about stopping kidney dialysis and one about whether or not to continue life prolonging treatment. No PtDAs specific to place of end-of-life care were found. One generic PtDA, *The Ottawa Patient Decision Guide*, developed by the Ottawa Health Research Institute (University of Ottawa) was found (<http://decisionaid.ohri.ca/decguide.html>). The *Guide* has been used as a template for over 30 PtDAs evaluated in clinical trials. While the *Guide* has been used as a template for a PtDA about whether to enter a long term care facility (<http://decisionaid.ohri.ca/AZsumm.php?ID=1025>) and guided a needs assessment of terminally ill women's decision making needs it has not been used specifically in the context of place of end-of-life care for cancer patients (Comeau, 2001; Murray et al., 2003).

Nurses' Role in Decision Support: Nurses are expected to formulate care plans that are tailored to the unique needs of the patient (College of Nurses of Ontario, 2006). Relationship factors, such as trust and communication behaviours influence the patients' subjective experience of decision making (Fraenkel & McGraw, 2007; Heyland et al., 2005; Saba et al., 2006). The influence of these factors has been demonstrated in multiple studies spanning several countries. For example, a systematic review on end-of-life care for adults found that ineffective communication often characterized end-of-life hospital care. Within the 91 studies, there were frequent reports of inadequate communication and disagreement

between patients and their families and nurses and physicians. Several studies in the review found that families and practitioners often had an incomplete understanding of patient preferences (Baggs, 2002). This inadequate communication could result in patients receiving unwanted interventions or receiving care in a non-preferred location.

Nurses, by their proximity, therapeutic agency and trusted interactions with patients, are well positioned to provide decision support and can assist patients to make sense of complex factors such as the impact of technology, hope, and uncertainty (Fins, 2006; Gauthier, 2005; Oliverio & Fraulo, 1998). Nurses may also help to avert the use of options that do not fit with patients' goals of care (O'Connor et al., 2004). Frequent contact with patients facilitates early recognition of subtle shifts in condition and the presence of uncertainty (Baggs & Schmitt, 2000; Oddi & Cassidy, 1998; Thompson et al., 2006). Moreover, nurses often act as intermediaries and knowledge brokers between physicians and patients and have a greater opportunity for communication with patients than physicians (May, 1993; Mezey et al., 1994; Oddi & Cassidy, 1998).

Despite patient preferences to participate in care planning, evidence confirms that nurses are uncomfortable in end-of-life care discussions with patients (Garland & Schrim, 1998; Schulman-Green et al., 2005); discussions are relatively infrequent even when patients are in hospice (Hall et al., 2005); and nurses report that they require further skill development in end-of-life decision support (Murray et al., 2004a). For example, how to talk with dying patients was identified as the top learning need for 56 oncology nurses in a US academic medical center (White et al., 2004). Other evidence indicates gaps in nurses' awareness of patient decision making needs. For instance, nurses' decisions are often based on concerns that differ from patients, they do not know their patients' preferences, and are generally unaware that differences in opinion exist (Cameron et al., 1995; Kane, 1996; Leidy & Haase, 1996; Leighl et al., 2001).

A qualitative study done with 21 oncology nurses highlights the challenges in discussing difficult issues around end-of-life care and participants' reflections about being unprepared for these conversations (Fitch, 2007). Participants reported that gaps in their education and support systems limited their ability to meet patients' decision making needs. They strongly recommended interactive programs with the opportunity for skill development and practice to address this practice gap (Fitch). However, how interactive programs impact nurses' intentions to engage in conversations about end-of-life issues and their perceptions of the utility of such training programs have not been evaluated.

Interventions to engage patients in decision making at end-of-life: Coupling decision support tools with high quality decision counselling is receiving more attention and there are now calls for Clinical Practice Guidelines to incorporate patient preferences (Kranh & Naglie, 2008; O'Connor et al., 2007b). A decision dialogue program aimed at improving the quality of decisions that cancer patients make with their physician has been initiated at a cancer center in San Francisco (Belkora, 2003). Prior to meeting with their oncologist, patients meet with a trained volunteer. Using a structured checklist, patients are guided to articulate their questions and concerns within six decision making domains (frame, values, alternatives, information, reasoning and commitment). While the intervention has been well received by patients it is yet to be evaluated and has only been used in initial treatment planning for breast cancer (J. Belkora, personal communication, July 2, 2008). Other decision support interventions have been instituted in Canada. For example, at the Ottawa Women's Health Breast Center all newly diagnosed women with breast cancer are given a resource booklet which includes a PtDA and an explanation of shared decision making. As well, population based nurse call centers have begun to use decision support tools into their database of resources nurses can access when providing telephone support (Stacey et al., 2006b).

Decision coaching has been used to prepare patients for decision making by helping them to deliberate about options, or strengthen their skills and confidence in implementing

changes (Stacey et al., 2008b). In a Canadian study, conducted at a provincial Health Line, nurses (n=19), who received decision coaching training, were more likely to address simulated callers' information, values clarification and support needs than controls (n=20) (Stacey et al., 2006). In the UK, specialist urology nurses found that decision coaching training combined with the availability of PtDAs was helpful in supporting men considering treatment options for prostate cancer (Archer et al., 2005). For 97 Canadian women, at high risk for breast cancer, coaching by an advanced practice nurse, helped women to meet their information needs (Stacey et al., 2002). Nurse coaching has also been described as an intervention to help cancer patients explore their beliefs and perceived barriers to pain management yet to date has not been evaluated in clinical practice (Fahey et al., 2008).

The Agency for Healthcare Research and Quality (AHRQ) synthesised evidence for end-of-life care and outcomes. The report concluded that when communication and planning occurs there is a tendency toward improved patient satisfaction and that flawed communication leads to frustration and disappointment for patients and families (Lorenz et al., 2004). Nevertheless, this evidence is thin due to the paucity of high quality research designs applied to these issues to date. Furthermore other systematic reviews confirm that cancer patients continue to have unmet communication needs about non-medical aspects of their illness and that preparing patients to identify their questions before consultations has shown some benefit (Hack et al., 2005; Kinnersley et al., 2008). Since practitioners are often not proficient in conducting end-of-life discussions several authors advocate that education programs be developed to teach requisite skills targeting particular end-of-life topics such as advance planning (Fitch, 2007; Sivesind et al., 2003; Sullivan et al., 2003).

Another high profile intervention to improve end-of-life decision making was the Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatment study (SUPPORT) (SUPPORT Principle Investigators, 1995). In the SUPPORT study an intervention designed to enhance communication regarding patients' preferences for end-of-

life care was trialed. In five US hospitals (n=9105 seriously ill patients), a specially trained nurse facilitated advance care planning and communication between patients and health team members. Although the outcomes of the SUPPORT (1995) are described as inconclusive, qualitative analysis of the SUPPORT nurses' narratives demonstrates their recognition of patient decision readiness and cues for further communication and clarification of options (Murphy et al., 2001)

While failure of SUPPORT (1995) to demonstrate improved patient and care outcomes is disappointing, closer scrutiny reveals several factors that may have impacted results. For example, nurses, who primarily delivered the intervention, did not participate in the study design; nor were they asked to respond to the SUPPORT conclusions (Oddi & Cassidy, 1998; Oliverio & Fraulo, 1998). Additionally, preliminary studies to ascertain feasibility, acceptability or utility of intervention content or delivery method were not undertaken. Therefore it is necessary to undertake efficacy studies to encourage promising approaches and tools for addressing barriers to the provision of quality decision support at end-of-life.

Decision Quality

Shared Decision Making (SDM): Decisions are seldom based solely on facts when outcomes are uncertain and choices depend on personal values and circumstances. SDM aims to help patients explicitly consider their choices, information needs, values and preferences when making health related decisions (Charles et al., 1997; Charles et al., 1999; Elwyn & Charles, 2001; Fraenkel & McGraw, 2007a). In SDM patients are guided through the decision making process (Coulter, 1999; Charles et al., 1997; Murray, 2007; O'Connor et al., 2008a; Stacey et al., 2008b). The goal is to arrive at a quality decision that is informed by both evidence and patient values (O'Connor et al., 1999). A systematic review, aimed at elucidating the conceptual understanding of SDM, confirmed that there is no commonly held definition of SDM (Makoul & Clayman, 2006). However, there is general consensus that

requisites for SDM include: having a choice; sufficient knowledge; encouragement to engage in decision making; an opportunity to clarify values; and two way communication in the patient/provider dyad (Charles et al., 1997; Charles et al., 1999; Coulter, 1999; Elwyn et al., 2003; Elwyn et al., 2005).

While SDM offers a useful approach to help patients facing end-of-life decisions make informed choices that are consistent with their values, SDM has not been widely adopted in clinical practice (Coulter & Ellins, 2007; Legare et al., 2008). For example, analysis of audio-taped consultations between cancer patients and oncologists showed a focus on disease management rather than psycho-social assessment (Rogers & Todd, 2002). In contrast, affective communication, where practitioners asked patients about their dying and related emotional and spiritual needs, was retained as a final factor in the *Preferences for Care at End-of-life Scale* (Gauthier & Froman, 2001). The inclusion of this factor in the final scale is consistent with recommendations from a study, examining decision uncertainty in cancer, that practitioners need to actively elicit patient concerns across a broader spectrum of health and social functioning (Kasper et al., 2008).

A systematic review, non-specific to cancer and end-of-life, has identified health care professionals' perceptions of barriers and facilitators to implementing shared decision making (Gravel et al., 2006). The most frequently reported barriers were: time constraints, non-applicability due to patient characteristics or clinical situation, perceived patient preferences for involvement in decision making and disagreeing with asking patients about their preferred role in decision making (Gravel et al., 2006). The most commonly reported facilitators were motivation of practitioners, perception that SDM would positively impact the clinical process and patient outcomes, perception that SDM is useful/practical, patient preferences for SDM and characteristics of the patient.

Participants in studies contained within the Gravel review (2006) were predominantly physicians (89%). Nurses or allied health professionals were identified as participants in 13

studies and represented a small proportion of the total sample in all studies (Ford et al., 2003; Hamann et al., 2006; Hammond et al., 1999; Holmes-Rover et al., 2000; Kim et al., 2005; Lester et al., 2006; Lewis et al., 2003; Naik et al., 2005; Ruland, 2006; Shulman-Green et al., 2006; Stacey et al., 2005; Thompson et al., 2006; Wirrmann & Askam, 2006). Of the 13 studies, 11 specified findings related to nurse participants and two reported aggregated findings. Nurses identified time and resource constraints as barriers in five studies (Ford et al; Hammond et al.; Hamann et al.; Naik et al.; Ruland; Stacey et al.). Facilitators included nurses' positive attitudes toward patient decision support in six studies and toward use of decision support tools in three studies (Hamann et al.; Naik et al. ; Stacey et al.; O'Connor et al., 2004). While knowledge of the influence, impact and role of non-physician practitioners on SDM is limited, implementation research aimed at addressing barriers and enablers is warranted. A recent update of that review revealed similar findings (Legare et al., 2008)

Patient participation in end-of-life care decision making: Generally there are positive links between patient satisfaction and interventions that improve communication or address other interpersonal aspects of care. However the relationship between satisfaction and interventions could be confounded by factors such as differences in patients, practitioners, or healthcare settings (Bruera et al., 1999; Ringdal et al., 2002; Schneiderman et al., 2003; Wilkinson et al., 1999).

A growing body of evidence shows that while many patients want to collaborate in decision making, preferences for participation are variable and situationally dependant (Arora & McHorney, 2000; Fraenkel & McGraw, 2007; Fried et al., 2007; Gattelari et al., 2001; Heyland et al., 2003). For instance, data from a longitudinal study involving 729 cancer patients found heterogeneity for decision participation preference within the group and also within individuals over time (Mallinger et al., 2006).

Moreover practitioners are not good at predicting patients' preferences for participating in decision making. For example a systematic review (n=47papers) describing

communication or SDM with advanced cancer patients reveals that the majority (about 2/3) preferred active participation in decision making while about one third preferred a more passive role (Gaston & Mitchell, 2005). Similarly interviews with 130 terminally ill patients about preferences for SDM found that more than half (52%) preferred to be make decisions in collaboration with their physician and that about a third (34%) preferred to make decisions independently (Nolan & Hughes, 2005). In another study 78 cancer outpatients were assessed for their preferences for SDM as well as their physician's perception of this preference. Most patients (49 (63%) of 78; 95% CI, 0.51 to 0.74) preferred a shared approach with physicians, while physicians (23 (29%) of 78) predicted that patients preferred a less shared approach (Bruera et al., 2001). Lack of concordance between desired and actual decision making of patients suggests the need for the development of tools and processes in combination with provider training on SDM to mediate this gap.

Patients and practitioners are often hesitant to raise psychosocial issues which can cloud practitioners' recognition that decisions need to be made. For example, palliative patients undergoing chemotherapy were more likely to discuss their illness and treatment rather than concerns about functioning and quality of life (Detmar et al., 2000; Detmar et al., 2001). In contrast, patients are often thinking about non-treatment issues as demonstrated in a multi-country study describing palliative patients' perceptions of the important decisions facing them (Voltz et al., 1998). Almost half (46%) of participants (n= 159) from Germany (34), Japan (n= 34) and the US (n=90) indicated that place of care was the most important decision they had thought about in the last weeks (26%) or would in the near future (15%) (Voltz). The discrepancy between what patients consider to be pressing and what they discuss with their health care provider may be partially related to limitations in practitioners' skill set in identifying these decision needs and providing decision support.

Decision impact: Involvement in end-of-life care decision making is considered a key component of a 'good death' (Miyashita et al., 2008; Steinhauser et al., 2000a; Steinhauser et

al., 2000b; Teno et al., 2004; Tong, 2003; Winslow & Jacobson, 1998) and maintaining control has been identified as an important domain of quality end-of-life care (Singer et al., 1999). Exercising control over care, treatment and remaining time also helps patients to maintain their dignity (Chochinov et al., 2002; Jacelon et al., 2004). In a study validating a decision regret scale, with a sample that included breast and prostate cancer patients, more regret was identified in situations where patients perceived others had made the decision for them (Brehaut et al., 2003). A review paper examining communication goals and needs of cancer patients found that mastery and control over the cancer experience are frequent themes in descriptive reports (Hack et al., 2005).

Terminally ill patients, when articulating care preferences, often consider a complex array of social, emotional, practical and existential concerns reflecting the preference sensitive nature of these decisions (Ferris et al., 2002; Hallenback, 2008; Kuebler et al., 2005; O'Connor et al., 2003a; Wennberg, 2002). Awareness of deaths' proximity combined with an uncertain, limited future can lead to trade-offs between various options as reported by 20 terminally ill women who expressed their dilemmas around place of care decisions against the backdrop of concern for others (Murray et al., 2003). Failure to assess preferences in a timely manner can lead to missed opportunities, decreased quality of life, dissatisfaction with care, and increased risk for complicated bereavement for survivors (Murray et al., 2004b; SUPPORT Principle Investigators, 1995; Valdimarsdottir et al., 2002). Failure to listen to patients' issues can lead to missed expectations, dissatisfaction and poor outcomes (Mckinley & Middleton, 1999; Stevenson et al., 2004; Teno et al., 2000).

A key focus of the Ontario Ministry of Health is to, 'get the right people the right treatment in the right place at the right time' (Health Results Team, 2005). However Ontario patients often remain in hospital when they could receive care elsewhere. For instance, delays in transition planning contributed to Ontario hospitals logging 600,000 Alternate Level of Care days in 2005/6 (Ontario Ministry of Health and Long Term Care, 2005). Poor

communication and inadequate information for patient decision making contributed to these delays (Change Foundation & Ontario Association of Community Care Access Centers, 2008).

Two studies with cancer patients confirm that positive outcomes occur when patients are engaged in decision making about their care. In a 3 year longitudinal study of 205 women with breast cancer, patients who had been engaged in decision making reported higher overall quality of life at follow-up; higher physical and social functioning; and less fatigue than non-engaged patients (Hack et al., 2006). In another study with 233 cancer patients 'perceived role in decision making' independently and significantly predicted satisfaction with both the clinical interaction and amount of information and emotional support received from the oncologist. Patients who reported a shared role in decision making were the most satisfied (Gattelari et al., 2001).

Summary of Literature Review

Patients living with terminal illness have unmet decision making needs and do not participate in decision making to the extent they desire. The scope of decisions that these patients consider goes beyond treatment and disease management. Evidence related to nurses' role in decision support with terminally ill patients, while incomplete, suggests that nurses favour patient decision support yet are hampered by a lack of skills, knowledge gaps, time and resource barriers. Training practitioners in decision support and the use of PtDAs are effective strategies for addressing these barriers. However there has not been widespread implementation or evaluation of these interventions in palliative care.

The present study considers the lessons of SUPPORT by involving nurses in intervention development and evaluation. Additionally, critiques regarding SUPPORT outcome measures will be addressed by selecting variables that are sensitive to change and extraneous variables will be recognized and controlled in the study design.

SECTION 3

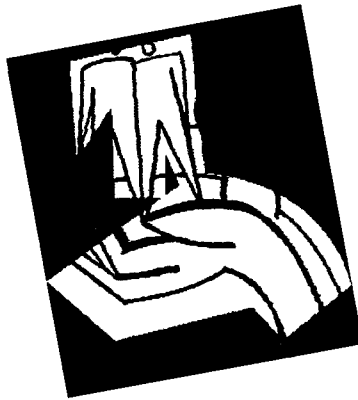
ADAPT KNOWLEDGE to the LOCAL CONTEXT

Adaptation of current knowledge concerning decision support for place of end-of-life care and factors influencing place of end-of-life care to a local context is presented in this section



Chapter 5

Research Proposal including Methods and Procedures



**Efficacy of a training intervention on the quality of practitioners' decision support for
patients deciding about place of care at the end-of-life: A randomized control trial:
Study protocol
(Manuscript 2)**

Note: Formatted for the journal: BMC Palliative Care

Abstract

Background: Most people prefer home palliation but die in an institution. Some experience decisional conflict when weighing options regarding place of care. Practitioners can identify patients' decisional needs and provide decision support, yet generally lack skills and confidence in doing so. This study aims to determine whether the quality of practitioners' decision support can be improved with a brief, theory-based, skills-building intervention.

Theory:

The Ottawa Decision Support Framework (ODSF) guides an evidence based, practical approach to assist practitioners in providing high-quality decision support. The ODSF proposes that decisional needs [personal uncertainty, knowledge, values clarity, support, personal characteristics] strongly influence the quality of decisions patients make. Practitioners can improve decision quality by providing decision support to address decisional needs [clarify decisional needs, provide facts and probabilities, clarify values, support/guide deliberation, monitor/facilitate progress].

Methods/Design: The efficacy of a brief education intervention will be assessed in a two-phase study. In phase one a focused needs assessment will be conducted with key informants. Phase two is a randomized control trial where practitioners will be randomly allocated to an intervention or control group. The intervention, informed by the needs assessment, knowledge transfer best practices and the ODSF, comprises an online tutorial; an interactive skills building workshop; a decision support protocol; performance feedback, and educational outreach. Participants will be assessed: a) at baseline (quality of decision support); b) after the tutorial (knowledge); and c) four weeks after the other interventions (quality of decision support, intention to incorporate decision support into practice and perceived usefulness of intervention components). Between group differences in the primary outcome (quality of decision support scores) will be analyzed using ANOVA.

Discussion: Few studies have investigated the efficacy of an evidence-based, theory guided intervention aimed at assisting practitioners to strengthen their patient decision support skills. Expanding our understanding of how practitioners can best support palliative patients' decision making will help to inform best practices in patient-centered palliative care. There is potential transferability of lessons learned to other care situations such as chronic condition management, advance directives and anticipatory care planning. Should the efficacy evaluation reveal clear improvements in the quality of decision support provided by practitioners who received the intervention, a larger scale implementation and effectiveness trial will be considered.

Trial registration: This study is registered as NCT00614003

Background

There are more choices for place of end-of-life cancer care due to shifts in care to the community, better understanding of the clinical course of cancers, equipment portability, pharmacology advances, and consumer expectations. Place of care has various meanings to patients and families and represents more than a particular geographic location [1]. Options can include hospice, private residence, nursing home, continuing complex care facility, homeless shelter, and/or hospital. For patients with good symptom control, instrumental support, and a predictable course of illness, decisions regarding place of care are often based on values and expectations [2-5].

Patients frequently experience decisional conflict (personal uncertainty about the best course of action) when considering place for end-of-life care. Personal preferences are weighed against practical considerations and concern for others [2,3,5,6], thus contributing to decisional conflict. Other modifiable factors such as knowledge gaps, unrealistic expectations about outcomes, lack of clarity about what matters most, and feeling pressured to choose a particular option exacerbates the decisional conflict [7]. Unresolved decisional conflict can lead to decisional delay or reversal, dissatisfaction, regret, and blaming the provider [8,9]. Failure to elicit the valued priorities of terminally ill patients and their families can result in missed opportunities, decreased quality of life, unwelcome interventions, and increased risk for complicated bereavement for survivors [3,10-12].

It is generally known that decisional conflict can be reduced with decision support interventions such as decision aids and nurse coaching [7,13]. However, there have been few studies evaluating either of these interventions for decisions at the end-of-life. Although patient decision aids may be useful for some common discrete crossroads decisions with standardized options and outcomes, there may be more payoffs in focusing on coaching interventions that can be applied broadly to care management at the end-of-life. While end-of-

life decisions are highly values-sensitive, they also bear a strong resemblance to chronic condition management decisions, which focus on situation monitoring, priority setting, and implementation [14-16], rather than discrete time-bounded decision making episodes.

There is evidence that influencing practitioners' knowledge and attitudes about communication and decision support can strengthen subsequent decision support practices, thus matching care planning to patient preferences and avoiding the use of non-valued interventions [17-20]. Nevertheless few studies have empirically examined the impact of a theoretically informed, decision support training intervention on the quality of decision support knowledge and practices provided by practitioners [21] and none have been undertaken within the context of palliative care practice.

Patients and families want practitioners to listen to their views and preferences [18] and standard palliative practice calls for patient inclusion in care planning [22,23]. Most patients with advanced cancer want full information and the majority wish to participate actively in decision making [24]. Although seriously ill hospital patients want to discuss end-of-life issues, their preferred decision making role varies and is difficult to predict [25], highlighting the need for active and regular assessment of patients' decision making needs. However, practitioners may avoid raising uncomfortable topics [26-28] and often lack skills and confidence in helping patients in non-directive ways [29].

Systematic review findings confirm that training practitioners in patient centered approaches is an effective strategy for increasing patients understanding of the evidence and implications [30]. For instance, decision coaching by nurses has helped to foster an informed use of resources and avoid the over-use of interventions that patients don't value in urology care [17] and in gynaecological care [31]. Practitioners, such as nurses and other professional care coordinators, through their trusted and frequent interactions with patients are well positioned to elicit and explore decisional needs such as decisional conflict and related factors (e.g.: knowledge, values clarity, and support) [32]. Practitioners can then

coach patients with information, values clarification, support and links to resources. While a key challenge is the need to strengthen practitioners' decision support skills [29] training interventions have been shown to markedly improve the quality of practitioners' decision support skills for other clinical problems [33].

Accountability to quality patient outcomes and fiscal responsibility confirms the need to practically and pragmatically address patients' end-of-life decision making needs. Systematic and rigorous evaluation of an evidence-based intervention designed to improve the quality of practitioners' decision support could illuminate best practices for decision support and advance the fields of shared decision making, patient-practitioner communication, palliative care, and ultimately improve the lives of those who are living with a terminal illness and their families.

Multifaceted interventions show promise in influencing professional behavior change [34-37]. An exploratory study to identify target variables, choose and refine interventions, and establish their theoretical basis prior to large scale effectiveness trials represents a sound research approach [38-40]. The paucity of empirical inquiry, in this area to date, warrants an exploratory study to describe the constant and variable components of a potential intervention and a feasible protocol for intervention delivery.

Guiding Theoretical Models: As the study aims to influence decision support behavior an understanding of factors that can be partially modified, such as attitudes and perceptions of norms that drive actions, is required to inform intervention messages and enhance the potential for behavior change. The pragmatic and conceptual focus of the study also requires an empirically proven, clinically relevant decision support framework to guide intervention content. The Theory of Planned Behavior (TPB) [41,42] and the Ottawa Decision Support Framework (ODSF) [43] fit these criteria. The former predicts the likelihood of behavior change while the latter provides a three step path to optimize quality decision

support. The TPB [40, 44-46] and the ODSF [3,47,48] are relevant to nursing and have performed well in numerous health-related studies.

Briefly, the TPB proposes that the strength of the intention to change is the primary determinant of actual behavior change. This intention is determined by: (1) a person's attitude to the new behavior (strength of perceived advantages and disadvantages); (2) the extent of self-perceived social pressure to perform or not to perform the new behavior, and (3) degree of perceived control over being able to perform the behavior [49].

According to the ODSF, decision support interventions can be tailored to address modifiable determinants of decisional conflict (knowledge; outcome expectations; values clarity; support factors) resulting in better quality decisions that are informed and consistent with patients' values [50]. In this study, the ODSF will guide decision support skill acquisition interventions and measures of change.

Clinician-identified factors associated with practice change: utility, strong evidence basis, and flexibility to acknowledge the individuality of patients [51] fit well with the ODSF. Historically, the ODSF has been well received by practitioners [3,33,48], has shown robustness in randomized control studies [7,33] and is predicated on a patient-centered approach which recognizes the unique context, circumstance and patient characteristics situated within the decision support encounter. The TPB and ODSF have guided the study design in the following ways:

1. The predictive potential of theory facilitates selection of training intervention components which offers the best probability of success [36,52]
2. The TPB offers a useful lens to examine attitudes, beliefs and perceived control for engaging in decision support practices and will inform the selection of key messages attached to intervention strategies.

3. Mapping the intervention components onto TPB variables provides a useful template to ensure multiple targets of behavior change are addressed and is consistent with knowledge dissemination best practices [35,53]
4. The ODSF describes a well defined approach to quality decision support provision and provides a practical vehicle to structure components of a knowledge and skill building intervention.
5. Availability of a broad inventory of theoretically grounded and empirically validated, reliable, time tested tools operationalizing ODSF constructs provides a rigorous platform to inform study interventions and will strengthen the trustworthiness of study findings.

Methods/Design

Aims of the study

The primary aim of this study is to evaluate the efficacy of a theory driven, framework-based training intervention, as compared with a control condition (usual care approach) in enhancing the quality of practitioners' patient decision support skills regarding place of care at end-of-life. In addition, we plan to assess participants' intention to engage in patient decision support in their practice and to determine the acceptability of the intervention components.

Specific objectives include:

1. identification of factors affecting the likelihood of practitioners' integrating decision support principles into their practice
2. determination of the quality of decision support practitioners provide
3. design and evaluation of components of a decision support training intervention

We plan to test the following study hypothesis:

H₁: A significantly greater proportion of practitioners, who are randomized to a multi-faceted, theory driven, training intervention, will obtain higher scores on quality of decision support following the intervention

H₀: No change in group means in decision quality following the intervention

Study Design and Methods:

A two phase, sequential, mixed method design is planned.

Phase 1 involves a focused needs assessment of key informants (practitioners, educators, administrators) who plan and provide palliative/oncology care. A purposive sample of about 12 key informants representing different levels of experience, responsibility, clinical focus and setting will be interviewed using a semi-structured interview based on the TBP [54].

Phase 2 is a randomized control trial of a brief educational intervention. Consenting/eligible participants will be randomly allocated to an intervention or control group. The intervention, informed by the needs assessment, comprises: an online tutorial; an interactive skills building workshop, a decision support protocol; performance feedback, and educational outreach.

Participants will be assessed: a) at baseline (quality of decision support); b) after the tutorial (knowledge); and 3-6 weeks after the other interventions (quality of decision support; intention to adopt decision support into clinical practice).

Sample Size: The estimated sample size for the Phase 2 study is based on a test for differences in mean scores of decision support quality and knowledge in the intervention versus the control group. An effect size of .70 requires $n=32$ / group, when alpha error = 0.05 and beta error = 0.20 [55]. This effect size is conservative in that a previous study (17) reported larger effect sizes which required only 18-20 per group.

Participants: Full or part time nurses and care coordinators (i.e.: social worker, case managers, pharmacists) from three Ontario regions (Ottawa, Toronto, Kingston), employed by one of the ten study partner organizations will be invited to participate. Study partners include hospital based institutions [Ottawa Hospital , Queensway-Carleton Hospital, SCO Health Services], community based organizations [Community Care Access Center Care (Toronto Central; Southeast Ontario); CareFor Nursing Agency; St. Elizabeth Health Care (

Toronto, Kingston); Hospice at May Court; Bayshore Home Health Agency (Cornwall, Toronto, Ottawa)]. Information flyers and information sessions explaining the study will be held at study partner organizations. Interested potential participants will be asked to contact the study coordinator if they have further questions or would like to participate in the study. Participants are considered eligible for study inclusion when they meet the following criteria:

- are a member of a regulated health profession
- care for palliative cancer patients, and/or
- cancer patients with advanced disease, and
- work at least 4 shifts per month,
- in a clinical area where end-of-life care discussions are likely to be undertaken, and
- are proficient in written and spoken English.

Ethical considerations: The protocol has been approved by the Research Ethics Committees of the University of Ottawa, The Ottawa Hospital and SCO Health Services. Trial registration with the International Standard Randomized Controlled Registry has been obtained (Trial #NCT00614003).

Procedures:

Phase 1: Needs Assessment. Semi-structured interviews with a purposive sample of key informants ($n \cong 12$ engaged in direct care, education and/or administration roles) will be used to elicit TPB related factors affecting intentions to provide decision support (personal attitudes, norms, and perceived control). Questions about other barriers to providing decision support will be elicited. Results will inform intervention content and key messages.

Phase 2 Intervention: Consenting practitioners will be randomly allocated to one of two groups. A computer generated randomization list for concealed allocation will be used. To avoid disparate sample sizes permuted blocks will be used. Participants will be allocated by

an external statistician, who has no connection to the study team, immediately after collection of baseline data.

Baseline measures of both groups:

- a. The quality of decision support skills will be assessed using audio-taped interactions between participants and simulated patients. Simulation scenarios have been created and vetted by a panel of Palliative Advanced Practice Nurses. Simulated patient callers will receive a training and feedback session facilitated by an experienced trainer prior to placing the call to participants. Simulated patient callers will contact each participant and engage in a standardized scenario expressing difficulty related to a place of end-of-life care decision. Calls will be tape recorded and quality scored using the Decision Support Analysis Tool (DSAT) [56].

Intervention (experimental) group: Participants assigned to the intervention group will:

- b. Complete an on-line decision support tutorial which introduces the 'When you need extra care decision aid', case studies and quizzes related to place of care decision support.
- c. Participate in a half day skills building workshop. The workshop contains aggregated feedback on baseline simulated calls; opportunities to observe, compare and contrast a traditional patient education approach to a patient decision support approach; role play using the 'When you need extra care decision aid' and peer scoring of the quality of their decision support provision using the DSAT. A module outlining the determinants of place of care will also be delivered. At the end of the workshop, participants will complete a questionnaire eliciting perceived utility/usability of the a) workshop content, and b) decision support protocol.

- d. Participate via telephone in an education outreach session to identify areas needing clarification, share problem solving in using the decision support protocol, and to obtain further feedback
- e. Complete a questionnaire eliciting satisfaction with content and process of education program

Post measures of both groups:

- f. After the auto-tutorial, knowledge tests will be administered.
- g. 2-6 weeks following completion of the full intervention a TPB based survey eliciting behavioral intention to integrate decision support in practice and related attitudes, norms, and perceived control will be administered.
- h. 2-6 weeks following completion of the full intervention the quality of the participants' decision support skills will be assessed with a different simulated patient scenario using the same methodology as the baseline assessment.

Proposed Intervention Details of the educational intervention follow.

Decision Support Tutorial: Developed by Ottawa Health Decision Centre, Clinical Epidemiology Unit of the Ottawa Health Research Institute (OHRI) this on-line, self-learning resource has been used to train practitioners , graduate students and undergraduate nursing students; US and BC tele-health center nurses; UK urology nurses; and nurses in family practice units in Ontario. Three modules provide 1) an overview of decisional conflict with a three step path to guide decision support, 2) case studies profiling decision support tools (including a decision support protocol) and processes with embedded quizzes to assess comprehension and provide feedback; and 3) a final integrated knowledge test. The original tutorial will be adapted to decisions about the place of terminal care. The tutorial is hosted by the University of Ottawa and is password protected. Participants will be asked to complete the auto-tutorial one week prior to the workshop.

Decision Support Protocol: Participants will be introduced to a decision aid in the tutorial. The decision aid guides patients in advanced planning of location of care and is entitled 'When you need extra care decision aid'. The decision aid is based on the Ottawa Decision Support Framework and the Ottawa Decision Support Practitioners Guide (OPDG). The four page decision aid provides a structured approach to assess patients' decisional needs, provide tailored decision support to address needs and evaluate patients' progress in decision making. There are five elements: 1) general information about place of care options and palliative care; 2) self report of functional and symptom status over the past week based on the Palliative Performance Scale [57] and the Edmonton Symptom Assessment Scale [58] respectively; 3) a self-ranking of which reasons for each option are considered most important; 4) an assessment of what else patients need to prepare for decision making; and 5) a summary of next steps.

Content is based on: a) systematic reviews of literature [4,59,60]; b) previous research on women's decision making needs regarding place of care at the end-of-life [3]; previous research on family members' decision making needs at the end-of-life [61] and d) the primary investigator's clinical experience in palliative care. Participants will be provided with a hard copy of the protocol as well as access to the online version.

Skill building workshop: Within three weeks of the online tutorial, a half day workshop will be conducted. Content will be based on the pre-intervention TPB needs assessment and also a) practical applications of material learned in the tutorial; b) a video illustrating a clinical application of the decision aid; c) a video contrasting a traditional patient education approach and a decision support approach in a clinical scenario d) role play using the decision support protocol; e) self and peer appraisal during role play and f) discussion about barriers and facilitators to integrating decision support into clinical practice. Use of a

facilitator who provides face to face communication and uses a range of enabling techniques has been shown to have some impact on changing clinical practice [62].

Specific workshop objectives are that participants will:

- understand concepts of decisional needs, decision support, and decision quality,
- learn to use decision support tools,
- evaluate decision support skills, and
- analyze barriers and facilitators to implementing decision support in practice.

Performance feedback: Results of the decision quality scored transcripts of baseline simulated calls will be presented and discussed at the workshop. Participants will also be provided with evaluation tools based on the Decision Support Analysis Tool (DSAT) to self appraise their own and workshop peers' quality of decision support during the case studies and role play activities. As well, the facilitator will provide ongoing feedback from case studies and role plays during the workshop. The DSAT self-appraisal tool has been used to train nurses and medical residents in self-appraisal at the University of Ottawa, the Dartmouth Hitchcock Medical Center, and the US Health Dialogue call center.

Education outreach Two weeks following the workshop intervention group participants will be scheduled for a personal academic detailing session with the workshop facilitator. Based on social marketing approaches, educational outreach provides a focused opportunity to personalize learning and behavioral objectives, provide unbiased descriptions of research evidence and opinion leaders' positions, augment educational materials and reinforce positive behavior [63]. Academic detailing using brief, face-to-face interactions has shown promise for modifying physician and dentists practices [64,65] although one study reported initial resistance to the approach [66] and it had no effect as a single intervention [67].

The detailer will provide individualized information and resources, reinforce decision support behaviors, and help participants to identify opportunities for incorporating decision

support behaviors into their practice. The one-to-one session will be scheduled at a mutually agreed time, will be conducted by telephone and should last about 15-30 minutes.

OUTCOME MEASURES

Primary Outcome Phase 2: Quality of Decision Support Skills will be measured with DSAT modelled on the ODSF and Ivey's Problem Solving Model [68]. The DSAT, with total possible score of 12, assesses the quality of decision support and consists of subscales measuring decision support and communication in a practitioner/patient dyad. The tool demonstrated adequate inter-rater reliability for scoring on both decision support skills (75%, kappa=0.58) and communication skills (76%, Kappa=0.68) when it was tested in physician/patient dyads (n=34 dyads). Construct validity was demonstrated when the scores were correlated to measures of patient and physician satisfaction[56] The DSAT also discriminates between trained and untrained nurses [33].

Secondary Outcomes Phase 2: Measures include:

- a knowledge test regarding decision support concepts;
- self assessment of decision protocol utility and helpfulness;
- behavioural intention to integrate decision support into clinical practice; and
- acceptability and utility of intervention components in the experimental group.

Analysis Plan:

Primary Outcome Phase 2: Quality of nurses' decision support skills.

1. Inter-rater reliability of DSAT scores; two raters, who are blind to group allocation, will independently score pre and post intervention simulated call audio tapes.
2. Primary analysis will be undertaken using a repeated measures ANOVA (baseline; post measures). For missing cases an 'intention to treat', approach will be used under the conservative assumption that no change would occur between pre and post

testing. Additionally, the impact of missing cases on findings will be explored between groups to provide further direction for the analysis.

Secondary outcomes Phase 2:

1. Descriptive measures (frequency; means; range) will describe participant characteristics and acceptability and utility of training intervention components.
2. Descriptive measures (frequency; means; range) of the TPB based survey eliciting behavioral intention to integrate decision support in practice and related attitudes, norms, and perceived control will be undertaken. Between group differences in intention to integrate decision support practices will be analyzed using a t test.
3. Data from qualitative open-ended questions using traditional content analysis techniques [69,70] with the TPB as an organizing framework will be undertaken. Thematic coding, followed by member checking to ensure trustworthiness of final themes, will be undertaken.

Discussion

This will be the first study to evaluate the impact of an educational intervention to improve the quality of decision support that practitioners provide to dying patients around place of care. This reproducible, portable intervention addresses a key policy mandate regarding choice for end-of-life care set out by health practitioners such as the Ontario Ministry of Health in Canada. This is a pragmatic trial with relatively inclusive entry criteria and we anticipate recruiting participants from across a spectrum of care sectors. As well, because we are bringing the intervention to participants in their home regions, we are able to include participants who may be unable to access centrally held education due to time and distance pressures in their clinical setting. These features will improve the generalizability of the findings.

Expanding our understanding of how practitioners can best support palliative patients' decision making will help to improve the quality of end-of-life and care for patients and those

who share their lives. If findings from this study show promise, a larger effectiveness trial assessing factors such as cost effectiveness, sustainability, and patient and system outcomes will be undertaken.

Results will be disseminated via a brief summary prepared for policy makers, a communication flyer for participants, a technical report for the participating organizations, publication in refereed scientific journals, newsletters of palliative care and relevant clinician associations, presentations at scientific and clinical meetings, and clinical rounds. Findings will be available online through the websites of the Canadian Virtual Hospice, Canadian Institutes of Health Research (CIHR) Family Caregiving New Emerging Team, CIHR End-of-Life Care for Seniors New Emerging Team, and the CIHR/NCIC Strategic Training Program in Palliative Care Research.

Design Limitations: Using a similar design in a call center nurses project, contamination was prevented using the following strategies: a) using a private room for simulated calls; and b) requesting that nurses not share or discuss decision support resources or approaches with others. Many of the skills are quite novel (values clarification) and it is unlikely that skills will improve without the workshop and subsequent practice.

Recruitment response may yield an over representation of those more motivated to learn and adopt the intervention than the average adopter. However, this should not pose a threat to internal validity. Moreover, involving early adopters is considered a wise strategy in innovation diffusion [71].

Participants will not be not blinded to the simulated call and know their performance is being monitored. However the use of simulated callers is recognized as a relatively reliable method for assessing professional performance, facilitates a standardized experience across participants, provides a clearer picture of decision support skills in general, is a more accurate measure of current practice compared to self-report or chart audit, and has been used widely [72-77].

The relative impact of each component of the intervention cannot be established with this design [40]. Feasibility constraints preclude a study design using a sequenced addition and evaluation of intervention components or assessing long term sustainability; however, recent studies suggest that evidence based education strategies may trigger long term practice change [78,79].

Authors Contributions: Murray is the initiator of the study and drafted the manuscript. O'Connor contributed significantly to the design of the study. O'Connor, Stacey and Wilson are providing supervision and mentorship during the implementation of the study and analysis of study data and have contributed to manuscript preparation. All authors read and approved the final manuscript.

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SECTION 4

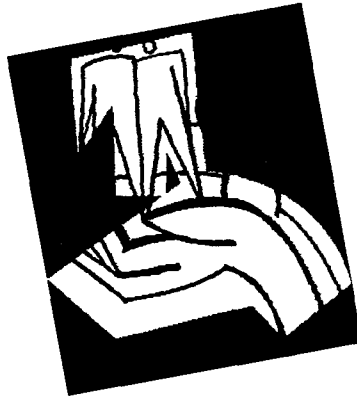
ASSESS BARRIERS TO KNOWLEDGE USE

Barriers and factors influencing the provision of decision support for place of end-of-life care are presented in this section



Chapter 6

Nurses' Views on Patient Decision Support for Place of End-of-life Care



**Nurses' Perceptions of Factors Influencing Patient Decision Support for Place of Care
at the End- of- Life
(*Manuscript 3*)**

Note: Formatted for the journal: American Journal of Hospice and Palliative Medicine

Abstract

While patients have more choices about where to receive care as death approaches, they often need help with decision-making. This study identified factors that influence nurses' provision of decision support. Twenty-two nurses, from three health networks, participated in semi-structured interviews. Overall nurses held favourable attitudes towards providing decision support for place of care at end-of-life. Overlap between other professionals' roles and nurses' clinical experience impacted nurses' decision support behaviors. While nurses considered decision support to be part of patient-centered care, they report a lack of skills, confidence and tools to help them provide it. These findings confirm the need to develop practical post-licensure education strategies and ways to embed patient decision support tools into systems of care.

Key words: patient decision support, terminal care, place of death, nurse

Introduction

Place of care has a direct and tangible impact on the quality of life experienced by patients who are approaching death (Mezey et al., 2002; Tang, 2000). However, there are conflicting descriptions of best place of care. For some, home is described as a place of safety, normalcy, belonging, and perceived control (Gott et al., 2004; Murray et al., 2003; Aoun et al., 2008; Tang, 2003g). For others, home is not considered a practical or desirable option and creates concerns about being a burden to family members (Gatrell et al., 2003a; Murray et al., 2003; Lee & Pang, 1998b; McPherson et al., 2007). Deciding the best course of action in the face of an uncertain future can be difficult. As well, often patients do not know about their options at end-of-life (Silveira et al., 2000). Decision support can help patients and families understand options, clarify which aspects of those options are the most important to achieve or avoid, and moderate feelings of being pressured or unsupported in decision making (O'Connor et al., 2008a).

While stated preference is an important determinant of place of end-of-life care, it is not sufficient to ensure that a patient's last days are lived in the desired location. Characteristics, content and timing of contact with local health care systems and practitioners also influence place of end-of-life care (Murray et al., 2009d). Nurses, through their therapeutic proximity and trusted relationship with patients, can recognize patient readiness to engage in decision making and can offer further communication about options (Murphy et al., 2001). Identifying factors that influence patient decision support for place of end-of-life care can provide insights to guide interventions aimed at improving the quality of decision support provided by nurses.

In a systematic review of 28 studies, health professionals identified several barriers to providing decision support including time constraints, patient characteristics or clinical situation, perceived patient preferences for involvement in decision making and disagreement

with asking patients about their preferred role in decision making (Gravel et al., 2006).

However, participants were predominantly physicians (89%) in the included studies; nurses represented a small proportion of the sample in 13 studies (Hamann et al., 2006; Hammond et al., 1999; Holmes-Rover et al., 2000; Kim YM et al., 2005; Ruland, 2006; Schulman-Green et al., 2005; Stacey et al., 2005; Thompson et al., 2006; Wirrmann & Askam, 2006; Ford et al., 2003b; Lester et al., 2006b; Lewis et al., 2003; Naik et al., 2005). Within these 13 studies nurses identified time constraints (Holmes-Rover et al., 2000; Lester et al., 2006b; Stacey et al., 2005; Wirrmann & Askam, 2006), workload concerns (Kim YM et al., 2005; Lester et al., 2006b; Wirrmann & Askam, 2006) and lack of structured processes and tools (Stacey et al., 2005) as barriers to providing decision support.

Facilitators included positive attitudes about patient decision support (Hamann et al., 2006; Hammond et al., 1999; Ruland, 2006) and availability of decision support tools (Naik et al., 2005; Stacey et al., 2005; Ruland, 2006). Only one study was conducted in an oncology setting (Ruland, 2006). This study evaluated the usefulness of a symptom management system that incorporated patient perspectives. Nurses rated the system as highly useful and used the assessment summaries for care planning significantly more frequently than physicians. Thus, preliminary evidence suggests that nurses are inclined to have positive views about incorporating patient perspectives, preferences and values into care planning.

Despite being generally positive about involving patients in decision making, evidence confirms that nurses are uncomfortable in end-of-life care discussions with patients (Garland & Schrim, 1998; Schulman-Green et al., 2005); discussions are relatively infrequent even when patients are in hospice (Hall et al., 2005); and nurses report they require further skill development in end-of-life decision support (Murray et al., 2004a). For instance, how to talk with dying patients was identified as the top learning need for 56 oncology nurses in a US tertiary care medical center (White et al., 2004). A Canadian study highlights nurses' reflections on the challenges in discussing difficult issues around end-of-life care and feeling

unprepared for these conversations (Fitch, 2007). Participants reported that gaps in their education and the support systems limited their ability to meet patients' decision making needs. Moreover, participants strongly recommended interactive programs with the opportunity for skill development and practice to address this gap.

The aim of this study was to elucidate nurses' perceptions of behavioral factors (attitudes and beliefs; perceived social pressures; perceived control) that affect patient decision support in the context of place of end-of-life care. Specific objectives were to elicit a) nurses' perceptions of good decision support; b) their role and the opinions of others about their role in the provision of decision support; c) barriers and facilitators to providing decision support; and d) ways to enhance the provision of decision support around place of end-of-life care.

Theoretical Framework Guiding the Study

The Theory of Planned Behavior (TPB) offers a useful lens to examine behavioural factors that impact upon patient decision support practices used by nurses (Ajzen, 1985; Ajzen, 1988). Briefly, the TPB proposes that intention is a precursor to behaviour. Intention is determined by three behavioural influences: (1) a person's attitude to the behaviour (strength of perceived advantages and disadvantages); (2) the extent of self- perceived social pressure to perform or not to perform the behaviour, and (3) the degree of perceived control for performing the behaviour (Ajzen, 1991).

The TPB can help identify factors that moderate nurses' practice behaviors. Salient, modifiable determinants of that behavior can then be targeted in subsequent interventions (Fishbein et al., 2001). As the goal of the study was to understand how nurses view patient decision support for place of end-of-life care, the TPB, with its focus on individual perceptions, was considered appropriate to guide data collection, analysis and interpretation.

Methods

Given the exploratory aim of the study, a descriptive qualitative approach was used, which is particularly suited to inquiries that seek to gain an accurate summary of a process, (Sandewlowski, 2000; Caelli et al., 2003). Ethical approval was obtained from local Research Ethics Committees and the University of Ottawa. Participation was voluntary, confidentiality maintained and informed consent obtained.

Recruitment

To gain a range of perspectives, oncology and palliative care nurses from a variety of roles were targeted (direct care nurses; case managers; advanced practice nurses; educators; administrators). Key informants were identified initially by the primary investigator, an advanced practice palliative care nurse through contacts in the Ontario palliative care practice community. Participants were selected from three regional health networks (Toronto Central; Champlain region; Southeast region). As interviews progressed, purposive snowball recruitment occurred as participants suggested other key informants (Patton, 1990; Tashakkori & Teddlie, 2003).

Data Collection

To obtain focused data while balancing the demands on the participants' time and impact on their clinical work commitments, semi-structured interviews were conducted. The interview schedule was formulated using standard TPB question stems developed by Ajzen(2006). The interview schedule was divided into sections, mirroring the three TPB behavioral factors (attitude; subjective norms; perceived control). Individual questions probed specific concepts linked to the each TBP behavioral factor. For instance, in probing attitudes, participants were asked to describe positive and negative outcomes or attributes associated with providing patient decision support for place of end-of-life care. To elicit perceptions about subjective norms, participants were asked a series of questions related to people or groups that would influence them in providing patient decision support. The dimension of perceived control included questions about facilitators and barriers to providing decision support.

Finally, participants were also asked if there were other considerations that might affect their thoughts and beliefs about providing patient decision support that had not been covered within the preset interview questions.

After 20 interviews were completed, two more interviews were conducted to confirm the completeness of information provided by participants. As no new information was uncovered in the confirmatory interviews, recruitment was stopped. Thus, 22 interviews were included in the analysis.

Data Analysis

Qualitative analysis emphasizes words rather than numbers. By preserving the individuality of the situation participants' insights of how events, actions and meanings are shaped by the context and circumstances can be more readily identified (Maxwell, 2005). Thus, analysis focused on interpreting participants' words within the context of the TBP based interview.

Audio-taped interviews were transcribed and entered into the NVIVO 8[®] software program. The TPB behavioral factors provided the organizing framework, in keeping with principles of descriptive qualitative approaches where preset operational definitions guide coding decisions (Sandewlowski, 2000). Individual responses to each of the TPB behavioral question probes formed the unit of analysis. Thus, question responses from each question probe were grouped together and then subjected to qualitative content analysis (Graneheim & Lundman, 2004).

Using a deductive approach, responses were reviewed for recurrence and repetition of ideas (Owen, 1984). Condensed meaning units were identified from the grouped responses (Graneheim & Lundman, 2004). Then, the condensed meaning units were grouped as response categories within the TPB behavioral factor. Two investigators (JK, MAM) compared and co-verified each response category and the underlying coding strips. Disagreement was resolved by consensus. Response categories mentioned by fewer than

three participants were not retained in the final data summary as lack of recurrence limited validation (Sandewlowski, 2000). Demographic data provided by participants were summarized using descriptive statistics.

Results

Characteristics of Participants

Twenty-two nurses were approached and agreed to participate (Table 1). All participants worked in outpatient settings. Interviews lasted less than one hour. All participants were Registered Nurses and were currently practicing in oncology and/or palliative care settings. Most were employed full time and had worked with this patient group for more than ten years; one participant was male. About a third of participants held a graduate degree. Participants held educator and manager roles as well as direct practice roles. Most interviews were conducted in person; seven were conducted via telephone.

TBP Factors

Participants described several influences affecting the provision of patient decision support for place of end-of-life care. Table 2 summarizes the categories according to each TBP factor. Exemplar quotes from participants illustrate each aggregated category.

Attitudes: Overall, participants indicated positive beliefs about providing patient decision support for place of care at the end-of-life. Participants valued patient decision support as a way to provide patient-centered care and to affirm patients' preferences. In their descriptions, patient decision support was not something that was done to the patient but rather done with the patient. While eight participants stated there were no disadvantages to nurses providing decision support, others were concerned that a lack of skills could limit their effectiveness and that they could bias or sway decisions. Outcomes of providing patient decision support included positive patient outcomes, professional fulfillment and an indication that the health system had met the patients' needs.

In describing nurses' role in patient decision support, participants discussed giving information and helping implement the decision more frequently than assessing patient values. Having local knowledge of resources, openness to revisiting the decision as the situation changed and using facilitative approaches were considered attributes of good patient decision support. The dynamic nature of place-of-care decisions was seen in comments describing decision support as a process rather than a one-time event. A tension between honouring patient preferences and working with available resources was acknowledged when participants discussed government policy directions for increasing options for place of end-of-life care.

Subjective Norms: Five sources of influence for nurses providing decision support for place of end-of-life care were identified in the interviews: allied health team members, patients, physicians, professional bodies and employers. While six participants indicated that no group or individual would disapprove of nurses providing patient decision support, others identified possible conflicts with other health professionals, particularly physicians and social workers. On the other hand, physicians were also seen as being supportive of nurses' providing patient decision support. Sources of conflict included overlapping roles and 'turf protection' issues. Organizations that have a vested interest in a particular care option, such as private nursing homes, were identified as potentially disapproving of nurses providing patient decision support. While participants saw patient decision support as an important nursing role, they noted variability in skills and knowledge for carrying out decision support within the nursing population.

Perceived Control: Participants identified thirteen circumstances and conditions that facilitate or impede nurses' provision of decision support for place of end-of-life care. Facilitating circumstances that made it easier to provide decision support included skills training, having decision support processes and tools embedded in systems of care and early identification of the client's prognosis and needs. Barriers that made it difficult to provide

decision support included a lack of skills, time and resource issues and referrals of clients late in the course of their illness. While participants indicated that variability existed in individual abilities in the provision of patient decision support, targeted education and practical support by employers were identified as strategies to narrow the skills/confidence gap. Participants also noted that practical, resource and cultural concerns could impact the implementability of decisions.

Discussion

This study aimed to improve our understanding of nurses' attitudes, the influence of others and barriers and facilitators that may impact the integration of patient decision support into standard nursing practice. Studies such as this are important for identifying intervention targets to help nurses build skills and confidence in providing quality patient decision support. The end goal is to provide ways to increase the rates of home death for patients who prefer to die at home and help those who do not wish for home death to plan for the best location of care to meet their needs.

Findings from this study illustrate the dynamic nature of end-of-life decision making. At end-of-life, determinations of what is most important shift with changes in function and perceived quality-of-life. Options identified at one point in time may not be relevant as circumstances change. Participants confirmed that quality decision support depends on an iterative process of assessment, discussion and feedback. Participants acknowledged that nurses are open to decision changes and begin setting the stage by trying to identify patients earlier in their illness trajectory, actively identifying back up plans and trying to adapt place of care discussions to meet cultural expectations. Overall, decision support for place of care at the end-of-life was seen as a fluid iterative interpersonal process.

Consistent with other studies, our findings confirm that nurses want further practical education to strengthen their skills in providing patient decision support (Fitch, 2007; Murray et al., 2004a; White et al., 2004). Lack of education and tools was seen as a barrier while

gaining access to education, tools and resources was seen as a means to address nurses' skills gap. Ambivalence about nurses' role in decision support was seen when participants discussed decision support as a way to promote patient-centered care while other comments indicated variability in nurse's recognition of their role and skill set in providing decision support. Our data suggest that effective decision support may be tied to how well nurses interpret patient cues and assess patients' decision making needs and readiness for decision-making, as well as influencing how and when information is presented to patients and family members.

Similar to findings from previous studies, participants expressed positive attitudes towards supporting patients in decision making (Fitch, 2007; White et al., 2004). However participants were more apt to describe information provision when discussing attributes of good decision support (Goss et al., 2007; Guimond et al., 2003; Shields et al., 2005; Stacey et al., 2005). Targeted education in decision support has been shown to improve nurses' skills in addressing other patient decision making needs, such as values clarification and feeling pressured or unsupported in decision making (Stacey et al., 2006b). Effective interventions to change practitioners' practice include educational outreach, dissemination of educational materials and audit and feedback (Grimshaw et al., 2004). Participants confirmed that strategies incorporating opportunities to practice and evaluate their evolving skills would help to enhance their decision support skills and confidence.

Although participants saw patient decision support for place of end-of-life care as part of their role, overlap with other professionals' roles was identified as a source of difficulty. Overlapping scopes of practice have been identified as both a limiting and facilitating factor to promoting greater interdisciplinary collaboration (Health Professions Regulatory Advisory Council (HPRAC), 2008). Therefore, following skills-building interventions aimed at the individual, attention to organizational and team roles is needed to embed and reinforce patient decision support into processes of care. Negative normative pressures might impede

nurses' provision of patient decision support regardless of positive attitude and/or perceived control. On the other hand, actual patient decision support behavior may turn out to be more sensitive to clinical activity intensity and organizational infrastructures, rather than internal motivational factors.

In discussing issues related to control, participants described the tension between policy statements and the need to back up these policy directions with concrete resources. Participants were concerned about setting up false expectations among patients and families if following decision support, choices could not be supported with current resources. A key element of patient decision support is to help align patient expectations with existing resources. However, these comments elucidate the need for decision makers to back up policy statements with requisite resources.

Limitations

Data were collected through self report rather than actual validation of behaviors. Although self-reports provide information regarding practitioners ' knowledge and perceptions about practice issues, they are subject to bias (Adams et al., 1999). However our recruitment procedures presumed that participants were involved in clinical situations related to place of care decision making and the interview guide included questions that asked participants how they understood and described patient decision support. As an exploratory study, our inventory of factors influencing nurses' perception of patient decision support for place of end-of-life care is preliminary and open to modification.

Conclusion

Generally nurses had positive attitudes towards patient decision support for place of end-of-life care and saw it as part of patient-centered care. Negative perceptions towards providing patient decision support were linked to a lack of skills and resource issues. The need for programs aimed at strengthening nurse's skills and confidence in providing decision support is highlighted.

One of the most important functions of nursing is to support people living through difficult times. Nurses in this sample believed that patient decision support for place of end-of-life care is important. Further research to demonstrate the effect of nurses' patient decision support practices on patient comfort, well being and quality of life and health services utilization is needed to confirm the validity of this belief. Our study suggests that nurses are amenable to incorporating decision support for place of end-of-life care into their practice and are interested in strengthening their decision support skills. A randomized control trial to evaluate the impact of an educational program aimed at helping nurses strengthen the quality of their decision support skills is currently underway (Murray et al., 2008d).

Table 1: Characteristics of Participants

Variable	n=22
Nurse role	
Educator	7
Direct practice	6
Case manager	5
Manager	4
Length of time in current role	
Less than 3 months	2
1-2 years	5
3-5 years	6
6-12 years	4
13+ years	5
Employment status	
Full time	17
Part time	5
Gender	
Female	21
Male	1
Age of participant	
30-39 years	3
40-49 years	9
50-59 years	9
60 +years	1
Highest level of education	
Diploma	8
Undergraduate degree	6
Graduate degree	8
Length of time working with oncology and/or palliative care patients	
Less than 2 years	1
2-10 years	5
11-20 years	8
21-30 years	6
31+ years	2

Table 2: Summary of Responses

TBP dimension	Related probes	Response category (n=participants)	Exemplar quotes
Attitudes	Advantages of nurses providing patient decision support for place of end-of-life care	responsive to patient (n=12) improved processes of care (n=10)	'...care that more tailored to the needs and the desires of the client...' '...better use of resources, a better use of people's time...' '...if it is not done well I think it could be a disadvantage and you just don't want to create that where you the family thinks you are not working with them....'
	Disadvantages of nurses providing patient decision support for place of end-of-life care	insufficient skills- getting it wrong (n=11) biasing the decision (n=4)	'...if you've had a number of bad situations that you get jaded ... you remember all of the bad things and then you start maybe framing options...' '...it's something that they do all the time; they may not call it that...'
	Importance of nurses providing patient decision support for place of end-of-life care	gives voice to something nurses do (n=3) end-of-life planning (n=3)	'...you can start some of the preparation before you actually get there and it becomes a much better experience because there's more time for planning adjustment coping...'
	Patient outcomes when nurses provide patient decision support for place of end-of-life care	patient is well supported (n=8) positive health outcomes family and patient (n=5)	'...client passes in a place of their choosing with symptoms that were well controlled in a way that they felt that their spiritual & psychological physical & emotional needs were met & that they died with dignity & integrity of who they felt they were as a person even in their death...' '...families that are well supported leading up and to the final days of a loved one probably will be in a healthier place post the client's passing...'
	Provider outcomes when nurses provide patient decision support for place of end-of-life care	rewarding (n=10)	'...sense of providing the best possible care...'
	System/organization outcomes when nurses provide patient decision support for place of end-of-life care	system works (n=12) cost effective (n=7)	'...people are getting what they want when they need it...' '...cost savings eventually by getting people to more appropriate care...'
	Role of nurses in providing patient decision support for place of end-of-life care	fits with nurses' identity (n=17) specific actions: giving information (n=10)	'...key person [the nurse] in that circle of care that sort of keeps everybody together to have those discussions...' '...timely communication about the choices ... with all of the information that is needed...'
			'...preparing people to understand what it is going to be like...'

		helping implement decisions (n=7) uncovering values (n=6) facilitating communication (n=5)	'...really understanding what the individuals' desires are or what their goals are what they want for their end-of-life care and helping to match places...' '...accurate information about what is possible for that particular client situation and family situation...' '...revisit that decision down the road in that option where it was no longer for some reason appropriate or where for some reason...' '...part of that whole concept of client focused care...if you're not really starting from where the client is it is hard to say that you are being client focused...' '...good decision support doesn't give a person the answer and respects all of the possibilities...' '...recognizing what the value system is of individual clients how it might differ from client to client how it might differ from decision support is not is just provision of information it is helping people to think about what is important to them...'
	Characteristics of good decision support	core knowledge of resources available (n=12) dynamic nature of decision making (n=11) being patient centered (n=9) facilitating decision process (n=7) uncover what's most important (n=7) need resources to match preferences with options (n=11) supporting patients in decision making (n=8) recognizes patient preferences (n=7) allied health (n=17) physicians (n=8) patients (n=13) professional bodies (n=7)	'...clients need to have the right to make a decision about where they wish to die ... and in order to facilitate that we need to make resources available...' '...try and honor what people's wishes are and to try and make sure that people are as fully informed as they can be ...' '...recognizing that people do have different values around that and giving them choices related to those...' '...people call us and consult with us ...implicitly you know they are supportive of that role...' '...most people would approve if it is done well...' '...CNO [regulatory body] would approve... we're trying to work towards that patient centered approach...'
Subjective Norms	What is your interpretation of Government policy for providing more choices for end-of-life care	Others who would approve of nurses providing decision support for place of end-of-life care	
	Others who would disapprove of	conflicting role with allied health	'...role ambiguity with some of the other Health Care

	nurses providing decision support for place of end-of-life care	(n=12) physicians (n=6) social work (n=4) business organizations (n=4)	professionals...' '... various groups out there in the community who perhaps may want a little more ownership of patient decision making and therefore may see a patient in the direction that suits their mandate...' '... they [nurses] play a big part in that [decision support]; it is very important to them '... it's a lot to do with their knowledge, their comfort and their experience...' '... they [organization] put a great deal of importance on it you know for an organization like ours that is really striving to be truly customer focused...'
	Nurses perceived importance of providing decision support for place of end-of-life care	important role in nursing (n=6) varies with experience (n=3)	
	Importance of nurses providing decision support perceived by other team members/employers	organization validation(n=7)	
Perceived Control	What makes it <u>difficult</u> for nurses to provide decision support for place of end-of-life care	not valued (n=4)	'... leadership and admin probably don't understand the slighter nuances of what that role is or what it should be and what is needed for that ...'
		skills gap (n=7)	'... not trained so lack of training would make that difficult because they're not understanding the full concept of decision support ...'
		time (n=5)	'... you get into all your busyness and all your tasks and all your things and to take the time to listen and that it is easier just to push it to the social worker...'
		competing priorities (n=4)	'... competing priorities for their time and resources that they have for each client...'
		resource issues (n=5)	'... resource issues that prohibit us from being able to achieve [decision support]...'
		not seen as part of role (n=5) late referrals (n=3)	'... there's a bit of a role confusion of whose role is this...' '... getting these clients so late in their illness trajectory that we probably aren't doing as good of a job as a result...'
	What makes it <u>easier</u> for nurses to provide decision support for place of end-of-life care	silos of care (n=3) training (n=8)	'... we work on things but then it is not always communicated back to the hospital and vice versa...' '... introducing [decision support] right from the orientation of a new employee and making it an ongoing and integrated part of their education and ongoing experience with the company I would even like to see it included in performance appraisals...'

		decision support embedded in processes of care (n=8) early identification of clients (n=8) tools (n=5) experience (n=4) team communication (n=4)	'...awareness of decision support as a role, having a structure to fit it in and being aware of what the options are...' '...identification of the client is critical much earlier on in the illness trajectory...' '...the tools would make it easier ...' '...experience and education and the skill set that can be developed over time...' '...you need people talking to each other across the different sectors...' '...need to build things in place or put things in place that will support and reinforce the behavior learning skill...' '...training sessions where they actually practice doing it...' '...the whole team recognizes that this is a valuable thing...' '...experienced nurse who has a handle on those things already may feel more comfortable around some of this more abstract therapeutic piece...' '... don't know where to start they don't know how to sort of get in there and or pick up on the cues...' '... a lot of nurses are not comfortable talking about dying...' '...their decision making is limited by the support that they can have at home...' '...if you sit down with people and you do really good job of really helping them sort this out with whatever tool you've got and they come up with this will be my choice then you say well too bad I guess it is not an option in Ontario we don't have service like that we don't have a place like that we don't have the system that would support you in that option in that choice...' '...cultures whose decision making capacity falls to family ...isn't really within the culture of self determination...'
	What would help to enhance decision support provided by nurses for place of end-of-life care	tangible support and recognition (n=13) education (n=10) valuing the provision of decision support (n=7) variable skills (n=13)	
	How prepared are nurses to provide decision support of place of end-of-life care	skill gap (n=10) confidence gap (n=6)	
	Other issues	Implementability practical concerns (n=13) service concerns (n=10)	
		cultural issues/ adaptations (n=8)	

SECTION 5

SELECT, TAILOR & IMPLEMENT INTERVENTION

Development of intervention tools designed to address identified barriers and the implementation and evaluation of the educational program are presented in this section



Chapter 7

Intervention Tools



Chapter 7 describes the development and evaluation of tools used in the intervention to address barriers identified by nurses related to providing decision support for place of end-of-life care.

Intervention Tools

Within the needs assessment nurses identified a lack of practical tools and education as a barrier to providing decision support for place of end-of-life care (Murray et al. 2009b). The following tools were developed or adapted to respond to their identified needs and overcome some of the known barriers (Table 7.1). These tools include: a decision support online auto-tutorial; a place of care PtDA; and a video with two scenarios contrasting exemplary decision support with traditional patient education. A description of adaptation, development, and evaluation of these tools follows.

Table 7.1: Intervention Elements and Barriers Addressed

Intervention Element	Barrier Addressed	Knowledge Transfer Strategy (Grimshaw et.al., 2002)	Procedure
Online tutorial	Knowledge	Educational material	Self- directed
Skill building workshop	Knowledge	Education meeting	Trainer facilitated
	Skills	Audit & feedback	Self practice
	Tools		Peer feedback
	Confidence		
Educational outreach	Confidence	Reminders	Trainer facilitated

Online Decision Support Auto-Tutorial

The purpose of the decision support auto-tutorial is to help learners understand concepts of decisional needs, decision support, and decision quality. The auto-tutorial is based on the ODSF and is publically available (www.ohri.ca/decisionaid). Ten modules provide information and examples of key concepts relevant to providing decision support for health or social decisions.

Following completion of the auto-tutorial learners should be able to recognize decisional conflict, describe decision support concepts, tailor decision support to address

patient decision-making needs, be aware of PtDAs, and be able to use a decision coaching protocol. Eleven mini-quizzes provide learners with feedback on their learning as they progress through the tutorial. A final 12 item knowledge test, based on the objectives of the auto-tutorial, allows learners to evaluate their overall learning.

The auto-tutorial has been used to train practitioners, graduate and undergraduate nursing students in Canada, the US and Australia and has been used as an intervention in several studies (Stacey et al., 2006; Stacey et al., 2008c). Following exposure to the auto-tutorial, undergraduate nursing students (n=280) had a medium score of 88.3% on the final knowledge test (Stacey et al. 2007). Among practitioners knowledge test scores discriminated between those exposed to the auto-tutorial and controls (n=41; 23.8 % difference in scores) in a RCT and between baseline and post tutorial (n= 32; 23.0 %) scores in a pre-post study (Stacey et al., 2006b; Stacey et al. 2008c).

For this study, the original auto-tutorial was adapted to include examples and case studies relevant to palliative care and decisions about the place of end-of-life care. To ensure realistic and accurate scenarios the case studies and quizzes were reviewed by clinical experts that included advanced practice nurses and a nurse educator. At the end of the tutorial, learners were introduced to a PtDA focused on place of end-of-life care. The adapted auto-tutorial was hosted on a password secured University of Ottawa website.

Comparison of Patient Education and Patient Decision Support Approaches Video

The Patient Education and Patient Decision Support Approaches Video was designed to help practitioners a) observe decision support skills; b) practice rating decision support quality; and c) discriminate between patient decision support and patient education (Table 7.2). To do this the video includes three modules: 1) a primer on the use of the place of care PtDA, 2) a scenario illustrating a decision support intervention using the place of care PtDA, and 3) a scenario illustrating a place of care counselling intervention using a traditional patient education approach. Previous research has shown that nurses can improve their

interviewing skills following self-rating and reflection on communication skills using a video of a nurse-patient interaction (Morita et al., 1999).

Table 7.2: Comparison of Elements in Patient Education and Decision-Support
(+ = included; - = not typically included)

Approach	Elements						
	Options & Outcomes	Information About Clinical Problem	Outcome Probabilities	Experience of Others	Explicit Values Clarification	Role of Others in Decision Making	Guidance in Steps of Decision Making
Patient Education	-/+	+	-	+/-	-	-	-
Decision Support	+	+	+/-	+/-	+	+/-	+/-

Adapted from: (Coulter & Ellins, 2007; International Patient Decision Aid Standards (IPDAS) Collaboration, 2005; Winterbottom et al., 2007)

The 20 minute video for this study was based on the ODSF, principles from shared decision making and simulation teaching strategies (Charles, Whelan & Gafni, 1997; Kohn et al., 2000; O'Connor et al., 2002). A script of an interaction between a nurse and cancer patient involved in a place of end-of-life discussion was developed. The video was then produced with a palliative care nurse experienced in decision support and patient education, and a simulated patient. To reinforce experiential learning with self reflection, learners can be encouraged to rate the quality of decision support provided in the two clinical scenarios and then discuss the observed differences and the utility of using these approaches in their clinical practice. The video was designed for use in educational sessions such as workshops, lectures and directed readings or as a stand alone teaching intervention.

Pretesting. Thirty undergraduate nursing students volunteered to evaluate the video for usefulness to learning and clarity of information, and to have their evaluations shared. Overall, the video was rated as a useful teaching aid. Evaluators indicated that the concepts were clear, the scenarios were realistic, and it was easy to identify the decision-making needs of the simulated patient and the decision support strategies used by the nurse. The most useful aspect of the video was the opportunity to observe decision support in action.

Place of Care Patient Decision Aid (PtDA)

PtDAs are guides that translate evidence into plain-language, give equal voice to the advantages and disadvantages of options, help clarify values for outcomes, and provide guidance in the steps of decision making (O'Connor et al., 2007). Compared to usual care patients exposed to PtDAs have improved knowledge, more realistic expectations, better congruence between values and their decisions, and participate more in decision making (Coulter & Ellins, 2007).

The '*When you need extra care, should you receive it at home or in a facility?*' PtDA (place of care PtDA) was developed to help guide patients in advance planning for place of end-of-life care (Table 7.3). The motivation to develop the place of care PtDA was based on clinical experience as a palliative care nurse hearing the needs of patients; experience in developing and implementing continuing palliative education programs for health professionals; and previous research on terminally ill women's and family members' decision making needs regarding place of care at the end-of-life (Murray et al., 2003; Young, 2006). Content for the PtDA was further informed by systematic reviews of literature on determinants of place of end of life care (Gomes & Higginson, 2006; Higginson & Sen-Gupta, 2000; Murray et al., 2009a).

The place of care PtDA is based on the ODSF (O'Connor et al., 2002), the Decisional Conflict Scale (O'Connor, 1998) and a decision aid template developed by the Ottawa Health Research Institute (www.ohri.ca/decsionaid) which has been used to structure several evidence based PtDAs and meets the International Patient Decision Aid Standards (IPDAS) criteria (Elwyn et al. 2006; O'Connor et al., 1999). The four page document includes five elements: 1) information about palliative care, place of care options and related advantages and disadvantages; 2) self report of functional and symptom status over the past week; 3) values clarification exercise to determine which reasons for choosing each option are most

important; 4) self-assessment of what else is needed to prepare for decision making; and 5) a summary of next steps.

The validated Edmonton Symptom Assessment Scale (ESAS) and Palliative Performance Scale (PPS) were included in the place of care PtDA to provide a snapshot of patients' current functional and symptom status (Anderson et al., 1996; Bruera et al, 1991). The ESAS was designed to enable symptom assessments (Bruera et al.). Patients self-report symptom intensity on nine common symptoms of advanced cancer using a 0-10 scale with higher scores representing higher symptom intensity (Bruera). The ESAS has performed well when compared to other validated pain assessment scales (Memorial Symptom Assessment Scale (MSAS); Functional Assessment Cancer Therapy (FACT) survey) and has been adopted nationally across Canada in many palliative care programs (Chang, Hwang & Feuerman,, 2000; Chow, et al. 2005; Dudgeon, Harlows & Clinch, 1999). The PPS, based on the Karnofsky Performance Scale (1948), guides assessment of functional performance and progressive decline in palliative patients (Anderson et al.). Assessment domains include intake, mobility and level of consciousness. A meta-analysis of published PPS survival prediction studies showed a consistent and strong association between PPS and survival across studies in cancer and non-cancer populations and across patient care settings (Downing et al., 2007).

Table 7.3: Summary of the Place of Care PtDA

Title	When you need extra care, should you receive it at home or in a facility?
Health Condition	End-of-life Issues
Type of Decision Aid	Planning
Options Included	Receive care at home. Receive care in a facility.
Audience	People living with advanced life-limiting illness who would like to plan for a time when they will need extra care and share their views with others
Developer	Mary Ann Murray; Annette M. O'Connor
Where was it developed?	University of Ottawa Canada
Year of last update or review	2008
Format	Paper or electronic version
Language(s)	English
How to obtain the decision aid	www.ohri.ca/decsionaid A-Z inventory Versions can be adapted for different communities by changing resource contact information.

Testing. Following development a panel of four Advanced Practice Nurses with expertise in oncology, end-of-life care and patient education reviewed place of care PtDA, found it to be clinically relevant, clear and did not suggest any changes. Next, two reviewers, not associated with the study and familiar with IPDAS standards, independently evaluated the place of care PtDA using the IPDAS standards based checklist (Table 7.4). Overall, the place of care PtDA met most of the IPDAS criteria; 8/9 the content criteria, 8/9 development criteria and 0/2 evaluation criteria. The content criterion missed was primarily because this data is not available. Criteria regarding field testing with patients facing the decision and effectiveness were not met as it was not feasible to pre-test the PtDA with patients currently living with a life limiting illness. Reading level of the place of care PtDA using the Flesch-Kincaid tool (<http://www.rfp-templates.com/readability-scores/Flesch-Kincaid-Readability-Score.html>) was scored at 73.2/100 with a reading grade level of 5.6.

Table 7.4: IPDAS Checklist

Content	
1. The decision aid describes the condition (health or other) related to the decision.	Yes
2. The decision aid describes the decision that needs to be considered (the index decision).	Yes
3. The decision aid lists the options (health care or other).	Yes
4. The decision aid describes what happens in the natural course of the condition (health or other) if no action is taken.	NA
5. The decision aid has information about the procedures involved (e.g. what is done before, during, and after the health care option).	NA
6. The decision aid has information about the positive features of the options (e.g. benefits, advantages).	Yes
7. The decision aid has information about negative features of the options (e.g. harms, side effects, disadvantages).	Yes
8. The information about outcomes of options (positive and negative) includes the chances they may happen.	No
9. The decision aid compares probabilities (e.g. chance of a disease, benefit, harm, or side effect) of options using the same denominator.	NA
10. The decision aid compares probabilities of options over the same period of time.	NA
11. The decision aid uses the same scales in diagrams comparing options.	NA
12. The decision aid asks people to think about which positive and negative features of the options matter most to them.	Yes
13. The decision aid makes it possible to compare the positive and negative features of the available options.	Yes
14. The decision aid shows the negative and positive features of the options with equal detail.	Yes
Development Process	
15. Users (people who previously faced the decision) were asked what they need to prepare them to discuss a specific decision.	Yes
16. The decision aid was reviewed by people who previously faced the decision who were not involved in its development and field testing.	Yes
17. People who were facing the decision field tested the decision aid.	No
18. Field testing showed that the decision aid was acceptable to users (the general public & practitioners).	Yes
19. Field testing showed that people who were undecided felt that the information was presented in a balanced way.	Yes
20. The decision aid provides references to scientific evidence used.	Yes
21. The decision aid reports the date when it was last updated.	Yes
22. The decision aid reports whether authors of the decision aid or their affiliations stand to gain or lose by choices people make after using the decision aid.	Yes
23. The decision aid (or available technical document) reports readability levels.	Yes
Effectiveness	
24. There is evidence that the decision aid (or one based on the same template) helps people know about the available options and their features.	No
25. There is evidence that the decision aid (or one based on the same template) improves the match between the features that matter most to the informed person and the option that is chosen.	No

Then, the place of care PtDA was evaluated by community living Canadian adults (n=8) who volunteered to review the PtDA for relevance, clarity and usability. Overall, these adults found the PtDA helpful and relevant. Most agreed or strongly agreed that the PtDA clarified the decision, listed the options in a realistic way, helped to identify decision making needs and would recommend the decision aid to others facing a place of end-of-life care decision. Two of the eight evaluators felt the PtDA was difficult to use without the assistance

of a practitioner to help walk through the decision making process. No changes were made to the PtDA.

Finally, during the RCT designed to address barriers to practitioners provision of quality decision support, 38 participants, in direct oncology and/or palliative care evaluated the decision aid. Overall, they found the PtDA was clear, easy to use, helpful and useful for clinical practice. They would recommend it to other practitioners (Table 7.5).

Table 7.5: Acceptability of Decision Aid by Nurses Practicing in Oncology and or Palliative Settings

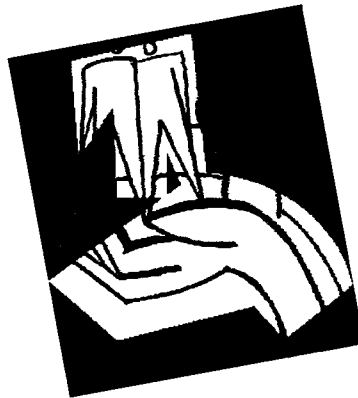
Item	Frequency (n=38)	Percent (%)
How clear are questions/ steps in the DA		
Everything clear	13	34.2
Most things clear	23	60.5
Some things clear	2	5.3
Most things were not clear	0	0
How easy to use		
Very easy	15	39.2
Moderately easy to use	21	55.3
Somewhat difficult	2	5.3
Very difficult	0	0
How helpful to clinical practice		
Everything helpful	15	39.2
Most things helpful	21	55.3
Some things helpful	2	5.3
Not helpful	0	0
How useful to clinical practice		
Very useful	20	52.6
Moderately useful	16	42.1
Somewhat useful	2	5.3
Not useful	0	0
How comfortable to use		
Very comfortable	19	50.0
Comfortable	15	39.5
Uncomfortable	4	10.5
Not comfortable	0	0
Would you recommend		
Definitely recommend	25	65.8
Probably recommend	13	34.2
Probably not recommend	0	0
Definitely not recommend	0	0

In summary these three tools (adapted online auto-tutorial; exemplar video; place of care PtDA) were designed to address the needs of participants and to facilitate the knowledge

transfer strategy developed for the study. Preliminary feed back on the usability and helpfulness of all of the tools was positive and minimal changes were made prior to using the tools in the study. However further evaluation of the PtDA is required to meet IPDAS criteria.

Chapter 8

Implementation and Evaluation of a Multi-Faceted Intervention



Efficacy of decision support skills training regarding a patients' location of end-of-life care: A randomized control trial

Short Title: Strengthening practitioners patient decision support skills
(Manuscript 4)

Note: Formatted for the journal: Psycho-Oncology and in accordance with CONSORT guidelines for reporting trials assessing non-pharmacologic treatments (Boutron et al., 2008)

Full Title: Skills training to support patients considering location of end-of-life care: A randomized control trial

Short Title: Enhancing practitioners patient decision support skills

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Abstract

Objective: To evaluate whether a multifaceted training program for practitioners results in enhanced skills related to support patients making decisions about place of end-of-life care.

Method: Eighty-eight nursing and allied health practitioners were recruited from oncology and palliative care settings in three Ontario health regions. Participants were assigned randomly to the education or control condition. Training elements included: 1) a self-directed online tutorial; 2) a 3-hour workshop including: performance feedback on participants' baseline skills, scoring a video contrasting exemplary decision support with traditional patient education, a patient decision aid, and role play; and 3) a follow-up educational outreach call. The Decision Support Analysis Tool was used to rate the quality of audio-taped phone calls with simulated patients before and after training. Participants were also surveyed regarding knowledge, the acceptability of the training program and intentions to engage in patient decision support.

Results: Compared to controls, those exposed to the intervention improved the quality of decision support provided (mean change +37.5 versus -6.67 out of 100; $p < 0.001$) and their interactions with simulated callers were slightly longer (mean 13.47 minutes versus 10.29, $p < 0.004$). The intervention group were more likely to address a wider range of decision making needs. Participants in the intervention group scored higher on a knowledge test of decision support than controls ($M = 69.2\%$ vs. $M = 60.5\%$, $p = 0.018$). The intervention group rated the components acceptable; however, only 26% used the online auto-tutorial.

Conclusions: Practitioners who received training overcame knowledge and skill gaps. Improvements in the quality of decision support can be accomplished by providing training and practical tools such as Patient Decision Aids.

Trial registration: NCT00614003

Key words: decision support; decision making; cancer; oncology; practitioner education; end-of-life; decision coaching

Introduction

Most terminally-ill cancer patients die in hospital despite a preference to die at home [1-4]. There are many options for care, including home, hospice, palliative inpatient unit, or hospital. Conflicting priorities such as preferences, concern for loved ones, practical needs and access to health services can contribute to personal uncertainty about what is the best choice [5;6]. Decision support or coaching can help patients understand options, clarify which options fit best with their values and reduce feelings of pressure or being unsupported in decision making [7].

Providing support to patients making decisions about place of end-of-life care is not straightforward. Despite patients' preferences to participate in decision making [8], practitioners are often uncomfortable with end-of-life care discussions [9;10]. Discussions are relatively infrequent even when patients are in hospice [11] and practitioners want knowledge and skills in end-of-life decision support [12]. Moreover, practitioners often do not know patients' preferences [13], are generally unaware that these differences exist [14] and base their decisions on concerns that differ from those of patients [15-17].

Patient decision aids (PtDAs) and decision coaching can improve the quality of decision support provided to patients [18]. Typically PtDAs help patients participate in their health care decisions in ways that they prefer. They provide facts about options, benefits, and risks, clarify which benefits and harms matter most, and guide patients in the steps of deliberation and communication [19;20]. Systematic reviews confirm that PtDAs improve patients' participation, increase knowledge of their treatment options and probable outcomes, and improve agreement between patients' values and subsequent treatment decisions. There is less evidence regarding the incremental value of decision coaching. Findings from a multi-

center randomized control trial of women considering options for the management of menorrhagia showed that decision coaching combined with a PtDA helped women to articulate preferences, improved long-term satisfaction and reduced hysterectomy rates [21].

A few studies have explored the effects of training practitioners to develop their coaching skills. A randomized trial at a Canadian provincial call center found that nurses who received an educational intervention were more likely to address simulated callers' needs for information, values clarification and support than control group participants [23]. Findings from a multi-center study of seriously ill patients revealed that nurses who had received specialty communication training in eliciting patient preferences were more likely to recognize seriously ill patients' cues for further communication, clarification of options and readiness to engage in decision making [22]. In a before/after study, Australian cancer call center nurses and allied health practitioners felt more prepared and confident in providing decision support following a decision support training intervention. Participants significantly increased their knowledge and provided higher quality of decision support to standardized patients following the training intervention [23].

PtDA's and decision coaching have not been adopted widely into clinical practice. Practitioner reported barriers to using PtDAs include: time constraints, non-applicability due to patient characteristics or clinical situation, perception that patients do not want to be involved in decision making and disagreeing with asking patients about their preferred role in decision making [24]. In terms of palliative care, additional barriers have been identified. Although palliative care nurses endorsed decision support as part of patient-centered care, they lacked skills, confidence and tools to facilitate implementation. Participants indicated that practical tools and resources would help them to strengthen their decision support skills and that they were interested in engaging in skills building activities with a view to integrating these skills into their usual practice [25]. These findings confirm the need to develop practical education strategies to overcome barriers for providing decision support.

The primary aim of this study was to evaluate the efficacy and acceptability of a multifaceted training program to strengthen practitioners' skills in supporting patients' decisions regarding the location of their end-of-life care.

Guiding Conceptual Framework

The Ottawa Decision Support Framework (ODSF) guided the development of a PtDA for place of end-of-life care and selection of the primary outcome measure. The ODSF asserts that the quality of decisions can be adversely affected by unresolved decisional needs [e.g. personal uncertainty; inadequate knowledge and unrealistic expectations; unclear values; inadequate support or resources; complex decision type; urgent timing; unreceptive stage of decision making; polarized leaning toward an option; and other personal characteristics which may limit decision making]. However, decision support can improve decision quality by addressing unresolved needs with clinical counselling, decision tools, and coaching [26]. The elements of decision support include: a) clarifying the decision and decisional needs; b) providing facts and probabilities; c) clarifying the personal importance of benefits and risks; d) guiding/coaching/supporting in deliberation and communication; and e) monitoring/facilitating progress.

The framework is acceptable to practitioners [2;27], has been validated in randomized trials of decision support [28;29] and recognizes the unique circumstance and patient characteristics situated within the decision support encounter.

Methods

Study Design

A randomized controlled trial was conducted (See Figure 1). Following consent, all participants received a call from a simulated patient who telephoned them regarding a location of care decision. Participants were then randomized to the training intervention or control group. Allocation was conducted through a computer generated random numbers

table provided centrally by a statistician external to the study. To avoid disparate sample sizes permuted blocks were used.

Participants in the intervention group received an education program which included three elements: 1) self-directed online tutorial; 2) skills-building workshop; and 3) follow-up educational outreach. Participants in the control group continued in their usual practice. Two weeks following completion of the education program, participants in both groups received second call from a simulated patient to re-evaluate their decision support skills (Figure 1). The study protocol received research ethics board approval from participating sites and the trial was registered with the International Standard Randomized Controlled Registry (Trial # NCT00614003).

Participants and Setting

To target practitioners who counsel terminally-ill patients, eligibility criteria included: 1) membership in a regulated health profession; 2) clinical practice with palliative cancer patients and/or cancer patients with advanced disease; and 3) working at least four shifts per month in a clinical area where end-of-life care discussions are likely to occur. Participants were recruited from seven community-based organizations and three hospital-based institutions in Ontario (Table 1). The study took place between July 2007 and July 2008.

Intervention

Interventions were chosen based on their proven effectiveness in addressing barriers to providing decision support and for improving practitioners' decision support knowledge and skills [23;29;30]. Details of the intervention components have been published previously [31]. Three components were delivered over six weeks (See Table 2). The first component was an online, self-directed, module-based tutorial. The tutorial provided an overview of decision support principles with end-of-life and oncology related case studies, an introduction to a decision aid, plus quizzes and feedback. Online access was individualized and password protected.

The second component was a three-hour skills-building workshop provided by a trained facilitator external to the project. There were several learning activities. Participants were provided feedback on their decision support skills during their baseline simulated calls. Next, they viewed and rated a video contrasting exemplary decision support with patient education. Then they had an opportunity to practice providing decision support using a patient decision aid during role play sessions. The PtDA developed for this study followed international standards for decision aid development and was based on known needs of patients considering place of end-of-life care options identified in systematic reviews [5;6;32].

Based on evidence from social marketing, educational outreach was chosen as the third component [33]. Education outreach was conducted via a telephone call to participants by the workshop facilitator two to three weeks following the workshop. It provided participants with a focused opportunity to personalize learning and to reinforce decision support behaviours learned during the workshop[33].

Two facilitators were trained to provide the skills-building workshop. In preparation for the workshop, the facilitators completed the intervention activities, practiced using the place of care PtDA and reviewed all workshop materials. Facilitators were provided with a workshop agenda, copies of all tools, and a standardized presentation which included structured, case-based exercises.

Outcome measures

Outcome measures were selected a- priori [31]. The primary outcome measure was change in the quality of decision support provided by practitioners to a simulated patient before and after the intervention. The secondary outcome measures addressed other constructs that were not the primary targets of the intervention but represented other important outcomes (knowledge, duration of interaction, intention to engage in patient decision support, acceptability of intervention components).

Primary outcome measure

The quality of participants' decision support was measured through analysis of their interactions with simulated patient callers who presented with uncertainty around a place of end-of-life care decision. Interactions were scored using the brief Decision Support Analysis Tool (DSAT10). The skills practitioners use to assess decisional needs and intervene is rated in five areas: decision status; knowledge of options; values; support; and commitment to act [34]. Combined scores range from 0 (low quality) to 10 (high quality). In a synthesis of 76 nurse-standardized patient encounters DSAT10 scores discriminated between trained and untrained nurses. The kappa co-efficient over all items was 0.55 (95% CI: 0.49,0.61) with higher agreement for encounters involving trained nurses (0.62:95% CI 0.43,0.80) [34]. Internal consistency on DSAT10 items for the sample used in the present study was Cronbach alpha 0.79.

DSAT10 scoring was done by one of two raters who were trained in the use of the DSAT10 and blinded to group assignment. The senior rater, an experienced DSAT coder, trained the 2nd rater. Calibration between raters was iteratively achieved using three independently coded calls.

The use of simulated patients facilitated a standardized experience across participants, provided a more accurate measure of current practice compared to self-report or chart audit, and has been shown to provide a clear picture of the quality of decision support provided by practitioners in previous studies [35-41] Five simulated patients (3 male; 2 female) were trained in a three-hour workshop. Training elements included: details of their expected role, review and practice of standardized scenarios; and orientation to the audio-taping equipment.

Simulated patients were provided with a written script for describing their personal uncertainty about the best place to receive end-of-life care. Two scenarios, typical of actual place of end-of-life care situations, were developed for the study and reviewed by a panel with expertise in decision support, oncology and palliative care. The first scenario focused on decision uncertainty related to unclear values; the second focused on feeling pressured to choose a particular place of care option. The research assistant used a coin toss to assign a scenario (unclear values or pressure scenario) for each baseline call. For the second call, the alternate scenario was used. The simulated patient contacted each participant at a mutually agreed time. Therefore, participants were not blinded to callers.

Secondary outcome measures

Knowledge of decision support was assessed using a 10 item multiple choice questionnaire. The questions focused on key content covered in the tutorial and reinforced in the workshop. Previous use of the knowledge test showed that it discriminates between those who have been exposed to decision support education and those who have not (74% vs. 60%, $p=0.007$) [29].

Length of interaction was measured in minutes from the time the simulated patient introduced themselves until the participant ended the call. Participants' perceptions of factors influencing future intentions for providing decision support were measured using 13 statements rated on a 5 point Likert scale ranging from strongly agree to strongly disagree. Questions in the *Intention to Use Decision Support Survey Tool* were grouped into the following categories: overall intention, attitudes, perceived expectations of others and perceived personal control related to providing decision support. The survey was based on the Theory of Planned Behaviour [42], findings from a previous study of nurses' perceptions of factors that influence decision support for place of end-of-life care [25] and tools used in previous decision support implementation studies [23;43]. In the current study internal

consistency of the *Intention to Use Decision Support Survey Tool* was good with a Cronbach alpha co-efficient of 0.79.

Acceptability and utility of the decision aid was assessed with a 31 item instrument adapted from the *Factors Influencing Health Professionals Providing Support for Patients Preparing to Make Health Decisions Survey Tool* [44]. Items include 22 statements rated on a 5 point Likert scale from strongly disagree to strongly agree about the clinical usefulness of the decision aid; 6 questions related to clarity and comfort in using the decision aid in clinical practice; and 2 open ended questions to elicit perceived barriers and advantages to using the decision aid . Reliability analysis for the adapted tool showed a Cronbach alpha co-efficient of 0.92.

Statistical methods

Power analysis: Sample size was based on a test of change in mean scores of decision support skills between the intervention and the control group. A previous study, conducted at a single location, with nurses experienced in telephone consultation, using a non-specific decision support protocol showed a significant difference in scores of quality of decision support provided to simulated callers between nurses who received decision support training (n=18) and controls (n=20) (81% vs. 44%, $p < 0.001$) [29]. As our study differed due to variability in participants experience in telephone consultation; recruitment from different professions and practice settings; and the use of a specific patient decision aid, we anticipated we would need a larger sample. To detect a difference of 0.70 change in mean score of decision quality (mean DSAT10 score) between the intervention and control groups we calculated that 64 participants would be required (n=32 in intervention group; n=32 in control group) using an alpha error = 0.05 and beta error = 0.20 [45]. To compensate for an anticipated 20% loss to follow-up we planned to recruit 80-85 participants.

Analysis: The main objective of the statistical analysis was to compare the change in DSAT10 scores between those exposed to the intervention versus usual care controls. The researcher who conducted and analysed before/after measurements was blinded to group allocation. All data were entered into the SPSS®, version 16, software program. DSAT10 data were verified using double entry to minimize data entry errors. For all other measures we conducted a random audit of 12% of all entered data for correctness with one outlier identified as a data entry error.

Analysis was conducted on complete cases. Listwise deletion, with omission of incomplete cases, occurred when post scores were unavailable due to loss to follow-up or if technical difficulties precluded an audible recording of the post call. While Listwise deletion can reduce power due to decreased sample size and there is a risk of a larger standard error because less information is available, it facilitates unbiased parameter estimates and reduces the potential for inferential errors [46].

Characteristics of participants, intentions to incorporate decision support into practice and acceptability of intervention components were summarized descriptively. Demographics of each group were compared using the non-parametric Mann-Whitney statistic for independent samples.

Prior to data analysis of the primary outcome measure, preliminary checks were conducted to confirm that there were no violations of assumptions of normality, homogeneity of variances and homogeneity of regression slopes. A t-test for independent samples was conducted to ascertain if there was a difference in decision quality following the intervention. An analysis of covariance (ANCOVA) was then calculated adjusting for the effect of baseline DSAT10 scores to determine changes between pre and post DSAT10.

A sub-analysis was then conducted on five DSAT10 items which have most frequently shown differences between those who have received training in providing decision support

and those who have not [23;29]. Using a Bonferroni procedure to guard against Type1 error the significance level was set at $p \leq .01$ [47]

For secondary outcomes length of call at the two time points between the control and intervention groups were analysed using independent sample t-tests with a significance level of $p \leq .025$. Differences in knowledge scores were analysed using an independent sample t-test.

Results

Characteristics of Sample: Of the 112 eligible practitioners who expressed interest, 88 (85%) consented to participate. Reasons for not consenting included: job or home relocation, time pressures, personal or family health issues, and timing of the intervention. Of the 88 consenting participants, 8 withdrew from the study after baseline measures were completed due to personal circumstances or work related issues (Figure 2). Participants, who withdrew prior to completing post measures, were not statistically different in socio-demographic characteristics or baseline DSAT10 scores than those who completed study measures ($p=.629$).

The typical participant was female, older than 40, had a nursing diploma and worked in an ambulatory care setting (Table 3). Most participants were nurses ($n=64$), 2 were pharmacists, 2 were non-nurse case managers who did not specify their discipline and 1 participant was a social worker. There was no statistically significant difference in socio-demographic characteristics of participants in the two groups ($p>.05$).

Quality of Decision Support: From 88 baseline calls, 78 paired calls (baseline and post) were included in the analysis ($n=42$ controls; $n=36$ intervention group). Eight participants withdrew prior to completing the post call and two calls were excluded due to recording equipment malfunction. Baseline scores for non-retained calls were not significantly different from baseline scores of complete cases ($p=.866$).

The mean score change from baseline in the intervention group 3.75, 95% C.I. (2.46, 5.03) was significantly greater than the mean score change in the control group -0.667, 95% C.I. (-1.57, 0.24) using the two sided t-test ($p < 0.0001$). When baseline scores were held constant, the mean score change from baseline in the intervention group was 4.74, 95% C.I. 3.51, 5.97, $p < 0.0001$ greater than in the control group.

Baseline DSAT10 scores had a significant effect on score change. Overall, those with lower DSAT10 scores at baseline showed more improvement on the post DSAT10 scores than those with higher DSAT10 baseline score. Intervention group members improved by about 4 points on their post DSAT10 scores, while controls did not significantly improve in the post call.

A sensitivity analysis for missing data was conducted. Missing post DSAT10 scores were imputed using the pre DSAT10 score (last value carried forward approach). The results were very similar regardless of which approach was used. Analysis of specific DSAT10 items revealed trends toward higher scores in the intervention group on all items, with assessing knowledge, discussing values and assessing support needs being significantly higher ($p \leq .001$) (Figure 2).

Call Duration The mean baseline call duration in the intervention group of 10.93 minutes, 95% C.I. (9.56, 12.29) was not significantly different from the control group of 12.61 minutes, 95% C.I. (11.01, 14.21) ($p\text{-value} = 0.115$). However, in the post calls the mean call duration was longer in the intervention group 13.47 minutes, 95% C.I. (11.88, 15) compared to the control group 10.29 minutes, 95% C.I. (8.79, 11.79) ($P\text{-value} = 0.004$) (Table 5).

Knowledge Seventy participants ($n = 35$ intervention; $n = 35$ control) completed the knowledge test. In the intervention group 10 participants completed the knowledge test on-line as part of the tutorial; the remaining 25 completed the knowledge test at the completion of the workshop. Participants, who did not complete the knowledge test, did not specify reasons for non-completion. The intervention group scored significantly higher on the

knowledge test than the controls ($M=69.2\%$, $SE=2.98$, range 41.6-100.0 vs. $M= 60.5\%$, $SE= 2.27$, range 25-83.3, $p=0.018$).

Intention to engage in decision support: Seventy-one participants (39 controls; 32 intervention group members) completed the intention to engage in patient decision support survey. All participants, regardless of group assignment, saw patient decision support as helpful to patients (98% controls; 100% intervention) (Table 6). While 87% of the intervention group and 84% of controls indicated a positive intention to engage in decision support, 16 of the intervention group strongly agreed that they could provide decision support compared to 11 from the control group (Figure 3).

Acceptability and utility of intervention components: Sixteen members of the intervention group (42%) logged into the autotutorial. Of those, eight completed the satisfaction survey. Of the eight all rated the tutorial as excellent to very good, seven indicated that the tutorial was helpful and six reported that the tutorial was very easy to complete.

Thirty-seven members of the intervention group (97%) commented on acceptability of the skills building workshop (Table 7). Most (94%) would recommend the workshop to others and 68% gave the workshop an overall rating of excellent. Workshop participants rated the workshop very well on helping them to understand and use decision support tools and to recognize quality decision support. Overall, workshop participants felt more prepared to provide decision support. Of the workshop strategies 81% of participants rated the video as the most important for their learning, followed by the review of decision support concepts and feedback on baseline calls.

Overall the patient decision aid was seen as acceptable and clinically useful by the 38 participants who provided data. Most participants (66%) would definitely recommend the patient decision aid to others, and 81% agreed that the decision aid would be acceptable to patients while 63% agreed it would be acceptable to practitioners (Table 8).

Of the 38 participants in the intervention group 2 declined the educational outreach call due to scheduling difficulties. All of the 36 who participated in the educational outreach call indicated an interest in using the place of care decision aid and expressed frustration that it was not available for wider use in their clinical practice setting. Other activities that occurred during the call included role play practice using the decision aid with the facilitator, clarifying how to systematically go through the steps of the decision aid and reflecting on how to overcome barriers in using decision support in practice. Barriers included integrating the structure of the tool into their usual interactions with patients and the challenge of tailoring the generalized decision aid to particular clinical circumstances. For instance several participants were concerned about over or under-representing services available within their community so tailoring information on options to fit their community context was identified as a necessary strategy to personalize the decision aid. The education outreach calls took about 10 minutes on average and ranged from 5 minutes to 45 minutes.

Discussion

The inevitability of death means that place of end-of-life care is and will continue to be a pressing social and health care issue. This trial demonstrated that practitioners' decision support for place of end-of-life care can be improved with a multi-faceted educational intervention. Following the educational program, the intervention group members provided higher quality of decision support than members of the control group. The difference was significant; with a medium effect size of 0.5 which in social science and health research is considered quite powerful[45;48]. While the intervention group post calls were significantly longer than those of control group participants the actual difference of about three minutes is likely not important in a typical one hour home visit or eight hour shift.

Participants in the intervention group were more likely to assess simulated patients' knowledge of the options, discuss values, and assess and provide support while control

group members primarily focused on providing information. The success of the intervention in improving practitioners' skills is consistent with previous research conducted with nurses in a Canadian provincial health call center [29] and in an Australian cancer call center [23]. However, the magnitude of change was less in our study. This could be due in part to the non-experimental design of the Australian study and participants' familiarity with telephone based care. While the British Columbia study used a randomized control design, its' setting in a nurse call center meant those participants were familiar with providing telephone based information and support and in the use of protocols to guide those interactions. Our participants were recruited from a variety of inpatient and outpatient settings and were likely to have been more familiar with providing in-person support. As such our findings may underestimate the potential improvement that participants may have demonstrated if engaged in their usual manner of patient interaction.

A novel feature of our study was the development and training in the use of a specific PtDA to guide the place of care discussions. PtDAs are most effective when they personalize information to patients circumstances, augment interactions with practitioners and are able to be revisited as situations change [49] . Although the PtDA used in this study was only used to guide interactions with simulated patients, previous research indicates that a combination of informative materials and repeated conversations over clinical visits are the most effective method of helping patients clarify and document their preferences within advance directives [50;51]. Participants indicated that the PtDA would be useful for documenting discussions about place of care and could provide a cue to revisit place of care decisions when and if circumstances changed.

Participants saw the PtDA as both useful and helpful for clinical practice. It is interesting that participants considered the PtDA to be more acceptable to patients than to fellow practitioners. The effects of organizational and regulatory levers on implementing change have been well described. For example managerial and organizational infrastructure

support, policy revisions and auditing influence nurses' use of research while lack of clarity about program directions, limited adaptation of tools and structures to different contexts of care and organizational pressures to minimize interaction duration constrain the decision support behaviors [44;52]. Participants may have been reticent to recommend a tool not currently sanctioned by organizational policy and or may considered the non-specific description of place of care options described in the PtDA in their assessment of its acceptability to their clinical reality. However when asked to consider the acceptability for patients and family participants may have been more likely to reflect on the plain language and empathic process conveyed in the decision aid. Thus the PtDA may have been seen as a tool to complement their interactions with patients with a recognition that variations in services and current service availability would need to be explained within the context of that interaction.

Of all the intervention components, the self administered online tutorial was the least accessed at 21%. Failure of the tutorial to be used to its full potential may be attributable to its use as a research tool rather than embedded into practitioners' systems of care. Participants had to link externally to the tutorial rather than through their organizations' intranets and many participants had limited computer interface time built into their daily practice. As such the tutorial may have been the least practical strategy and time for taking the tutorial may have been pre-empted by clinical priorities. The need to embed education strategies into clinical practice has been widely identified as a means of facilitating uptake [53]. Considering that those who completed and evaluated the tutorial rated it highly indicates that ways to enhance tutorial access should be addressed when planning future implementation trials. On the other hand, given that intervention group members, who did not complete the tutorial, gained sufficient knowledge during the workshop to outscore controls it may be worth using the tutorial as an optional resource with the focus on in-person knowledge transfer during the workshop.

While the difference in the knowledge scores was statistically significant the actual difference was about eight percent. In considering the participants knowledge scores in relation to the DSAT scores it appears that knowledge in and of itself is not sufficient to move behaviour into practice. Other evidence confirms that practical training including audit and feedback and interactive education are effective for implementing innovations into practice [54;55]. As such our study adds to the evidence that giving practitioners the resources and opportunities to build decision support skills leads to improvements in the quality of decision support provided.

Common barriers to nurses providing end-of-life care decision support include time constraints, lack of applicability to patient characteristics or clinical situation [24]. This study was able to overcome these barriers. Specifically the educational intervention was designed to address barriers identified by practitioners and decision support tools were developed in response to practitioner identified need confirming that tailored interventions are effective in addressing barriers [25]. Encounter time with the simulated patients was slightly longer with the PtDA and participants endorsed the usefulness and importance of providing decision support to palliative patients. Further research that attempts to directly answer the question of whether or not strengthening practitioners' skills in decision support produces improvements in the decision making process and patients' quality of life at end-of-life is needed.

Findings should be interpreted in light of study limitations. Firstly, participants were not blinded to the simulated calls and were aware their responses were being audited. Knowing that their interactions were being monitored may have resulted in a stronger performance however we still showed shift between trained and untrained participants. Moreover, the use of simulated callers is widely regarded as a reliable method for assessing professional performance, facilitates a standardized experience across participants, provides a clearer picture of decision support skills in general and is a more accurate measure of current

practice compared to self-report or chart audit [35-40]. The possibility exists that participants in the intervention group could have shared the intervention tools with control group participants which could have elevated control group scores. However control group scores were overall lower in the post call compared to their baseline call. Moreover, many of the skills needed to provide quality decision support are quite novel (values clarification) and it is unlikely that these skills would be present without exposure to the intervention. Furthermore, intervention group participants were asked not to discuss the education program outside of the planned activities; the intervention was diffusely spread across 3 geographic regions and 13 agencies; and most participants practiced autonomously with minimal contact with other potential participants.

Conclusions

To our knowledge there have been no previous studies that have evaluated a multi-faceted educational intervention which included a place of care PtDA to help practitioners improve the quality of decision support provided to palliative cancer patients. Following education, feedback and practice, participants were more likely to respond to a wider range of patients' decision making needs (e.g.: values clarity and support issues) when compared to controls. Participants, regardless of group assignment, endorsed the helpfulness of providing decision support to patients. Overall, components of the education intervention were deemed helpful and clinically relevant. These findings are being used to design a pragmatic trial to evaluate the impact on a place of care decision aid guided consultation. More specifically the study will be aimed to determine with real patients on patient, provider and health care system outcomes are warranted.

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Tables and Figures

Table 1: Recruitment Partners

Health Region	Recruiting Organization	Mandate
<u>Toronto Central:</u> Services 1,146,800 people (9.3% of population of Ontario Cancer prevalence: 181.4 /100,000 [56]	Community Care Access Center (CCAC)	Community based case coordination
	Saint Elizabeth Health Care Agency	Community based home visit services
	SRS Nursing Agency	Community based home visit services
<u>Southeast Region</u> Services 442,800 people (3.8% of population of Ontario Cancer prevalence: 200.3 /100,000 [57]	Community Care Access Center (CCAC)	Community based case coordination
	Saint Elizabeth Health Care Agency	Community based home visit services
	Bayshore Home Health Care Agency	Community based home visit services
<u>Champlain</u> Services 1,176,600 people (9.5% of population of Ontario Cancer prevalence: 409.4 /100,00[58]	The Ottawa Hospital Oncology program Regional Cancer Center Gynaecologic oncology chemotherapy day unit	Ambulatory cancer services Ambulatory care chemotherapy services
	Gynaecologic oncology unit Radiation oncology unit Medical oncology unit	Inpatient care Inpatient care Inpatient care
	Queensway Carleton Community Hospital	Community based inpatient care
	SCO Health Services Pain and Symptom Management Team	Community based symptom management consultation
	Carefor Nursing Agency	Community based home visit services
	Bayshore Home Health Care Agency	Community based home visit services
	Hospice at May Court	Residential and outpatient hospice

Table 2: Description of the Intervention

Intervention component	Objective	Procedure	Time
Online auto-tutorial (individual) • Series of 10 modules with embedded oncology and palliative care cases • Questions and feedback to ascertain learning • Introduction to place of care patient decision aid	To gain knowledge of patient decision support principles and strategies	Self-directed	60-90 min
Interactive skill-building workshop (group) • performance feedback decision support skills during simulated baseline calls • video scenarios contrasting differences between exemplary decision support skills and traditional patient education. • Demonstration and practice using place of care patient decision aid • Rating the quality of decision support provided in the video scenarios using DSAT10 to score quality of decision support in the video scenarios. • Role play scenarios	To strengthen decision support skills through use of patient decision aid To obtain feedback on baseline performance To engage in skills practice with peers vs. audit and feedback.	Trainer facilitated	3.5 hours
• Discussion of participant's experience using decision support and patient decision aid plus challenges/barriers to use • Opportunity to practice decision support skills and to clarify use of tool.	To reinforce decision support knowledge and skills.	Trainer facilitated phone call	5-45 min

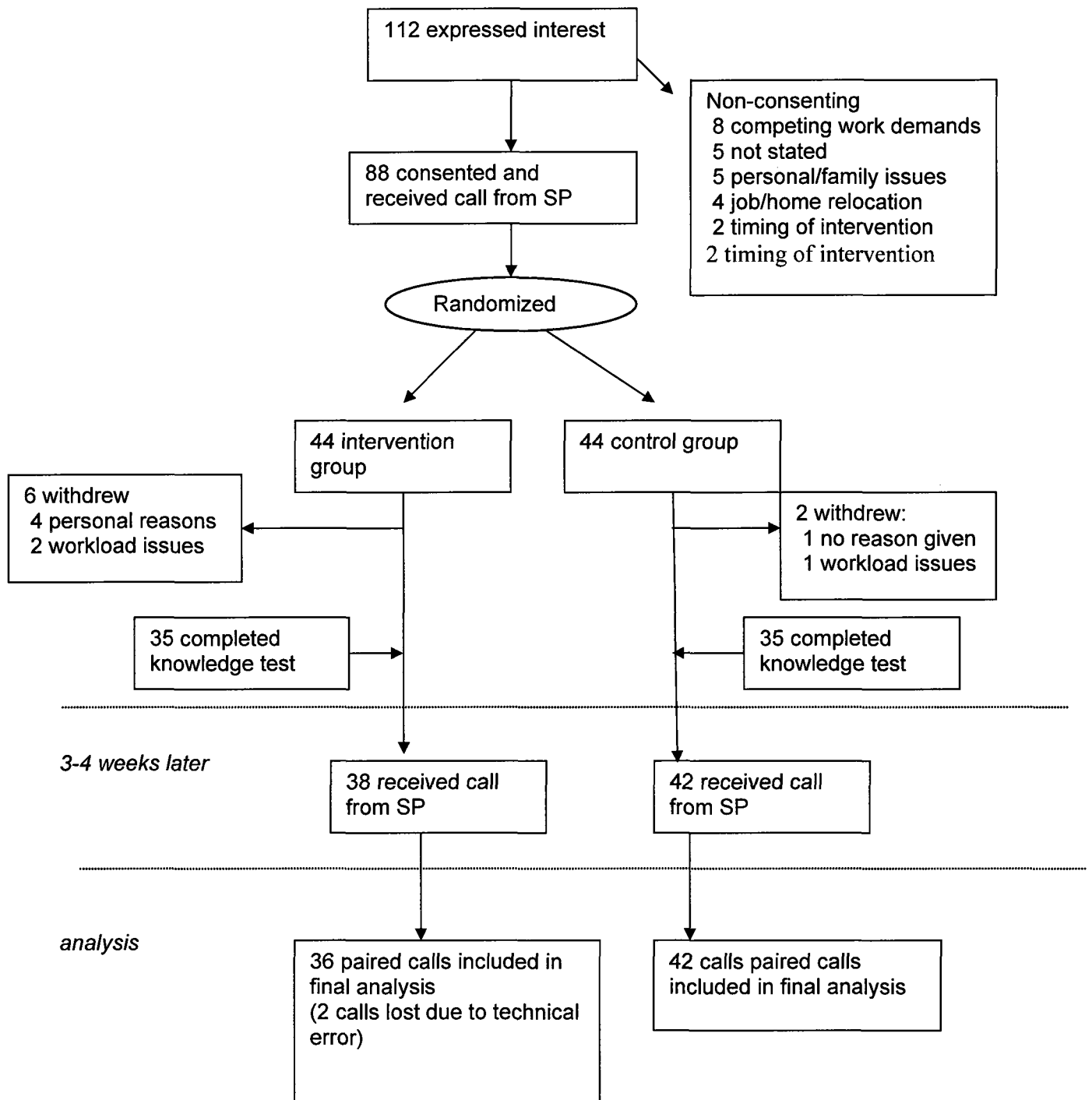


Figure 1: Study flow

Table 3: Characteristics of Participants by Group

Characteristic	Control (n=42)	Intervention (n=38)
Gender		
Female	40	38
Male	2	0
Age		
20-39	6	6
41 or older	33	26
No answer		5
Education		
Diploma	21	14
Undergraduate degree	12	10
Graduate degree	4	7
Specialty certification	4	2
No answer	1	7
Practice Setting		
Inpatient	13	9
Outpatient	29	29
Role		
Nurse		
Direct care	24	24
Administration	1	5
Educator	1	0
Case Manager		
Nurse	6	3
Non-nurse	7	1
Pharmacist	0	2
Social worker	0	1
No answer	3	2
Employment status		
Full time	35	26
Part time	4	6
No answer	3	5
Experience in oncology/palliative care		
1-15 years	28	21
16+ years	11	11
No answer	3	7
Provide decision support for place of care as part of daily practice		
Yes	33	24
No	3	6
No answer	6	8

Figure 2: Comparisons of Post Call Scores for Intervention and Control Group Members on Key Elements of Quality Decision Support

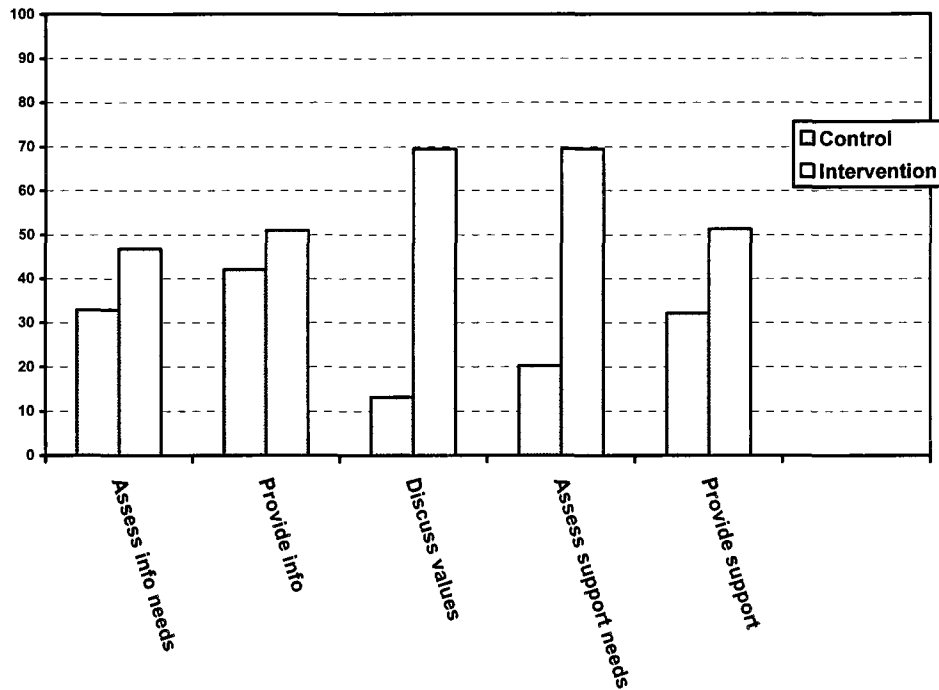


Table 4: Length of Call

Variable	Control M (SD) (n=42)	Intervention M (SD) (n=36)	Significance
Baseline call (minutes)	12.61 (5.14)	10.93 (4.02)	0.109
Post call (minutes)	10.29(4.81)	13.47 (4.70)	0.004

Significance: $p \leq 0.025$ (2 tailed t-test independent groups)

Table 5: Decision Support for Place of End-of-life Care in Practice Measured Post Intervention

Item	Control: n= 39 (%)	Intervention n=32 (%)
Intend to implement patient decision support into practice...		
Strongly agree	20 (51)	24 (75)
Agree	14 (36)	3 (9)
Neutral	5 (13)	5 (16)
Patient decision support is helpful to patients...		
Strongly agree	26 (67)	26 (81)
Agree	12 (31)	6 (19)
Neutral	1 (2)	
Most people expect me to provide patient decision support in my role...		
Strongly agree	16 (41)	14 (44)
Agree	13 (33)	10 (31)
Neutral	9 (23)	3 (9)
Disagree	1 (2)	4 (12)
Strongly disagree		2 (6)
I could provide decision support in my role...		
Strongly agree	12 (30)	16 (50)
Agree	11 (28)	7 (22)
Neutral	9 (23)	4 (12)
Disagree	4 (10)	4 (12)
Strongly disagree	1 (2)	1(3)
Mostly up to me whether or not I provide patient decision support in my role...		
Strongly agree	3 (8)	3 (9)
Agree	11 (28)	11 (34)
Neutral	15 (38)	4 (12)
Disagree	8 (20)	13 (41)
Strongly disagree	2 (5)	2 (6)

Figure 3: Intentions and attitudes to providing patient decision support for place of care (agree or strongly agree)

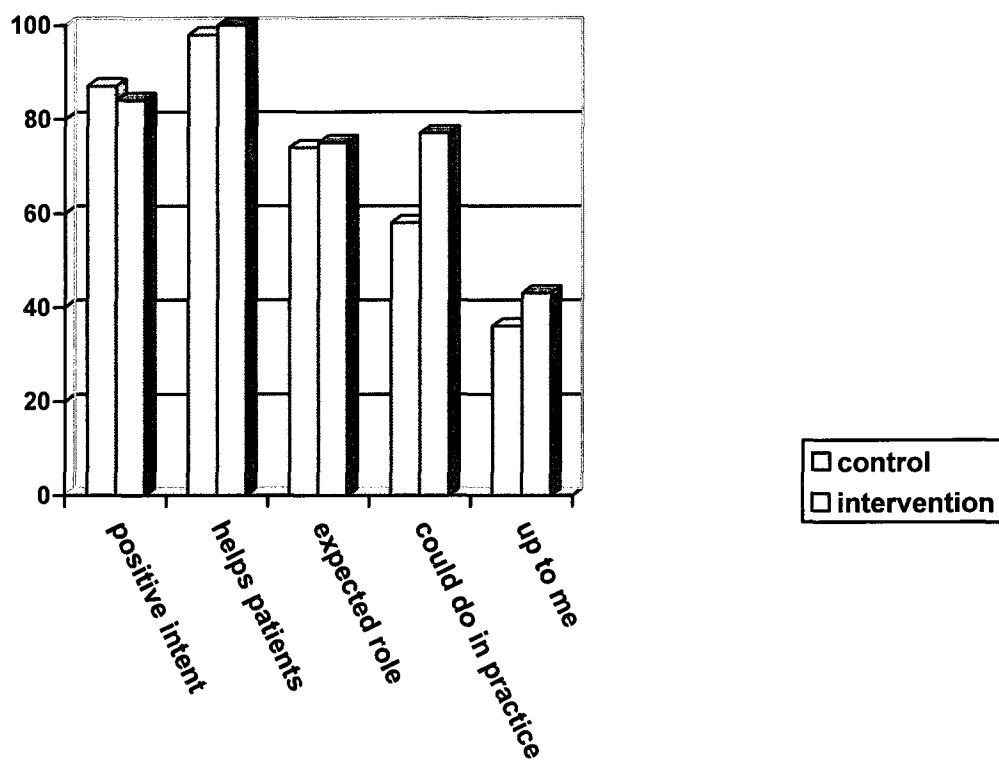


Table 6: Acceptability of Decision Support Skills Building Workshop

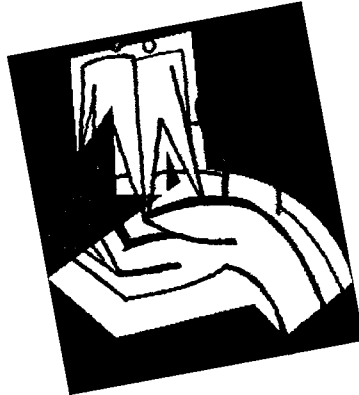
Questionnaire Item		Rating	Frequency n=37 Proportion (%)
How well did the workshop help you to...	understand decision support and decision aids	Very well Quite well Fairly well	23 (62%) 13 (35%) 1 (3%)
	identify quality decision support	Very well : Quite well: Fairly well:	19 (51%) 17 (46%) 1 (3%)
	develop your skills in using decision support tools	Very well: Quite well: Fairly well:	13 (35%) 19 (51%) 5 (13%)
	use decision support tools in your practice	Very well Quite well Fairly well	14 (38%) 16 (43%) 7 (19%)
Ratings of workshop elements ...	information easy to understand	Excellent Good Fair	21 (57%) 15 (41%) 1 (3%)
	good use of time	Excellent Good Fair Adequate Poor	6 (16%) 15 (41%) 9 (24%) 5 (14%) 1 (3%)
	useful skills learned	Excellent Good Fair Adequate	17 (46%) 17 (46%) 1 (5%) 2 (2%)
	feel more prepared to provide decision support	Excellent Good Fair	16 (43%) 16 (43%) 5 (14%)
How well did each element contribute to your learning...	review of decision support concepts	Excellent Good Fair	15 (41%) 14 (38%) 3 (8%)
	feedback on baseline call	Excellent Good Fair Adequate	10 (27%) 18 (49%) 3 (8%) 1 (3%) (5 responses missing)
	video exemplar	Excellent Good Fair Adequate	17 (46%) 13 (35%) 1 (2%) 1 (2%) (5 responses missing)
	practice & peer feedback	Excellent Good Fair Adequate Poor	11 (30%) 9 (24%) 6 (16%) 2 (5%) 1 (2%)

Table 7: Evaluation of Patient Decision Aid

Item	Frequency (n= 38) (%)
How clear are questions/ steps in the DA	
Everything clear	13 (34%)
Most things clear	23 (61%)
Some things clear	2 (5%)
How easy to use	
Very easy	15 (40%)
Moderately easy to use	21 (55%)
Somewhat difficult	2 (5%)
How helpful to clinical practice	
Everything helpful	12 (32%)
Most things helpful	20 (53%)
Some things helpful	6 (16%)
How useful to clinical practice	
Very useful	20 (53%)
Moderately useful	16 (42%)
Somewhat useful	2 (5%)
How comfortable to use	
Very comfortable	19 (50%)
Comfortable	15 (39%)
Uncomfortable	4 (10%)
Would you recommend	
Definitely recommend	25 (66%)
Probably recommend	13 (34%)
Help to guide patients through decision making in a systematic way	
Strongly agree	20 (53%)
Agree	12 (32%)
Neutral	2 (5%)
Disagree	3 (8%)
Acceptable to practitioners	
Strongly agree	14 (37%)
Agree	10 (26%)
Neutral	10 (26%)
Disagree	1 (3%)
Strongly disagree	2 (5%)
Acceptable to patients	
Strongly agree	16 (42%)
Agree	15 (39%)
Neutral	3 (8%)
Disagree	1 (5%)
Strongly disagree	2 (3%)

Chapter 9

Integrated Discussion



Integrative Chapter

Chapter 10 presents an integrated discussion related to the decision support implementation strategy, contributions of the study to the discipline of nursing and implications for practice, education, policy and research in the context of end-of-life care.

Integrated Discussion

Summary of Decision Support Implementation Strategy Using the Knowledge-to-Action Framework

A knowledge-to-action process provided the organizing framework for this research project as nursing is fundamentally a therapeutic, goal-oriented process directed at meeting patients' needs (Graham et al., 2006).

Problem Identification. Experience as a palliative care nurse and as a novice researcher examining women's decision making needs for place of end-of-life care highlighted the gap between where most terminally ill cancer patients prefer to receive care as death approaches and actual place of care (Murray et al., 2003). To more closely examine factors contributing to this gap an iterative, multi-step research inquiry was undertaken.

Knowledge Synthesis. To synthesize current knowledge a systematic review of the determinants of place of end-of-life care was conducted. Findings indicated that patient-stated preference, practical concerns and the quality and quantity of contact with health care services and practitioners influence place of end-of-life care (Murray et al., 2009a). Another body of evidence suggested that practitioners generally avoid end-of-life care discussions and patients may not feel comfortable in sharing their preferences without prompting from practitioners (Murray et al., 2004a; Voltz et al., 1998). While decision coaching and PtDAs are effective in helping patients to articulate their preferences and preparing them for decision making they have not been widely adopted into clinical practice (Legare et. al., 2008).

Adopt Knowledge to Local Context. Integration of findings from the systematic review of determinants of place of end-of-life care, evidence on the effectiveness of decision support

tools, the need to better support patients facing place of care decisions and recent Ontario policy directions for documentation of place of end-of-life care discussions confirmed the need to develop and implement a knowledge transfer strategy to address nurses' perceptions of barriers to providing patient decision support. Therefore a multi-step research study was designed to facilitate the integration of patient decision support related to place of end-of-life care into practice. A research team with expertise in palliative/ oncology care, patient decision support, knowledge transfer and implementation of innovations was assembled. Support was obtained from several health service agencies.

Identification of Barriers to Knowledge Use. A qualitative study was undertaken to elicit factors that influence the provision of decision support for place of end-of-life care. Twenty-two nurses from three Ontario health networks shared their perspectives about a) the value of patient decision support; b) expectations of others for providing decision support; and c) factors that facilitated or constrained the provision of decision support for place of end-of-life care. Participants verified that providing decision support for place of end-of-life care was important for holistic, responsive palliative care yet a lack of processes and preparation to engage in high quality decision support was a barrier. Participants noted that practical, clinically based tools would help them to strengthen their skills in providing quality decision support (Murray et al., 2009b). A knowledge-transfer intervention was developed to overcome barriers and was based on effective interventions for changing practitioners' behaviours (Grimshaw et al., 2004; Grol et al., 2005). Specific elements included clinically based tools (place of care PtDA; teaching video; decision quality monitoring tools) along with opportunities for knowledge acquisition, skills building, audit and feedback and follow-up educational outreach.

Intervention to Address Barriers to Knowledge Use. To test the efficacy and acceptability of the knowledge transfer intervention a randomized control trial (RCT) was conducted. Practitioners, exposed to the intervention, provided a statistically higher quality of

decision support and addressed a wider array of patient decision making needs than those who had not received the intervention. Participants' knowledge of decision support and application of decision support tools were measured within the online autotutorial, workshop activities and conversations with simulated patients. Participants confirmed that patient decision support for place of end-of-life care was helpful to patients and that overall the intervention components were acceptable and clinically relevant. Although trained participants talked longer with the simulated patients (n=3 minutes) this is likely not clinically significant. For instance, a three minute difference over the course of a one hour assessment or eight hour shift nursing visit would not add substantially to visit time. Moreover, further practice and familiarity with the tools would likely improve time spent.

Monitoring Knowledge Use & Evaluating Outcomes. The next steps in the knowledge-to-action framework involve the monitoring of knowledge use, evaluating outcomes (i.e.: patient, practitioner, system) and reassessing the barriers and enablers for ongoing, sustainable knowledge use (Graham et al, 2006). Results have been shared with study partners and next steps are being explored. For instance, there is interest in implementing and evaluating the place of care PtDA in a large tertiary care institution which would enable an evaluation of the intervention within a clinical context. From that a study could be designed to measure the impact of integrating the PtDA and training interventions on patient, practitioner and health system outcomes and on uncovering barriers and enablers to sustainable change within the clinical setting.

In summary, a systematic examination of place of end-of-life care issues led to verification of the problem in clinical practice, the development of practical tools and evaluation of an intervention designed to address identified barriers. This enquiry has extended existing knowledge regarding the nature end-of-life decision support and how practitioners can support patients in decision making. Findings demonstrate that it is possible to modify practitioners' decision support behaviors and to implement an evidence based

place of care PtDA. Finally, the knowledge-to-action process was useful in guiding the examination of a research-to-practice gap in patient decision support for place of end-of-life care and could be considered for other practice change initiatives requiring the integration of scientific knowledge with local realities.

Lessons learned and implications of findings from this study for practice, theory, research, and policy follow. Study conclusions and examples of recommendations for practice, education, policy and research are then outlined in Table 9.1.

Lessons Learned and Logistic Considerations

Given the strength of a comparative groups design for making causal claims and the added strength of random assignment an experimental pretest/posttest design was chosen (Campbell et al., 2000). However conducting a randomized control trial in the real world was at times difficult. Logistic challenges included multiple partners and study sites in several geographic regions. These were very busy programs with high workload demands. At times, participants found it difficult to meet the demands of the study.

Relationship building with the study partners began more than 18 months prior to recruitment and there was an ongoing need to be flexible and responsive to service needs when arranging study activities. The logistics of managing scheduling from a distance were cumbersome. Flexibility in scheduling study activities and planning meetings with study partners was essential. For instance, activities were strategically scheduled to avoid peak times such as summer vacations and holiday periods and were held at locations that would offer the most convenience for participants.

Despite these logistical issues there were benefits to conducting the intervention at multiple sites. Several participants indicated that the opportunity to meet and discuss mutual and differing challenges offered important insights that they had not appreciated. For instance, an inpatient nurse noted that following interaction with a home visit nurse in the workshop role play she now has a better understanding of community nursing and has

incorporated that awareness into her discharge teaching. Another benefit of the wide scale implementation of the intervention was building awareness of patient decision support across many practice settings and care regions which in itself could be considered a knowledge transfer strategy. Finally the intervention effect was robust enough to demonstrate a significant improvement in the quality of decision support provided to simulated patients following training despite the diversity in implementation settings and participants practice background.

In summary, challenges in study implementation were most often related to organization and logistic detailing. The importance of establishing and maintaining respectful relationships with study partners cannot be overemphasized. Flexibility and openness to understanding how organizations strive to balance the need for research to help them provide the most efficacious and evidence-based care while trying to meet everyday service demands were key to moving this study from conceptualization to actualization.

Implications for Theory and Theory Testing

ODSF. This study contributes to the existing body of knowledge about decision-making processes and how to build skills and capacity for providing high quality decision support among practitioners in the context of end-of-life care. Findings confirm the relevance of the ODSF to a palliative care context and the descriptive and predictive utility of the ODSF as a conceptual framework. Specifically, the study demonstrates that decision support processes can be changed with structured protocols and tools that are based on the framework.

Two main perspectives on decision support exist (Makoul & Clayman, 2005). One perspective describes decision support in the context of a dyadic relationship between patient and provider (Charles et al., 1997; Whitney, 2003). A second perspective suggests that decision support is a process focusing on factors that can influence the outcome of the

decision (Coulter & Ellins, 2007; O'Connor et al., 1998; O'Connor et al., 2008b). In our study, participants' describe decision support as intrinsic to the nurse/patient therapeutic relationship and confirmed that frequent reassessment of decision making needs is needed given the fluidity of decision making at end-of-life. These findings suggest that the two perspectives of decision support described in the literature are not mutually exclusive. The ODSF, with its dual focus of provider-mediated decision support to address sources of patients' decisional conflict and facilitate the decision making process, seems to provide a bridge between these two perspectives.

Similar to other studies, operationalization of ODSF theoretical constructs (decisional conflict; decision quality) was effective in explaining and improving the quality of decision support provided (Legare et al., 2006a; Stacey, 2006b). A place of care PtDA and video demonstrating its use in clinical practice was created using ODSF concepts. The place of care PtDA is novel and has been added to the online A-Z Inventory of Patient Decision Aids maintained by the Ottawa Health Research Institute (<http://decisionaid.ohri.ca/AZinvent.php>).

To date decision support assessment has mainly focused on the provider/patient dyad. However end-of-life decisions typically occur within the patients' social network of kin and close friends (Stajduhar et al., 2008; Stajduhar & Davies, 2005; Steinhauser et al., 2000b). How well ODSF constructs and assumptions capture the dynamics of group decision making have not been examined extensively. Further theory testing with non-cancer populations, interprofessional groups and diverse cultural populations is required. It would be interesting to audio-tape care planning conferences attended by patients, family and interprofessional team members as part of a study examining the impact of patient decision support in patient and health system outcomes. Assessment of the dialogue could reveal two dimensions of decision support; decision making needs of care recipients and their families and the quality of decision support provided within the interaction.

TPB. Combining the ODSF with the TPB helped to a) elucidate practitioners' perspectives about the place of end-of-life decision support; b) build and test an intervention that addressed practitioner identified needs; c) verify implementability of the intervention with practitioners; d) demonstrate an improvement in the quality of decision support provided by trained participants and e) confirm that practitioners value and are ready to embrace decision support. Specific to the TPB, intention and beliefs about capabilities are most often linked to behavior performance (Godin et al, 2008). In this study, nurses in the needs assessment confirmed the importance of providing decision support and intentions to engage in decision support were high among participants in the RCT. The intervention focused on building decision support capability and was effective in strengthening the quality of decision support participants' provided to simulated patients. Theoretically, this should translate to an increased uptake of decision support behaviors in clinical practice and supports the argument for broad implementation of the training intervention as an effective strategy to reduce the research-practice gap related to decision support for end-of-life place of care.

Implications for Research

Patient-Oriented Outcomes. Further research to directly answer the question of whether or not strengthening practitioners' skills in decision support improves the quality of decisions and their consequences in terms of patients' quality of life and health care experience at end-of-life is needed. This is likely a complex question conditioned to a large degree by subjective evaluations. The difficulties and methodological challenges in conducting randomized control trials in palliative care are well known (Wee et al., 2008). However large, prospective, well-formulated observational studies can offer equivalent results to randomised controlled trial (Higginson, 1999; Benson & Hartz, 2000). Thus a series of research studies beginning with longitudinal work to understand the current profile of palliative care in particular regions followed by pragmatic implementation trials that assess

the impact of tailored decision support interventions would be reasonable to contemplate. Capturing patient-oriented outcomes such as use of decision support tools in the context of advance care planning and match between planned and actual place of end-of-life care could provide important insights into variations and similarities between and within regional health networks. Furthermore, more deliberated decision making for place of care at the end-of-life could result in reduced Emergency Room visits and improved quality of life if patients and families are more informed of their options and available resources.

This type of research could help clarify the relative influence of different determinants of place of end-of-life care and findings could inform the development of measures to predict best fits between patients informed preferences and their personal circumstances. Additionally, this information could assist health care planners in knowing where to direct resources and education and would alert practitioners to situations that may require focused and ongoing decision support interventions. Moreover longitudinal studies could track economic costs and impacts on informal caregivers related to end-of-life care provision in different settings.

Implementation Considerations. Similar to many implementation studies this study focused on examining and modifying intrinsic and extrinsic factors at the practitioner level (van Achterberg et al., 2006; Holleman et al., 2006). Typically intrinsic strategies focus on behavior oriented activities; in this case feedback and monitoring. Extrinsic strategies, such as training, generally focus on competence and attitude (van Achterberg et al., 2009). However as nurses typically practice within groups and as part of an organization a continued focus on individual behavior is insufficient to move this intervention into the wider practice environment.

Accordingly, implementation needs to focus on processes of interprofessional approaches to decision support and sustainability (Greenhalgh & Peacock, 2004, Legare et al, 2008). The effects of organizational and regulatory levers on implementing sustainable

changes are generally well known. For example, managerial and organizational infrastructure support, policy revisions and auditing influence nurses' use of research while lack of clarity about program directions, limited adaptation of tools and structures to specific care environments and organizational pressures to minimize interaction duration constrain the decision support behaviors (Gifford et al., 2007; Stacey et al., 2005). Thus, research is required to examine what aspects of an implementation program account for sustainable integration in one context and failure in a different context.

Participants in both the needs assessment and RCT confirmed the importance of decision support as a key element of patient-centered care. In the RCT study participants valued patient decision support regardless of whether or not they received the intervention. There is emerging evidence that using injunctive norms to describe what we think a situation should be (e.g. 'we believe that not assessing patients decision making needs and supporting them in decision making is unacceptable and contrary to patient centered care') shows promise in changing behavior. Aligning descriptive norms (what people typically do) with injunctive norms (what people typically approve or disapprove) could optimize the power of normative appeals (Cialdini & Goldstein, 2004). For instance, the use of injunctive norm messages was more effective in influencing positive environmental conservation behaviors among tourists than descriptive norm messaging (Cialdini, 2003). Therefore a study of the effectiveness of normative messaging as an implementation strategy could examine best practices for embedding palliative care decision support interventions into clinical practice.

Implications for Practice

Nurses critically appraise, develop and manage the care systems they interact with (Forbes & While, 2009). As the care system is central to effective care, there is an opportunity for nursing to take leadership in designing and implementing processes that integrate decision support. This is consistent with nursing's tradition of 'putting the patient in the best position for healing to occur' (Nightingale, 1969).

Nurses in the needs assessment held positive attitudes towards providing decision support for place of end-of-life care and RCT participants, regardless of group assignment, indicated an intention to engage in patient decision support. However, decision support skills displayed by participants in the control group were suboptimal. The place of care PtDA and skills learned in the educational intervention were effective in assisting participants to enhance their decision support skills.

Evidence from the systematic review, conducted for this project, confirms that patients and families value discussions about place of end-of-life care options. Introducing patient decision support concepts and tools into practice through nursing orientation programs with concomitant implementation of the place of care PtDA into palliative care pathways is a practical way to begin. At a broader level, other strategies could include embedding expectations for providing patient decision support for place of end-of-life care in existing structures such as job descriptions, performance review criteria, facility accountability agreements and institutional policies and standards of practice (Murray, 2008b).

Implications for Informed Consent. Disagreement between patients and practitioners about treatment decisions is ranked as the top ethical health care challenge; care planning in terminal or serious illness and achieving informed consent are ranked at six and seven respectively (Breslin et al., 2005). Moreover, conflict between practitioners and patients and families is the most common trigger for ethics consultation (DuVol et al., 2001). Arguably, improvements in end-of-life care may be best realized by examining the perspectives of patients and their families and focusing on issues considered important to them (Singer et al., 1999; Steinhauser et al., 2000a; Steinhauser et al., 2000b; Wensing & Elwyn, 2003).

This suggests that informed consent, which assumes informed decision-making, must include practical strategies to ensure patients have both information about options and are clear about what factors are most important to achieve or avoid among the options under consideration (O'Connor et al., 2007b). Participants in both the needs assessment and RCT

stressed that decision support was an iterative process (Murray et al., 2009a; Murray et al., 2009b). The need to balance the idiosyncratic nature of individualized care that attends to patient need within a standardized approach was clearly described by nurses in the needs assessment (Murray et al., 2009b).

Similar to other studies, participants reported that tools and processes help overcome barriers to providing patient decision support (Stacey et al., 2005). The PtDA, developed for this study is patient-centered and could be used to facilitate informed consent. Specifically the place of care PtDA provides a means to validate patients' voices and document the patient's clinical, values, and support profile. The place of care PtDA facilitates a tailored assessment using a standardized process. The clinical relevance of PtDAs is evident from findings from a systematic review evaluating PtDAs (34 studies) which found that patients using cancer-related PtDAs had increased knowledge compared to usual practice without increased anxiety (O'Brien et al., 2009).

Clearly findings from the systematic review, the needs assessment and comments from the intervention group in the RCT study indicate that there is no perfect place to receive end-of-life care. There may be rapid and wide variations in care needs and preferences may change under different circumstances. The role of decision support is to acknowledge tensions between what is most important at one point in time while recognizing that preferences can vary and that preferences should be reassessed regularly. Making explicit the role of decision support in patient-centered care and informed consent could be facilitated by building cues for decision support assessments into existing care pathways and documentation tools.

Improving End-of-life Communication. Cancer patients want to be informed about potential issues and difficulties they may face in the future. There are also differences between what a cancer patient experiences and chooses to talk about and what practitioners observe during a clinic or home visit (Fitch et al., 2008). The role played by nurses in

rewording and re-explaining information provided by physicians and in informing and assisting patients in taking part in medical decisions is well documented (Bottoroff, Gogag, Engelberg-Lotzkar, 1995; Roberts et al., 2002). Devices such as boundary objects can be used to facilitate communication (Star & Griesemer, 1989).

Essentially boundary objects serve as an interface between different perspectives and can create a common point of reference to facilitate understanding and communication (Star & Griesemer, 1989). Comments from participants suggest that the place of care PtDA acted as a boundary object. For instance, following the intervention a participant revealed that she was facing a place of end-of-life care decision in her personal life but had been avoiding the topic. She indicated that the place of care PtDA provided a way *'to objectify the decision and bring the topic into open discussion'*. Other participants commenting on the advantages of using the PtDA indicated that *'patient/caregivers can "see" their decisions -gives an opening for discussion'* and another stated *'it is something to use with clients to increase their input and shows their feelings better. Using it provides better understanding of clients idea(s)'*.

Although training in decision support focuses on communication and changing the way practitioners relate with patients, changing behavior is complex (Grimshaw et al., 2002). In the RCT study, training in decision support occurred during a four hour workshop. The post call with the simulated patient occurred two-three weeks after the workshop. It is probably unrealistic to expect that a complete change would occur following this relatively short exposure. Changing communication patterns over the long term likely requires time to practice new patterns with opportunities for reinforcement and organizational processes that support the change. Nevertheless, results from this study show that it is possible to influence practitioners' communication using a brief targeted intervention complemented by an evidence-based PtDA.

In summary, effective communication facilitated by evidence-based tools and practitioner skill in providing decision support plays an important role in how discussions

about end-of-life care unfold and subsequent decisions. Creating practical tools targeting end-of-life place of care, providing an opportunity to use those tools and receive feedback and reinforcement in providing decision support was an effective means of enhancing practitioners' skill and confidence. However, evaluation of the impact of this intervention in actual clinical practice and monitoring retention of these new behaviors is needed.

Implications for Education

Effective integration of palliative care and improving end-of-life care requires education of both the public and health care practitioners (Stjernsward et al., 2007). Additionally patient and family access to information is a pre-requisite for active participation in decision making (Coulter & Ellins, 2007). As terminally ill patients receive the bulk of their care from family and friends, educational and public awareness interventions need to target both groups.

Heightening patient and caregiver awareness of options for place of end-of-life care and tools to facilitate discussions about place of end-of-life care could foster communication between patients and family caregivers. Practical ways to achieve this include posting lay summaries of the research findings from this research on publically available websites such as National Cancer Institute and Canadian Virtual Hospice. Making decision support tools available to patients and families could also help generate consumer expectation for participation in end-of-life care planning particularly related to place of end-of-life care. In keeping with this philosophy the PtDA developed for this study has been made publically available in the A-Z inventory housed at the Ottawa Health Research institute (<http://decisionaid.ohri.ca/AZinvent.php>).

Nurses in the needs assessment confirmed the iterative nature of place of end-of-life care decision making (Murray et al., 2008g). Exposure to the place of care PtDA, as part of patient and family conferences, could help prepare families to participate in decision making. A meta-analysis (35 studies) reveals that mental practice enhances performance by offering

an opportunity to rehearse and code behaviors into words and images that aid recall (Driskell et al., 1994). Thus repeated exposure and use of the PtDA could act like a simulator allowing patients to practice and become more familiar with participation in decision making. Should circumstances change the decision could be revisited using the place of care PtDA. Previous exposure and use of the place of care PtDA could help smooth the path for decision making at a time when patients have fewer cognitive and emotional reserves such as when death becomes more imminent.

A predominant finding from the needs assessment was nurses' awareness and concern that their biases could influence patients' decisions and the decision making process. Decision coaching is predicated on decision support provided by persons neutral to the decision (Stacey et al., 2008b). In practice the concept of neutrality is abstract; difficult to measure and implement. However, awareness of bias may be a more clinically relevant concept. While professional standards mandate that nurses do not let their biases impact patients' choices, building self-awareness needs to be planned and supported with education and quality assurance initiatives (College of Nurses of Ontario, 2002). Planned education, targeting both pre and post licensure practitioners, focusing on principles and applications of patient decision support could facilitate this.

Embedding core competencies of patient decision support into undergraduate and post graduate curricula and continuing education courses is a recognized strategy for optimizing patient participation in decision making (O'Connor et al., 2007b). Quality decisions are informed by both patients' knowledge of options and likely outcomes and their personal values and preferences (Sepucha et al., 2007). Thus two core competencies for decision support are 1) assessment of knowledge needs and 2) skill in values clarification. Discussing values was the largest area of difference between the intervention and control groups following training (70% vs.12%) suggesting that the intervention is effective in helping practitioners build competency in values clarification. There may be some merit in levelling

the workshop from basic skills building, with a focus on assessment and values clarification, to advanced workshops that would be expanded to include other support issues. Using a competency based model, practitioners would provide basic decision support and refer patients with refractory decisional conflict or more complex decision needs for advanced level decision support from practitioners with advanced skills and knowledge.

Experiential learning is more effective than didactic methods in helping practitioners gain skills in discussing advance care planning with patients (Furman et al., 2006). As well, the design of the workshop is consistent with evidence indicating the importance of providing interactive education to assist practitioners in initiating difficult conversations and addressing sensitive issues (Barnett, 2007; Hales & Hawryluck, 2008). The intervention was developed to be portable and transferable across settings. The intervention components proved robust to different contexts given its successful use in six different settings with two different workshop facilitators. Adapting the intervention to teleconferencing and clinical teaching rounds may increase reach. With this in mind the intervention is being modified for delivery via distant education to a group of diploma Registered Nurses enrolled in an undergraduate course. Evaluation of the adapted intervention will provide important information on how to further tailor the intervention for wider dissemination.

Implications for Policy

High Level Policy Implications. Policy makers can facilitate an environment that supports patients and their families during end-of-life. Some practical directions to improve the situation for patients and families making decisions about end-of-life place of care follow.

The Canadian Hospice Palliative Care Association national strategy for end-of-life care is based on the Square of Care Framework (Canadian Hospice Palliative Care Association, 2002). Within the Square of Care, patient decision support and participation in decision making is identified yet not well described or defined. Findings from this work offer

an opportunity to more clearly articulate how patient decision support can be operationalized in clinical practice.

Decision makers must incorporate local evidence of patient-oriented, as well as process-oriented outcomes before making decisions for resource allocation. For example, nurses in the needs assessment reiterated the importance of establishing a trusting therapeutic relationship with patients prior to engaging in decision making. These nurses felt that multiple interactions with patients were needed to establish this type of relationship. This finding complements other evidence which suggests that continuity of care facilitates shared decision making (Murray et al., 2007). There is most likely a trade off between palliative programs that facilitate speedy access using multiple practitioners and programs that focus on continuity of care. When policy makers identify priorities for palliative programs and services, they must be wary of the inherent trade-offs.

The Government of Canada's Science and Technology Strategy indicates that research and innovation play a key role in Canada's economy (Industry Canada, 2007). Place of care at the end-of-life has direct economic implications for health spending. Every day about 5200 acute care beds are occupied by patients waiting for an alternate level of care placement (ALC). Palliative care is cited as the most common reason for direct ALC admission (33%) (Canadian Institute of Health Information, 2009). Findings from this work will be of interest for decision makers looking for concrete strategies to address use of acute care beds and planning for community based palliative care services.

Policy Implications at the Provider Level: Practitioners can catalyze policy change by working with patient/caregiver advocacy groups, supporting initiatives and working with professional organizations to create evidence based guidelines and establish standards of practice. For instance, the Registered Nurses Association of Ontario (RNAO) is deeply invested in developing tools to help nurses engage in evidence based practice (Davies & Edwards, 2004). Currently RNAO is pulling together a panel to develop a best practice

guideline for end-of-life care. Integrating decision support tools developed in this project into a Best Practices for End-of-Life Care Toolkit could facilitate awareness at the practitioner level and offer another mechanism to evaluate uptake.

Embedding decision support cues into care pathways is another policy mechanism that directly impacts practitioners (O'Connor et al., 2007b). A specific strategy could be the inclusion of the decision support tools and teaching resources developed in this study into the federally funded Public Information and Awareness Working Group interprofessional education module on advance care planning (Health Canada, 2008).

Conclusions and Recommendations

Terminal cancer patients' decision making about place of care is complex, with numerous determinants influencing the final choice. Accountability to quality patient outcomes and fiscal responsibility confirms the need to practically and pragmatically address patients' end-of-life decision making needs. Nurses believe they have a role in providing decision support, but lack skills, confidence and tools. These barriers can be addressed with a multi-faceted educational program and a PtDA.

Implementation of the multifaceted intervention on a broader scale may help to improve end-of-life care planning leading to better quality of life for patients and families, more effective use of health resources, and less emergent contact with health care providers. Timely access to PtDAs and decision coaching may help patients to better match their place of end-of-life care with their informed preferences. However, full implementation of the multi-faceted intervention requires examination of broad system perspectives. To ensure sustainability and responsiveness to patient needs, contextual barriers within practice environments with accompanying macro-level policy support should be addressed and patient outcomes evaluated. By customizing educational processes for building capacity in providing decision support to local realities and carefully monitoring outcomes and progress, population-based coverage is possible. The final outcome will be relief of unresolved

decisional conflict related to place of end-of-life care and improvement in the quality of life for patients and families living with advanced end-stage illness.

Table 9.1: Implications for Practice, Education, Policy and Research and Associated Outcomes

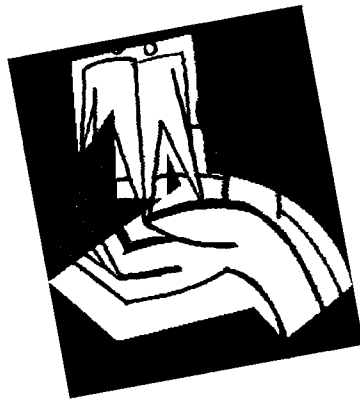
Study conclusions	Recommendation (<i>Domain impacted</i>)	Intermediate Outcomes (<i>Domain impacted</i>)	Long Term Outcomes (<i>Domain impacted</i>)
Stated preference, care-giver presence and contact patterns with health care services influences place of end-of-life cancer care	Develop an educational intervention and advocacy tools to engage media and heighten public awareness of place of end-of-life care options (<i>Education</i>)	- Media and public awareness campaign initiated (<i>Education</i>) - Place of end-of-life care will be expressly explored and documented during advance care planning discussions (<i>Practice</i>)	- Increased public, media and health professional awareness of options for place of end-of-life care (<i>Education</i>) - Place of end-of-life care matches patients informed preferences (<i>Practice</i>)
Patient decision support for place of end-of-life care is an important part of patient-centered care	- Ensure that informed consent laws and regulations include requirements for patient decision support documentation (<i>Policy</i>) - Establish an inventory and distribution system for validated, evidence based place of care decision support tools (<i>Practice</i>)	- Consent policies incorporate decision support principles as priorities (<i>Policy</i>) - Funding and service delivery models established to support the provision of quality decision support in all settings where patients receive end-of-life care (<i>Policy</i>) - Accreditation standards reflect the provision of end-of-life decision support services (<i>Policy</i>)	- National policies and regulations support patient decision support as a core element of palliative care best practice (<i>Policy</i>) - Multiple health care organizations incorporate decision support into the end-of-life care strategies, programs and services (<i>Practice</i>) - Decision support services are adequately funded within provincial reimbursement programs (<i>Practice</i>) - Practitioners provide quality decision support tailored to meet patients needs (<i>Practice</i>)
Lack of skills, confidence and tools are barriers to implementing decision	Incorporate core competencies of patient decision support onto undergraduate and post graduate curricula and continuing education curricula for practicing professionals	- Education programs provide: - Core knowledge and skills in patient decision support to many practicing health professionals	- A large number of professional and non-professional practitioners have core knowledge of patient decision support (<i>Practice</i>) - A significant number of oncology/palliative experts have

Study conclusions	Recommendation (Domain impacted)	Intermediate Outcomes (Domain impacted)	Long Term Outcomes (Domain impacted)
support for place of end-of-life care	(Education) • Include questions on end-of-life decision support in undergraduate and post graduate examinations required for certification and registration (Education). • Develop a specialized program to provide advanced training in decision support for oncology/palliative care experts who will staff national centers of excellence and provide consultation education and mentorship to primary and secondary level practitioners (Education)	and non-professionals (i.e.: non-regulated practitioners) ○ Expert knowledge and skills to few selected health professionals who will lead end-of-life care service planning and delivery ○ Education in professional curriculum (nursing, medicine, pharmacy, social work, psychology) (Education)	advanced knowledge and skills in patient decision support (Practice) • All health care trainees and newly registered professionals have core patient decision support knowledge and skills (Practice)
An evidence based intervention combining a specific place of care PtDA and opportunities for audit and feedback is an effective strategy to enhance practitioners' quality of	• Patient decision support for end-of-life care included in advance care planning (Practice) • Evaluate the effect of high quality decision support for end-of-life care on patient and family experience of health care (i.e.: qol; bereavement risk) practitioners outcomes (i.e.: retention, burnout), organization outcomes (i.e.: ER visits, after hours crisis calls to practitioners) and system outcomes (i.e.: service cost effectiveness)	• End-of-life patient decision support services are functional within Centers of Excellence (Practice) • Advance care planning is initiated in community and health care organizations that provide care to patients living with advanced end stage illness (Practice) • National and organizational quality initiatives include assessment of decision support provided to patients living with advanced end	• Communities support patient decision support as a core element of palliative care delivery (Practice) • Good coverage (i.e.: 80%) of the patients living with end stage illness have their decisional needs for end-of-life care assessed and addressed (Practice) • Quality of life is improved for patients and families (as identified by select outcome indicators such as reduced ER visits, unplanned admissions to facilities, reduced after hours calls for crisis health care) (Practice)

Study conclusions	Recommendation (Domain impacted)	Intermediate Outcomes (Domain impacted)	Long Term Outcomes (Domain impacted)
decision support for place of end-of-life care.	(Research) • Explore organizational and system barriers and facilitators to practitioners providing high quality decision support to patients living with end stage illness (Research) • Replicate this study province wide in real time with real patients living with a variety of end stage illnesses (Research) • Conduct a longitudinal study monitoring the impact of decision support at end-of-life on patient, family and health service outcomes (Research)	stage disease (Practice) • A funded program of end-of-life research is underway to facilitate an inventory of validated decision support tools relevant to end-of-life situations (Research)	• Benchmarking/accreditation process is underway to compare and improve decision support services in end-of-life care (Practice) • End-of-life best practice guidelines for end-of-life care are based on the synthesis of sound evidence, incorporate patient preferences, are updated on a regular basis and include evidence based implementation strategy (Practice). • Consumption of end-of-life decision support tools is increased (Practice)

Chapter 10

Contributions of Collaborators



Chapter 10 describes the contributions of collaborators in accordance with guidelines of the Faculty of Graduate and Postgraduate Studies at the University of Ottawa. Operational and personal support is also acknowledged.

Contribution of Collaborators

Research Collaborators

Mary Ann Murray RN, MScN, PhD(c) (MAM) conceptualized, participated in and led all aspects of the research study as part of the requirements for completion of the degree of Doctorate in Philosophy at the University of Ottawa. Collaborators were selected in order to gain a broad perspective on the development of new knowledge in patient decision support, practitioner education and end-of-life care.

MAM, is a nurse with expertise in palliative care research and clinical practice, decision support, education for nurses and patient education. MAM holds Canadian Nurses' Association specialty certification in oncology, gerontology, and hospice palliative care. MAM is an associate member of the Nursing Best Practice Research Unit, a joint initiative between the Registered Nurses Association (RNAO) and the University of Ottawa. MAM received a doctoral training award from the Canadian Institute of Health Research (CIHR) and an award from the National Cancer Institute of Canada as well as a Scholarship of Excellence from the University of Ottawa.

Thesis committee members, Dr. Annette M. O'Connor (AO), Dr. Dawn Stacey (DS) and Dr. Keith G. Wilson (KW), collaborated in the development of the research proposal, provided consultation throughout the research process, participated in the analysis and interpretation of results, and contributed to the intellectual content of the included manuscripts and final version of the thesis document (Table 10.1)

AO, an internationally recognized researcher and senior Ottawa Health Research Institute scientist, was the thesis supervisor. AO holds a Canada Research Chair award in consumer decision making and has expertise in decision support with the development and

evaluation of a framework, tools, and evaluation measures for patient decision support and PtDAs. She is a professor at the University of Ottawa, Faculty of Health Sciences (School of Nursing) and Faculty of Medicine (Department of Epidemiology and Community Medicine) and a visiting professor at Dartmouth Hitchcock Medical School.

DS is a PhD prepared registered nurse with clinical and research expertise in cancer, decision support, PtDAs, decision coaching, interprofessional practice and education, and knowledge translation. DS is an assistant professor in the School of Nursing at the University of Ottawa, member of the Nursing Best Practice Research Unit, and an associate scientist at the Ottawa Health Research Institute. She is certified in the specialty of oncology nursing by the Canadian Nurses' Association.

KW is a clinical psychologist with extensive expertise in palliative care practice, research applications and methods. KW has significant experience conducting qualitative and quantitative research involving the needs of palliative patients. KW is a mentor with the CIHR Strategic Training in Palliative Care Research Training Program and a member of the End-of-life Care for Seniors New Emerging Team. KW is an associate professor of medicine and psychology at the University of Ottawa.

Additional research staff and consultants included statisticians, a researcher with expertise in qualitative analysis and nurses experienced in the provision of post licensure nursing education. Mary Ellen Macdonald PhD, a sociologist with expertise in qualitative methods, provided consultation on qualitative analysis and shared her expertise in deductive content analysis. MJ Jacobsen RN, MEd and Jennifer Kryworuchko RN PhD(c) (JK) facilitated the skills building workshop. JK also participated in data interpretation of the systematic review and coding and interpretation of data for the qualitative needs assessment. Valerie Fiset, RN, MScN (VF) and Sandra Young RN MScN (SY) participated in data review and quality assessments for the systematic review. Debbie Morris, an administrative assistant

with OHRI co-ordinated access to the online auto-tutorial. Liz Drake MHA, administrative co-ordinator from OHRI helped to manage research grant funds. Research assistant Prudy Menard RN MScN co-ordinated scheduling for the simulated patient calls. Research assistants Sara Khangura and Lee Anne Coward rated simulated patient calls. Jim Jaffey MSc and Elhan Sabri, members of the OHRI methods department provided statistical advice on sample size calculations, approaches to dealing with missing data and quantitative statistical analysis.

Photographs from the section pages are by photojournalist Roger Lemoyne and are available from Living Lessons® (<http://www.living-lessons.org/main/photos.asp>). The sponsor, Glaxo-Klein has given permission for these photos to be used for building public awareness of end-of-life issues.

Manuscript Co-authors

Authorship for the included manuscripts was based on International Committee of Medical Journal Editors authorship guidelines (International Committee of Medical Journal Editors, 2008) and recommendations for doctoral research publication described by Morse (Morse, 2009). All members of the thesis committee participated in the key components necessary to qualify as authors:

- substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;
- drafting the article or revising it critically for important intellectual content; and
- final approval of the version to be published. Authors should meet conditions 1, 2, and 3. (International Committee of Medical Journal Editors, 2008)

MAM conceived the study, developed the protocol in collaboration with thesis committee members (AO, DS, KW), obtained research ethics board approval, recruited participants, collected, managed data, analyzed data in collaboration with co-authors, drafted manuscripts and refined manuscripts in collaboration with co-authors (AO, DS, KW, JK, VF,

SY). All co-authors approved final manuscripts which included reviewing peer reviewers' comments and responses to editor. Specific contributions are outlined in Table 10.1.

Table 10.1: Summary of Author Contributions

Element	Manuscript			
	Where the Dying Live: A systematic review of determinants of place of end-of-life cancer care	Efficacy of a training intervention on the quality of practitioners' decision support for patients deciding about place of care at the end-of-life: A randomized control trial: Study protocol	Nurses Perceptions of Factors Influencing the Patient Decision Support around Place of Care at the End-of-life	Efficacy of an evidence-based educational intervention to strengthen practitioners decision support skills for place of end-of-life care: A randomized control trial
Conceptualize & design	MAM	MAM	MAM	MAM
Collect data	MAM	MAM	MAM	MAM
Analyze & interpret data	MAM VF SY JK	MAM	MAM JK KW	MAM DS KW
Draft manuscript	MAM	MAM	MAM	MAM
Revise manuscript for important intellectual content	MAM VF SY JK	MAM AO DS KW	MAM AO DS KW JK	MAM AO DS KW
Approve final version to be published	MAM AO VF SY JK	MAM AO DS KW	MAM AO DS KW JK	MAM AO DS KW
Responsible for overall content	MAM	MAM	MAM	MAM

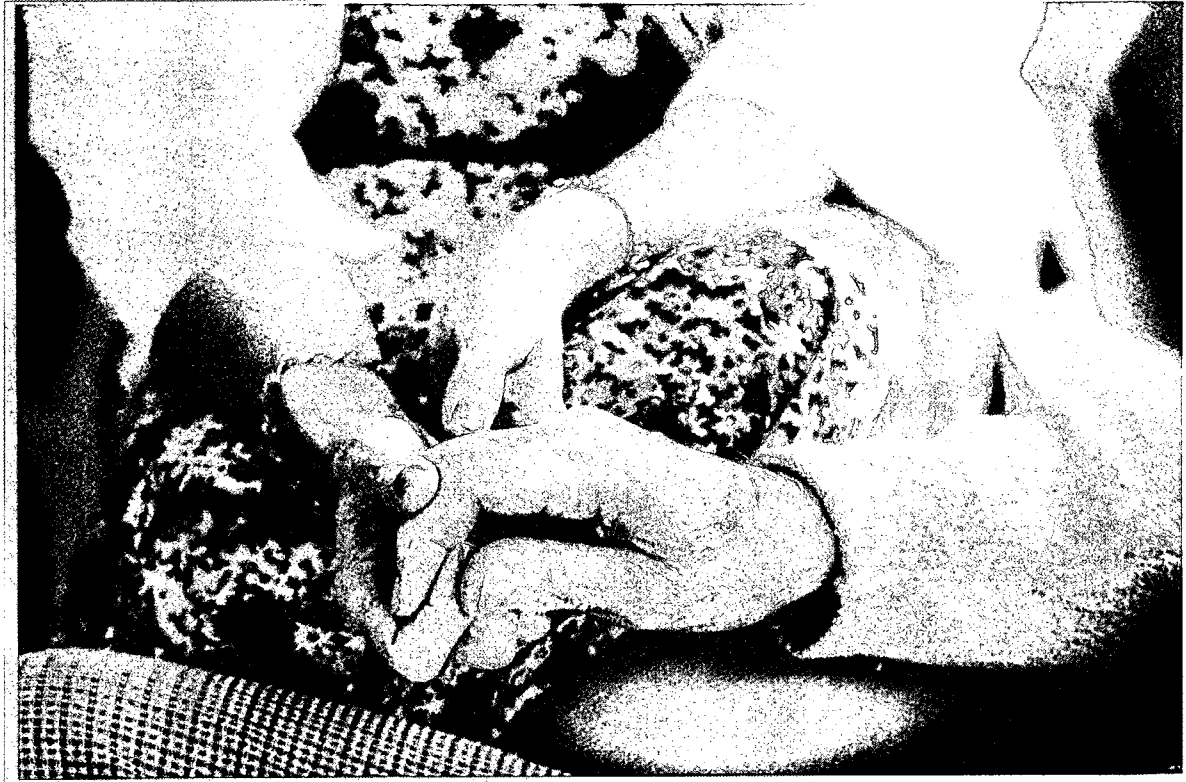
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- Canadian Federation of University Women
- Canadian Nurses Foundation
- Foundation for Informed Medical Decision Making
- National Cancer Institute of Canada Socio-Behavioral Cancer Network
- Registered Nurses Foundation of Ontario Parent Board
- University of Ottawa Scholarship of Excellence

SECTION 6

REFERENCES & RELATED APPENCICES



COMMON REFERENCES FOR NON-MANUSCRIPT ELEMENTS OF THESIS

Note: References linked to manuscripts have been maintained with the associated manuscript and formatted according criteria established by the journal to which the manuscript was submitted

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Appendix A

Letters of Support

1. Ontario Association for Community Care Access Centers
2. The Ottawa Hospital
3. South East Community Care Access Center
4. Saint Elizabeth Health Care

December 15, 2006

Research Ethics Board
University of Ottawa
Ottawa, Ontario

Re: Research proposal entitled: Efficacy of a Training Intervention on the Quality of Patient Case Coordinators and Nurses' Decision Support for Patients Deciding about the Place of Care at the End-of-Life: A Randomized Control Trial

Dear University of Ottawa Research Ethics Board Members,

On behalf of the Ontario Association of Community Care Access Centres (OACCAC), I am pleased to offer this letter of support in principle for Mary Ann Murray's University of Ottawa, School of Nursing Doctoral program research proposal entitled: *Efficacy of a Training Intervention on the Quality of Patient Case Coordinators and Nurses' Decision Support for Patients Deciding about the Place of Care at the End-of-Life: A Randomized Control Trial*.

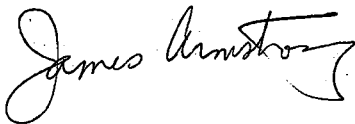
Promoting health by simplifying access and managing care across the health system and helping people make informed decisions concerning their health care are key goals of the Community Care Access Centres. In keeping with the Ontario Ministry of Health and Long Term Care strategic directions for enabling more choices for people on how they can live out their remaining days, this research project is timely and relevant.

An area we would like to strengthen and evaluate is the provision of patient decision support by our professionals providing end-of-life care. As well, we are particularly interested in learning about the factors influencing the provision of patient decision support in the context of end-of-life care. This information will be relevant for future development of our program services and professional development programs.

Subject to approval of the University of Ottawa Research Ethics Board the OACCAC will support the conduct of this study. We will facilitate entry to host CCAC agencies by sending Ontario CCACs a letter outlining the study and our endorsement as being relevant and valuable to the goals of Ontario CCAC's. We note that the researcher will undertake all recruitment and that participation is voluntary; program directors or supervisors will not recruit participants.

We look forward to collaborating on this research proposal to enhance the quality of patient decision support regarding end-of-life place of care for cancer patients and their families. Please do not hesitate to contact me if further information is required.

Sincerely,

A handwritten signature in black ink, appearing to read "James Armstrong". The signature is fluid and cursive, with a large initial "J" and a long, sweeping underline.

James Armstrong, PhD
Chief Executive Officer



January 31, 2007

Re: Research proposal entitled: Efficacy of a Training Intervention on the Quality of Patient Case Coordinators and Nurses' Decision Support for Patients Deciding about the Place of Care at the End of-Life: A Randomized Control Trial

Dear University of Ottawa Research Ethics Board Members,

On behalf of Saint Elizabeth Health Care (SEHC), I am pleased to offer this letter of support in principal for Mary Ann Murray's University of Ottawa, School of Nursing Doctoral program research proposal entitled: *Efficacy of a Training Intervention on the Quality of Patient Case Coordinators and Nurses' Decision Support for Patients Deciding about the Place of Care at the End of-Life: A Randomized Control Trial*.

Promoting health by simplifying access to information, education and care to help people make informed decisions concerning their health care are key goals of SEHC. In keeping with The Ontario Ministry of Health and Long-Term Care strategic directions for enabling more choices for people on how they can live out their remaining days this research project is timely and relevant.

An area we would like to strengthen and evaluate is the provision of patient decision support by our professionals providing end of life care. As well, we are particularly interested in learning about the factors influencing the provision of patient decision support in the context of end of life care. This information will be relevant for future development of our program services and professional development programs.

Subject to approval of the University of Ottawa Research Ethics Board SEHC will support the conduct of this study. We will facilitate access to our nursing staff through our Clinical Consultant for Palliative Care, and fully support their participation in this study. We note that the researcher will undertake all recruitment and that participation is voluntary; program directors or supervisors will not recruit participants.

We look forward to collaborating on this research proposal to enhance the quality of patient decision support regarding end of life place of care for cancer patients and their families. Please do not hesitate to contact me if further information is required.

Sincerely,

Nancy Lefebvre
Chief Clinical Executive
SVP, Knowledge and Practice

South East
Community Care Access Centre



Centre d'accès aux soins communautaires
du Sud-Est

Head Office
1471 John Counter Blvd
Suite 300
Kingston ON K7M 8S8
Tel.: 613 544 8200
Fax: 613 544 3888

Siège sociale
1471, boul. John Counter
Bureau 300
Kingston ON K7M 8S8
Tél.: 613 544 8200
Télééc: 613 544 3888

February 1, 2007

Research Grants and Ethics Services
Tabaret Hall (159)
550 Cumberland Street
Ottawa, ON K1N 6N5

Re: Research proposal entitled: *Efficacy of a Training Intervention on the Quality of Patient Case Coordinators and Nurses' Decision Support for Patients Deciding about the Place of Care at the End of-Life: A Randomized Control Trial*

Dear University of Ottawa Research Ethics Board Members,

On behalf of the South East Community Care Access Centre I am pleased to offer this letter of support in principal for Mary Ann Murray's University of Ottawa, School of Nursing Doctoral program research proposal entitled: *Efficacy of a Training Intervention on the Quality of Patient Case Coordinators and Nurses' Decision Support for Patients Deciding about the Place of Care at the End of-Life: A Randomized Control Trial*.

The key goals of the Ontario Community Care Access Centres (OCCAC) is to promote health by simplifying access and managing care across the health system and helping people make informed decisions concerning their health care. In keeping with the Ontario Ministry of Health and Long-Term Care strategic directions for enabling more choices for people on how they can live out their remaining days, this research project is timely and relevant.

An area we would like to strengthen and evaluate is the provision of patient decision support by our professionals providing end of life care. As well, we are particularly interested in learning about the factors influencing the provision of patient decision support in the context of end of life care. This information will be relevant for future development of our program services and professional development programs.

Subject to approval of the University of Ottawa Research Ethics Board the South East Community Care Access Centre will support the conduct of this study. We will facilitate entry to host CCAC agencies by

sending Ontario CCACs a letter outlining the study and our endorsement as being relevant and valuable to the goals of Ontario CCACs. We note that the researcher will undertake all recruitment and that participation is voluntary; program directors or supervisors will not recruit participants.

We look forward to collaborating on this research proposal to enhance the quality of patient decision support regarding end of life place of care for cancer patients and their families. Please do not hesitate to contact me if further information is required.

Sincerely,

A handwritten signature in black ink, appearing to read "Stacey Roques". The signature is fluid and cursive, with the first name "Stacey" being more prominent than the last name "Roques".

Stacey Roques,
Senior Director, Client Services



The Ottawa Hospital | L'Hôpital
d'Ottawa

December 20, 2006

Re: Research proposal entitled: Efficacy of a Training Intervention on the Quality of Patient Case Coordinators and Nurses' Decision Support for Patients Deciding about the Place of Care at the End of-Life Randomized Control Trial

Dear University of Ottawa Research Ethics Board Members,

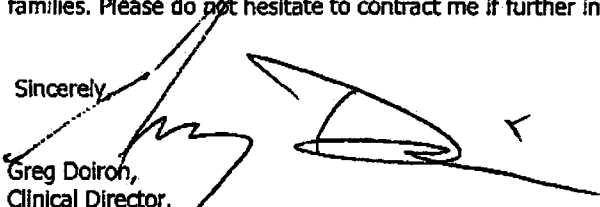
On behalf of The Ottawa Hospital Regional Cancer Centre I am pleased to offer this letter of support in principal for Mary Ann Murray's University of Ottawa, School of Nursing Doctoral program research proposal entitled: *Efficacy of a Training Intervention on the Quality of Patient Case Coordinators and Nurses' Decision Support for Patients Deciding about the Place of Care at the End of-Life: A Randomized Control Trial*.

Partnership in care and enabling people to participate in making health decisions are central elements of the philosophy underlying of the Ottawa Hospital Oncology Program. An area we would like to strengthen and evaluate is the provision of patient decision support by nurses and case co-ordinators related to place of end of life care options. As well, we are particularly interested in learning about the factors influencing the provision of patient decision support. This information will be relevant for future development of Ottawa Oncology program services and professional development programs.

Subject to approval of the University of Ottawa Research Ethics Board the Ottawa Hospital Regional Cancer Centre will support the conduct of this study. We will facilitate entry to the agency by the researcher; provide access to staff through email explaining the study with contact information for the investigator and space to post study information posters, facilitate staff to participate in the survey, interviews and training, facilitate the use of a room to hold the workshop, facilitate the use of simulated callers for evaluation. We note that the researcher will undertake all recruitment and that participation is voluntary; program directors or supervisors will not recruit participants.

We encourage you to seriously consider this research proposal and look forward to applying the results of this work in our effort to improve the quality of patient decision support regarding end of life place of care for cancer patients and their families. Please do not hesitate to contact me if further information is required.

Sincerely,


Greg Doiron,
Clinical Director,
The Ottawa Hospital Regional Cancer Centre

Appendix B

Ethical Approvals

1. The University of Ottawa
2. The Ottawa Hospital
3. SCOHS (now Bruyere Continuing Care)



Université d'Ottawa University of Ottawa

Service de subventions de recherche et déontologie Research Grants and Ethics Services

HEALTH SCIENCES AND SCIENCE RESEARCH ETHICS BOARD

CERTIFICATE OF ETHICAL APPROVAL

This is to certify that the University of Ottawa Health Sciences and Science Research Ethics Board has examined the application for ethical approval of the research project entitled **“Efficacy of a training intervention on the quality of case managers and nurses decision support for patients deciding about place of care at the end-of-life: a randomized control trail (file # H-01-07-09)”** submitted by Annette O'Connor of the School of Nursing & Clinical Epidemiology Program. The Board found that this research project met appropriate ethical standards as outlined in the Tri-Council Policy Statement and in the Procedures of the University of Ottawa Research Ethics Boards, and accordingly gave it a Category 1a (approval). This certification is valid one year from the date indicated below.

Date: March 9, 2007

Dorothyann Curran
Protocol Officer for Ethics in Research
For Dr. Daniel Lagarec, Chair of the
Health Sciences and Science REB

550, rue Cumberland 550 Cumberland Street
Ottawa (Ontario) K1N 6N5 Canada Ottawa, Ontario K1N 6N5 Canada

(613) 562-5841 • Téléc./Fax (613) 562-5338
<http://www.uottawa.ca/services/research/rge/index.html>



The Ottawa Hospital | L'Hôpital d'Ottawa

**Research Ethics Board
Conseil d'éthique en recherches**
798-5555 ext 14146, 14902 or 15072
Fax No. ~ 761-4311
<http://www.ohri.ca/ohreb/>

Monday, April 23, 2007

Ms. Mary Ann Murray
53 Woodhall Crescent
Gloucester, Ontario
K1B 3B7

Dear Ms. Murray:

Re: Protocol # 2007098-01H Efficacy of a Training Intervention on the Quality of Care Coordinators and Nurses Decision Support for Patients Deciding About Place of Care at the End-of-Life: A Randomized Control Trial

Protocol approval valid until - Tuesday, April 22, 2008

I am pleased to inform you that your study (listed above), the Protocol dated 20/10/06, the English Needs Assessment Individual Interview Guide, the English Pre Intervention Questionnaire, the English Post Intervention Questionnaire, the English and French Flyers, the English Information Sheet, the English Consent Form - Individual Interviews (Phase 1 of study), and the English Consent Form - Education Program (Phase 2 of study) were given expedited review by the Ottawa Hospital Research Ethics Board (OHREB) and are approved. No changes, amendments or addenda may be made in the protocol without the OHREB review and approval.

The validation dated should be indicated on the bottom of all consent forms and information sheets (see copy attached). Approximately two months prior to the expiration date listed above, a single renewal form should be sent to the OHREB office.

The Tri-Council Policy Statement requires a greater involvement of the OHREB in studies over the course of their execution. The OHREB will review the new information to determine if the protocol should be modified, discontinued, or should continue as originally approved.

Yours sincerely,

Raphael Saginur, M.D.
Chairman
Ottawa Hospital Research Ethics Board

Encl.

/cb



Centre de santé Élisabeth-Bruyère
Élisabeth Bruyère Health Centre
43, rue Bruyère St.
Ottawa (Ontario) K1N 5C8
Tél./Tel.: 613-562-0050
Télééc./FAX: 613-562-6367

Hôpital Saint-Vincent
Saint-Vincent Hospital
60, rue Cambridge St. N.
Ottawa (Ontario) K1R 7A5
Tél./Tel.: 613-233-4041
Télééc./FAX: 613-782-2785

Résidence Saint-Louis
879, ch. Hiawatha Park Rd.
Orléans (Ontario) K1C 2Z6
Tél./Tel.: 613-824-1720
Télééc./FAX: 613-824-8064

Villa Marguerite
75, rue Bruyère St.
Ottawa (Ontario) K1N 5C8
Tél./Tel.: 613-562-6369
Télééc./FAX: 613-562-4223

Fondation du Service de santé SCO
SCO Health Service Foundation
43, rue Bruyère St.
Ottawa (Ontario) K1N 5C8
Tél./Tel.: 613-562-6319
Télééc./FAX: 613-562-6023

Institut de recherche Élisabeth-Bruyère
Élisabeth Bruyère Research Institute
43, rue Bruyère St.
Ottawa (Ontario) K1N 5C8
Tél./Tel.: 613-562-6045
Télééc./FAX: 613-562-4256

Centre de médecine familiale Bruyère
Bruyère Family Medicine Centre
75, rue Bruyère St.
Ottawa (Ontario) K1N 5C8
Tél./Tel.: 613-241-3344
Télééc./FAX: 613-241-1971

Centre de médecine familiale Primrose
Primrose Family Medicine Centre
35, rue Primrose St.
Ottawa (Ontario) K1R 0A1
Tél./Tel.: 613-230-7788
Télééc./Fax: 613-230-7778

mailrequest@scohs.on.ca
www.scohs.on.ca

Affilié à / Affiliated with



uOttawa

L'Université canadienne
Canada's university

May 19, 2007

Mary Ann Murray
53 Woodhill Crescent
Ottawa, ON
K1B 3B7

RE: Efficacy of a Training Intervention on the Quality of Case Managers and Nurses Decision Support for Patients Deciding about Place of Care at the End of-Life: A Randomized Control Trial

Dear Mary Ann Murray,

Thank you for your revised Research Ethics Board Application, your letter of May 16, 2007 and the documentation of Dr. O'Connor's appointment to the EBRI that you have sent me in response to my letter of May 8, 2007.

I am writing to inform you that you have addressed all of the issues raised by the Research Ethics Board reviewers. It is therefore with pleasure that the SCC Health Service Research Ethics Board (REB) gives ethical approval for one year to proceed with your study.

Please note that any future changes to the protocol must be submitted to the REB for approval. You are also expected to provide notification of the termination of the study.

We wish you much success with this study.

Best regards,

Dr. Richard Blair
Director, Ethics
Chair of the SCO Research Ethics Board
SCO Health Service
43 Bruyere St.
Ottawa, Ontario
K1N 5C8

(613) 562-4262 ext 4002
rblair@scohs.on.ca

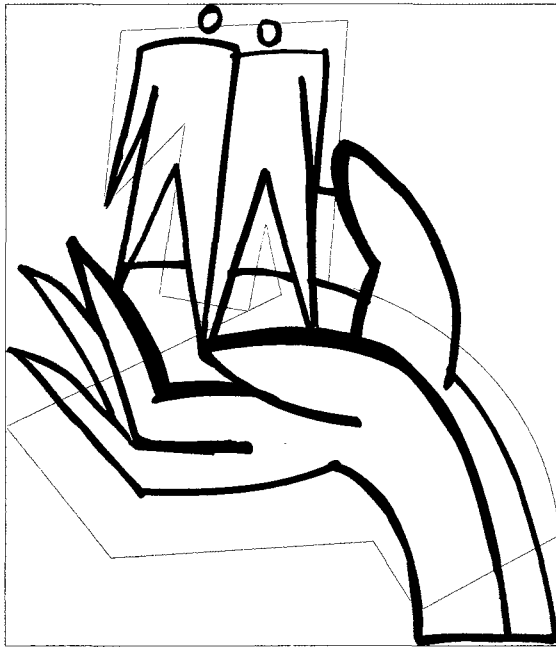
Appendix C

Recruitment Flyers

1. Brief Flyer
2. Detailed Flyer

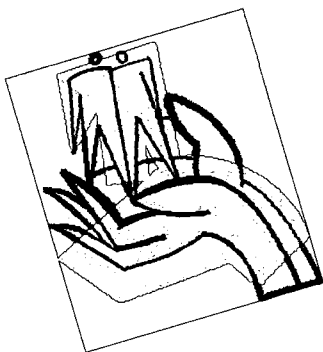
Efficacy of a Training Intervention on the Quality of Nurses' and Care Coordinators Decision Support for Patients Deciding about the Place of Care at the End of-Life

A University of Ottawa Research Study



Are you a full or part time case manager or nurse????
Do you work with oncology patients who have advanced disease and or
palliative patients????
Do you work in a setting where place of end-of-life discussions occur???
Are you interested in strengthening your skills in providing patient
decision support????

**For more information please call Mary Ann Murray RN (613) 837 7284 or email
mmurr070@uottawa.ca**



You are invited to participate in:

A research study to enhance decision support by nurses and care coordinators for patients making decisions about place of care at the end-of-life

Two Projects

1. **Survey of Barriers:** to understand barriers and supports to providing patient decision support. We are inviting nurses, care coordinators, educators and managers to participate in a brief interview. It will take about 20-30 minutes.
2. **Educational Program:** to enhance knowledge and skills in providing decision support particularly for decisions about place of care at the end-of-life. We are looking for 75 nurses and care coordinators who work with patients with advanced cancer and or palliative patients. Participating involves about 6 hours of education, completing 4 questionnaires that will require about 10-15 minutes each to complete.

By participating, you will have a chance to....

- Enhance your knowledge and skills
- Meet CNO and other regulatory colleges requirements for continued learning
- Discuss these types of situations with other nurses and care coordinators
- Be a leader in expanding the ways to support and empower patients to be involved in their health

As a research study:

Saint Elizabeth's Health Care Agency, Toronto Central CCAC, South Eastern CCAC, The Ottawa Hospital, Queensway Carleton Hospital, Hospice at May Court, SCO Health Services and Carefor Nursing Agency have provided approval for this study

The study has received ethical approval from the University of Ottawa Research Ethics Board

Joining this study is your choice and you may withdraw from the study at any time without negatively affecting your position with your employer

Confidentiality will be maintained using code numbers; no personal identifying information will appear in any publications

To find out more about these two projects, please contact
Mary Ann Murray at 613 837 7284 or email at maryannmurray@rogers.com
When is the study happening? March 2007-Sept 2007

Appendix D

Consent for Individual Interviews: Needs Assessment (Nurses Views on Patient Decision Support for Place of End-of-life Care)

CONSENT FORM – Individual Interviews (Phase 1 of study)
Efficacy of a Training Intervention on the Quality of Care Coordinators' and Nurses'
Decision Support for Patients Deciding about the Place of Care at the End of-Life

Research Team: Mary Ann Murray RN MScN, PhD(c), Dr. Annette O'Connor RN PhD., Dr. Dawn Stacey RN, PhD., and Dr. Keith Wilson PhD.

Purpose of the Study:

Researchers at the University of Ottawa are testing the design, implementation and evaluation of a patient decision support strategy. As part of developing the education strategy we would like to get a better understanding of the perspectives of professionals who are involved in planning, delivering, teaching and evaluating palliative and oncology care. This will help us to develop education strategies to better meet the needs of nurses and care coordinators such as case managers.

Your participation would involve:

1. Taking part in a face-to-face interview. The purpose is to discuss your views about factors influencing case managers' and home visit nurses' provision of decision support, as well as barriers and facilitators to providing decision support to palliative/oncology patients who are facing decisions regarding place for end-of-life care. You will also be asked to identify strategies that could be used to address any barriers and enhance the facilitators. The interview will take about 30-45 minutes and will be audio-taped.
2. Reviewing a summary of the results of all of the interviews. You will be asked to verify that the results reflect your main thoughts that you shared during the interview and identify any concerns or errors regarding the interpretation.

How would the interview be conducted?

We will arrange a convenient time and location to meet with you. The interviewer is a nurse who has experience in palliative care and decision support. The interview will be audio-taped so that we can compare your responses to those of other participants.

What will happen to the information I share in the interview?

Your comments will be transcribed and reviewed by the research team to identify your main thoughts. The tape and transcripts will be kept in a locked cabinet in a secure office at the Ottawa Health Research Institute for 10 years and then will be destroyed.

Your comments and responses to the interview questions will be kept strictly confidential and your responses will be anonymous. All information you share with the interviewer will only be available to the research team and if requested to the Research Ethics Board of the University of Ottawa. If the results of the study are published or shared in presentations, your name will not be associated with the data.

Are there any risks or benefits to participation?

Your decision about participation is voluntary, and will not affect your position in any way. There are no known risks of taking part in this study. A potential inconvenience is the time taken in participating in the interview and review of the summary. There are no direct benefits for participants. Overall the possible benefits of the study include helping to shape an educational intervention related to patient decision support that would be helpful to care coordinators and nurses in the future. As well, this educational program may help us to develop better ways to help to support patients who are facing tough decisions.

What are my rights as a participant?

Joining this study is your choice. You are under no obligation to take part in the study and you may stop the interview at any time. You can refuse to answer any individual question in the interview. Should you wish to discontinue the interview you will be asked if information you shared before withdrawing can be included in the study

If I have any questions about the study, now or later you may call the leader of the research team (Mary Ann Murray) at (613)837 7284 or email maryannmurray@rogers.com. If you have any questions about your rights as a research subject, you may contact the Protocol Officer for Ethics in Research at the University of Ottawa, Room 159, 550 Cumberland Street, Ottawa, Ontario, K1N 6N5, ethics@uottawa.ca

Will I be compensated for my participation?

A donation to the education fund of your organization will be made to acknowledge your time.

Can I obtain the results from the study once it is completed?

Yes, a summary of the findings will be compiled and made available to you if you wish

If I decide to stop the interview what will happen to information I shared before deciding to withdraw from the study?

You will be asked to indicate if the information you have provided before withdrawing can be used in data analysis or if you wish to have the data destroyed and not used in the data analysis.

Please initial one of the following options:

- ☐ In the event of my withdrawal from the study, I would agree to have information I have shared to that time included in the data analysis
- ☐ In the event of my withdrawal from the study, I do not agree to have information I have shared to that time included in the data analysis and would like any data shared by me destroyed.

Consent:

I have read the above information and understand this consent form. I have also had the chance to ask questions and they have been answered to my satisfaction. I am aware that I am to keep one of the two copies of this consent form. I agree to take part in this study. You will be given a copy of this consent form for your records.

With full knowledge of this, I voluntarily consent to participate in the study.

Participant's Name (printed)

Participant's Signature

Date

Investigator/Delegate's Name (printed)

Investigator/Delegate's Signature

Date

I wish to receive a summary of the study findings? Yes ☐ No ☐

Participant's Name (printed)

Participant's Signature

Date

For questions about this study, please contact:

Mary Ann Murray RN MScN, PhD candidate (613) 837-7284 (Primary Investigator); Annette O'Connor RN PhD (613) 798 5555 ext. 17582 (Thesis supervisor); Dr. Dawn Stacey RN PhD (613) 562 5800 ext. 8419 (Thesis committee member); Dr. Keith Wilson PhD (613) 737 7350 ext. 75608 (Thesis committee member).

Appendix E

Interview Guide for Needs Assessment (Nurses Views on Patient Decision
Support for Place of End-of-life Care)

Phase 1: Needs Assessment Individual Interview Guide

Set up

- ☐ Arrange meeting time and location
- ☐ Bring water, juice
- ☐ Connect audio recorder
- ☐ Arrange chairs around table to improve visibility and discussion
- ☐ Create a non-judgemental supportive environment that encourages participant to share their views
- ☐ Ensure cell phone/pager off prior to interview commencing

Introduction

1. The purpose of this interview is to identify factors influencing Nurses providing decision support for terminally ill cancer patients facing decisions about end-of-life place of care

Preference sensitive decisions are those decisions in which the best choice is unclear because of inadequate evidence or the benefit/harm ratio is close. Therefore the best choice for these decisions depends on how the patient values the known benefits, harms and lack of evidence. For example, palliative patients thinking about place of care at the end-of-life may consider home or hospice. However these decisions require careful weighing of the associated pros and cons for each option and how much each pro or con is valued by the patient. We want to identify factors affecting nurses' intentions to provide decision support as well as barriers and supports to Case managers and nurses for providing decision support for situations similar the example of place of end-of-life care.

2. Assurance of confidentiality- Assure participants of anonymity and that although some information that they provide will be publishes, their name will not be associated with the specific published information or shared with their employer. Inform participants that they may stop the interview are any time or refrain for answering any questions and that there will be no negative consequences
3. Ground rules – There are no right or wrong answers- we are just trying to determine what factors influence Case managers and visit nurses intentions to provide decision support as well as barriers and supports for providing decision support for situations similar the example of place of end-of-life care.
4. Role of interviewer- facilitate progress through the questions and to take notes

- ☐ Informed consent explained and signed
- ☐ Sign in sheet with their email address to be able to send the results for their review
- ☐ Demographic questionnaire completed

Debriefing at end of interview:

Ask if there are any other comments the participant would like to share
Thank participants for their time and for sharing their thoughts

Interview guide

TPB element	Specific questions	Notes
Introductory questions	Part of the Ontario Ministry of Health goal is to help people to have more choices about place of care at the end-of-life. • What does that mean to you? • What role do case managers/ nurses role have in providing decision support to palliative patients regarding place of care at the end-of-life? • What do you believe to be the attributes of good decision support? • How well prepared are case managers and nurses to provide decision support to patients with advanced cancer and or palliative patients regarding place for end-of-life care? • What outcomes (for patients, the clinician, the organization, the health care system overall) occur when case managers and nurses provide decision support to patients with advanced cancer and or palliative patients regarding place of care at the end life? • What importance do you think your <i>managers and your organization</i> place on providing decision support to patients with advanced cancer and or palliative patients regarding place for end-of-life care • What importance do you think <i>other members of the professional interdisciplinary health care team</i> place on providing decision support to patients with advanced cancer and or palliative patients regarding place for end-of-life care? • What importance do you think <i>case managers and nurses</i> place on providing decision support to patients with advanced cancer and or palliative patients regarding place for end-of-life care?	
Attitudes	• What do you believe the <i>advantages</i> of case managers and nurses in providing decision support to patients with advanced cancer and or palliative patients regarding place of care at the end life? • What do you believe the <i>disadvantages</i> of case managers and nurses in providing decision support to patients with advanced cancer and or palliative patients regarding place of care at the end life? • Is there anything else you associate with case managers and nurses in providing decision support to patients with advanced cancer and or palliative patients regarding place of care at the end life?	
Norms	• Are their any individuals or groups who would <i>approve</i> of case managers and nurses providing decision support to patients with advanced cancer and or palliative patients regarding place for end-of-life care within their current duties? • Are their any individuals or groups who would <i>disapprove</i> of case managers and nurses providing decision support to patients with advanced cancer and or palliative patients regarding place for end-of-life care within their current duties?	

	Are there any other individuals or groups who come to mind when you think about case managers and nurses providing decision support to patients with advanced cancer and or palliative patients regarding place for end-of-life care within their current duties?	
Perceived control	- What factors or circumstances would make it <i>difficult</i> for case managers and nurses to provide decision support to patients with advanced cancer and or palliative patients regarding place for end-of-life care within their current duties? - What factors or circumstances would make it <i>easier</i> for case managers and nurses to provide decision support to patients with advanced cancer and or palliative patients regarding place for end-of-life care within their current duties? - Are there any other issues or circumstances that come to mind when you think about the difficulty case managers and nurses may have in providing decision support to patients with advanced cancer and or palliative patients regarding place for end-of-life care within their current duties? - What would help case managers/ nurses to enhance the support they provide to patients with advanced cancer and or palliative patients making decisions regarding place of care at the end-of-life?	

Demographics

Please tell me a bit about yourself....

- What is your position? (circle appropriate response)
 - Case manager (nurse)
 - Case manager (non nurse)
 - Inpatient care nurse
 - Community based nurse (home visit nurse)
 - Educator
 - Manager
 - Other _____
- How long have you been working in this role?

☐ 3 or fewer months	☐ 3-5 years
☐ 4 to 12 months	☐ 6 – 12 years
☐ 1- 2 years	☐ more than 13 years
- Are you currently working: ☐ Full-time ☐ Regular part-time
☐ FTE (full-time equivalent) status: _____
- Your age range:

☐ Under 29	☐ 40 to 49	☐ 60 and older
☐ 30 to 39	☐ 50 to 59	
- Your gender:

☐ Female	☐ Male
------------------------------	----------------------------
- Your highest level of education completed:

- ☐ College diploma (RN / RPN Diploma)
- ☐ Undergraduate university degree
- ☐ Graduate university degree
- ☐ Other, specify _____

7. How long have you been working with oncology patients with advanced diseases or palliative patients?

- | | | |
|---|--------------------------------------|--|
| ☐ Less than 2 years | ☐ 11 to 15 years | ☐ 26 to 30 years |
| ☐ 2 to 5 years | ☐ 16 to 20 years | ☐ more than 30 years |
| ☐ 6 to 10 years | ☐ 20 to 25 years | |

Thank you for participating in this interview

Appendix F

Consent for Phase 2: Implementation and Evaluation of a Multi-Faceted Education Program

CONSENT FORM - EDUCATION PROGRAM (Phase 2 of study)
Efficacy of a Training Intervention on the Quality of Care Coordinators' and Nurses'
Decision Support for Patients Deciding about the Place of Care at the End of-Life

Research Team: Mary Ann Murray RN MScN, PhD(c), Dr. Annette O'Connor RN PhD., Dr. Dawn Stacey RN, PhD., and Dr. Keith Wilson PhD.

Purpose of the Study:

Researchers at the University of Ottawa are testing the design, implementation and evaluation of a patient decision support strategy. The strategy involves an educational intervention. This strategy has the potential to help care coordinators such as case managers and nurses to build skills and confidence in providing patient decision support by a) use of an evidence-based, consistent approach to decision support and b) may help professional care coordinators nurses to feel more confident in providing decision support to patients and families facing decisions about place of end-of-life care.

Your participation would involve:

1. Responding to a call from a simulated patient (caller) according to your usual practice, after consenting to participate and again about 2 months later. A simulated caller is a person who has been coached to ask you for help regarding a health decision he/she is facing. The phone call will be audio-taped and should take about 10-20 minutes;
2. Being randomly (by chance) assigned to either be in the decision support education program or to be in the control group (and therefore do not receive the education program);
3. *If randomly selected to the decision support education program* participating in the following activities:
 - a. An online auto tutorial outlining patient decision support concepts, clinical examples and a patient decision support protocol;
 - b. A half day training workshop to practice using the decision support protocols with colleagues; and
 - c. A follow-up phone call with the workshop facilitator to answer any questions about using the protocol in practice, and
 - d. Providing feedback to the researchers on the acceptability of the components of the education program ;
4. Completing a knowledge questionnaire about patient decision support and place of end-of-life care determinants. As well, you would be asked to complete a survey regarding your satisfaction with patient decision support you provide and your use of patient decision support in your practice. Each questionnaire should take about 15-30 minutes to complete.

Are there any risks or benefits to participation?

Your decision about participation is voluntary, and will not affect your position in any way. There are no known risks of taking part in this study. A potential inconvenience is the time participating for responding to calls from simulated callers, educational program, and completing a survey. There are no direct benefits to participating in the study. Overall the possible benefits of the study include helping to shape an educational intervention related to patient decision support that would be helpful to case managers and home visit nurses in the future. As well, this educational program may help us to develop better ways to help to support patients who are facing tough decisions.

What are my rights as a participant?

Joining this study is your choice. You are under no obligation to take part in the study and you may withdraw from the study at any time. If you withdraw from the study, any data you have provided up to the time of withdrawal will be used in the data analysis.

The information collected during the study will be kept confidential. A code number will be used to identify any data collected (audio-tapes, transcripts, questionnaires). If the results of the study are published or shared in presentations, your name will not be associated with the data. All relevant information obtained from you will be only available to the research team and if requested to the Research Ethics Board of the University of Ottawa. All data related to the study will be kept in a locked cabinet in an office of the Ottawa Health Research Institute for ten years and will then be destroyed.

If I have any questions about the study, now or later you may call the leader of the research team (Mary Ann Murray) at (613) 837-7284 or email maryannmurray@rogers.com. If you have any questions about your rights as a research subject, you may contact the Protocol Officer for Ethics in Research at the University of Ottawa, Room 159, 550 Cumberland Street, Ottawa, Ontario, K1N 6N5, ethics@uottawa.ca

If I decide to stop the interview what will happen to information I shared before deciding to withdraw from the study?

You will be asked to indicate if the information you have provided before withdrawing can be used in data analysis or if you wish to have the data destroyed and not used in the data analysis.

Please initial one of the following options:

- ☐ In the event of my withdrawal from the study, I would agree to have information I have shared to that time included in the data analysis
- ☐ In the event of my withdrawal from the study, I do not agree to have information I have shared to that time included in the data analysis and would like any data shared by me destroyed.

Will I be compensated for my participation?

A donation to the education fund of your organization will be made to acknowledge your time

Can I obtain the results from the study once it is completed?

Yes, a summary of the findings will be compiled and made available to you if that is your wish.

Consent:

I have read the above information and understand this consent form. I have also had the chance to ask questions and they have been answered to my satisfaction. I am aware that I am to keep one of the two copies of this consent form. I agree to take part in this study.

You will be given a copy of this consent form for your records.

With full knowledge of this, I voluntarily consent to participate in the study.

Participant's Name (printed)

Participant's Signature

Date

Investigator/Delegate's Name (printed)

Investigator/Delegate's Signature

Date

I wish to receive a summary of the study findings? Yes ☐ No ☐

Participant's Name (printed)

Participant's Signature

Date

For questions about this study, please contact:

Mary Ann Murray RN MScN, PhD candidate (613) 837-7284 (Primary Investigator); Annette

O'Connor RN PhD (613) 798 5555 ext. 17582 (Thesis supervisor); Dr. Dawn Stacey RN PhD

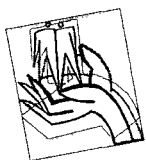
(613) 562 5800 ext. 8194 (Thesis committee member); Dr. Keith Wilson PhD (613) 737 7350

ext. 75608 (Thesis committee member)

Appendix G

Simulated Caller Training Materials

1. Training Workshop Teaching Module
2. Simulated Patient Tracking Log
3. Simulated Patient Scenarios
 - I. Man with Lung Cancer – Source of decisional conflict – unclear values
 - II. Woman with Lung Cancer – Source of decisional conflict – pressure from others



Place of Care at End of Life Decision Support Simulated Patient Workshop

Mary Ann Murray

Objectives

Workshop completion will prepare you to:

- Describe your role as simulated patients
- Demonstrate realistically your simulated patient role based on scenario script
- Understand your role in the study
- Know the steps to follow in conducting the simulated patient call
- Use the recording equipment to tape calls

Outline

The study

- What are health care decisions
- Place of care at end of life decisions
- Study settings

Making the simulated call

- Setting up and using the equipment
- Trouble shooting
- Role as a simulated caller

Role practicum

Decision Making

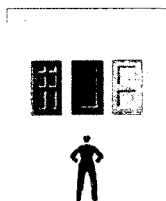
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- **Choosing** between 2 or more options
- People generally choose options that:
 - are likely to have outcomes that they value
 - avoid undesirable outcomes

'Tough' Decisions

- **multiple options**
- **risky outcomes**
- **outcomes have benefits/harms that people value differently**
- **anticipated regret**



Canadians say they need and want help in making tough health decisions

Signs of Difficulty

- Unsure
- Unclear about best choice
- Concern about bad outcomes
- Waver between choices
- Delay making decision
- Questioning what's important
- Worry, distress, tense
- Preoccupied with decision
- Other



Steps in Decision Making

- Clarify the decision
- Do you:
 - Feel sure about the best choice for you?
 - Feel sure that you know the pros and cons of each option?
 - Feel clear about which pros and cons matter most to you?
 - Feel you have enough advice/ support to make a choice?
- Decide your preferred role in decision making?
- Plan next steps such as:
 - Get more information
 - Find resources/ support
 - Explain personal values to others

(Ottawa Personal Decision Guide, 2008)

Place of care at end of life decision



Participants and Setting

- Nurses and allied health professionals
- Ontario
- May be practicing in outpatient or out patient setting

YOUR ROLE

- To role play a patient considering options for end of life place of care
- Each participant will receive 2 calls

Where do participants come from?

- St. Elizabeth's Health Care Agency
 - Community nursing services
 - Toronto & Kingston
- Bayshore Health Agency
- Ottawa Hospital
 - Inpatient cancer unit
 - Outpatient cancer clinics
- Community Care Access Agencies
 - Community nursing services
 - Toronto Central & South East (Brockville, Smith Falls, Kingston)
- Carefor Nursing Agency
 - Community nursing services
- SCOHS
 - Palliative Outreach Service

Making the Call

- Two call periods
- About 40 calls in each period
- About 10-20 minutes each
- Audio-tape calls
- Minimal background noise
- Pre-scheduling of calls
- Participants know you are a simulated patient
- Calling cards to cover call costs



Expectations of Simulated Callers

- Accurately follow scripted case
- Be as realistic as possible
- Be consistent across calls
- Contact investigator if any difficulty with recording equipment
- Sign off on log sheet when call completed

Role Play and Practice Session

- Rehearse scenarios
- Practice with audio recording equipment
- Review use of call log
- Fill in session evaluation form

**Thank you for your help in
making this study possible**

Simulated Patient Log

Simulated Patient Name: _____

Call Instructions:

1. Connect voice tracer to telephone and turn on
2. Confirm participants name and the date
3. Tell participant you are the simulated patient caller that they have been scheduled to receive as part of the decision support study
4. Start simulated role
5. At end of call thank participant and say good-bye
6. Before stopping voice tracer and after participant has hung up state participant name and date
 - a. i.e.: "This is a call with (*state participants name*) on (*state date*)"

Study contacts: Prudy Menard Mary Ann Murray
 613 821 0618 613 837 7284
 613 782 6922 (pager) maryannmurray@rogers.com
 Pmenard@uottawa.ca

Thank you for your help and support with this project

Participant Name	Study ID#	Pre or post call	Date scheduled	Time scheduled	Contact#	Length of call in minutes	Comments (i.e., difficulties with equipment, call interruptions, other note)

Simulated Caler Scenarios

Scenario: Man (George Cowan) with End Stage Lung Cancer

Primary decision support need: Values clarification

Identity: Mr. George Cowan, a 67 year old man with end stage Non Small Cell Lung Cancer (diagnosis 1 year ago). Your cancer was inoperable. You declined chemotherapy and accepted palliative radiation. Your disease has spread. You understand your disease is not curable. You are concerned about where you will receive care in your final days and where you will die. You live in a city in Ontario.

Background

At your regular cancer clinic visit, your oncologist talked to you and your wife about what lies ahead. You want no further cancer treatment. You are sad but feel you have lived a good life. You are a bit scared about what lies ahead. Your priority is to spend as much time with your family as possible.

Some people prefer to stay at home with home nursing and medical care. Others plan for care elsewhere where staff and services are available 24/7 (i.e.: residential hospice, nursing care home, hospital, palliative care unit). Thinking about the decision in advance gives people a chance to plan for future care needs and to connect with resources.

Reasons people choose to stay at home include:

- Being in a familiar environment, close to family, friends and pets
- Less travel or inconvenience for family and friends
- Being able to set own routines and be in control.
- Prefer to be in a home setting

Reasons people may NOT choose to stay at home include:

- Having pain and symptoms that are difficult to control.
- Concern about being a burden to family and friends
- Needing more help or special equipment than is available at home
- Lack of onsite 24/7 care availability
- Not having a family doctor who will make house calls

You have read an information sheet summarizing the resources available in your community. You have a return appointment in two weeks. You are feeling unsure and are very worried about your family. You telephone the clinic for help with deciding what to do.

Beginning the interview

"I have lung cancer and it's not curable. I'm worried about where I can get the kind of care I need at the end.. I'm very confused. I know about the services available here. I'm torn about whether to plan to be at home or to go to hospice or hospital."

Your attitude during the call

- ☐ worried about making the decision
- ☐ unsure what to do about making plans for place of end-of-life care.
- ☐ wavering between choices – *in the morning you think you should try to stay at home and get extra help at home; by the afternoon, you think that you should not bother your family and that you should make plans not to be at home..*
- ☐ a little worried about having problems with pain and shortness of breath;
- ☐ have not had any problems with symptoms so far; your doctor has told you the medications you may need can be given easily at home.

Extra background information (only if the nurse asks)

More information about your medical history and lifestyle

(a) Medical history:

1. Diabetic for the past 2 years; well controlled with diet
2. Palliative radiation for lung cancer completed 2 months ago
3. No pain
4. Short of breath after climbing the stairs
5. Easily tired these days

(b) Family History:

- ☐ Mother, died at the age of 83, in her sleep- lived in a nursing home
- ☐ Father, died suddenly at home at age 81, of a stroke
- ☐ Your wife, age 65, had a small heart attack last year- takes daily medication.
- ☐ 3 adult children - they are aware that your illness has progressed and that you may live for only a few more months.

(c) Current lifestyle activities:

- ☐ live with your wife of 44 years,
- ☐ you and your wife are retired,
- ☐ Have an adequate pension and feel financially secure; you have additional health insurance which could cover home nursing and other home services,
- ☐ Live in same bungalow for 30 years (within the city),
- ☐ A friend died of cancer last year stayed at home; you have two other friends who died recently in hospital,
- ☐ You have a family doctor; who will make house-calls,
- ☐ You used the Internet to search information about hospice and palliative care. You have also used the cancer clinic library to get information

(e) Previous experiences with making decisions:

After your diabetes diagnosis, your doctor talked to you about taking medication but you decided to manage by changing your diet. You and your wife have made changes in the family meal planning. Your blood sugar is well controlled and you have not had to take medication. You had expected to live to be as old as your parents and had not thought much about death or dying in the past.

More information about how you see the decision

Decision	Whether to plan for care at home or elsewhere
Deadline for making decision	@ 2 weeks when you have your next cancer clinic appointment
Stage of decision making	thinking about whether to start planning for care at home or elsewhere
Preferred role in decision making	share the decision with your wife and oncologist. You will tell your adult children what you decide
Information	You feel you understand the information you need to make the decision – see below
Values/Importance	not sure about what is most important in the reasons to choose home or care elsewhere.

Other people:

- Your wife is feeling as unsure as you are.
- Your adult children have said that will support any decisions you make
- You do not want to speak with friends about this decision.

Your choice: At the *beginning of the interview you are unsure*; if the nurse asks you to think about how importance of the reasons to choose one option or another (or asks you to rate them with stars), you will decide to plan to stay at home, but still want to confirm this with your oncologist.

If the nurse asks you these questions before she asks you to rate how important the advantages and disadvantages are (at the beginning of the call), you can answer...

Are you clear about the best choice for you?	No
Are you sure what to choose?	No
Do you know the options ?	Yes
Do you know your reasons to choose each option ?	Yes
Do you know how important the reasons to choose each option are to you ?	Yes
Are you clear about which reasons are most important to you?	No
Are you clear about which of the reasons are most important for you to avoid ?	No
Do you have enough support to make a choice?	Yes
Are you choosing without pressure from others?	Yes
Do you have enough advice to make a choice?	Unsure

If the nurse asks you what you know,

- give her the list of advantages and disadvantages from the table below.

If the nurse asks you to rate how important the advantages and disadvantages are, provide the number of stars give the boxes.

Reasons to Choose Home	Reasons to Avoid Home
I would be in a familiar place and it would be more private (*****5 STAR RATING)	I could be a burden to my wife and family (****4 STAR RATING)
My family would find it easier to be with me (****4 STAR RATING)	If there was a serious problem, I would have to wait to get help (**3 STAR RATING)
I would be in control of things and what happens during the day(**3 STAR RATING)	It could be upsetting for my wife to continue to live in the house if I die there (** 2 STAR RATING)
I know the home care nurses and am comfortable with them (**** 4 STAR RATING)	We would have to make some changes in the family room so a hospital bed could fit. (** 2 STAR RATING)

Preferred Choice: You are leaning toward making plans to stay at home for end-of-life care

If you rate the pros and cons and if the nurse asks what you will do next:

- you can say that you plan to tell your oncologist that you want to make plans for care at home because you would be more comfortable in familiar surroundings

If you rated the pros and cons and the nurse asks these questions, you can tell her (**at the end of the call**)...

Are you clear about the best choice for you?	Yes, I think so
Are you sure what to choose?	Yes, I think so
Do you know the options?	Yes
Do you know the reasons to choose each option?	Yes
Do you know the reasons to avoid each option?	Yes
Are you clear about which reasons are most important to you?	Yes
Are you clear about which reasons are most important to avoid	Yes
Do you have enough support to make a choice?	Yes
Are you choosing without pressure from others?	Yes
Do you have enough advice to make a choice?	Yes, I think so now

If the nurse asks you about others opinions, you can share with her that:

Other people	What are their opinions?	Are you feeling support?	Are you feeling pressure?
Your wife	Need to think about advantages and disadvantages	Yes	No
Your children	Unsure	Yes	No

A few additional cues for telephone calls

- ☐ Possible questions:
 - If I don't make plans for hospice and things don't work out at home can I still go there?

Scenario: Woman (Doris Jenkins) with End Stage Lung Cancer

Primary decision support need: Handling pressure from others

Identity: Mrs. Doris Jenkins, 69 year old widow, with end stage lung cancer. You know your disease is incurable and are starting to think about what you need to plan for. You are particularly concerned about where you will die. You live in a city in Ontario.

Background: You have Non Small Cell Lung Cancer. You had surgery followed by chemotherapy and radiation. Lately you have had pain in your ribs, are more short of breath and tired. One month ago, your oncologist told you that your lung cancer had spread and that it was incurable. You have a family doctor who makes house calls.

You are very proud of being organized, in control of things and being independent. You are not surprised that the cancer has spread and want to make sure you have things in order. Your family doctor told about the services that are available for end-of-life care in your community. You think that a hospice/palliative care setting sounds like a good place to be.

You visited the hospice/palliative unit and started to fill in papers. When you told your daughter that you were thinking about the palliative care unit, she said you should move in with her and her family. You are now feeling unsure. You telephone the community care case manager to talk about your options.

Reasons people choose to receive care in a place other than home include:

- Having staff available 24/7
- Not having to rely on family members for personal care needs
- Feeling it may be less disruptive for family and friends
- Having access to more help or special equipment than is not available at home
- Not being able to afford extra home nursing services to meet care needs

Reasons people may NOT choose receive care in a place other than home include:

- Wanting to be in a home setting close to family, friends and pets
- Less travel or inconvenience for family and friends
- Being able to set own routines and be in control
- Needing more help or special equipment than is available at home
- Not having a family doctor who makes home visits

Beginning the interview

"Last month I was told that my lung cancer has spread. I don't have a lot of time - my doctor thinks a couple of months. I think it would be best if I made plans for the palliative care place but my daughter wants me to move in with her. I don't know what to do."

Your attitude during the call

- ☐ frustrated with your daughter(Julie).
 - she wants you to move in with her. You know she means well.
- ☐ think that going to the hospice/palliative unit would be easier for everyone.
- ☐ don't like feeling dependant on anyone.
- ☐ pressure from your daughter makes you wonder if you are making the right choice in thinking about hospice.
- ☐ unsure what to do

Extra background information (only if the nurse asks)

More information about your medical history and lifestyle

(a) Medical history:

- 6. bone metastasis to your ribs and liver
- 7. gall bladder surgery in the past

(b) Rib pain questions on scale of 1 (no pain) to 10 (worst pain)

No pain	1	2	3	4	5	1	2	3	4	5	Worst pain
---------	---	---	---	---	---	---	---	---	---	---	------------

You have rib pain of 4/10 before medications; after taking morphine pain is typically 2/10.

Shortness of breath on scale of 1 (no pain) to 10 (worst pain)

No pain	1	2	3	4	5	1	2	3	4	5	Worst pain
---------	---	---	---	---	---	---	---	---	---	---	------------

You have shortness of breath 7/10 going up stairs and 3/10 at rest.

You take Morphine for the pain and shortness of breath. Do not have any side effects. You are ok with your level of pain and shortness of breath control. You have been told that your symptoms can be well controlled as your condition changes. You have been offered home visit nursing services but so far have declined.

(c) Family History:

- ☐ Husband: died of a heart attack, about 3 years ago
- ☐ Father: died in a car accident at age 56
- ☐ Mother: age 86, lives in a nursing home and has severe Alzheimer's disease (doesn't recognize you when you visit)

(d) Current lifestyle:

- ☐ Smoke about a ½ pack a day.
- ☐ live alone in a condominium apartment in the downtown area.
- ☐ very independent- you no longer drive; you live close to a major bus route; a grocery store and bank are next door.
- ☐ have a pension and feel financially secure
- ☐ one daughter (Julie) is married with 2 teenage children. She lives in the suburbs. She has a spare bedroom waiting for you.
- ☐ retired from work as a government secretary.
- ☐ have good friends who live in your neighborhood; you see them often

(e) Information access:

- ☐ have a computer but rely on your daughter or your doctor to give you information about your health care and resources.

More information about how you see the decision

Decision	Where to receive end-of-life care
Deadline for making decision	@ 3 weeks, at your next doctors appointment
Stage of decision making	you were very close to choosing hospice/ palliative care unit but since talking to your daughter you are wavering
Preferred role in decision making	you feel it is your decision to make but also want your daughter to agree
Information	you feel you understand the information you need to make the decision
Values/Importance	you feel clear about what is most important to you.

Other people

- Your daughter does **NOT** want you to go to the hospice/palliative care unit. She says: "we want you to be with us. We want to take care of you- like you always cared for us." You are *very worried about upsetting her* if you do not do, as she wants.
- Your best friend, who has breast cancer, is happy with home visit nursing that she is receiving; she says it is your decision and will support you
- Another friend died at the palliative unit- you visited her often, you got to know some of the nurses and were pleased with what you saw
- Your family doctor has had patients at the hospice/ palliative unit but she is sitting on the fence until you make your decision

Your choice: You think that overall the hospice/palliative unit would be your best choice but need to figure out how to convince your daughter

Plan: Need to talk to your family doctor about what you want within about 3 weeks.
If the nurse asks you these questions before she asks you to rate how important the advantages and disadvantages are (at the beginning of the call), you can answer...

Are you clear about the best choice for you?	Yes
Are you sure what to choose?	No (because of your daughter)
Do you know the options ?	Yes
Do you know the reasons to choose each option?	Yes
Do you know the reasons to avoid each options?	Yes
Are you clear about which reasons are most important to you?	Yes
Are you clear about which reasons are most important to avoid for you?	Yes
Do you have enough support to make a choice?	No
Are you choosing without pressure from others?	No (pressure from your daughter)
Do you have enough advice to make a choice?	Unsure

If the nurse asks you what you know, give her the list of reasons to choose and reasons to avoid care in the palliative care unit from the table below.

If the nurse asks you to rate how important the pros and cons are, provide the number of stars give in some of the boxes.

Reasons to Choose the Hospice/Palliative Unit	Reasons to Avoid the Hospice/Palliative Unit
You will not feel that you are a burden to your daughter. (***** 5 STAR RATING this is very important to you)	Your daughter will have to drive about 20 minutes to visit you (** 2 STAR RATING)
There would be nurses available in the hospice 24 hours a day. (** 2 STAR RATING)	You may not have space for your personal possessions as at your daughters house (0 STAR RATING)
You think you will be treated well at the palliative care unit and you know some of the nursing staff_ (** 3 STAR RATING)	You may have to follow a routine that you are not used to and can't smoke when you want (****3 STAR RATING)
You would not have to dip into your savings to pay for extra nursing services if needed. (****4 STAR RATING)	If you get much weaker you may need more nursing services than home care can provide and you will have to use your savings to pay for this (***3 STAR RATING)

Preferred Choice: You want to make plans for hospice

If the nurse asks you about others opinions, you can share with her that:

Other people	What are their opinions?	Are you feeling pressure?	Are you feeling support?
Your daughter	<u>NOT palliative care unit</u>	Yes	Not really
Your family doctor	She is waiting for you to make a choice	No	Yes
Your best friend	It is your decision	No	Yes, she will help me whatever my decision

☐ Other information to share:

If the nurse asks:

- You have called the Community Care Access Center in the past; your daughter has encouraged you to call for more information about place of end-of-life care planning.

Appendix H

Autotutorial Elements

1. Autotutorial: Training Practitioners in Decision Support
2. Knowledge Quiz

Decisional Conflict: Supporting People Experiencing Uncertainty about Place of Care
Mary Ann Murray (December 2007)

Based on: Decisional Conflict: Supporting People Experiencing Uncertainty about Options Affecting their Health
AM O'Connor & MJ Jacobsen (May, 2007)

1. The Concept of Decisional Conflict

Every day, people are faced with options affecting their health.

- Surgery or medical management?
- Condoms or the Pill?
- More aggressive options when simpler strategies are not controlling acne, depression, cholesterol, blood sugar, menopause symptoms, insomnia, or attention deficit disorder?
- Care at home or in a nursing home?

Decision making is the process of choosing between alternatives, which may include doing nothing. It is an important phase in self care or change (1,2), and competent decision makers need to understand and consider:

- the **courses of action** open to them;
- the chances of **positive and negative effects**; and
- the **desirability or value** of these effects.

People are more likely to choose an option they think is likely to achieve valued outcomes and to avoid undesirable outcomes.

Unfortunately, many health care decisions have alternatives that:

- have both desirable and undesirable outcomes;
- have desirable outcomes occurring partly with one option and partly with another.

Thus, no alternative will satisfy all our personal objectives and no alternative is without its risk of undesirable outcomes.

This situation is known as a 'choice dilemma' or 'conflicted decision' (3). It is characterized by uncertainty or difficulty in identifying the best alternative due to:

- the **risks** or scientific uncertainty about benefits or harms;
- the need to make **value judgments** about potential benefits versus potential harms (4); and
- anticipated **regret** over the positive aspects of rejected options (3).

Janis (5) describes decisional conflict as "the simultaneous opposing tendencies within the individual to accept and reject a given course of action"(p.46). The North American Nursing Diagnosis Association includes decisional conflict in its taxonomy of problems:

Decisional Conflict (specify) is the uncertainty about which course of action to take when choice among competing actions involves risk, loss, regret or challenge to personal life values (specify the focus of conflict, such as personal health, family relationships, career, finances, or other life events) (6).

2. Defining Characteristics or Manifestations of Decisional Conflict

The primary characteristic of decisional conflict is verbalized uncertainty. However, any of the characteristics described below may be present (6,7). Their frequency can vary among different individuals, types of decisions, and time frames (8-17). They become more frequent as a person starts to consider the options and then tend to diminish after the decision is made (5).

- **Verbalizes uncertainty about choice**
(e.g., "I'm not sure what to do")
- **Verbalizes concern about undesired outcomes**
(e.g., "I keep thinking about the things that could go wrong if I have this surgery;" "I could get a complication;" "I may not recover.")
- **Waivers between choices**
(e.g., "One day I think I will take the medication, the next day, I change my mind")
- **Delays the decision**
(e.g. "I keep putting it off...I don't want to have to face this choice right now")
- **Questions personal values** or what is desirable or important to them
(e.g., "I don't know about amniocentesis.... I have to think carefully about what I would do if I found out the baby was abnormal...what are my beliefs?")
- **Is preoccupied with decision**
(e.g., "This decision is all I have been thinking about lately... my family is getting impatient with me because I keep dwelling on this decision and neglecting them")
- **Shows signs and symptoms of distress or tension**
(e.g. signs of increased muscle tension, restlessness, increased heart rate. "I feel wound up... I can't sleep...my hands shake")

See Table 1: Research on manifestations of decisional conflict

3. Factors Contributing to Decisional Conflict

Decisional conflict arises from two sources:

1. People are uncertain because of the inherent difficulty of the choice with both positive and negative effects. (e.g., a medical treatment that relieves symptoms but also has unpleasant side effects and inconvenience; deciding about extended maternity leave with benefits of maternal, infant, and family well-being but also loss of income, personal stimulation, or career advancement)
2. There are modifiable factors that make an inherently difficult decision even more difficult (7-18). These include:
 - **lack of knowledge** about options and potential outcomes of options
(e.g., "I don't know what I can do to relieve these symptoms.. I need to find out about the side effects.")
 - **unrealistic expectations** or perceptions of the likelihood of outcomes, such as exaggerating or minimizing the chances of outcomes
(e.g., "That treatment gives everyone cancer;" "My mother had a beautiful natural childbirth when I was born and I will do the same;"... Other terms people use when discussing expectations include: 'how likely', 'what are my chances', 'what are the probabilities', 'how frequently/often does that happen'.)
 - **unclear values**, or the personal importance or desirability of outcomes
(e.g., "I feel miserable and need some relief, but I don't believe in taking pills"...it is hard to say whether the positives outweigh the negatives...;" Other terms people use when discussing values include: 'good/bad,' 'important', 'worried', 'concerned about', 'tolerate', 'desire', 'comfortable', 'unacceptable', 'bothersome', 'tradeoffs', 'worth it', 'priority', 'put up with', 'happy with', 'personal cost too great'.)
 - **unclear perceptions of others**, including opinions and practices
(e.g., "I'm not sure what my [doctor/family] thinks of these options;"... "What do other people do in this situation?"")
 - **social pressure** to choose one option
(e.g., "My family has made it very clear they think I should breast feed;"..."I feel society disapproves of people choosing any other option but this one.")
 - **lack of support, or mismatch between preferred and actual role in decision making** (e.g., "...my doctor is hopeless in discussing options...it's his way or the highway" ... "I have no one to talk to about this decision;"..."My mother can't take care of herself...my sisters have told me they want nothing to do with figuring out where she should live...it's up to me.... I would rather share the decision with my family)
 - **lack of skills/self-confidence**
(e.g., "I've never had to make a decision like this before, I'm not sure I can do this.")
 - **lack of other resources**
(e.g., "We don't have any groups in our town that provide information or support for families affected by schizophrenia".)

Fortunately, many of these modifiable factors contributing to decisional conflict can be addressed by counseling and coaching interventions.

See **Table 2: Research on factors contributing to decisional conflict**

4. Examples of Decisions that May Create Decisional Conflict

Emergence of health problems

With new health problems, people face options regarding diagnosis, treatments, or lifestyle changes. The degree of decisional conflict experienced may depend on whether the intervention being discussed is considered:

- a) **‘effective care’**, which has clear answers with large benefits and minimal harms, e.g. calcium and vitamin D for osteoporosis. Most practitioners would recommend these treatments and many people who were offered the options would agree to take them. The challenge lies more in implementation and maintenance than deliberation.

OR

- b) **‘values-sensitive care’**, whose effects are either unknown or dependent on the personal value/importance placed on known benefits versus harms. People’s opinions differ regarding whether the benefits outweigh the harms. They may also experience more decisional conflict. Examples include:
 - **An option involving value tradeoffs between benefits and harms** e.g. amniocentesis with a small risk of miscarriage and not all women would choose to act on the information about an abnormality (21); mastectomy with or without reconstructive surgery versus lumpectomy followed by radiation therapy for breast cancer; choice of different colon cancer screening methods such as FOBT or colonoscopy.
 - **Inadequate scientific information about the option**, e.g. prostate cancer screening tests of asymptomatic men is controversial because the benefits of early detection on mortality have not been established.

Maturation or Situational Transitions

Another time of difficult decision making occurs during developmental or situational transitions such as those related to education, career, pregnancy, parenting, caregiving, and retirement (22).

Each transition (e.g. pregnancy) sets up a cascade of decisions (personal lifestyle and nutrition, infant nutrition, child care, employment) that may directly and indirectly affect the health of individuals and their families.

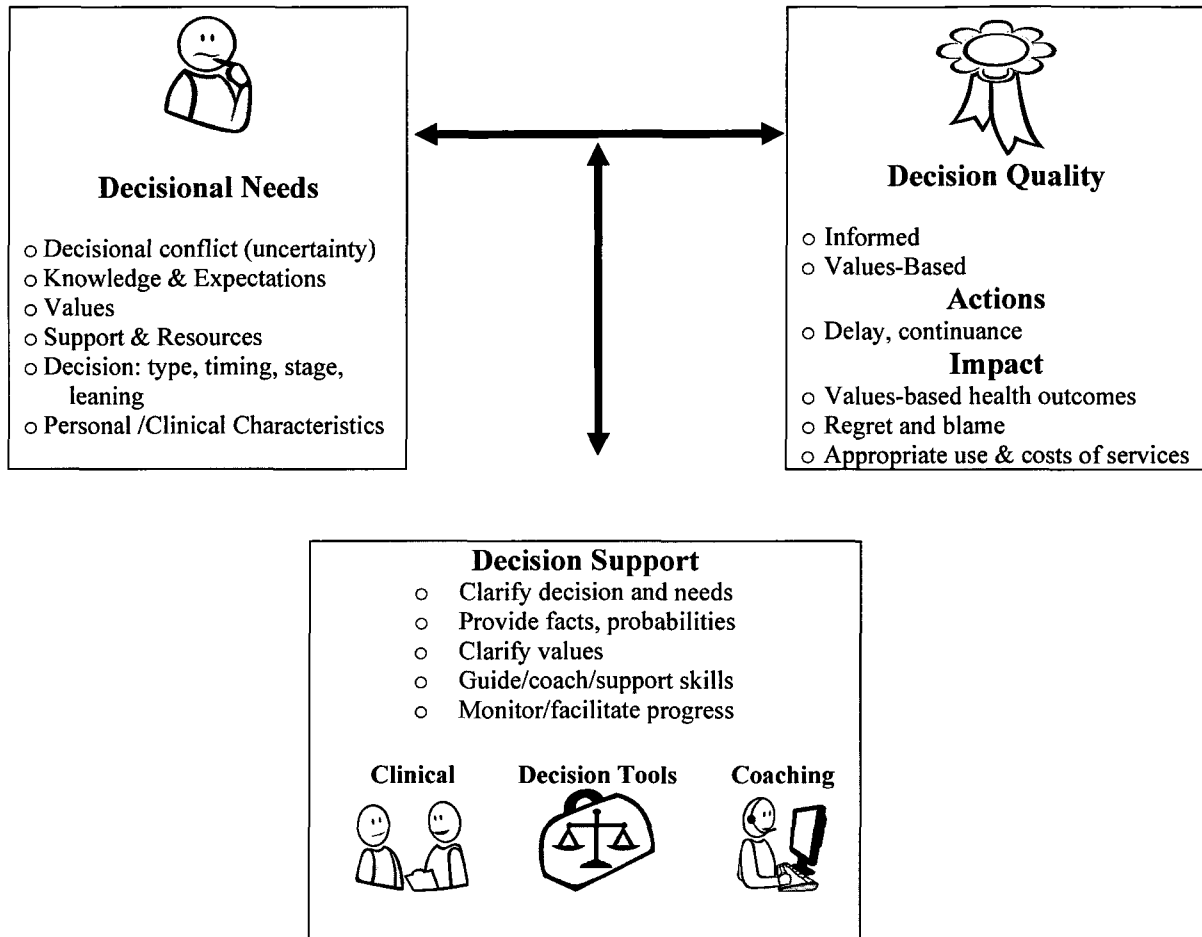
For many of these decisions, there is no right or wrong answer, and people need to carefully deliberate on the best option for them.

See Table 3 Examples of potentially difficult decisions which may create decisional conflict

5. Ottawa Decision Support Framework to Address Decisional Conflict

Our decision support framework, (Figure 1), to address decisional conflict, uses concepts and theories from psychology, social psychology, economics, and social support (2,4,5,23-27).

Figure 1 Ottawa Decision Support Framework



It applies to all participants involved in decision making, including the individual, couple, or family and their health practitioner. The framework asserts that participants' decisional needs will affect decision quality (informed, values-based choices), which in turn affects actions or behaviour (e.g. delay), health outcomes, emotions (regret, blame), and appropriate use and costs of services. See **Table 4 Glossary of terms for Ottawa Decision Support Framework**.

Unresolved decisional needs that adversely affect decision quality include: decisional conflict; inadequate knowledge and unrealistic expectations; unclear values; inadequate support or resources; complex decision type; urgent timing; unreceptive stage of decision making; polarized leaning toward an option; and participant characteristics such as cognitive limitations, poverty, limited education, or physical incapacitation.

Decision support in the form of clinical counselling, decision aids and coaching can improve decision quality, by addressing unresolved needs. Decision support involves: clarifying the decision and the person's needs; providing facts and probabilities; clarifying values; guiding/coaching/supporting in deliberation and communication; and monitoring/facilitating progress. Health professionals tend to over-use factual information about options and under-use other strategies. Specific strategies tailored to needs are discussed next.

Decisional conflict is usually resolved by addressing the modifiable factors contributing to uncertainty.

Knowledge deficits are addressed by helping a person to access information on his/her health situation, the options available and the potential outcomes of the options. Both potential benefits and harms should be presented in sufficient detail for decision making. The information may be delivered by the practitioner or provided as written materials or multimedia presentations. The medium and pace with which the information is provided should be appropriate to the person's needs. It is important to assess the person's comprehension of the information after it is provided; the focus should be on information that is 'essential' for decision making.

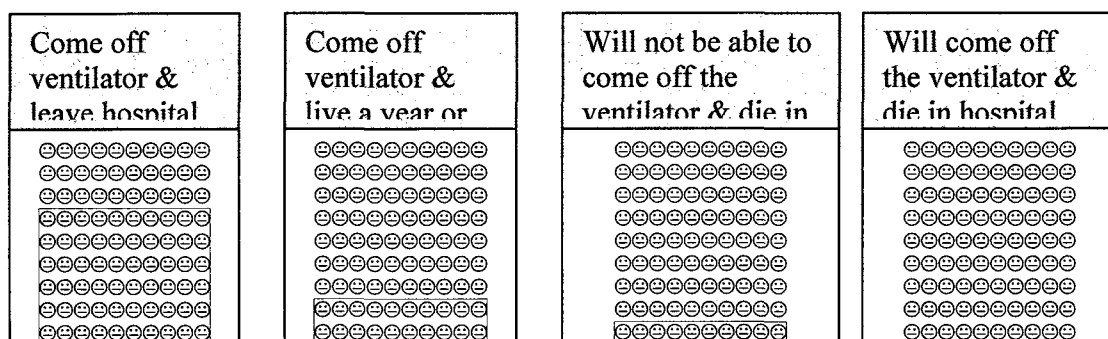
Unrealistic expectations can be **re-aligned** in two ways. First, by providing information on the probabilities of the outcomes for each option, observed in people with characteristics similar to the person facing the decision. Second, by describing the outcomes in ways that make them easier to imagine and identify with (23). In cases where a person over-estimates the chances of an outcome occurring, the practitioner should acknowledge the possibility, but then describe anecdotes in which the outcome did not happen. In cases where a person under-estimates the chances of an outcome occurring, the practitioner should acknowledge the possibility, but then describe vivid stories (anecdotes) in which the outcomes did happen.

Example of Re-aligning Expectations

Marguerite, a 67 year old woman, with advanced Chronic Obstructive Lung Disease (COPD), visits the Respiratory Clinic. She is looking for information about her options if her condition worsens and she is no longer able to breathe on her own. She would like to make advanced care directives. Her husband states he will support her decisions and has encouraged her to talk to her practitioners about her options. Her sister died of COPD after being on a ventilator. She thinks she doesn't have much chance of coming off a ventilator if she needed this intervention in the future.

Using Numbers. "Many believe that their chances of being able to breathe on their own again and leave the hospital are very low, so you are not alone in thinking this way. But the chances are quite high. If 100 people were put on a ventilator to relieve breathlessness, about 70 of them will likely come off the ventilator and leave the hospital. About 30 out of 100 patients will come off the ventilator and live a year or more. About 20 out of 100 people will likely never come off the ventilator and will die in hospital. About 10 out of 100 people will come off the ventilator but will die before leaving the hospital."

'Here is an example of what may happen using a block of 100 faces. 70 of the people with advanced COPD [shaded in pink] might come off the ventilator and leave the hospital and the number drops to 30 who leave the hospital and live a year or longer.'



Using Stories. If the woman still believes her risks for getting off the ventilator are very low, providing examples of her sister who also had advanced COPD and who died while being on a ventilator, the practitioner may ask her if she knows of other friends and acquaintances who were able to breathe on their own after being on a ventilator, and ask her what happened to them. The practitioner may add: “All I can do is share with you my experience with the many people with COPD we see at our practice who go on a ventilator. If the chances of getting off the ventilator were as low as you think they are, we would be seeing far fewer patients who in clinic who had been on a ventilator at some time in their illness than we do.”

Unclear values around the benefits and risks of the options can be addressed using values clarifications strategies. First, the outcomes need to be described in familiar, simple, and experiential terms to facilitate the person’s understanding so as to better judge their value or personal importance (24). This means that, rather than providing a label for an outcome (e.g. pain from osteoarthritis), a person is helped to understand how the outcome will affect them physically (characteristics of pain, effects on ability to walk, work, and carry on daily activities), emotionally (discouraged), and socially (withdrawn, avoid social activities).

Next, a person is asked to consider the personal importance of the positive and negative outcomes. Sometimes, explicit values clarification exercises are implemented using numerical [rating scales] or graphic exercises [adding stars as shown in Fig.3.], to help the person indicate what is personally important (40).

Finally, a person needs a strategy for communicating their values when discussing the options with others. People, including practitioners and family members are not very good at judging the values of others. It may be helpful to use rating scales (0= not at all important to 5= very important) or balance scales, using stars to show what is important, which can be viewed ‘at a glance’.

Case study: 46-year-old Marcia has been the primary care giver for her mother who has severe Alzheimer’s disease for the past three years. She is married with two teen age children. In the past months her mother’s care needs have increased and her dementia has worsened. Previously Marcia’s mother had said she wanted to grow old at home and expected her daughters to take care of her. Marcia is concerned that her mother needs more care than she can provide and that her quality of life is deteriorating. Her practitioner has explained the advantages and disadvantages of care at home and admission to a long term care facility but Marcia remains unsure. Given her mother’s needs and the current care giving situation her practitioner asks Marcia to rate the importance of advantages and disadvantages of care at home using ‘0 to 5 stars’. Five stars means it is very important to relieve her symptoms, 1 star means it is a little important, and 0 stars means it is not at all important. As shown in Figure 3, Marcia says benefits of long term care admission are worth 5 stars (*****). Then the practitioner asks her to rate the importance of her worry about the disadvantages. Monica says she would rate the worry about disadvantages to be 2 stars (**). When her practitioner asks Monica what that means to her, she realizes that the knowing her mother is in a safe environment where her care needs can be met 24 hours a day is more important to her than the worry about disadvantages. She decides to fill out the forms for long term care admission.

<i>Benefits of LTC</i>	<i>Risks of LTC</i>
-Staff available 24 hours basis	-Less care over the quality of care provided
-Services to meet most needs	-Less personalized care
-More time with children	-Getting to the facility for visits may be difficult.
-Relief from most caregiving responsibilities	
-Supervised environment to	

Support & Resources Deficits

Unclear or biased perceptions of others' opinions. First, it is important to present all available options, so that a person is aware of the alternatives they can consider. Next, the practitioner can present examples of others' choices, in a balanced manner, so that a person is aware that people choose different options and there is no "one size fits all" answer. Finally, the practitioner can provide statistics on variation in choice: e.g. the percentage of people who choose the different options that are available; the differences in practitioners' opinions; or differences in practice guidelines. It is also helpful to present the rationales behind the differing opinions. Often, differences in choices reflect scientific uncertainty, differences in people's circumstances, tolerance for risk or uncertainty, or their values.

Social pressures are addressed first by exploring the nature of the pressure, including its source, the areas of agreement and disagreement, and the reasons behind differences in points of view. Next, a person is guided to: a) verify their perceptions of others' opinions in case there are misconceptions; b) focus on only the opinions of those whose opinions matter most (e.g. ignore peer pressure to choose an option); and c) handling relevant sources of pressure (e.g. family members who have a legitimate stake in a decision about placement of an elderly relative). Strategies for dealing with people who are exerting pressure include: a) planning how to communicate information and values; b) inviting others to discuss their perceptions of options, benefits, harms, and values to find areas of agreement and disagreement; c) mobilizing social support; and e) identifying a mediator, if needed. Role play and rehearsal of strategies can also be helpful.

Lack of support or resources The practitioner should help a person to access support or resources needed to make the decision. Resources may include health professionals that are personal advocates, family and friends, support groups, or services from voluntary or government sectors. In some cases the practitioner's support is all that is needed to make the decision.

Lack of skills or confidence in decision making may be improved by providing structured guidance, or coaching in the steps of decision making, (deliberating about a decision), and communicating preferences (41-48).

Preferred role in decision making. The type of guidance will depend on the role people prefer to take in decision making. According to Rothert and Talarczyk (49), the practitioners' expertise lies in providing information about the options available, their outcomes, the associated risk/probability, and the health care resources required and available. The patients' expertise includes their preferences or values and personal, social, and available economic resources.

Degner et al. (28, 50) found that people can be classified into three profiles of preference for decisional control: those who want to *keep*, *share*, or *give away* control for decision making. "Keepers" might guide the deliberation and ask their practitioner for input on the scientific facts. Practitioners might start by providing guidance to "sharers", who would then become actively involved in the decision. A more advisory role might be used by practitioners with "givers away" who would then be asked to provide informed consent. It is important, however, for practitioners not to take preferred roles in decision making completely at face value; providing people with decision support often increases their desire for active participation in decision making (59). Therefore, people need adequate information and time to consider which decision making role they prefer to take.

Decision type, timing, stage and leaning. Practitioners need to tailor decision support to the type of decision. For example, the approach may differ if the focus is on a screening for prostate cancer, treatment of early stage disease, treatment of recurrence, or end of life care. Tailoring support also depends on timing. Short timelines to make big decisions often increases stress but very long time lines may increase decision delay.

The very early and very late stages of decision making it is important to gauge a person's receptivity to new information and further deliberation. Otherwise decision support may be irritating or unproductive. The aim of decision support is to help the person progress in their stage of decision making, not necessarily 'change'. Sometimes 'maintaining the status quo' is a reasonable option (e.g. forgoing PSA testing, amniocentesis, hormone therapy).

Stage of Decision Making	Decision conflict is usually	Decision Support
Not thinking about options	High	Gauge receptiveness to new information (e.g. a person may still be in shock or denial). If unreceptive, discuss issues that are immediately relevant to the person.
Actively deliberating	High	Decision support is usually most helpful now.
Close to making a choice	Lower	Gauge receptiveness to discussing what led them to the choice they are close to making.
Taking steps, already implemented	Low and often will increase with additional decision support (17)	Gauge receptiveness to discussing what led the person to the steps/choice they have taken. Sometimes people will start implementing a process even though they are not fully committed to it (e.g. putting a family member's name on a waiting list for a nursing home that specializes in dementia, even though the decision about placement has not been finalized by the family). Others are implementing choices that tend to fluctuate over time (e.g. menopause, attention deficit disorder).

Personal/Clinical Characteristics. Decision support should be gender-sensitive and appropriate for an individual's age, developmental stage, education, socioeconomic status, and ethnicity. Adjustments should be made to accommodate a person's physical, emotional and cognitive capacities (31,32). Involving the family or a personal advocate is important when the person's capacities are limited. The characteristics of the practitioner will also influence decision support provided based on a person's training, experience, and counseling style.

Monitoring and Facilitating Progress. Once needs have been addressed, it is important to monitor progress in resolving needs, moving through the stages of decision making, and achieving the goal of decision quality. It is a challenge to define a 'good' decision when the best choice depends on how a person values benefits versus harms. The international patient decision aids standards collaboration (66) has reached a consensus that a good decision is one

that is ‘informed’ and values-based’. Monitoring tools are described in the next sections. They also help a patient to consider and become committed to taking the next steps.

6. General Decision Support Guides

General guides and tools have been developed to assess needs and plan decision support (5,38). The Ottawa Personal Decision Guide is a framework-based tool to help people and their practitioners to structure, record and communicate needs and plans. The guide may be useful when a practitioner anticipates a person may have difficulty making a decision, or when a person expresses difficulty making a decision. The guide can be self-administered or practitioner-administered. A computer-based one page PDF version is available, (Appendix A), and a two-page paper version is also available (Appendix B). Instructions for the one page version are described below.

Decision: The first steps focus on clarifying what specific decision has to be made, when the decision has to be made (timing), the stage of the person's decision making, and their leaning.

Certainty: One question elicits decisional conflict about the course of action. The subsequent questions focus on factors contributing to uncertainty such as:

Knowledge: whether a person feels they know the options, benefits and harms.

Values: whether a person is clear about which benefits and risks matter most to them.

Support: whether a person has adequate support and advice, or whether they feel pressured to make a particular choice.

These questions are simplified items from the decisional conflict scale. Their responses are organized to be able to identify problems 'at a glance': if a person responds 'yes' to the items, there is no decisional difficulty. If the response is 'no', there is decisional difficulty. The detailed version of this reliable and valid tool (10,12,14,18,39) shows that greater decisional conflict occurs in those who: delay decisions; score lower on knowledge tests; are in the early phases of decision making; have not yet received decision support. High decisional conflict after decision support predicts downstream: delay or discontinuance of chosen option, regret and the tendency to blame their practitioner for bad outcomes (67,68). The scale elicits people's overall comfort level regarding their knowledge, values, and support; however, probing is still required to find out specifically what a person knows and values and the role they prefer to play in the decision making process.

Probing: Subsequent questions probe a person's knowledge, values, and support.

Knowledge, expectations and values are probed by completing the balance scale located in the middle of the form. First a person lists the main benefits and risks to ascertain knowledge of options and outcomes. Then a person is asked to underline the benefits and risks that are most likely to happen to ascertain expectations. This is followed by assigning stars (1-5) to indicate how much each benefit and risk matters to the person (values). In some cases, it will be clear that a person is unable to respond to answer the questions. It is not necessary to complete the balance scale in one sitting; the purpose is to determine gaps as a basis for planning next steps.

Support is probed by determining what role in decision making a person prefers. More information about others involved (people, opinions, pressures, ways they can support) can be probed if there appear to be support problems from earlier questions. The focus should be on those who are most involved and important in the decision.

Next Steps: Lists of general strategies to address a person's unresolved needs pertaining to knowledge, values clarity and support are provided at the bottom of the OPDG, so that the decision support can be planned to address those decisional needs. As the decisional needs resolve or change, questions can be repeated and updated.

An evidence-based decision aid entitled ‘When you need extra care, should you receive it at home or in a facility?’ (Appendix C) has been developed to help guide ‘place of care’ discussions and help prepare patients for place of care decisions. The decision aid is based on the Ottawa Decision support Framework (ODSF), and includes assessment scales typically used in palliative and oncology care (The Edmonton Symptom Assessment Scale (ESAS) and the Palliative Performance Scale (PPS)). The workshop will feature this decision aid and provide an opportunity to practice with the tool.

7. Condition-Specific Patient Decision Aids or Shared Decision making Programs

Generic decision guides can be supplemented with condition-specific decision aids. Patient decision aids or “shared decision making programs” are interventions designed to prepare people for decision making; they do not replace counseling (21,51-56). They help people to: 1) understand the probable benefits and risks of options; 2) consider the value they place on the benefits versus the risks; and 3) participate actively with their practitioners in deciding about options.

According to the International Patient Decision Aids Standards (IPDAS) Collaboration (66), patient decision aids provide:

- information on the disease/condition, options, benefits, harms, scientific uncertainties;
- the probabilities of outcomes tailored to a person’s health risk factors;
- an explicit values clarification exercise; and
- guidance in the steps of decision making and communicating with others.

Decision aids may be administered using various media before, during or after counselling. Most developers are moving toward web-based materials that can be printed or used online.

Excluded from the definition of decision aids are passive informed consent materials, educational interventions that are not geared to a specific decision, or interventions designed to promote compliance with a recommended option rather than a choice based on personal values.

Patient decision aids have been developed for a variety of screening, diagnostic, medical, therapeutic, and end-of-life decisions (57,58,59). A list of currently available decision aids is found in the ‘A to Z inventory of decision aids’ at the Ottawa Health Decision Centre website <http://decisionaid.ohri.ca/AZinvent.php>.

Several randomized controlled trials of decision aids show they increase participation in decision making without increasing anxiety and improve decision quality (improved knowledge, more realistic expectations, better match between personal values and choices). They also lower decisional conflict and result in fewer people remaining undecided. Decision aids may also have a role in addressing under-use and over-use of options. They reduce the uptake of expensive surgical options that informed people don’t value when baseline rates of these procedures are high. They also increase the uptake of colon cancer screening options, which are under-used, and lower the rates of Prostate Cancer Screening tests, which are over-used.

See Table 5: Research on patient decision aids.

8. Communication when Supporting Decisions

Adapted from Bunn H, O'Connor AM, Jacobsen MJ Analysing decision support and related communication 1998, 2003

Effective communication skills are essential for good decision support. Ivey & Bradford-Ivey caution against overemphasizing communication skills, which can result in talk rather than action, and technique rather than substance (60). The key to effective decision counseling is to move beyond the mere mechanistic application of a range of communication skills to focus on being with a person in a true encounter (61-64). However, there needs to be a balance between the skill and art of communication. The practitioner who is confident and competent in using communication skills may be freed up to focus on relating to the person that they are counseling.

There may be a tendency in decision making interviews to be more mechanistic, rely more heavily on questioning skills and focus on the cognitive elements of the decision. However, it is important to remember that when people are trying to make decisions, all aspects of the person – cognitive, affective, social and spiritual, are involved.

Key communications techniques (60,64) include:

- listening skills (e.g. encouraging, paraphrasing, reflecting feeling, summarizing, validating);
- questioning skills (e.g. open-ended and closed-ended questions); and
- sending messages skills (e.g. providing feedback and providing information).

Listening Skills

Listening skills include encouraging talk, paraphrasing content, reflecting feelings, summarizing key comments and validating accuracy of perceptions.

Encourage talk. 'Encouragers' are prompts to encourage a person to continue.

Prompts the person to continue talking using encouragers or key words	May be cues ("uh huh"), leads ("go on"; "and then?") or repeating a person's key words or phrases (It's upsetting.)
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Paraphrasing content. The goal is to promote personal exploration, clarify the content or cognitive component of a person's message and communicate that a person's unique perspective has been heard and understood (61). To paraphrase properly, the practitioner must communicate back to the person (in his/her own words) the essence of what has been said. It is often helpful to include a few key words, which a person has used, but avoid 'parroting' or repeating the exact response, which can be irritating and disrupt communication.

Shortens and clarifies the essence of what the person has just said (content) and feeds back in practitioner's own words	<u>Marcia</u> : "I spent a long time trying to sort out the information package you gave me on long term care facilities." <u>Practitioner</u> accurately feeds back Monica's content. ("So, you found it difficult to understand the material.")
--	--

Reflection of feelings. People are usually reluctant to disclose personal feelings until trust has been established. Practitioners should avoid eliciting in-depth reflection of feeling early in the

relationship, as the person is likely to be resistant or frightened by the experience (61). It is wise to use brief reflections, at an interchangeable level, (reflect back feelings at the level of awareness and intensity communicated by the person without taking away from the meaning of the message). Such reflection communicates that the practitioner understands the feelings being experienced by the person and often serves to free-up the person for further problem solving.

Identifies what the person is feeling now and feeds back in practitioner's own words	<u>Marcia</u> : "I've looked at the material but I seem to go back and forth and still don't know what to do." <u>Practitioner</u> accurately feeds back Monica's current feelings. ("So, you're unsure about which option is best for you and your mother")
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Summarization of a person's key comments can be used effectively mid-way through an interaction and in the final stage of the interview (61). The practitioner notes the person's verbal behaviour over a period of time and communicates his/her understanding of key concepts back to the person. Effective summarization, by tying together critical elements of the situation, assists people to gain a broader perspective of the situation rather than becoming mired in detail.

Condenses several key comments made by the person over time during the interview (content &/or feelings and feeds back in practitioner's own words	<u>Practitioner</u> focuses on Marcia's key content and/or feelings ("So, you've read the information, you've discussed the issue with your sisters but you're having difficulty making a decision because you're worried about the disadvantages.")
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Perception checks are used to verify with a person that the practitioner is interpreting the person's message clearly. Perception checks are often used following a paraphrase or a summary.

Checks to ensure that what is said or heard is accurate; may be used after a paraphrase, reflection or summary	<u>Marcia</u> : "It's difficult to decide. Some days with my mother are not too bad - other days she needs more care than I can provide and still have time for my kids. I don't know." <u>Practitioner</u> validates accuracy of understanding with Monica. ("You're saying that you're not ready to make a decision at this time. Am I hearing you correctly?")
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Questioning Skills

Open and Closed questions. While both open and closed questions are useful in interviewing, it is recommended that practitioners rely primarily on open questions to ensure that a person has some control over what to reveal (61). Closed questions may be needed to obtain specific information necessary to understand a person's perspective.

Open questions Asks for elaboration or clarification; cannot be answered with yes / no / one word	<u>Practitioner</u> : ("What else might influence you to continue to care for your mother at home or to consider admission to a long term care facility?")
Closed questions Asks for minimal and specific information; can usually be answered with yes / no / a few words	<u>Practitioner</u> : ("Is your partner supportive?")

Practitioners can use other skills (paraphrase, reflection of feeling) to respond to the information gathered through questioning. This is advisable to prevent a person from feeling 'grilled' and to communicate that the practitioner has understood the cognitive and affective information provided. If the practitioner feels a need to move away from the person's immediate concern, it is not necessary to use questions. The practitioner can link the response to something the person has mentioned earlier in the interview. For example she can introduce the topic by stating "You mentioned earlier--". Ivey & Bradford-Ivey (61) describe staying with the topic presented by the person or explaining the switch to another topic as verbal tracking, an important aspect of 'attending' behaviour. They view attending behaviour as the foundation skill for all other communication skills.

Sending Messages Skills

Messages are sent by **providing information** and **providing feedback**. Information giving responses should be clear and related to the person's situation. The emphasis should be on sharing information and not on advice giving. According to Sundeen, Stuart, Rankin & Cohen (64) 'information giving' allows a person to supplement his/her own knowledge and often leads to a more informed decision, while 'advice' takes the focus away from personal or shared decision making and places it on the practitioner.

Providing feedback deals with the practitioner's perception of a person's behaviour. People often tend to focus on past events or future hopes, but may have difficulty dealing with current thoughts and feelings related to those past events or future hopes. In the interaction, the practitioner should try to achieve a balance of focus on the past, present and future (exploring the person's vision of his/her ideal outcomes).

The practitioner should try to maintain a balance between facts and the person's values that influence the decision making. It is also important to focus on the person's strengths (such as the personal and external resources the person brings to the decision making situation, especially for people who tend to focus on the problems associated with the decision.

Provide information new information, explanations, teaching, responds to questions	Practitioner: ("If we look at what each option has to offer, the disadvantage for being at home would be--- and the advantage would be.")
<i>Provide feedback</i> Provides the person with practitioner's perception of person's behaviour	Practitioner: (" I notice that you have been focusing more on what happened in the past rather than how you are presently dealing with the decision") Practitioner: ("You seem to have a good grasp of the key facts; you also value input from your partner.")

Overall Assessment of the Interaction: Person/Practitioner Centered

It is important to determine whether the interaction is person centered or practitioner centered. In a successful person-centered interview, practitioners use a range of communication skills at a satisfactory level, are able to establish the beginnings of a trusting relationship and facilitate

adequate exploration, understanding and action in relation to the decision being made. Criteria for evaluating person-centeredness are described below.

<i>Reasonable balance between:</i>	<i>Intended Interpretation</i>
practitioner vs person focus, talk time	Not equal focus or use of talk time, but a reasonable balance Agenda reflects balance between a person's and practitioner's thinking and issues
use of questions, listening skills and sending messages	Questions not used as the only way to obtain information. (Too many questions make a person feel grilled.) Good use of listening skills or interviewing a talkative person may decrease need for questions. Focusing primarily on sending messages (providing information) will reduce listening
open and closed questions	Generally, more open than closed questions. May need closed questions with talkative person, to focus discussion, or to obtain specific factual data
Practitioner tailors to a person's needs	Acknowledges person's questions or situation and provides relevant information (related to needs) Determines person's needs before providing information Does not ignore questions or provide unsolicited advice

Tools for practitioners to use in self-assessment of decision support and communication skills, (using the above examples), have been refined and validated by Guimond et al.(65)

9. Case Study: Using the Place of Care Decision Aid:

“When you need extra care, should you receive it at home or in a facility?”

Mr. David L., a 67 year-old man living with his 65 year old wife. They are both retired, having sold their corner grocery store to their only child, a 40 year old son who manages it with his wife. His son lives nearby and has 2 young children. Mr L. had been diagnosed with pancreatic cancer and understands his life expectancy is short. His main symptom is pain which is fairly well controlled with medication. When he was first diagnosed with cancer he and his wife discussed care at home. However now that he is getting weaker he is concerned that it may be too hard for his wife because she has a bad back. Today, his home care nurse visited and they had a discussion about the advantages and disadvantages of continuing care at home. After discussion his nurse informed him that the decision hinged on his quality of life and practical concerns. His visit nurse referred Mr. L to case manager MA to provide further information on the options.

Case Manager MA and Mr. L exchange greetings. MA asks him to explain what brings him here.

Mr. L: I want to learn more about my options for care. I had always wanted to be at home but lately I am worried it may be too hard for my wife... We have been managing ok now... I am worried about the future... I have been visiting the hospice one day a week... they are very nice and I have a friend who died there and I know the nurses at the hospital. I always took care of things before... I want to have things organized. . . . My home care nurse said you had information . . . I would like to know my chances of being able to stay home. . . maybe it would be worth it to be at home with my dog and personal things . . . and be close to my grandchildren . . . but, I am not going to take a big risk on making things too difficult for my wife . . . we went through my mother-in-law dying at home and I don't want to make things too difficult for my family if I can help it . . .

MA: So you are not sure whether to continue to stay at home or think about hospice or maybe the hospital. . . . you need more information about the advantages and disadvantages . . . so you can judge whether the advantages of being at home outweigh the disadvantages or if there is another option, like hospice, that would meet your care needs and what is important for you . . . is that what you are saying?

Mr. L: Yes, that's right.

MA: Is there anything else making this difficult to decide?

Mr. L: I can't think of anything . . .

MA: Who else is involved in making this decision?

Mr. L: Well, there is my doctor . . . my wife is interested in knowing more . . . naturally she is concerned about how we will manage . . . although she thinks the choice is up to me ...and so do I . . .

MA: We have a decision aid you can work through [Appendix C]. It is tailored to people like you who are thinking about place of care. The decision aid helps you think about different care options, how you are feeling right now, what matters most to you in choosing an option, what you need to do to prepare for making a decision, then consider what are the next steps for you.

Mr. L: I will give it a try . . .

MA: Is there anything else you would like to discuss right now?

Mr. L: No, I don't think so . . . Could you stop by next week?

MA: Yes, I can arrange to see you next Wednesday . . . in the meantime complete the needs assessment and we will discuss it next week . . . [discusses time details].
Mr. L and MA exchange goodbyes.

Follow-up contact with the Case Manager
[Mr. L forgot to complete the Decision Aid]

Mr. L and MA exchange greetings.

MA: How far along are you with this decision?

Mr. L: I am pretty sure I know what I want . . . to stay at home.

MA: Would it be helpful if we go over the things you considered before deciding?

Mr. L: Yes, that would be fine.

MA: So would you say you know the options that are available to you?

Mr. L: Yes, the information pamphlet had the options you talked about last week, home, hospice or care residence... I also thought about the hospital because I know the nurses and the unit

MA: Do you feel you know both the advantages and disadvantages of each option

Mr. L: Yes

MA: What do you see as the main differences between home and hospice?

Mr. L: Well, being at home is more personal and being at the hospice is a somewhat like home with nurses there all the time. Also at home I would be close to my family and my dog... but it could be harder on my wife... but she doesn't drive so if I was at hospice she would have to take a bus or get a drive. Also if my pain becomes worse it may be hard to manage at home... and pain is the main problem that I can expect...

MA: Your big concern before was getting enough help at home, what did you think of that?

Mr. L: Well, I was surprised that there are services that we can get . . . I thought it would be much less, . . . also my wife and I have talked about setting things up in the family room and my church wants to help too. So there is a good chance we could manage at home if the pain doesn't get too bad.. .

MA: You have mentioned several places where you could get help at home. Another concern you had was symptoms- pain and nausea. What do you think about that now?

. . .

Mr. L: Yes . . . I talked to my oncologist as you suggested. He tells me that I can expect some nausea and that there are medications and treatments that will help- While he can't predict what my pain will be, the team will follow me closely and adjust my pain meds as things happen . . . and right now it is pretty well controlled...

MA: So if you and your wife decided on continuing care at home, you would need to consider if that is still best depending on how things change... for instance if you needed treatments for pain that couldn't be given at home or if your care needs became too difficult for your family

Mr. L: Yes . . . that makes sense . . .that's what I'm saying

MA: You seem to be very informed. Would you say your questions have been answered?

Mr. L: Yes, the information helped . . .

MA: ...And you are clear about which benefits and risks matter most to you? . . . how being in familiar surroundings weighs against the impact of being at home on your family

Mr. L: To me, the most important thing is to be in a place where I am comfortable without making things too tough for my family. . . . I know that things could change and we may have to make another decision in the future . . . the risk is that my pain becomes too big of a problem or I need more help than we can get at home

MA: . . . So there is a risk that your pain could become an issue and that it may not be practical for you to continue to be at home... and you would reassess things if that happened?

Mr. L: Yes

MA: So would you say you have enough support and advice to make a choice?

Mr. L: Yes, my wife is happy with my decision . . . I would like to run this by Dr. R of course . . .

MA: Would you say you are choosing without any pressure from others?

Mr. L: Everyone has told me it is up to me . . . I don't feel anyone is trying to get me to choose one way or another . . .

MA: So you are saying you feel sure about the best choice for you?

Mr L.: Yes, as long as things stay manageable.

MA: You seem comfortable with your decision . . . Do you have any other questions about this? As next steps we can talk about the services you have now and other things we can do. As well, we could work with your social worker and family doctor to fill in an application for the hospice so that if things do change in the future you would already have a backup plan in place. How is that for you?

Mr. L: Yes that sounds like a good plan. . . . thanks very much . . .

Follow-up Contact with the Case Manager

[Mr. L remembered to bring his completed the Decision Aid.]

MA: How far along are you with this decision?

Mr L: I am pretty sure I know what I want . . . To be at home.

MA: Would it be helpful if we review your responses to the decision aid together? . . . the guide summarizes your thoughts . . . you can take a copy to show the social worker and Dr. R . . .

Mr L: Yes, that would be good.

[MA and Mr. L look at his copy of the Decision Aid together]

CERTAINTY

MA: As you mentioned, you feel continuing care at home is the best choice for you?

Mr. L: Yes.

KNOWLEDGE

MA: Looking at your answers to the questions here . . . you know the differences between the options . . . that being at home and the hospice are possible options and that being in hospital is less of a good option. . . . You mentioned last week that a big concern was getting enough help and support at home. What do you think now?

Mr. L: Well, I was surprised to find out just what was available . . . and that other people like my church group could help...

MA: When we talked last week another big concern you talked about was the chance of having more pain or nausea; what do you think now since we talked and you talked to your doctor?

Mr. L: I was relieved to hear that it is likely that my pain could be managed quite well at home... and that the visit nurse and the doctor would follow this closely . . . I thought that I wouldn't be able to get these drugs at home, but no . . . to me there is a good chance it could be managed at home . . .

MA: You realize that things could change...we can't always predict exactly what will happen . . .

Mr. L: Yes . . . I understand . . .

MA: So if you and your wife decided on continuing to be at home, you would need to consider your decision if your situation changed, and your care needs couldn't be met at home.

Mr. L: Yes . . . that makes sense . . .

MA: What other questions did you have?

Mr. L: I can't think of any . . . the information was clear . . .

VALUES

MA: You say here that you are clear about which advantages and disadvantages matter most to you? . . . being in familiar surroundings and close to family is '5 out of 5' in importance, and that you are concerned about the impact on your wife, so you need to think about this if your situation changed.

Mr L: Yes, being with family at home is more important as things are now . . .

SUPPORT

MA: You seem to have good support from decision making . . . you seem comfortable with the decision . . .

NEXT STEPS

MA: What do you see as the next steps? . . .

Mr. L: I plan to discuss this with the social worker and my doctor. . . I think it would be good to have a back up plan for hospice

MA: Sounds good . . . is there anything else you need from me . . .

Mr L: No . . . I think this is a good plan . . .

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Table 1. Research on manifestations of decisional conflict

Population Studies. One Canadian national telephone survey elicited the frequency of behavioural manifestations of decisional conflict when people faced a ‘complex’ decision affecting their health (8). A complex decision was characterized as one in which the best choice depended on how people weighed the personal importance of the benefits versus risks. Among the respondents, [n=635], 65% reported making ‘complex’ health decisions, commonly about medical or surgical treatments or birth control, and more commonly by women and by married/separated individuals. When asked about difficulties in decision making:

- 59% reported they were unsure about what to choose, the hallmark of decisional conflict;
- 77% questioned what was important to them when making the decision;
- 61% worried about what could go wrong (61%);
- 26% wavered between the available options;
- 27% wanted to delay the decision.

Two of these behaviours were associated with the type of decision. Higher rates of physical stress were reported by those who had made decisions about institutionalisation (54%) or medical treatment (46%), compared to those pondering birth control decisions (23%). Decision delay was more common among those deciding about institutionalisation (50%), compared to those making surgical decisions (20%).

Clinical Studies. Several small pilot studies have found a considerable portion of their respondents expressed uncertainty about what to choose, the main manifestation of decisional conflict (see below)

Study	N	% Uncertain
Osteoporosis Rx: women considering changing Rx (9)	20	69%
Amniocentesis: pregnant women over 35 years (10)	21	67%
Tamoxifen chemoprophylaxis: women high risk for breast cancer (11)	17	63%
Menopausal hormones: women considering current choice (about half are currently using) (12)	94	52%
Location of care for relative with dementia: proxy decision by caregivers (13)	27	48%
Stage IV lung cancer Rx: men/women after consultation with oncologist (14)	12	47%
Location of death: terminally ill women at various stages of decision making (15)	20	43%
Circumcision male newborns: prospective parents attending prenatal classes (16)	88	33%
Pre-donating blood before cardiac surgery: men/women after consultation with surgeon (17)	59	15%

These studies are limited to Canada and the clinical samples were small. More research is needed on the prevalence of decisional conflict and related factors for the many decisions people face (See Table 3). Our group is working with investigators in other countries to learn more about the prevalence of the problem and contributing factors.

Table 2. Research on factors contributing to decisional conflict

Population Studies. The aforementioned Canadian national telephone survey (8) examined the reported factors contributing to decisional conflict. The overall prevalence of problems was low, with 9 to 27% reporting problems such as unclear values, pressure from others, or deficits in motivation, skill, support, or knowledge. However, these problems were much greater in those who had experienced uncertainty when choosing (the main hallmark of decisional conflict) than those who had not. For example, about a third of the uncertain group reported information deficits regarding the options, pros, and cons and their likelihood, compared with 16% of the certain group. At least a quarter reported social deficits such as not knowing what others decide or recommend, pressure, and lack of support. About 17 to 19% reported deficits in skills and readiness for decision making. The most frequently cited other factor contributing to the difficulty of the decision was the highly charged emotional environment in which the decision was made. When we examined the association between decision type and each of the reported factors, more respondents making decisions about birth control felt they had the ability or skill to make the decision (95%) compared to those making decisions about surgery (80%).

Clinical Studies. Several small pilot studies have found a considerable portion of their respondents expressed factors contributing to decisional conflict (see below).

Study	N	Uninformed	Unclear values	Unsupported
Osteoporosis Rx (9)	20	59%	31%	39%
Amniocentesis: pregnant women over 35 years (10)	21	76%	54%	61%
Tamoxifen chemoprophylaxis: high risk women (11)	17	73%	63%	53%
Menopausal hormones (12)	94	43%	42%	52%
Dementia: location of care proxy decision by caregivers (13)	27	30%	37%	45%
Stage IV lung cancer Rx after consultation with oncologist (14)	12	25%	28%	13%
Location of death, terminally ill women (15)	20	38%	20%	17%
Prospective parents: circumcision male newborns (16)	88	45%	51%	35%
Pre-donating blood before cardiac surgery (17)	59	13%	15%	14%

You can see the most common factor contributing to decisional conflict varies by the type of decision. These studies need to be enlarged with more representative populations before drawing firm conclusions.

Table 3. Examples of potentially difficult decisions which may create decisional conflict

Difficult decisions in a population-based survey[§] (n = 635)

Treatment Decisions		
Surgery (30 %) • Hysterectomy • Tumour removal • Laminectomy • BPH • Prostate cancer	Medications (27%) • HRT • Atrial fibrillation • Chemotherapy • Lipid lowering medication • Antidepressants	
Reproductive Decisions		
Contraception (24%) • Method • Sterilization • Abortion • Adoption	Pregnancy (5%) • Childbirth (Delivery) • Fatherhood / motherhood • Breastfeeding	
Lifestyle Decisions	Investigation Decisions	End of Life Decisions
Lifestyle (5%) • Nutrition • Weight loss • Stress • Smoking • Drug or alcohol use	Diagnostic tests (1%) • Amniocentesis • Radiography • Ultrasound	Discontinuation of life support (0.5%) Institutional placement (6%)

[§]O'Connor et al. A survey of the decision making needs of Canadians faced with complex health decisions. Health Expectations 2003; 6, pp.97-109.

The A - Z Inventory

The Ottawa Patient Decision Aids website lists patient decision aids in an A-Z Inventory:
<http://decisionaid.ohri.ca/AVinvent.php> .

Table 4. Glossary of terms for Ottawa Decision Support Framework

DECISIONAL NEEDS
DECISION Type: class or characteristic of the choice that needs to be made [e.g. developmental transition or clinical options (screen, test, treat, palliate)]; number of options, degree of risk/uncertainty, seriousness of outcomes, whether it is irrevocable Timing: time frame or urgency with which a decision needs to be made Stage: phase of decision making: not thinking about options; considering options; close to selecting an option; taking steps towards implementing option; have already carried out choice. Categories are similar to Prochaska's Stages of Change (1), with one important difference. Deciding <u>not</u> to change is a viable option because often there is no recommended course of action, e.g. amniocentesis. Leaning: inclination to choose one option over the other
DECISIONAL CONFLICT uncertainty about course of action to take when choice among options involves risk, loss, regret, challenge to personal life values
KNOWLEDGE & EXPECTATIONS Knowledge: cognizance of the health problem or situation, options, and outcomes Expectation: perceived likelihood or probability of outcomes of each option
VALUES desirability or personal importance of outcomes of options
SUPPORT & RESOURCES Others' opinions/ practices: perceptions of what others decide or what others think is the appropriate choice. This may include a person's spouse, family, peers, and practitioner(s). For practitioners: the patient, professional peers, and personal network Pressure: perception of persuasion, influence, coercion from important others to select one option Role in decision making: the way a participant is or wants to be involved in decision making; do they prefer to: make the choice themselves after considering opinions; share decision making with another; have others decide after considering their opinion Experience: past exposure to the situation, options, outcomes, decision making process Self-efficacy: confidence or belief in one's abilities in decision making, including shared decision making Motivation: readiness and interest in decision making, including shared decision making Skill: abilities in making and implementing a decision External support: Available, accessible assets from others that are required to make and implement the decision. Types include: information, advice, emotional support, instrumental help, financial assistance, health & social services. Sources include: social networks, professional networks, support groups, voluntary agencies, and the formal health care, education, and social sectors
PERSONAL & CLINICAL CHARACTERISTICS Patient: Age, gender, education, marital status, ethnicity, occupation, locale, diagnosis & duration of condition, health status (physical, emotional, cognitive, social) Practitioner: age, gender, ethnicity, clinical education, specialty, practice locale, experience, counseling style

DECISION SUPPORT:

PATIENT DECISION AIDS

Evidence-based tools to prepare people to participate in making specific and deliberated choices among healthcare options in ways they prefer. They supplement (not replace) clinician's counseling and aid decision making by: a) providing evidence-based information about a health condition, the options, associated benefits, harms, probabilities, and scientific uncertainties; b) helping people to recognize the values-sensitive nature of the decision and to clarify the value they place on the benefits, harms, and scientific uncertainties. Strategies include: describing the options in enough detail that clients can imagine what it is like to experience the physical, emotional, and social effects; and guiding clients to consider which benefits and harms are most important to them; and c) providing structured guidance in the steps of decision making and communication of their informed values with others involved in the decision (e.g. clinician, family, friends).

DECISION COACHING

Support provided to people facing a decision by a trained facilitator who is supportive but neutral in the decision. Coaching can be provided face to face (individual, group) or using communication technologies (telephone, Internet). Decision coaching is used alone or in combination with patient decision aids. The strategies may include: a) clarifying decision and monitoring needs; b) facilitating access to evidence-based information, verifying understanding, clarifying values, building skills in deliberation, communication, and accessing support; and c) monitoring and facilitating progress in decision making and decision quality.

DECISION QUALITY

QUALITY OF THE DECISION

The extent to which the chosen option best matches informed clients' values for benefits, harms, and scientific uncertainties

QUALITY OF THE PROSESS OF DECISION MAKING

The extent to which a person is helped to: a) recognize that a decision needs to be made; b) know about the available options and associated procedures, benefits, harms, probabilities, and scientific uncertainties; c) understand that values affect the decision; d) be clear about which features of the options matter most to them (e.g. benefits, harms, and scientific uncertainties); e) discuss values with their clinician(s); and f) become involved in decision making in ways they prefer.

Table 5. Research on patient decision aids

There is an ongoing systematic review conducted by an international team of investigators through the Cochrane Collaboration (57,58,59). In their 2003 update, they found over 200 decision aids, of which over 130 are available for use. A complete list of decision aids that are in development or completed is found at <http://decisionaid.ohri.ca/cochinvent.php> in the Cochrane Inventory.

The systematic review found 62 randomized trials of decision aids completed or in progress. When the 34 completed and published trials were analysed, the following conclusions were made. Decision aids improve decision quality by:

- increasing knowledge of the options;
- creating realistic expectations of the benefits and harms of options; and
- improving the agreement between personal values and the options chosen.

. Decision aids improve decision making by:

- reducing decisional conflict scores, particularly in the area of feeling informed
- reducing the number of people who are uncertain about what to do;
- increasing people's participation in decision making without increasing anxiety;

The impact of decision aids on satisfaction with decision making is more variable. Moreover, decision aids have not affected health outcomes; however, measures of outcomes were not linked to patients' values [e.g. did patients achieve outcomes they preferred most and avoid outcomes they preferred least]. The trials in progress should shed more light on the influence of decision aids on: diverse groups of practitioners and patients; patient-practitioner communication; and downstream effects such as persistence with chosen therapies, distress, regret, and the extent to which patients achieve outcomes they prefer and avoid outcomes they do not prefer.

Final Quiz

Question 1 (1 point)

THREE (3) of the following people HAVE manifested behaviours of decisional conflict. Which ONE does NOT:

- ☒ a. Sara, who has prepared her advance directives and has identified her husband as power of attorney for her personal care.
- ☒ b. Andrew, who is putting off the decision about radiation treatment
- ☒ c. Marie, with breast cancer, who says she is very worried that her cancer would return if she just had a lumpectomy instead of a mastectomy.
- ☒ d. Karl, who thinks he will opt for PSA testing, then changes his mind about PSA testing 3 times over the next week.

Save answer

Question 2 (1 point)

Identify which of the following represent MODIFIABLE FACTORS contributing to decisional conflict, as opposed to the inherent difficulty of the choice. (Choose the best TWO answers)

- ☐ a. Feeling unclear about the importance of pain control versus concerns about addiction.
- ☐ b. Feeling unsure about how to work through a difficult decision about pain control
- ☐ c. Facing a decision between two pain control options, where there are potential benefits and risks associated with each option.

Save answer

Question 3 (1 point)

Anna indicates that she is experiencing unwanted pressure from her husband to make a specific choice regarding radiation and chemotherapy treatments. Which intervention would be most helpful? (Choose the best answer.)

- ☒ a. Providing information on how others decide
- ☒ b. Suggesting that she confront her partner and make the decision herself
- ☒ c. Role playing ways she could communicate her values to her husband and elicit his values.
- ☒ d. Directing her to ignore the pressure.

Save answer

Question 4 (1 point)

Jeremy understands the options he has - either home or hospice, and has enough information. He is trying to decide between remaining in his apartment or going to hospice - because he thinks this is what his family wants. Jeremy indicates that he would like to make things easier for his family, but would miss his dog and would not feel comfortable in the hospice. Which of the following would be appropriate decision support interventions for Jeremy? (Choose the best TWO answers).

- ☐ a. clarify his personal values about what is most important to him
- ☐ b. provide him with information about the hospice
- ☐ c. explore his expectations to see if they are realistic
- ☐ d. Provide him with information about home care

Save answer

Question 5 (1 point)

Jean has breast cancer. A friend has told her that she knows several people whose cancer was cured after they started a macrobiotic diet. Jean is considering stopping her Tamoxifen and using the money to buy the food for the macrobiotic diet. This shows that Jean has: (Choose the BEST answer.)

- ☐ a. lack of support
- ☐ b. unclear values
- ☐ c. unclear perception of others
- ☐ d. unrealistic expectations

Save answer

Question 6 (1 point)

It is important to find out who else is involved in a decision making situation for a variety of reasons. Which of the following is NOT a correct reason? Choose ONE.

- ☐ a. the client may wish to share the decision making with others
- ☐ b. others' opinions may influence the client positively or negatively
- ☐ c. the best decisions are made when others are involved
- ☐ d. others may be able to provide the client with emotional and instrumental support

Save answer

Question 7 (1 point)

According to the International Patient Decision Aids Standards (IPDAS) Collaboration, which of the following are hallmarks of a "good" client decision? (Choose the best answer.)

- ☐ a. Shared equally with practitioner, informed
- ☐ b. Consistent with personal values, shared equally with practitioner
- ☐ c. Informed and values-based
- ☐ d. None of the above

Save answer

Question 8 (1 point)

What are the key steps in a decision support process for people with decisional conflict? (Choose the best answer.)

- ☐ a. Identifying decisional needs, facilitating interventions to address these needs and evaluation of the decision making process and outcomes
- ☐ b. Helping practitioners identify the best options, and assessing confidence to implement a choice
- ☐ c. Eliciting patient's values, guiding implementation of decision support, and coaching in communicating with others
- ☐ d. Assessing needs, coaching in strategies to manage pressure, and implementing preferred options

Save answer

Question 9 (1 point)

The Decisional Conflict Scale, as used in the Ottawa Guides, assesses a client's problems with: (Choose the best answer.)

- ☐ a. Certainty, norms, support
- ☐ b. Values, knowledge, outcomes
- ☐ c. Knowledge, values, support
- ☐ d. Certainty, support, self-help skills

Save answer

Question 10 (1 point)

In 'effective care', practitioners routinely recommend options: (Choose the best answer.)

- ☐ a. classed as likely beneficial, congruent with client's values
- ☐ b. where benefits are large and harms are minimal
- ☐ c. having benefits and harms, involving scientific uncertainties
- ☐ d. preferred by the patient, having no right or wrong answer

Save answer

Question 11 (1 point)

Monica has just initiated a discussion with the nurse: **Monica says:** "I don't think my mother is safe to stay alone any more. My sister doesn't do anything to help, so it is all my responsibility. I don't know what would be the best thing to do."

The nurse responds: So, you're not sure what would be best to do for your mother. . .

The nurse's response is an example of a: (Choose the best answer.)

- ☐ a. paraphrase
- ☐ b. reflection of feeling
- ☐ c. summarization
- ☐ d. perception check

Save answer

Question 12 (1 point)

Which of the following approaches best contribute to client-centeredness in an interview? (Choose the best answer.)

- ☐ a. Using a balance between questions, listening and sending messages
- ☐ b. Anticipating the client's needs and providing evidence-based information
- ☐ c. Using skills such as paraphrasing in order to let the client know that you understand the feelings they are expressing
- ☐ d. Focusing on asking client-centred questions to demonstrate your interest in the client's thinking

Save answer

Finish

Appendix I

Comparison of Patient Education versus Patient Decision Support Video

1. Video (DVD Contact Author)
2. Scenario used in Patient Decision Support- Patient Education Video
3. Survey of Usefulness of Video as a Teaching Aid

Scenario: Woman with End Stage Breast Cancer

Patient Education Scenario for Video

Primary decision support need: Values Clarification

The focus on this scenario will be the nurse giving you information and you looking and feeling overwhelmed.

You are Mrs. Nancy Cooper, a 41 year old woman, who lives in Ottawa with end stage breast cancer. You are a single mom with two teenage daughters. Your mother lives close by, in the same neighborhood. You understand your time is limited and are starting to think about what you have to plan for. You are particularly concerned about where you will die and the impact this could have on your family, particularly your daughters

Setting the stage

You were diagnosed with Breast Cancer about 5 years ago. You had chemotherapy to shrink the tumor and then surgery to remove part of your breast. Following surgery, you had radiation treatment. Two years ago you found out the breast cancer had spread to your bones and more recently to your lungs. You are aware that your cancer is not curable and progressing quickly. You are followed by the oncology team at the cancer clinic and have a family physician who will home visit.

At your last clinic visit the social worker mentioned to you that several options for place of care exist. Some people plan for Hospice care in a facility such as a hospice, palliative care unit or community hospital. Others would prefer to stay at home with home nursing and medical care. Thinking about the decision in advance gives people a chance to make plan for future care needs and to connect with resources.

The reasons people choose to stay at home include:

- Being in a familiar environment
- Less travel or inconvenience for family and friends
- Being able to set own routines and be in control.
- They prefer to be in a home setting

The reasons people may NOT choose to stay at home include:

- They may have pain and symptoms that are difficult to control.
- They are concerned about being a burden to their family and friends
- They may need more help or special equipment than is available at home
- Nursing staff are not available 24 hours a day
- They don't have a family doctor to take care of them at home

You have always been very proud of being organized and in control of things. You are very sad but determined to make sure you have all your things in order. You have been considering staying at home or going to the residential hospice. You feel you are well informed about the resources each place would be able to offer. You would prefer to continue to receive care at home however you are very unsure about which would be the best place for you (home or hospice). Your main concern is about your daughters, causing further disruption in their lives and causing them more unhappiness and difficult memories.

You want to be prepared to talk about this further with your social worker at your next appointment (in 3 weeks). Your mother has told you that it was your decision and that she would support anything you choose to do. She refuses to offer an opinion about what she thinks is the best choice. Your mother suggested you talk to the nurse who helped you when you had your radiation and chemotherapy

Beginning the interview

"A few months ago I learned that my breast cancer has spread. I don't have a lot of time - my doctor thinks may-be a couple of months. I would prefer to be at home but also thinking it might be easier on my daughters if I went to the hospice. I don't know what to do. One day I think I should be at home and the next day I think I should make plans for the hospice.

Your attitude during the call

- ☐ You feel worried about making the decision
 - You are concerned about causing pain or difficulty for you daughters and mother
- ☐ Your father died in hospital and you found it a very institutionalized experience, not family friendly
- ☐ You are wavering between choices
- ☐ You are a little worried about having problems with pain and shortness of breath but have not had any problem so far and your doctor has told you the medications you may need can be given easily at home.

Extra background information, only if the nurse asks

More information about your medical history and lifestyle

(a) Medical history:

- 8. Previously well
- 9. You have some bone pain in your ribs and right arm. This is well controlled with regular medication
- 10. You are short of breath after climbing the stairs or doing any housework
- 11. You are more easily tired these days

(b) Family History:

- ☐ Mother, age 61, alive and well, lives in the same neighborhood (walking distance)
 - o Widowed 13 months ago,
- ☐ Father, died at age 60, of a stroke (13 months ago)
- ☐ You have been divorced for 8 years. Your husband lives in Ottawa.

- ☐ Your 2 teenage daughters are both healthy- they are aware that you have incurable cancer and that you may live for only a few more months. You have not talked specifically to them about planning for place of care.
 - o Erin, age 17, is in grade 12, and a member of the high school swim team. She is planning to attend College next year to study animation
 - o Jessie, age 13, is in grade 7, and takes figure skating and dance lessons weekly.
- (c) Current lifestyle activities:
 - ☐ You live with your daughters.
 - ☐ You are on fairly good terms with your divorced husband and consider him supportive but not heavily involved in your life
 - He is remarried with a young family.
 - Your daughters see him about once a month
 - He has agreed that your mother will care for the girls in your home following your death
 - ☐ Your mother lives close by
 - She is supportive
 - ☐ You previously worked for the government in an administrative position. You have been on long-term disability for the past year.
 - You feel financially secure although don't have a lot of extra money at the end of the month;
 - you have additional health insurance which could cover home nursing and other home services
 - ☐ You have a family doctor

Information access:

- ☐ You have access to the Internet and have used it to search information about hospice and palliative care. You have used the cancer clinic library to get information in the past
- (e) Previous experiences with making decisions:
 You have been involved in all of the treatment decisions and prefer a shared decision role..

More information about how you see the decision

About the decision

Decision: whether or not to make plans for a home death.

Deadline for making decision: ~3 week when you see your social worker

Stage of decision making: thinking about whether or not to plan for care at home or in a facility when your care needs increase and your condition worsens

Your desired role in making the decision

Preferred role: to share the decision with doctor and your mother and daughters. You will tell your ex-husband after you make your decision

Information: You feel you have enough information about the resources available for care in your community

Values/importance: You are not sure about what is more important to you in the pros and cons for the decision.

Other people:

- Your social worker has clearly explained that there are pros and cons to being at home or being at hospice.
- Your mother has not expressed an opinion but says she will support any decision you make; she says she wants what you think is best.
- Your teenage daughters are aware that you have incurable cancer and that you may live for only a few more months. Since you told them about your cancer spreading they have said that will support any decisions you make
- You do not want to speak with your ex husband about this decision.

Your choice: At the beginning of the interview you are unsure; if the nurse asks you to think about how important the pros and cons are (or asks you to rate them with stars), you will decide to make plan to stay at home, but still want to confirm this with your social worker.

Plan: You are booked to see your social worker in 3 weeks so you want to know your decision by then.

If the nurse asks you these questions before she asks you to rate how important the pros and cons are (more at the beginning of the call), you can answer...

Are you clear about the best choice for you?	No
Are you sure what to choose?	No
Do you know the options?	Yes
Do you know the pros of the options?	Yes
Do you know the cons of the options?	Yes
Are you clear about which pros are most important to you?	No
Are you clear about which cons are most important to you?	No
Do you have enough support to make a choice?	Yes
Are you choosing without pressure from others?	Yes
Do you have enough advice to make a choice?	Unsure

If the nurse asks you what you know,

- you can give her the list of pros and cons from the table below.

If the nurse asks you to rate how important, the pros and cons are,

- you can provide the number of stars give in some of the boxes.

PROS	CONS
I could be in a familiar place where I feel comfortable and it would be more private (*****5 STAR RATING)	I could be a burden to my daughters and mother (**3 STAR RATING)

My family would be close by and I would be involved in their lives (***** 5 STAR RATING)	If there was a serious problem, I would have to wait to get help (**2 STAR RATING)
I can be in control of my routines and what happens during the day (**3 STAR RATING)	It could be upsetting for my daughters to continue to live in the house if I die there (**3 STAR RATING)
I know the home care nurses already and am feel comfortable with them (***** 4 STAR RATING)	My daughters may not feel comfortable inviting their friends to the house when I am sick (** 2 STAR RATING)

Preferred Choice: You are leaning toward making plans to stay at home for end of life care

If you rate the pros and cons and if the nurse asks what you will do next:

- you can say that you plan to tell your social worker that you want to make plans to die at home because you would be better able to be part of your daughters day to day activities and have more time with them.

If you rated the pros and cons and the nurse asks these questions, you can tell her (**at the end of the call**)...

Are you clear about the best choice for you?	Yes, I think so
Are you sure what to choose?	Yes, I think so
Do you know the options?	Yes
Do you know the pros of the options?	Yes
Do you know the cons of the options?	Yes
Are you clear about which pros are most important to you?	Yes
Are you clear about which cons are most important to you?	Yes
Do you have enough support to make a choice?	Yes
Are you choosing without pressure from others?	Yes
Do you have enough advice to make a choice?	Yes, I think so for now

If the nurse asks you about others opinions, you can share with her that:

Other people	What are their opinions?	Are you feeling pressure?	Are you feeling support?
Your mother	Wants you to choose what you think is best for you	No	Yes
Your children	Unsure	No	Yes

Note: You do not want to speak to your brother, your ex husband or friends yet.

A few additional cues for telephone calls

☐ Possible questions:

- If I don't make plans for hospice and things don't work out at home can I still go there?

Place of Care at End of Life: VIDEO Teaching Aid Evaluation

Please indicate your agreement with the following items. Your feedback will help us to refine the VIDEO teaching aid. Thank you

	Strongly agree	Neutral	Strongly disagree
The VIDEO clarified decision support concepts	☐	☐	☐
The explanation of the use of the 'When you need extra care' decision guide was clear	☐	☐	☐
The scenarios were authentic and realistic	☐	☐	☐
Overall, it was easy to identify the decision making needs of the patient	☐	☐	☐
Overall, it was easy to identify the decision support strategies used by the nurse in the decision support vignette	☐	☐	☐
I would recommend the VIDEO to others who are learning to use decision support approaches in clinical practice	☐	☐	☐
Other Comments:			

Please rate your overall impression of the VIDEO teaching aid by circling a number in

Relevance my learning about decision support	Clarity of the information presented	Helpfulness to my learning	Good use of my time	Made me feel that I could use decision support strategies in my practice
1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5

each column. (1 = Poor 5 = Excellent)

What was the most useful thing(s) you saw demonstrated in the VIDEO?

Thank you. Your feedback is very valuable and appreciated

Appendix J

Place of Care Patient Decision Aid



When you need extra care, should you receive it at home or in a facility?

A decision aid to prepare you to discuss the options

This decision aid is for you if:

- you are living with an advanced illness that cannot be cured.
- you would like to plan where you would receive extra care when you need it.
- you want to share your views with others.

What are the care options when you need extra care?

When an illness advances, care focuses on easing symptoms and promoting quality of life. This is called hospice or palliative care. Your health care team can work with you to assess your needs, recommend equipment, and arrange care-giving help. Care can be provided at home or in facilities such as hospitals, nursing homes or hospices. Types of palliative care services are listed below.

Types of Palliative Services

Care at Home



Care in a Facility



Visiting health professionals:

- | | | |
|--|-----------------------|----------------|
| • Nurse | Up to 40 hours a week | 24 hours a day |
| • Physiotherapist, occupational therapist,
social worker, dietician. | As needed | As needed |

Personal care and support:

- | | | |
|---|-----------------------|----------------|
| • Personal support workers, health care aids,
attendants. | Up to 15 hours a week | 24 hours a day |
|---|-----------------------|----------------|

Homemaking:

- | | | |
|---------------------------|-----------------------|----------------|
| • Home care workers. | Up to 15 hours a week | 24 hours a day |
|---------------------------|-----------------------|----------------|

Community support services:

- | | | |
|---|--------------|--------------|
| • Non-profit groups, private companies, service
clubs, charitable and volunteer
organizations, friends, relatives | As available | As available |
|---|--------------|--------------|

How can I find out more about the services available in my community?

- Your health care team
- The CCAC-Community Care Access Center (www.ccac-ont.ca)
- The toll free Hospice Palliative Care Information Line (1-877-203-INFO)
- The Canadian Cancer Society (1-888-939-3333) (www.info@cis.cancer.ca)

Working through the steps of this decision aid may help you decide.

Step 1: How are you feeling right now?

Step 2: Which reasons to choose each option matter most to you?

Step 3: What else do you need to prepare for decision-making?

Step 4: What are the next steps?

Step 1: How are you feeling right now?

Your Daily Activities

Adapted PPS tool (Karnofsky, 1949)

Check ☒ how you have been on average in the past week.

Moving About	☐ I am able to move about as usual	☐ I move about less than usual	☐ I am mainly sitting	☐ I am mainly in bed	☐ I am in bed all of the time		
Activity	☐ I am able to do my usual activities such as job, hobbies, housework	☐ I am able to do my usual activities <i>with effort</i>	☐ I am unable to do my usual work	☐ I am unable to do my usual hobbies or housework	☐ I am unable to do any work	☐ I am unable to do most activity	☐ I am unable to do any activity
Self Care	☐ I am able to do all my personal care such as washing, dressing, going to the bathroom	☐ I need occasional help with my care	☐ I need a lot of help with my care	☐ Someone else provides most of my care	☐ Someone else provides all of my care		
Eating & Drinking	☐ I am able to eat and drink as usual	☐ I eat and drink less than usual	☐ I eat small amounts of food and sips of fluids	☐ I am not able to eat or drink			
Alertness	☐ I am alert as usual	☐ I am less alert than usual	☐ I am drowsy most of the time	☐ I sleep all of the time			

Your Symptoms

ESAS (Bruera, 1991)

Please circle the number that best describes how you felt on average in the past week:

No pain	0	1	2	3	4	5	6	7	8	9	10	Worst possible pain
Not tired	0	1	2	3	4	5	6	7	8	9	10	Worst possible tiredness
Not nauseated	0	1	2	3	4	5	6	7	8	9	10	Worst possible nausea
Not depressed	0	1	2	3	4	5	6	7	8	9	10	Worst possible depression
Not anxious	0	1	2	3	4	5	6	7	8	9	10	Worst possible anxiety
Not drowsy	0	1	2	3	4	5	6	7	8	9	10	Worst possible drowsiness
Best appetite	0	1	2	3	4	5	6	7	8	9	10	Worst possible appetite
Best feeling of wellbeing	0	1	2	3	4	5	6	7	8	9	10	Worst possible feeling of wellbeing
No shortness of breath	0	1	2	3	4	5	6	7	8	9	10	Worst possible shortness of breath

Step 2: Which of the reasons for each option matter most to you?

Think about the future when you will need extra care. Where would you want to receive this care? Common reasons to choose either care at home or in a facility. Check ✓ how much each reason matters to you on a scale from '0' to '5'. '0' means it is **not** important to you. '5' means it is **very** important to you.



Reasons to choose...

Care at home

Not
Important

Very
Important

How important is it for you to have more privacy at home? . . . ① ② ③ ④ ⑤

How important is it for you to have more control over your daily routines and timing of your care? ① ② ③ ④ ⑤

How important is it for you to be close to family, personal belongings, pets and friends? ① ② ③ ④ ⑤

List other reasons to choose care at home:



Reasons to choose...

Care in a facility

① ② ③ ④ ⑤
Not
Important

Very
Important

How important is it for you to have staff available 24 hours a day ? ① ② ③ ④ ⑤

How important is it for you to have staff manage most of your personal care? ① ② ③ ④ ⑤

How important is it for you to free up your family from giving personal care and medications? ① ② ③ ④ ⑤

How important is it for you for you to have staff around for safety and security? ① ② ③ ④ ⑤

List other reasons to choose care at home:

① ② ③ ④ ⑤

Now, think about which option has the reasons that are most important to you.

Which option do you prefer? Check ☒ one.

- ☐ Care at home
- ☐ Care in a facility. Specify: _____
- ☐ I am not sure

Step 3: What else do you need to prepare for decision-making?



Support

Who else is involved in this decision?

Who is the person?	Name:	Name:	Name:
Which option does this person prefer?			
Is this person pressuring you?	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
How can this person support you in decision making?			
I prefer to	☐ share the decision with:	☐ decide myself after hearing the views of:	☐ have someone else decide for me. Who?



Knowledge

Do you know enough about the **reasons to choose** each option? ☐ Yes ☐ No



Values

Are you clear about which reasons to choose each option **matter most** to you? . . ☐ Yes ☐ No



Certainty

Do you **feel sure** about the best choice for you? ☐ Yes ☐ No

Step 4: What are the next steps?

Check ☒ what you need to do before you make this choice.

- ☐ Nothing, I am ready to make my plan.
- ☐ I need to discuss the options with _____.
- ☐ I need to learn more about my options.
- ☐ **Other. Please specify:** _____.

Appendix K

Community Living Adults Evaluation Survey of Place of Care Patient Decision Aid

**'When you need extra care, should you receive it at home or in a facility?' Patient
Decision Aid Evaluation**

Please indicate your agreement with the following items. Your feedback will help us to refine the decision aid. Thank you

Item	Strongly Agree	Neutral	Strongly Disagree
The decision aid clarified the decision	☐	☐	☐
The explanation of who may benefit from using the decision aid 'When you need extra care' decision guide was clear	☐	☐	☐
The reasons to choose one option or another were authentic and realistic	☐	☐	☐
Overall , after using the decision aid it would be easy to identify your decision making needs	☐	☐	☐
I would recommend this decision aid to people who are facing decisions about place of care	☐	☐	☐
Other Comments:			

Relevance for people making choices for place of care	Clarity of the information presented	Helpfulness for people who are facing decisions about place of care	Good use of my time if I was facing this decision	Made me feel that I could use this decision aid if I was facing this decision
--	---	--	--	--

Please rate your overall impression of the decision aid by circling a number in each column.

(1 = Poor 5 = Excellent)

1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
-----------	-----------	-----------	-----------	-----------

What do you think is the most useful thing(s) about the decision aid?

Thank you. Your feedback is very valuable and appreciated

Appendix L

Practitioner Usability Survey of Place of Care Patient Decision Aid

Workshop Date:

Participant ID #:

Usability of the 'When You Need Extra Care...' Decision Aid

Please comment on the clinical usability of the 'When You Need Extra Care...' Decision Aid. As well, we are interested in your perception of possible factors influencing its use. Please give the completed survey to the workshop facilitator.

1. How clear were the steps/questions in the 'When You Need Extra Care...' Decision Aid?
 - ☐ Everything was clear
 - ☐ Most things were clear
 - ☐ Some things were clear
 - ☐ Many things were not clear
2. How easy is it to use the 'When You Need Extra Care...' Decision Aid in helping someone making a decision about place of end of life care?
 - ☐ Very easy
 - ☐ Moderately easy
 - ☐ Somewhat difficult
 - ☐ Very difficult
3. How helpful would the 'When You Need Extra Care...' Decision Aid be in supporting patients making choices about place of end of life care?
 - ☐ Everything was helpful
 - ☐ Most things were helpful
 - ☐ Some things were helpful
 - ☐ Many things were not helpful
4. How useful was the 'When You Need Extra Care...' Decision Aid in helping you identify a plan to address the decision support needs (e.g. information gaps, unclear values, support problem)?
 - ☐ Very useful
 - ☐ Moderately useful
 - ☐ Somewhat useful
 - ☐ Not helpful
5. How comfortable would you be using the 'When You Need Extra Care...' Decision Aid with a patient?
 - ☐ Very comfortable
 - ☐ Comfortable
 - ☐ Uncomfortable
 - ☐ Very uncomfortable
6. Would you recommend using the 'When You Need Extra Care...' Decision Aid to colleagues?
 - ☐ Definitely recommend
 - ☐ Probably recommend
 - ☐ Probably not recommend
 - ☐ Definitely not recommend

Usability of the 'When You Need Extra Care...' Decision Aid continued

How much you agree or disagree with the following statements.

From my perspective, using the 'When You Need Extra Care...' Decision Aid as a clinical decision support tool with patients making decisions about place of end of life care will:

Item	Strongly disagree		Neutral		Strongly agree	
7. allow practitioners to guide patients through their decision making in a systematic way						
8. be acceptable to practitioners						
9. be acceptable to patients						
10. help prepare patients for discussing the decision with team members						
11. be TOO complex						
12. help patients participate in ways they prefer in the decision making process						
13. improve the chances that patients decisions are informed						
14. improve the chances that patients decisions are based on personal values of what is most important						
15. do more good than harm						
16. be easy to use						
17. could fit in well with usual practice approaches						
18. be useful for patients making place of care decisions more than 60% of the time						
19. is compatible with how I think patients should make place of care decisions						
20. be useful in my practice						
21. complement my usual approach in these situations						
22. require a major change to the way I currently handle these types of situations						
23. help me to more fully explore issues of importance to patients facing place of care decisions						
24. increase patients satisfaction with our health care services						
25. help me use my time more effectively						
26. improve my usual approach						
27. help me tailor my approach to better meet patients needs						
28. be easy to try out before deciding to use regularly						
29. be easy to use if it was included in orientation or continuing education initiatives						

31. What are the top 3 barriers that are likely to interfere with using the *'When You Need Extra Care...'* Decision Aid?

1. _____
2. _____
3. _____

32. What are the advantages of using the *'When You Need Extra Care...'* Decision Aid compared to your usual approach for supporting patients facing decisions about place of end of life care?

33. How likely are you to use the *'When You Need Extra Care...'* Decision Aid as a clinical tool within the next 3 months with a patient facing a decision about place of end of life care?

- ☐ very likely
- ☐ likely
- ☐ somewhat likely
- ☐ not at all

34. Do you think practitioners in your organization should use the *'When You Need Extra Care...'* Decision Aid to help patients facing end of life place of care decisions

- ☐ yes
- ☐ no
- ☐ undecided

35. On average in a three month period, how many times would you help patients making end of life place of care decisions?

- ☐ 0
- ☐ 1-5
- ☐ 6-10
- ☐ 11-15
- ☐ 16- 20
- ☐ 21 +

Appendix M

Workshop Materials

1. Agenda
2. Teaching Module
3. Skills Building Practice Cases
 - a. Case 1: Dorothy Walker- unclear values
 - b. Case 2: Jim Jackson- pressure from others
4. DSAT10 tool
5. Usability of place of care decision aid
6. Workshop evaluation survey

Decision Support Skill Building Workshop Outline

Facilitator:

Objectives

1. Understands concepts of decisional needs, decision support, and decision quality
2. Learns to use decision support tools
3. Evaluates decision support skills
4. Analyses barriers and facilitators to implementing decision support in practice

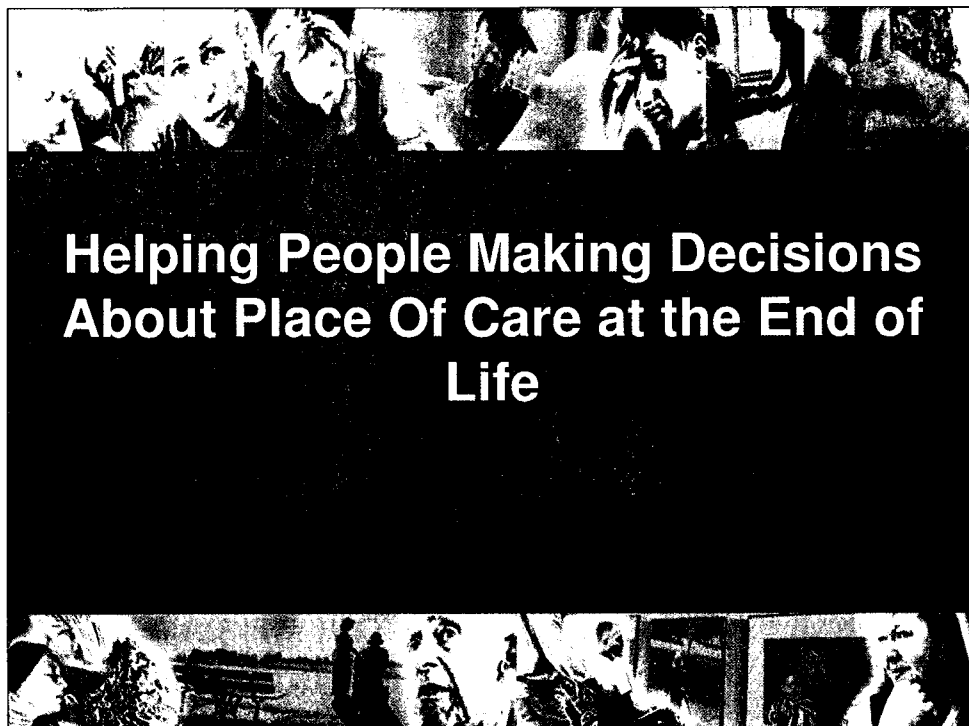
Schedule

Time	Activity
08:30- 8:45	Welcome Review of Workshop Outline
8:45-9:45	Understanding decision support and decision aids Implementing tools in practice
9:45- 10:15	Evaluating decision support skills • Use DSAT to appraise decision support provided in VIDEO
10:15- 10:30	Break
10:30- 11:30	Skill Building using decision aid • Role play client-practitioner interaction • Peer appraisal using DSAT
11:30- 11:50	Implementing tools in practice • Identifying barriers and facilitators
11:50-12:00	Workshop evaluation Next Steps

Resources for future reference

- Handouts during workshop
 - Decision Aid: When you need extra care
 - DSAT: Decision Support Analysis Tool
 - Slide deck handout
- Decision aids <http://decisionaid.ohri.ca/FamilyMedicine> (Healthwise Decision Points)
 - Should I stop life prolonging treatment?
 - Should I receive artificial hydration and nutrition?
 - Should I receive CPR and mechanical ventilation?
 - Making Choices: The Use of Intubation and Mechanical Ventilation for Severe Chronic Pulmonary Disease
 - Making Choices: Care at Home or Admission to a Care Facility
 - Making Choices: Long Term Feeding Tube Placement in Elderly Patients
- RNAO Client Centered Care BPG supplement
(http://www.rnao.org/Storage/15/933_BPG_CCCare_Supplement.pdf)

Thank you. Your help and support is valued and appreciated.



Helping People Making Decisions About Place Of Care at the End of Life

Introduction and welcome

Workshop facilitator and participants introduce each other

Topics

1. Understanding decision support and decision aids
2. Evaluating decision support skills
3. Implementing tools in practice

Refer participants to agenda

By the end of this workshop you will:

-understand the process of Decision Support, and Decision Aids – as tools to assist people who are facing tough decisions

-be able to Evaluate your skills in providing decision support about place of care .

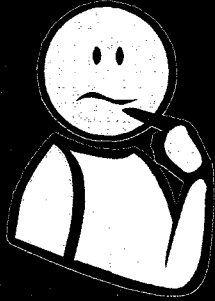
-Consider how to Implement tools in practice

Topics

1. Understanding decision support and decision aids
2. Evaluating decision support skills
3. Implementing tools in practice

Lets start with decision support and decision aids

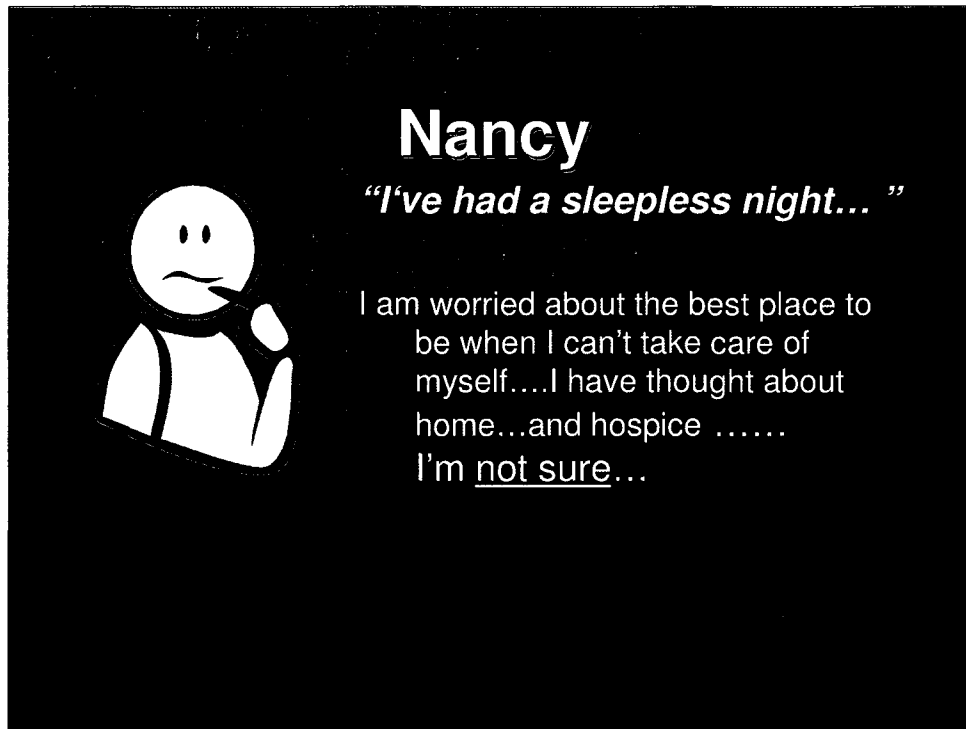
Nancy



- End-Stage Breast Cancer
- Receiving home care
- 1-2 months to live
- Single mom
- 2 teenage daughters
- Mother is her main support

To illustrate how decision support works, let's consider Nancy's case

- She has end stage breast cancer and is receiving home care
- Her doctor estimates she has a couple of months to live
- She is a single mom with 2 teens at home.
- She relies on her mother for support



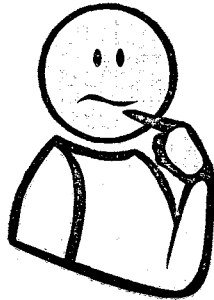
Nancy stays up at night worrying about where she will be when she cant take care of herself

She knows about home care and hospice

BUT

Is not sure which option would be best for her and her daughters.....

Well, would you help Nancy deal with this personal uncertainty.....



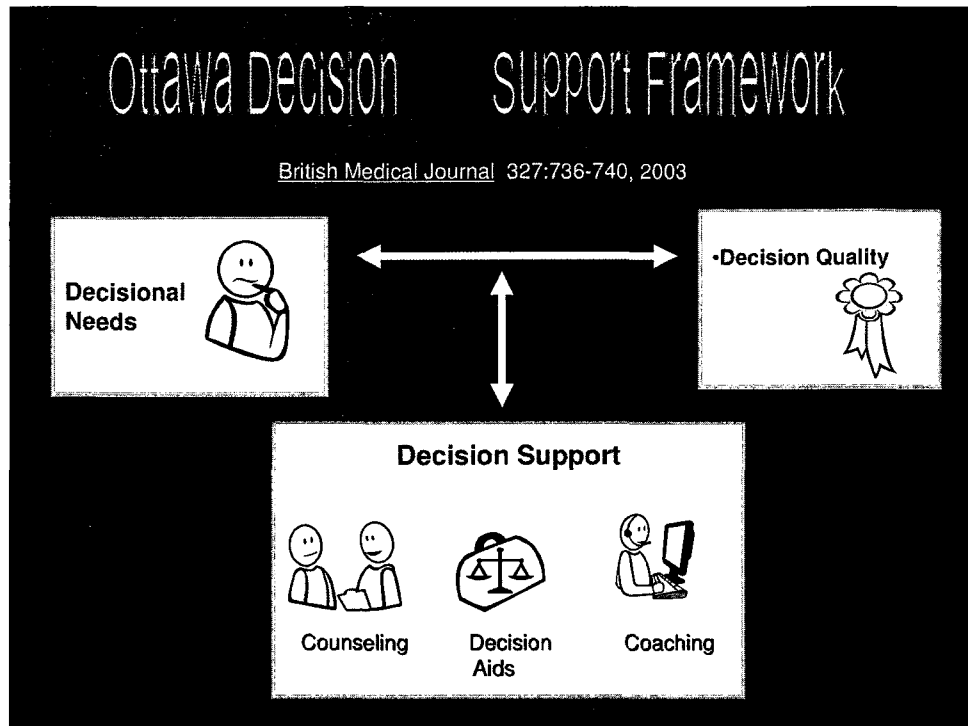
I'm not sure....

How would
you manage
Nancy's
uncertainty?

Engage group in short discussion....

i.e.

- Write on board / flip chart
- Categorize later



This framework can be used to guide the support you provide to patients like Nancy
It has **3 key elements**.....

1. Decisional needs such as those presented by Nancy, which will have a strong influence on
2. The quality of decision that Nancy makes
3. We can improve the quality of the decision Nancy makes by providing decision support that addresses her decisional needs

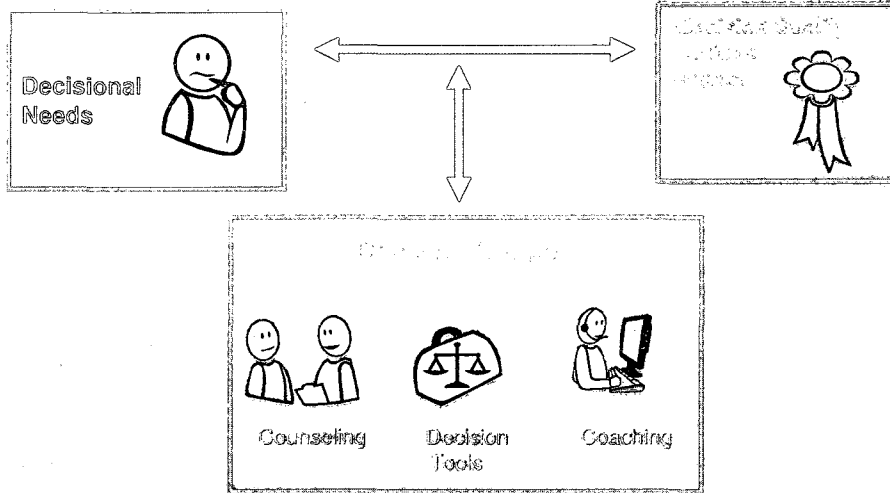
..The types of decision support vary depending on the type of decision and care delivery, but it may include some combination of
clinical counseling about options
decision aids
and...coaching in the steps of decision making and communication

Let's review each of these elements in more detail...

Ottawa Decision

Support Framework

British Medical Journal 327:736-740, 2003



Firstdecisional needs that patients face

End of Life Decisions

Voltz1998; Pearse 2005, Lynn xxxx

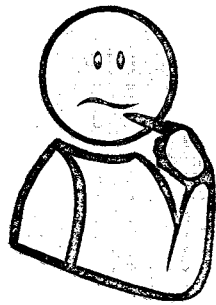
- Negative emotions about future decisions (45-85%)
 - fear, loss of control, frustration, concern
- 34% want health providers advice
- Place of care most important decision
 - in last weeks (26%)
 - near future (15%)
- Barriers
 - Delayed conversation
 - Non-recognition of dying trajectory
 - Provider gaps
 - Skills
 - Confidence
 - Protocol to guide place of care decision support



- Near the end of life there are a cascade of decisions about the future
 - Patients are thinking about them even if practitioners or family members are not talking to them about it
 - 45 to 85% of the time, there are negative emotions...
 - About a third want advice from health providers about issues/ decisions other than about treatment options. Issues can include things like life transitions, social considerations, what does the future hold.....
 - A research study done with palliative patients in Japan, USA and Germany found patients 28% of patients thought that place of care was the most important decision they faced in the past few weeks and that a further 15 % considered it the most important decision they would face in the coming weeks.
- If patients are thinking about these decisions why don't they take place? Often we.....
- delay the conversation because we are uncomfortable or not sure if it's the right time
 - don't always know how close to death the person is
 - it's not something we've been taught to do - don't know how to start the conversation, what to do in the conversation or how to get out of the conversation
 - we don't have a process/tools to help guide us in the conversation

So how do we frame these decisional needs.....we find that the construct of "decisional conflict" is a useful frame of reference

Decisional Conflict



yes



no

- uncertainty about which course of action to take

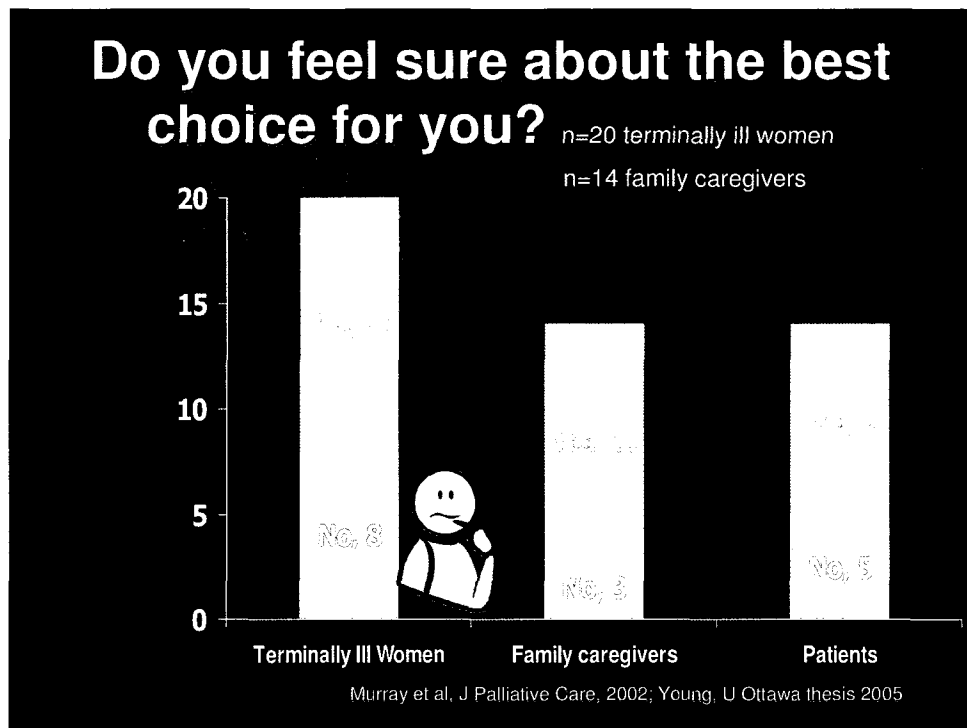
North American Nursing Diagnosis Association, 2002

One of the central decisional needs which patients like Nancy have is decisional conflict....or personal uncertainty about which course of action to take

In essence she is wavering

.....saying yes and no to each option she is considering....

..... For example home versus hospice

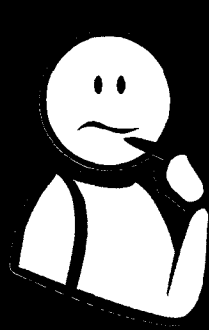


You can see this in a study that looked the decision making needs of 20 terminally ill Ontario women. 40% of them were like Nancy and weren't sure about what was the best choice for them.

In the terminally ill women's study the women had very advanced disease- were all palliative and while most had made their choice quite a few still were having difficulty with the decision

In another study of 14 Ontario family caregivers while most were sure about the where terminal care should be provided they were less sure that the patient was sure- For example while 3 caregivers felt they were unsure 5 felt that their patient family member was wasn't sure about place for end of life care

'Innate' contributing factors



2 or more options



Outcomes: risky/uncertain,
permanent, serious



Value tradeoffs: benefits
versus harms



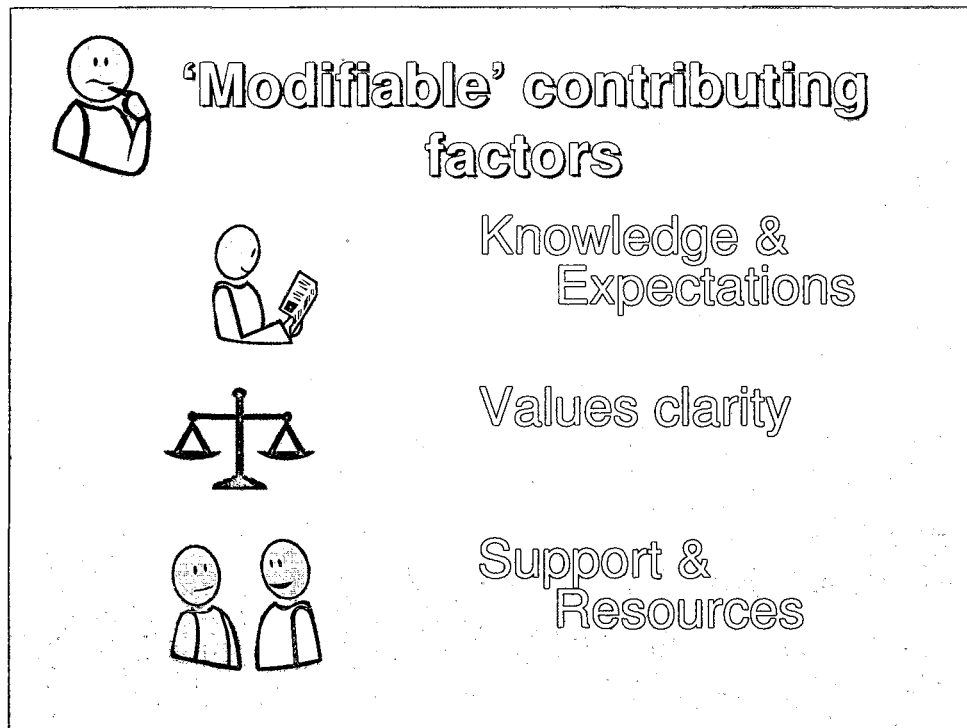
Anticipated regret:
'missed' benefits of
option not chosen

What factors contribute to uncertainty?

First there are the innate factors stemming from the nature of the decisions.....

People have more decisional conflict when there are two or more medically reasonable options.....

With risky or uncertain outcomes, especially if the outcomes are serious and permanent.....and having to make value tradeoffs between the benefits and harms of each option.....patients also say they worry about regretting the positive features of the options they did not choose



In addition to the innate challenges in the decision, people like Nancy may have additional modifiable factors contributing to his decisional conflict about what to choose....

For example....Nancy may feel more uncertain if she....

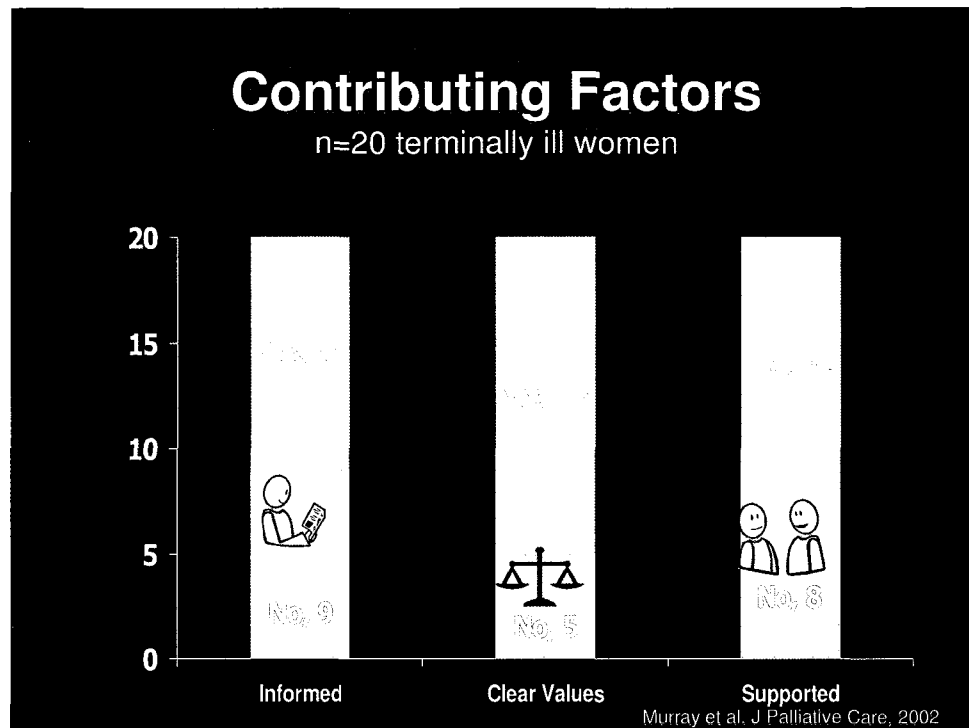
... does not know much about the options, or she has unrealistic expectations.....

OR

....if she does not feel clear about her values....or the personal importance of benefits versus harms....

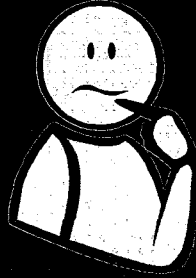
OR

---if she has inadequate support or resources to participate in the decision....



In the study I referred to earlier, the terminally women had different decision needs. 45% felt they did not have enough information, 25% were unclear about their values and 40% did not feel they had enough support in making the decision about place of care

Consequences: unresolved decisional conflict & related factors



- **59 times** more likely to **change mind**
- **23 times** more likely to **delay decision**
- **5 times** more likely to **have regret**
- **3 times** more likely to **fail knowledge test**
- **19%** more likely to **blame practitioner for bad outcomes**

Sun, Q. [MSc thesis]. University of Ottawa, 2005.
Gattelari & Ward J Med Screen 2004;11:165-169

So....why is it important to address these unresolved needs.....

Studies have shown that if decisional conflict and contributing factors are not resolved.

Patients are much more likely to

change their mind,

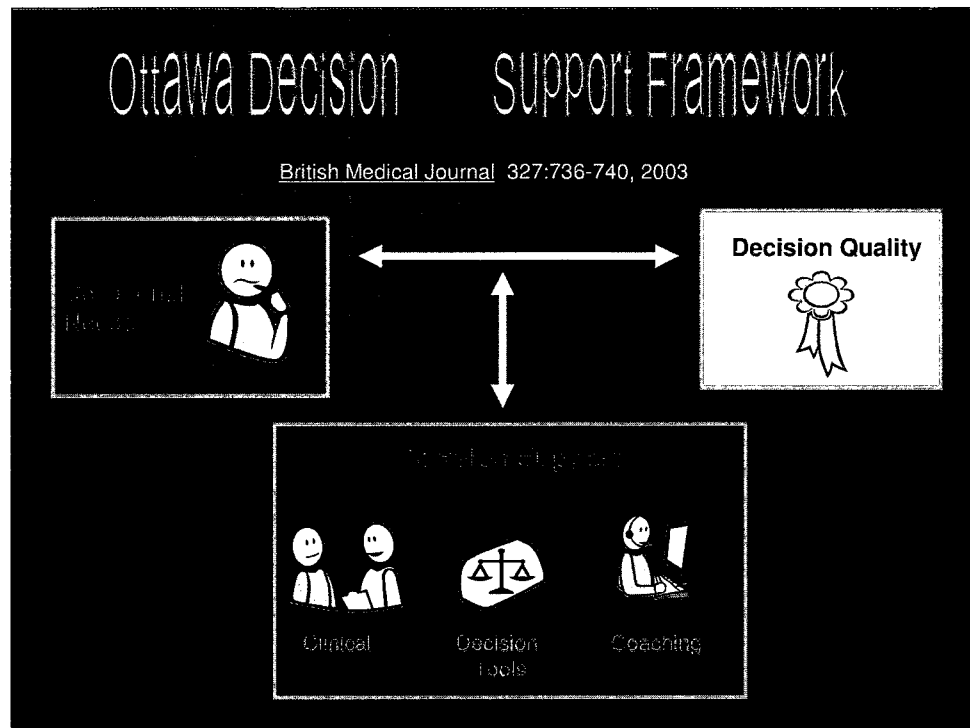
delay their decision

have regret

fail a knowledge test

blame the practitioner for bad outcomes

therefore, it may be worthwhile to address the unresolved needs of people like Nancy



We've looked at decision needs..

Now lets look at the goal we are trying to accomplish.....decision quality

Well what is a good decision for people like Nancy?

What is a good decision?

1. Nancy chooses hospice
2. Nancy chooses care at home
3. Does not matter as long as decision is
.....
4. Nancy adheres to option suggested by
team



Where are both advantages and disadvantages about each option, so the question iswhat is a good decision????????????????

Engage group in discussion

Decision Quality



- informed
- based on values

Researcher opinions
 Mulley, Sepucha Health Affairs. 2004;Suppl Web Exclusive:VAR54-62
 Briss, Rimer, Reilley, Coates, Lee, Mullen, (US-CDC) Am J Prev Med 2004;26:67-80
 Rattliff, Angell, Dow, Kupperman, Nease, Fisher, Fisher, Redelmeier, Faughnan, Rimer, Pauker, Pauker, Sox. Effective Clinical Practice 1999;2:185-97
 O'Connor Med Decision Making 1995;15:25-30.; Nursing Diagnosis and Interventions 1989; JNCI 1999

Public survey Health Expectations 2003;6:97-109

Physician survey Patient Education and Counseling. 30:143-153, 1997

International Patient Decision Aids Standards Collaboration 2005 www.ohri.ca/decisionaid

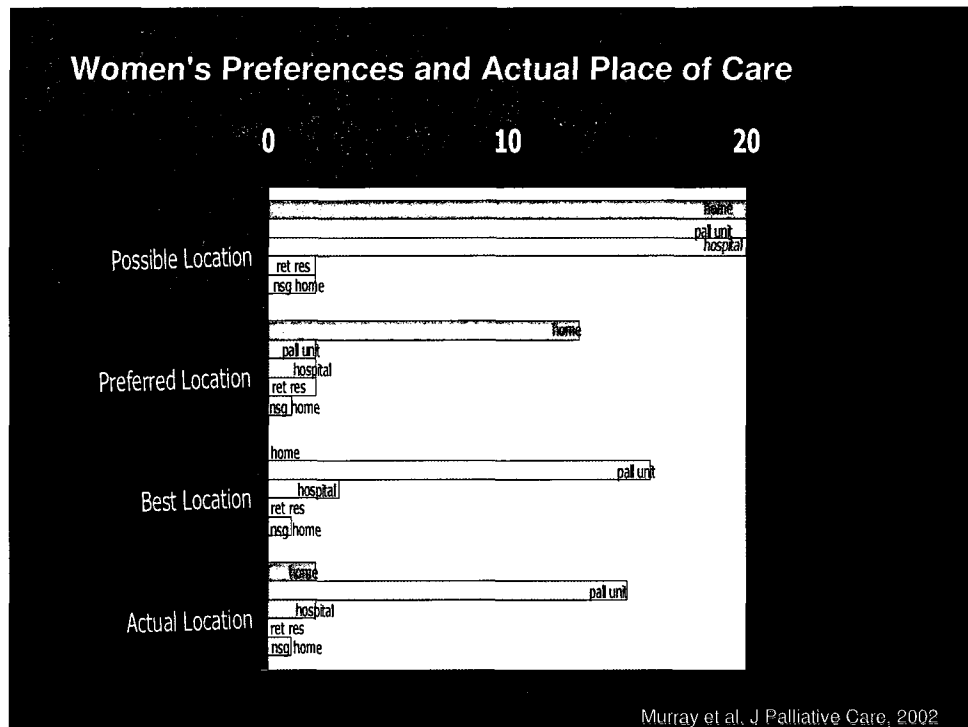
There is growing consensus from researchers, the public, and practitioners, that for patients like Nancy ,

a good decision is one that is informed and consistent with personal values

....this means that patients

understand the benefits and harms of options and

and receive the option that best matches what matters most to them....



Well, which options do patients prefer?

This slide shows, that when women are asked about possible locations of care at the end of life, home, palliative units, and hospital are listed most often

AND

The majority PREFER to die at home

But, when asked what they thought was the BEST location, $\frac{3}{4}$ considered the palliative unit best

Where did they actually die? Most died at the palliative unit.

So this data shows the mismatch between preferred and actual location of care

What factors affect these types of decisions?

Predictors: Place of Care

Patient factors

- Stated preference
- Kin support
- Pt/Kin caregiver agreement
- Feeling prepared

Illness factors

- Cancer site
- Functional status
- Symptom profile

System factors

- Home care support & intensity
- Proximity to hospital
- Exposure to hospice



Ahler-Elmqvist. 2004; Bruge, 2004; Chvetzoff. 2005.; Gomes. 2006; Gott. 2004; Gyllenhammar. 2003; Higgenson, 2000; Murray, 2003; Murray 2007; Tang, 2003; Thomas, 2004; 2005

There are predictors of the place of care

In terms of patient factors,

Stating a preference out loud and telling family or main care giver about preference is the strongest predictor of being at home for patients who prefer home.

.....This shows the importance of having the conversation and opening space to allow the conversation to happen in a timely manner.

There is also kin support, and agreement with the patient.....As well feeling prepared predicts these decisions

There are illness factors,....

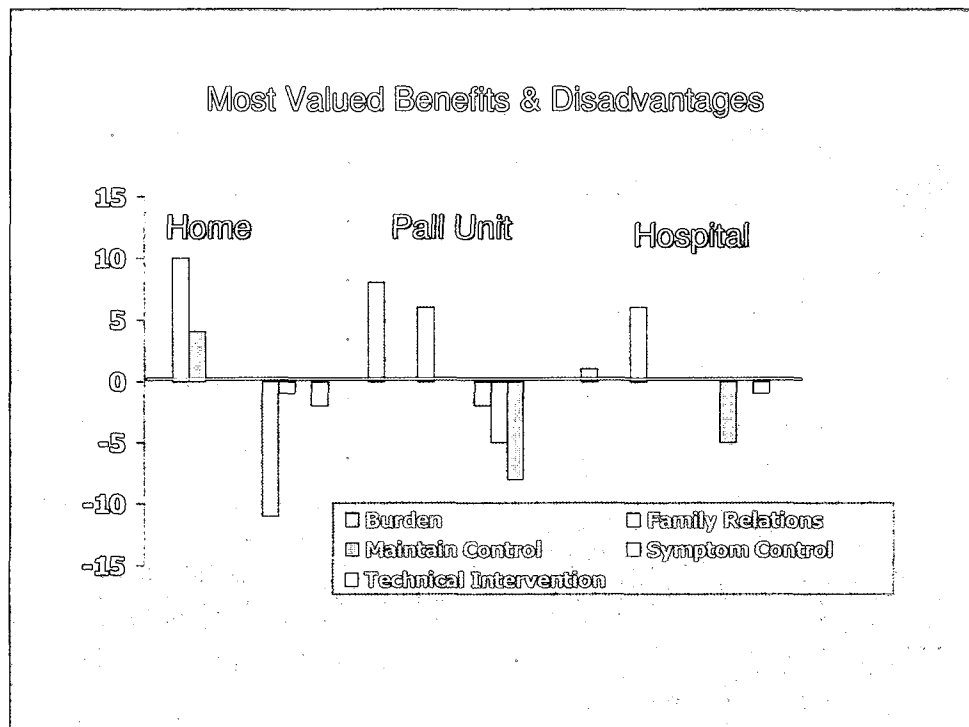
In a recent systematic review of factors affecting place of care type of cancer (ie: non-solid tumours), intractable symptoms and general poor health were linked to non home locations such as hospital and nursing home

There are environmental factors

In the systematic review I referred to greater use and intensity of home care services pointed to home death. Living close to a hospital, home care affiliation with a hospital and regional trends were linked to non-home settings

Having previous exposure to hospice was linked to admission to hospice for end of life care.

.....There is no 1 'best' place ---- many factors need to be considered and patients needs and decision making needs will vary.....

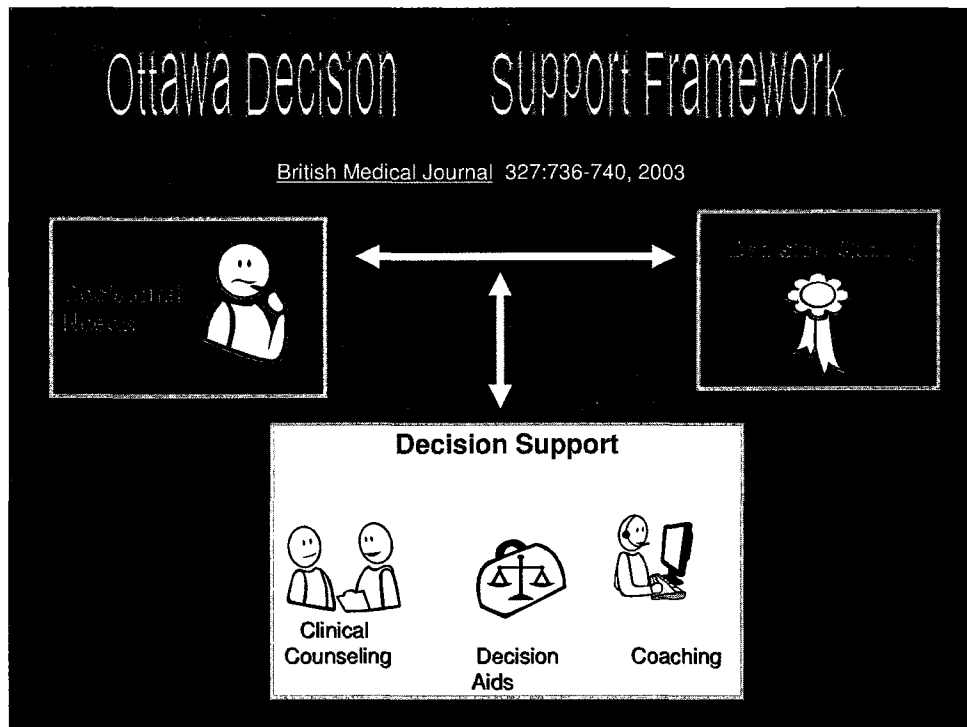


This slide presents what patients valued most as advantages and disadvantages of each option

For the home option, the pros were strengthening relationships and maintaining control....but the cons were burden on the family

For the Palliative option, the pros were relieving the family of the burden, and controlling symptoms, whereas the cons were losing control and weakening relationships

For Hospital, the main pro was symptom management but loss of control was a trade off to consider.



Lets move to the third dimension the decision support which addresses Nancy's decisional needs so that decision quality is improved

This is delivered through clinical counseling, decision aids, and coaching

...

Decision Support

- **Clarify decision and needs**
- **Provide facts, probabilities**
- **Clarify values**
- **Support/Guide/Coach**
- **Monitor/Facilitate progress**



British Medical Journal 327:736-740, 2003

There are 5 key elements.....

Clarifying the decision and needs

Providing facts and probabilities

Clarifying values

Supporting or guiding in the steps of deliberation and communication

And Monitoring or facilitating progress

This decision support is delivered in some combination of personal contact plus decision aids

Decision Aids



British Medical Journal 327:736-740, 2003

Let' talk about decision aids.....

Patient Decision Aids

adjuncts to counseling



- **Inform**

- Provide facts
 - Condition, options, benefits, harms
- Communicate probabilities



- **Clarify values**

- Patient experience
- Ask which benefits/harms matters most
- Facilitate communication



- **Support**

- Guide in steps in deliberation/communication
- Worksheets, list of questions

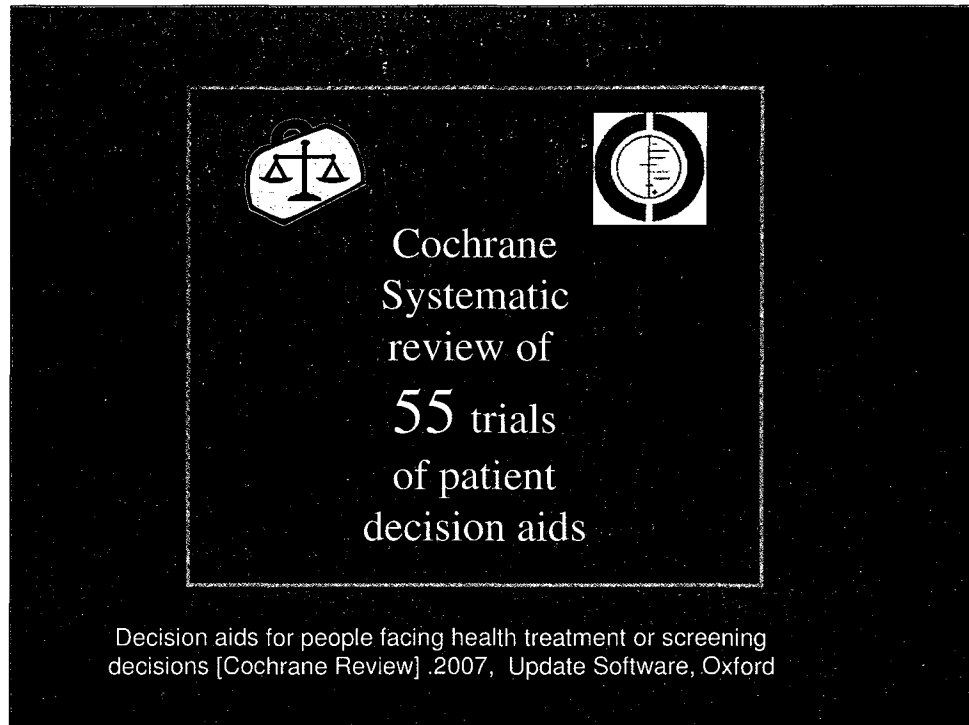
Patient Decision Aids are ADJUNCTS, NOT REPLACEMENTS for counselling

First, they inform.....by providing not only facts, but also probabilities

Second, they clarify value in three ways....

1. They describe what it is like to experience the consequences of options so patients are better able to judge their values
2. They ask patients to consider which benefits/harms are most important to them
3. They also facilitate the communication of values to others such as practitioners and family members

Finally, decision aids support or guide patients in the steps of deliberation and communication.....often with the use of worksheets or lists of questions



Well, what's the evidence that these decision aids improve decision quality?
O'Connor and group have conducted a systematic review of all the 55
randomized trials published in the world...as part of the international
Cochrane collaboration....a group of researchers dedicated to summarising
what works in health care....



Compared to standard care, decision aids...

- ✓ Improve decision quality
 - ✓ 20% higher knowledge scores
 - ✓ 44% more realistic expectations (probabilities)
 - ✓ better match between values & choices
- ✓ Reduce decisional conflict (9 points)
- ✓ Help undecided to decide (+57%)
- ✓ Patients 30% less passive in decisions
- ✓ Reduce over-use & under-use

O'Connor, Stacey et al., *Cochrane Library*, 2003

The trials have shown that compared to standard care, decision aids
Improve decision quality such that patients score 20% higher on knowledge tests

They are 44% more likely to have realistic expectations

They have reduced decisional conflict

Are 57% more likely to help the undecided to decide

And reduce passivity by 30%

Decision aids have a role in reducing over-use and under use of options

Decision Aid: Location of Care

When you reach the end of life, should you live at home or in a facility?

Types of Palliative Services

Types of Palliative Services	Home	Facility
Living Health in different places	- Physiotherapy, occupational therapy, social worker, dietitian - Home care services, including nursing, physiotherapy, occupational therapy, social work, dietitian - Home care services, including nursing, physiotherapy, occupational therapy, social work, dietitian	- Up to 45 hours a week 24 hours a day
Community support services Non-profit groups, service organizations, religious organizations, family, friends	- As needed - As needed	
Your goals and needs - How much time you want to spend at home - How much time you want to spend in a facility - How much time you want to spend in a facility	- As needed - As needed	

- Guides discussion about place of care
- Assessment uses PPS and ESAS
- Prepare patients for decision making
- Communicates needs and values to others
- Episodically revisit guide as circumstances change

Is there a decision aid for patients considering the location of care at the end of life?

We have developed one to guide discussions about planning for future care needs and place of care.

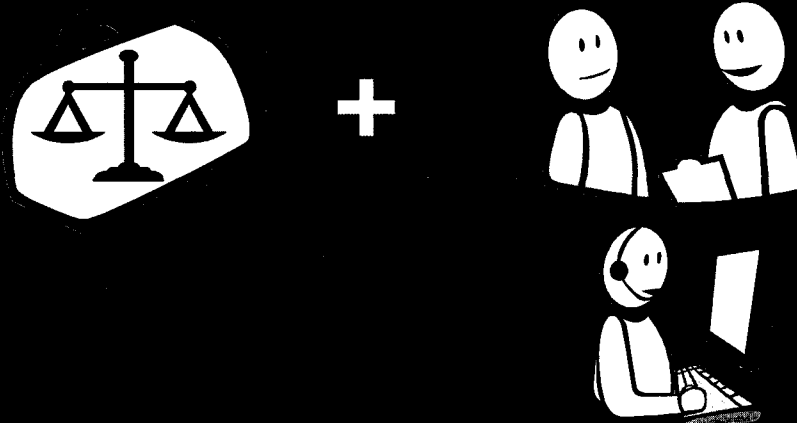
The tool also features functional and symptom assessment scales commonly used in palliative care

- The PPS (Palliative Performance Scale)
- the ESAS (Edmonton Symptom Assessment Scale)

This decision aid can help to prepare patients for decision making by helping them to clarify there decision making needs and communicate these needs to their care team and loved ones.

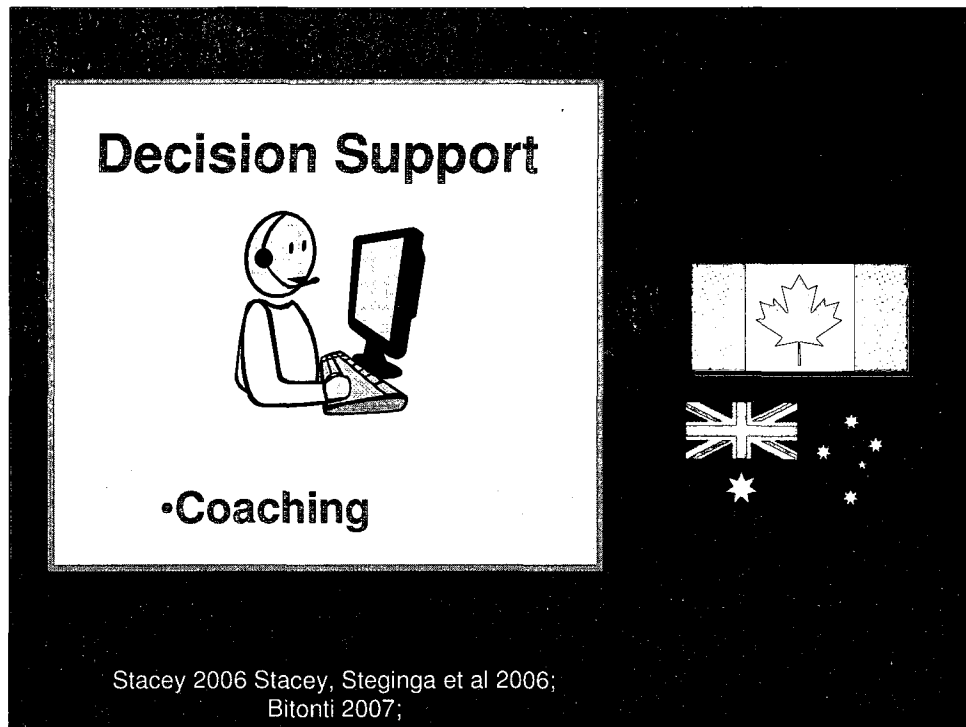
The aid can be used as circumstances change to see if previous decisions still reflect changing circumstances and patients ideas of what is most important at the current time.

**But decision aids are not
enough!**



But remember, I said that

- decision aids supplement, don't replace counselling or coaching, **and**
- I would like to focus on the coaching role**



Health coaches help patients build their skills in deliberating on the options and communicating with their practitioner

Nurses and social workers are often in a coaching role with patients

I would like to present some data about coaches from a call center in Canada and Australia

Decisional Needs

Assess



Do you feel sure about the best choice for you?



Do you know the benefits and risks of each option?



Are you clear about which benefits and risks matter most to you?



Do you have enough support and advice to make a choice?
Who else is involved?
Which role do you prefer?

The coaches were trained to use a structured protocol to assess and address decisional needs

They asked patients about their needs.....whether they felt certain, informed, clear about values and supported.

Decisional Needs		
	Assess	Intervene
	Do you feel sure about the best choice for you?	Address modifiable factors contributing to uncertainty
	Do you know the benefits and risks of each option?	Reinforce, clarify facts Re-align expectations
	Are you clear about which benefits and risks matter most to you?	Clarify values
	Do you have enough support and advice to make a choice? Who else is involved? Which role do you prefer?	Develop skills, confidence • decision making steps • communicating needs • accessing support & resources • promoting self-efficacy • handling pressure

Based on the patient's response, they tailored interventions to meet their needs.

For example, uncertainty was addressed by tackling modifiable factors contributing to uncertainty

Lack of knowledge was addressed by providing facts and re-aligning expectations or perceived probabilities of outcomes

For those with unclear values, strategies such as patient experience, asking them to consider which benefits/harms mattered most were used

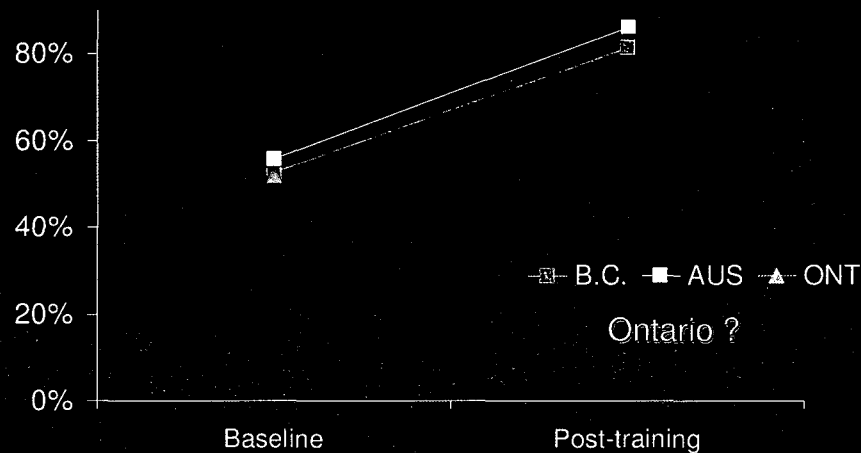
Finally, support deficits were addressed by helping patients learn about steps in decision making, how to communicate needs, access support, feel more confident, and handle pressure



Training improves decision support skills

Stacey 2007, Murray 2007

Mean quality scores



This is what happened before and after the nurses training

We tape recorded the dialogue between the call center and simulated patients and rated the quality of the support provided.

These are the average scores before and after training.

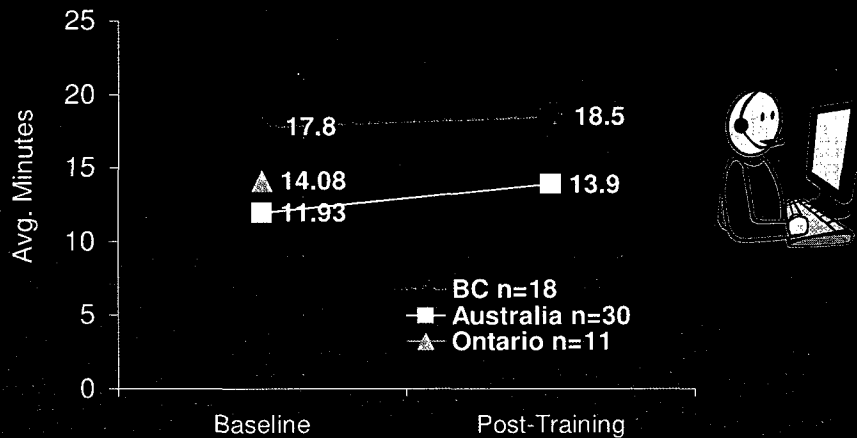
There was a significant improvement after training.

You recall that you also had simulated patients call you about a decision

How did the group perform as a whole?

We have not analysed all of the simulated calls so far.....of the ones we analysed calls the quality of decision support was about 50%-- we will be continuing to analyse the calls so this number could change... and we will be seeing if there is a difference in the Ontario group after training.....

Without affecting call length

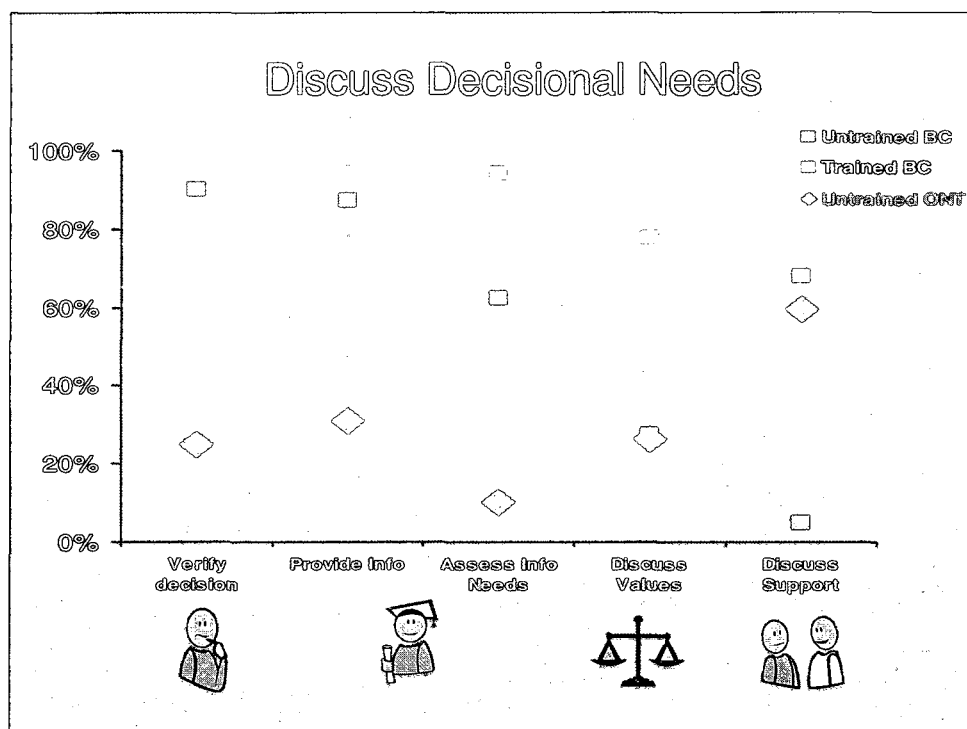


Stacey 2007

When we looked at length of call in BC and Australia, there were no statistically significant differences between groups on the mean length of calls at baseline and one month post-workshop.

Therefore, we can conclude that the quality of decision support can be improved without increasing the call length.

In the current study of the 11 calls we have analyzed so far....they take about 14 minutes



These are the elements of decision support provided by the groups

Both trained and untrained BC Nurses verified decisions and provided information

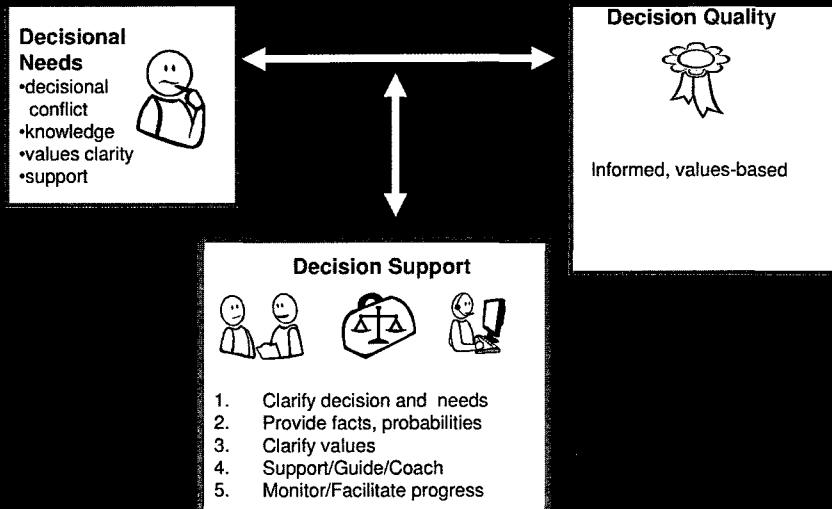
But the trained nurses did a better job assessing information needs, discussing values, and discussing support

How are we doing so far.... Of the calls so far which have been analysed in detail you can see that we do best at assessing who else is involved in the decision. We more often go straight to providing info without first assessing what the information needs are. Values or what is most important about the potential advantages and disadvantages associated with the place of care options is discussed about a quarter (25%) of the time.

Ottawa Decision

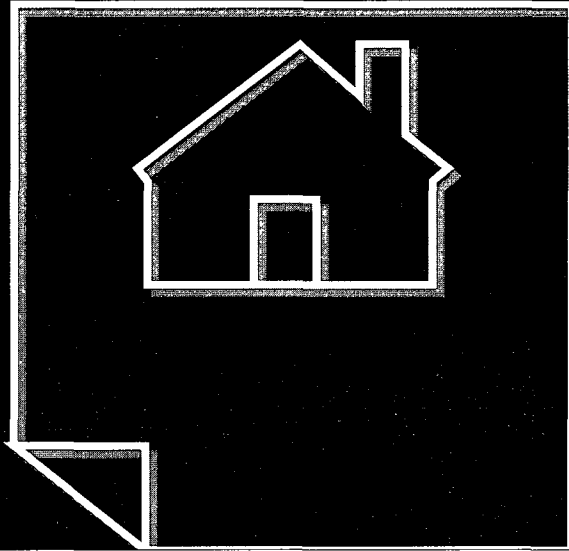
Support Framework

British Medical Journal 327:736-740, 2003



So now we have put all the elements together

Take-Home Message



So what is the take-home message about decision support?

Main Take Home Messages

- Decision Quality: informed, values based
- Knowledge, values and support needs need to be assessed & addressed
- Standard care isn't enough to help patients decide
- Decision aids & decision support training improve decision quality

Good decisions are informed and consistent with personal values

You won't have good decisions unless you know and address patients needs....knowledge, values, and support

Standard care isn't enough to help patients decide

Decision aids and decision support training improve decision quality

Topics

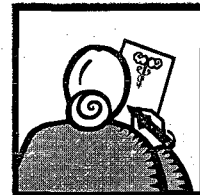
1. Understanding decision support and decision aids
2. Evaluating decision support skills
3. Implementing tools in practice

Now lets focus on evaluating your skills in providing decision support.....

Decision Support Analysis Tool (DSAT)

Evaluates decision support skills

Guimond et al. *Patient Education and Counseling* 2003; 50: 235-245



You are going to use the Decision Support Analysis Tool – to rate the quality of the coaching provided.

This is the same tool we used to rate your calls with simulated patients

In this session we are going to:

- Use the DSAT a tool to assess the quality of decision support provided in a video as well as when you role play with one another later on

DSAT: Decision Support Analysis Tool				
Element	Assessment Criteria	Hear and acknowledge or assess in interaction	Intervened	Comments/ Notes / Examples
    	Decision making status	Identify actual decision being made; be able to specify		
		Timing for when decision needs to be made is discussed/ acknowledged		
		Stage of decision making: assessed or self-evident		
	Knowledge of	Options Identified		
		Potential benefits of options		
		Potential harms of options		
 	Values /preference associated with	Importance of benefits		
		Importance of harms		
 	Others' involvement in the decision	Discuss preferred role in decision making, others involvement and their opinions		
		Discuss pressure or support from others		
	Next Steps	Near end of the call, there is a summary of the next steps to address caller's decision making needs		

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As you can see, DSAT elements follow the elements of decision support we have been discussing. These are

1. knowledge of options,
2. potential harms /benefits related to options
3. patients rating of personal Importance of benefits/harms
4. others involvement in the decision

As you listen to the practitioner provide decision support to the patient, you need to pay attention to how the practitioner discusses

1. the decision and uncertainty, such as ...whether the decision the patient faces is either assessed by the practitioner or heard and acknowledged by the practitioner

Similarly, whether timing is discussed or is self-evident, and also stage, and uncertain

2. Is knowledge discussed...such as the health condition, options, benefits, harms....if they are discussed are patients needs assessed and if they are, is their an intervention in which facts are re-enforced or clarified or expectations re-aligned
3. Are values assessed and addressed? That is does the practitioner ask about the personal importance of the benefits and harms
4. Is support assessed and addressed? For example, the preferred roles, others involvement, opinions, and pressure
5. Are next steps discussed

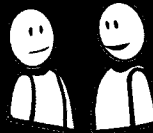
In each of the boxes you would check if you hear that particular element. There is also a comment column on the far right of the tool to write notes or examples of what you heard.

So let's try this out now with an example.....

Use DSAT to Evaluate how Val Helps Nancy

1. Patient Education

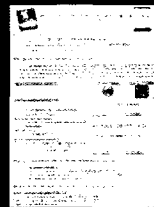
2. Decision Aid



+

Pt
Education
Pamphlets

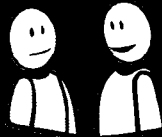
+



Show video.....

Ask participants to take out 2 DSAT sheets from their package and score patient education approach and decision support approach

Discussion



Pt
Education
Pamphlets



How was the interaction different in each scenario?

- Which interaction did you prefer most?
- How useful would this support be in your practice?

Group discussion comparing 2 scenarios

What were the differences between the 2 scenarios.

Which interaction would you have preferred if you were a patient?

In what way did the decision aid help Nancy?

How useful would this support be in your practice?



Let's take a break

Now its your turn!

- Form groups of three
 1. 'Client' is making place of care decision
 2. 'Practitioner' interviews patient with the Decision Aid
 3. "Observer" uses DSAT to evaluate decision support
- All discuss ways to address gaps from DSAT
- Switch roles and repeat



Practice session #1

Provide participants with the case scenario (woman with hypercalcemia). Quickly brief participants on case... ask participants who are acting as 'patient' to gather apart from other and review with them their 'decision need' as per the case study

Group practice---- circulate and assist prn.

After about 12 minutes close conversation and group discussion

How did it feel to be in the patient role---- nurse role----observer role

What was most helpful

Could you see doing this in your practice.....

Practice session #2

Break into groups again

Provide participants with the case scenario (man living in shelter). Quickly brief participants on case... ask participants who are acting as 'patient' to gather apart from other and review with them their 'decision need' as per the case study

After about 12 minutes close conversation and group discussion

How did it feel to be in the patient role---- nurse role----observer role

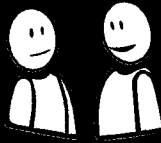
What was most helpful

Could you see doing this in your practice.....

Topics

1. Understanding decision support and decision aids
2. Evaluating decision support skills
3. Implementing tools in practice

Now let's talk about using these tools in your practice



- What fits in the way you provide care?
- What are **barriers** to integrating decision support in your practice?
- What factors would **facilitate** integrating decision support in your practice?

Brainstorming, flip charts.

- Asking them to describe their care pathways
- How do you see integrating the decision aid or decision support principles into your regular practice?
- Will it address the barriers?
- What else is needed?

Questions?

Can I ask you to complete a Usability Survey for us and also a Satisfaction with the Workshop Survey?

Workshop Evaluation Survey



Thank you!

Please complete Satisfaction Survey for me?

Next Steps

- Follow up call from workshop facilitator
- Study questionnaire
- Follow up call with simulated patient

??MAM Will be contacting you to arrange 2 follow up calls

1. From the workshop facilitator to see if you have further questions or need some clarification after the workshop and you are back in your practice
2. Our follow-up call with the simulated patient. You can use the decision aid we practised with today when you have that call

As well we will be sending you a questionnaire about decision support

Please remember.... this is a research study so please don't talk about what you are learning or share the resources we've given you with your colleagues. They could be in the control group and this could affect the study findings.

(Study – probably ongoing until Easter) – then OK to discuss / use tools after this.

**Decision Support Skills Building Workshop
Practice Cases**

CASE # 1

‘Practitioner’ Role

Case #1: Dorothy Walker

72yo woman with breast cancer, bone and liver mets (original diagnosis 6 years ago treated with surgery and chemo, bone mets x 3 years, liver mets 8 months ago). She was admitted to hospital with acute hypercalcemia (high calcium). Median survival post hypercalcemia is 3 months).. Feeling better now with referral to palliative care. Needs to decide whether to plan for admission to palliative care unit or return home.

Practitioner perspective:

- You are the palliative care consult nurse.
- When you see her in the hospital, she is feeling tired and uncertain about whether to plan for admission to the palliative unit or to return home.

Decision Support Skills Building Workshop Practice Cases

‘Patient’ Role

Case #1: Dorothy Walker

72yo woman with breast cancer, bone and liver mets (original diagnosis 6 years ago treated with surgery and chemo, bone mets x 3 years, liver mets 8 months ago). She was admitted to hospital with acute hypercalcemia (high calcium). Median survival post hypercalcemia is 3 months). Feeling better now with referral to palliative care. Needs to decide whether to plan for admission to palliative care unit or return home.

Patient perspective:

- “I don’t know what to think. I want to go home but worried it will be too hard on my husband. I am not sure what to do.”
 - You live in a medium size town about an hour away from the city. The palliative unit is in a hospital in the city. You know about the local CCAC resources. Your sister died at the palliative unit last fall. You were happy with the care she received. You feel fairly clear that you would like to be at home but are very worried that it would be too hard on your husband. You also have a small dog who is your ‘baby’ and many friends in your town- it would be difficult for them to visit you at the palliative unit. .
 - You have 3 children that are in their 40’s with 2 in the Kingston area and the youngest daughter, Sophie, in Toronto. You also have 3 grandchildren in Ottawa – Son has 2 children (ages 9 and 12) and eldest daughter has 1 child (age 13). Your husband is healthy, helps with the household chores and drives you to your appointments – he has offered no opinion on this decision.
- Are you sure which choice is best for you? NO
 - Do you feel you are informed enough about the options? YES
 - Do you know what matters most to you, the risks or the benefits? **NO** unclear about what is most important to you
 - Do you have enough support or do you experience undue pressure? YES

Name: Dorothy Walker

Date:

Clinical Priority

Adapted PPS Tool	Moving about	As usual	Less than usual	Mainly sitting	Mainly bed	Bed all the time	
Total score (%)	Activity: Job, hobbies, housework	Able to do usual activities	With effort, able to do usual activities	Unable to do usual work hobbies house work	Unable to do any work	Unable to do most activities	Unable to do any activity

	Self Care	Able to do all personal care	Need occasional help	Need a lot of help	Someone provides most care	Someone provides all care
53%	Eating & drinking	As usual	Less than usual	Small amounts food/ sips	Not able	
	Alertness	As usual	Less than usual	Drowsy most of the time	Sleep all the time	

ESAS Symptoms
Total score (%)

51%

Pain	3	5
Nausea	3	7
Anxious	3	
Appetite	3	7
Short of Breath	3	5

See patient reported WOMAC

Patients' Preference & Decisional Needs

Certainty Prefers: **Care at Home**
 ✗ feels sure about best choice

Knowledge ✓ feels knows enough

Values ✗ feels unclear re values

Home Care Reasons

More privacy
 Control daily routines & timing of care
 Close to family, personal belongings, pets & friends
 Other: *friends don't have to travel to visit*

Facility Care Reasons

Staff available 24/7
 Staff manages most of personal care
 Staff around for safety & security
 Other

Not Important			Very Important		
0	1	2	3	4	5
			3		
			3		
					5
					5
			3		
0			3		
	1				

Support ✗ has enough support/advice Prefers to share decision with: husband

Person
Husband

Preference
Neutral

Pressure
No

Possible Support
listen

Building Decision Support Skills Practice Cases
CASE # 2

‘Practitioner’ Role

Case #2 Jim Jackson

54yo man with colon cancer and end stage liver disease (alcohol induced cirrhosis). Formally, homeless; now living in a room at the local shelter. Previously a heavy drinker; lately no alcohol consumption. Has been estranged from his family for years. His parents are deceased. Recently has reconnected with his brother who visits him, brings him clothes and helps with his banking. He has visited his brother home for holidays.

Practitioner perspective:

- You are the public health nurse assigned to the shelter.
- 1 week ago the support staff approached you because they are worried Jim may die at the shelter and that his brother thinks he would be ‘better off’ at the hospice
- You met with Jim last week to talk about his options
- At today’s follow-up visit a decision needs to be made about the next step: plan to stay at the shelter with extra support or transfer to the mission hospice.

Decision Support Skills Building Workshop

Practice Cases

‘Patient’ Role

Case #2 Jim Jackson

54yo man with colon cancer and end stage liver disease (alcohol induced cirrhosis). Formally, homeless; now living in a room at the local shelter. Previously a heavy drinker; lately no alcohol consumption. Has been estranged from his family for years. His parents are deceased. Recently has reconnected with his brother who visits him, brings him clothes and helps with his banking. He has visited his brothers’ home for holidays.

Patient perspective:

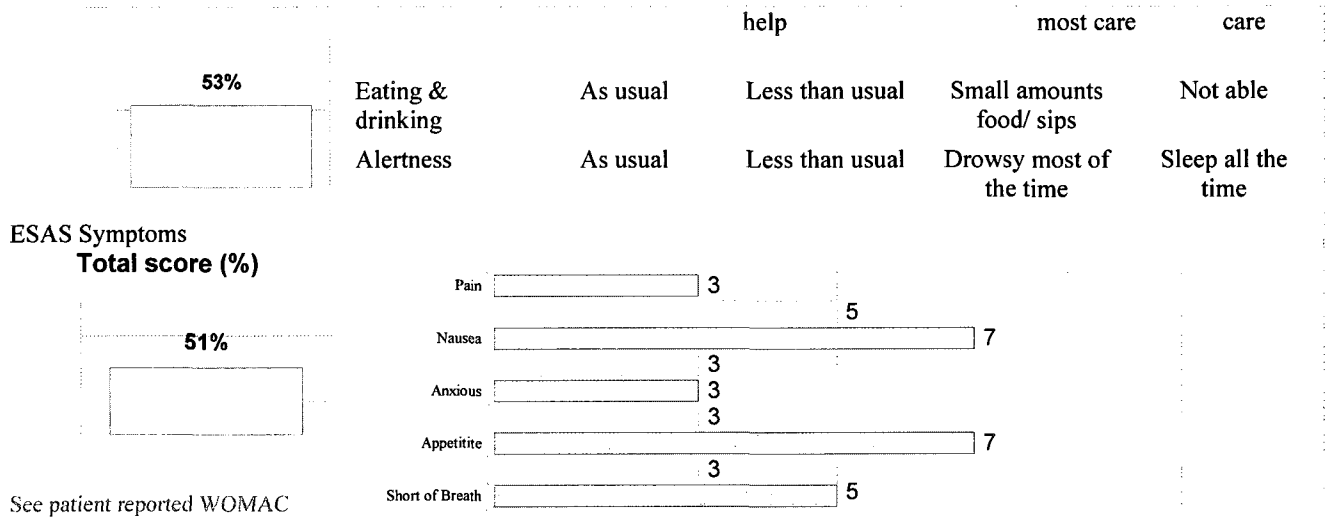
- *“I know you said that I have a choice about where I want to be but how am I supposed to figure it out? I don’t want to go somewhere else – I want to stay here where my friends are- but my brother wants me to go to the hospice. I can’t sleep thinking about it. I don’t want to leave here but I just got back to a good relationship with my brother and I don’t want him to be mad at me. I feel liked I am being forced to go to the hospice.”*
 - You are not afraid of dying. You have always valued being independent and able to survive on the street.
 - The thought of going to the hospice scares you. You have many ‘street friends’ who live in or near the shelter. Your ‘street friends’ say you should do what you want.
 - You have a good relationship with the shelter staff and trust them.
-
- Are you sure which choice is best for you? NO
 - Do you feel you are informed enough about the options? YES
 - Do you know what matters most to you, the risks or the benefits? Yes
 - Do you have enough support without undue pressure? NO, feeling pressure from brother

Name: Jim Jackson

Date:

Clinical Priority

Adapted PPS Tool	Moving about	As usual	Less than usual	Mainly sitting	Mainly bed	Bed all the time
Total score (%)	Activity: Job, hobbies, housework	Able to do usual activities	With effort, able to do usual activities	Unable to do usual work	Unable to do usual hobbies house work	Unable to do any activity
	Self Care	Able to do all personal care	Need occasional	Need a lot of help	Someone provides	Someone provides all



Patients' Preference & Decisional Needs

Certainty Prefers: **Care at Home**

✗ feels sure about best choice

Knowledge ✓ feels knows enough

Values ✗ feels unclear re values

Home Care Reasons

More privacy

Control daily routines & timing of care

Close to family, personal belongings, pets & friends

Other: *friends don't have to travel to visit*

Facility Care Reasons

Staff available 24/7

Staff manages most of personal care

Staff around for safety & security

Other

Not Important	0	1	2	3	4	5	Very Important
				3			
				3			
						5	
						5	
				3			
0				3			
	1						

Support ✗ has enough support/advice

Prefers to share decision with: brother and shelter staff

Person
Brother

Preference
Hospice

Pressure
Yes

Possible Support
Listen to your preferences

DSAT 10: Brief Decision Support Analysis Tool

Purpose: A tool for evaluating the quality of decision support provided by call centre nurses to callers facing tough health decisions.

Procedure:

1. Listen to the interaction between nurse and patient.
2. Check the boxes if the items were present and **adequately** addressed within the interaction (turn page over for descriptions of each criterion). Not applicable (n/a) is used in rare circumstances when it was not necessary to have assessed or intervened for that specific item (e.g. if clearly the patient does not know enough about options then the nurse does not need to explore benefits and harms; if the caller is the only one that is making the decision and has no pressure or need for support then the nurse does not need to intervene in this area).
3. Identify examples from practitioner dialog to support that the criterion was met.

Element	Assessment Criteria	Hear and acknowledge or assess in interaction	Intervened	Comments/ Notes / Examples
Decision making status	Identify actual decision being made; be able to specify	☐		
	Timing for when decision needs to be made is discussed/ acknowledged	☐		
	Stage of decision making: assessed or self-evident	☐		
Knowledge of	Options identified	☐	☐	
	Potential benefits of options	☐	☐	
	Potential harms of options	☐	☐	
Values /preference associated with	Importance of benefits	☐		
	Importance of harms	☐		
Others' involvement in the decision	Discuss preferred role in decision making, others involvement and their opinions	☐	☐	
	Discuss pressure or support from others	☐	☐	
Next Steps	Near end of the call, there is a summary of the next steps to address caller's decision making needs	☐		

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Workshop Date:

Participant ID #:

Usability of the 'When You Need Extra Care...' Decision Aid

Please comment on the clinical usability of the 'When You Need Extra Care...' Decision Aid. As well, we are interested in your perception of possible factors influencing its use. Please give the completed survey to the workshop facilitator.

7. How clear were the steps/questions in the 'When You Need Extra Care...' Decision Aid?
 - ☐ Everything was clear
 - ☐ Most things were clear
 - ☐ Some things were clear
 - ☐ Many things were not clear
8. How easy is it to use the 'When You Need Extra Care...' Decision Aid in helping someone making a decision about place of end of life care?
 - ☐ Very easy
 - ☐ Moderately easy
 - ☐ Somewhat difficult
 - ☐ Very difficult
9. How helpful would the 'When You Need Extra Care...' Decision Aid be in supporting patients making choices about place of end of life care?
 - ☐ Everything was helpful
 - ☐ Most things were helpful
 - ☐ Some things were helpful
 - ☐ Many things were not helpful
10. How useful was the 'When You Need Extra Care...' Decision Aid in helping you identify a plan to address the decision support needs (e.g. information gaps, unclear values, support problem)?
 - ☐ Very useful
 - ☐ Moderately useful
 - ☐ Somewhat useful
 - ☐ Not helpful
11. How comfortable would you be using the 'When You Need Extra Care...' Decision Aid with a patient?
 - ☐ Very comfortable
 - ☐ Comfortable
 - ☐ Uncomfortable
 - ☐ Very uncomfortable
12. Would you recommend using the 'When You Need Extra Care...' Decision Aid to colleagues?
 - ☐ Definitely recommend
 - ☐ Probably recommend
 - ☐ Probably not recommend
 - ☐ Definitely not recommend

Usability of the 'When You Need Extra Care...' Decision Aid continued

How much you agree or disagree with the following statements.

From my perspective, using the 'When You Need Extra Care...' Decision Aid as a clinical decision support tool with patients making decisions about place of end of life care will:

Item	Strongly disagree					Neutral					Strongly agree				
7. allow practitioners to guide patients through their decision making in a systematic way															
8. be acceptable to practitioners															
9. be acceptable to patients															
10. help prepare patients for discussing the decision with team members															
11. be TOO complex															
12. help patients participate in ways they prefer in the decision making process															
13. improve the chances that patients decisions are informed															
14. improve the chances that patients decisions are based on personal values of what is most important															
15. do more good than harm															
16. be easy to use															
17. could fit in well with usual practice approaches															
18. be useful for patients making place of care decisions more than 60% of the time															
19. is compatible with how I think patients should make place of care decisions															
20. be useful in my practice															
21. complement my usual approach in these situations															
22. require a major change to the way I currently handle these types of situations															
23. help me to more fully explore issues of importance to patients facing place of care decisions															
24. increase patients satisfaction with our health care services															
25. help me use my time more effectively															
26. improve my usual approach															
27. help me tailor my approach to better meet patients needs															
28. be easy to try out before deciding to use regularly															
29. be easy to use if it was included in orientation or continuing education initiatives															

31. What are the top 3 barriers that are likely to interfere with using the *'When You Need Extra Care...'* Decision Aid?

1. _____
2. _____
3. _____

32. What are the advantages of using the *'When You Need Extra Care...'* Decision Aid compared to your usual approach for supporting patients facing decisions about place of end of life care?

33. How likely are you to use the *'When You Need Extra Care...'* Decision Aid as a clinical tool within the next 3 months with a patient facing a decision about place of end of life care?

- ☐ very likely
- ☐ likely
- ☐ somewhat likely
- ☐ not at all

34. Do you think practitioners in your organization should use the *'When You Need Extra Care...'* Decision Aid to help patients facing end of life place of care decisions

- ☐ yes
- ☐ no
- ☐ undecided

35. On average in a three month period, how many times would you help patients making end of life place of care decisions?

- ☐ 0
- ☐ 1-5
- ☐ 6-10
- ☐ 11-15
- ☐ 16- 20
- ☐ 21 +

Decision Support Skills Building Workshop Evaluation

Help us understand how to best meet your learning needs in providing patient decision support. Please answer these questions and return the questionnaire to the workshop facilitator.

1. Overall, how well did the workshop meet your learning needs about providing patient decision support? *Circle your response*

Not Very Well	Fairly Well	Quite Well	Very Well
---------------	-------------	------------	-----------

2. How well did the workshop help you to understand decision support and decision aids
Circle your response

Not Very Well	Fairly Well	Quite Well	Very Well
---------------	-------------	------------	-----------

3. How well did the workshop help evaluate decision support *Circle your response*

Not Very Well	Fairly Well	Quite Well	Very Well
---------------	-------------	------------	-----------

1. How well did the workshop meet your learning needs about providing patient decision support?
Circle your response

Not Very Well	Fairly Well	Quite Well	Very Well
---------------	-------------	------------	-----------

2. Did the workshop meet the learning objectives? (*Circle your response*)
- a. Yes No Unsure
 - b. Yes No Unsure
 - c. Develop skills in using a decision aid Yes No Unsure
 - d. Recognize opportunities for shared decision making Yes No Unsure

3. How easy was it to understand the information presented in the workshop?

- ☐ Very easy
- ☐ Somewhat easy
- ☐ Just right
- ☐ Somewhat complex
- ☐ Too complex

4. Was enough time allocated to trying the, 'When you need extra care' Decision Aid?
Too much time ☐ Just right ☐ Not enough time ☐

5. Having participated in the workshop how confident do you feel in providing support patients making decisions about place of care at the end of life?
- ☐ I felt confident before the workshop
 - ☐ I feel more confident
 - ☐ I do not feel confident

☐ Not sure

6. Would you recommend this workshop to other health practitioners ?

Yes ☐ No ☐ Unsure ☐

7. Please rate the following by circling a number in each column. (1 = Poor 5 = Excellent)

Amount of information and content covered in the workshop	Quality of information and content covered in the workshop	Usefulness of information and content covered in the workshop to your work	Overall impression of the workshop
1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5

8. What was the most useful activity in the workshop?

9. What was the most important learning you will take from this workshop?

10. How could this workshop be improved?

Thank you for helping us to better understand how to meet the learning needs of nurses and care coordinators in providing patient decision support.

Appendix N

Post Questionnaires

**Efficacy of a Training Intervention on the Quality of Care Coordinators' and Nurse
Decision Support for Patients Deciding about the Place of Care at the End of-Life**

Participant
#

Post Intervention Questionnaire

Please take a minute to complete the following questions. Your comments are valuable and

The purpose of this survey is to find out about your beliefs and possible factors that influence practitioners in providing decision support to patients with advanced disease regarding place at the end of life care. The survey will take about 15 minutes to complete. Please choose the best option for completing and returning the survey.

Options:

1. Save file as a new word file with your initials in the label. Fill in survey electronically. Send completed file to pmenard@uottawa.ca
2. Print document. Complete by hand. Fax to Mary Ann Murray at 613-761-5402
3. Print document. Complete by hand. Mail to:
Mary Ann Murray RN, PhD(c),
Decision Support Study Investigator,
OHRI , 1053 Carling Ave Room 2-005
Ottawa Ontario Canada K1Y 4E9

Your feedback and impressions are very important and valued. Please answer the following questions.

1. Within the last 4 weeks I have provided decision support to oncology patients with advanced disease and or palliative patients and families regarding place of care at the end of life care?
 - o No,
 - o Yes, if yes how many times have you used it in the last 3 weeks?
 - o Once
 - o 2 to 3 times
 - o 4 to 5 times
 - o More than 6 times
2. If you have helped a patient or family with a health problem or decision within the past 3 weeks please briefly describe

3. Please estimate how often you would typically provide decision support to oncology patients with advanced disease and or palliative patients and families regarding place of care at the end of life in a 4 week period?
- Never
 - Yes, if yes how many times have you used it in the last 3 weeks?
 - Once
 - 2 to 3 times
 - 4 to 5 times
 - More than 6 times

Please show how strongly you agree or disagree with these statements by circling the number from 1 (strongly agree) to 5 (strongly disagree)

- | | | | | | | |
|---|--|---------------------|------------|---------------------------------|---------------|------------------------|
| 1 | I intend to provide decision support regarding place of care at end of life when interacting with patients with advanced cancer and or palliative patients in my practice. | 1
Strongly Agree | 2
Agree | 3
Neither Agree Nor Disagree | 4
Disagree | 5
Strongly Disagree |
| 2 | I will try to provide decision support regarding place of care at end of life when interacting with patients with advanced cancer and or palliative patients in my practice. | 1
Strongly Agree | 2
Agree | 3
Neither Agree Nor Disagree | 4
Disagree | 5
Strongly Disagree |
| 3 | I plan to provide decision support regarding place of care at end of life when interacting with patients with advanced cancer and or palliative patients in my practice. | 1
Strongly Agree | 2
Agree | 3
Neither Agree Nor Disagree | 4
Disagree | 5
Strongly Disagree |
| 4 | Providing decision support regarding place of care at end of life to patients with advanced cancer and or palliative patients is helpful to them. | 1
Strongly Agree | 2
Agree | 3
Neither Agree Nor Disagree | 4
Disagree | 5
Strongly Disagree |

- | | | | | | |
|-------------------------------|---|---|---|---|---|
| 5. Providing decision support | 1 | 2 | 3 | 4 | 5 |
|-------------------------------|---|---|---|---|---|

regarding place of care at end of life to patients with advanced cancer and or palliative patients is beneficial to them.	Strongly Agree	Agree	Neither Agree Nor Disagree	Disagree	Strongly Disagree
6. Most people who are important to me in my professional practice think that I should provide decision support regarding place of care at end of life to patients with advanced cancer and or palliative patients.	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree
7. It is expected of me that I provide decision support regarding place of care at end of life to patients with advanced cancer and or palliative patients.	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree
8. I could provide decision support to regarding place of care at end of life to patients with advanced cancer and or palliative patients if I wanted to.	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree
9. It is mostly up to me whether or not I provided decision support regarding place of care at end of life to patients with advanced cancer and or palliative patients.	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree
10. I expect that added work related time demands will be placed on me in the coming months.	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree
11. I expect that work related	1	2	3	4	5

time demands in the coming months will make it more difficult to provide decision support regarding place of care at end of life to patients with advanced cancer and or palliative patients.	Strongly Agree	Agree	Neither Agree Nor Disagree	Disagree	Strongly Disagree
12. I expect that education and training will be available to me in the coming months.	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree
13. I expect that education and training in the coming months will make it easier to provide decision support regarding place of care at end of life to patients with advanced cancer and or palliative patients.	1 Strongly Agree	2 Agree	3 Neither Agree Nor Disagree	4 Disagree	5 Strongly Disagree

Please tell us a bit about yourself....

3. What is your position? (circle appropriate response)

- a. Case manager (nurse)
- b. Case manager (non nurse)
- c. Inpatient nurse
- d. Community based nurses(home visit nurse)
- e. Other health professional_____

4. How long have you been working in this role?

- ☐ 3 or fewer months ☐ 3-5 years
- ☐ 4 to 12 months ☐ 6 – 12 years
- ☐ 1- 2 years ☐ more than 13 years

3. Are you currently working: ☐ Full-time ☐ Regular part-time

☐ FTE (full-time equivalent) status: _____

4. Your age range:

- ☐ Under 29 ☐ 40 to 49 ☐ 60 and older
- ☐ 30 to 39 ☐ 50 to 59

5. Your gender:

☐ Female

☐ Male

6. Your highest level of education completed:

☐ College diploma (RN / RPN Diploma)

☐ Undergraduate university degree

☐ Graduate university degree

☐ Other, specify _____

7. How long have you been working with oncology or palliative patients?

☐ Less than 2 years ☐ 11 to 15 years ☐ 26 to 30 years

☐ 2 to 5 years ☐ 16 to 20 years ☐ more than 30 years

☐ 6 to 10 years ☐ 20 to 25 years

THANK YOU for all your help and support in this study. Your contribution is very much appreciated.

After completing the survey, please choose the best option for returning.

Options:

1. Save file as a new word file with your initials in the label. Fill in survey electronically. Send completed file to pmenard@uottawa.ca

2. Print document. Complete by hand. Fax to Mary Ann Murray at 613-761-5402

3. Print document. Complete by hand. Mail to:

Mary Ann Murray RN, PhD(c),

Decision Support Study Investigator,

OHRI , 1053 Carling Ave Room 2-005

Ottawa Ontario Canada K1Y 4E9

Appendix O

Published Versions of Manuscripts Included in Thesis

1. Efficacy of a training intervention on the quality of practitioners' decision support for patients deciding about place of care at the end of life: A randomized control trial: Study protocol; Mary Ann Murray, Annette O'Connor, Dawn Stacey and Keith G Wilson , *BMC Palliative Care* 2008, 7:4doi:10.1186/1472-684X-7-4). Open access Journal. Reprinted with permission
2. "Where the Dying Live: A Systematic Review of Determinants of Place of End-of-Life Cancer Care," by Mary Ann Murray, RN, MScN, CON(C), GNC(C), CHPCN(C), Valerie Fiset, RN, MScN, Sandra Young, RN, CHPCN(C), and Jennifer Kryworuchko, RN, BScN, 2009. *Oncology Nursing Forum*, 36(1), pp. 6977. Copyright 2009 by the Oncology Nursing Society. Reprinted with permission.

Study protocol

Open Access

Efficacy of a training intervention on the quality of practitioners' decision support for patients deciding about place of care at the end of life: A randomized control trial: Study protocol

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Abstract

Background: Most people prefer home palliation but die in an institution. Some experience decisional conflict when weighing options regarding place of care. Clinicians can identify patients' decisional needs and provide decision support, yet generally lack skills and confidence in doing so. This study aims to determine whether the quality of clinicians' decision support can be improved with a brief, theory-based, skills-building intervention.

Theory: The Ottawa Decision Support Framework (ODSF) guides an evidence based, practical approach to assist clinicians in providing high-quality decision support. The ODSF proposes that decisional needs [personal uncertainty, knowledge, values clarity, support, personal characteristics] strongly influence the quality of decisions patients make. Clinicians can improve decision quality by providing decision support to address decisional needs [clarify decisional needs, provide facts and probabilities, clarify values, support/guide deliberation, monitor/facilitate progress].

Methods/Design: The efficacy of a brief education intervention will be assessed in a two-phase study. In phase one a focused needs assessment will be conducted with key informants. Phase two is a randomized control trial where clinicians will be randomly allocated to an intervention or control group. The intervention, informed by the needs assessment, knowledge transfer best practices and the ODSF, comprises an online tutorial; an interactive skills building workshop; a decision support protocol; performance feedback, and educational outreach. Participants will be assessed: a) at baseline (quality of decision support); b) after the tutorial (knowledge); and c) four weeks after the other interventions (quality of decision support, intention to incorporate decision support into practice and perceived usefulness of intervention components). Between group differences in the primary outcome (quality of decision support scores) will be analyzed using ANOVA.

Discussion: Few studies have investigated the efficacy of an evidence-based, theory guided intervention aimed at assisting clinicians to strengthen their patient decision support skills. Expanding our understanding of how clinicians can best support palliative patients' decision-making will help to inform best practices in patient-centered palliative care. There is potential transferability of lessons learned to other care situations such as chronic condition management, advance directives and anticipatory care planning. Should the efficacy evaluation reveal clear improvements in the quality of decision support provided by clinicians who received the intervention, a larger scale implementation and effectiveness trial will be considered.

Trial registration: This study is registered as NCT00614003

Background

There are more choices for place of end-of-life cancer care due to shifts in care to the community, better understanding of the clinical course of cancers, equipment portability, pharmacology advances, and consumer expectations. Place of care has various meanings to patients and families and represents more than a particular geographic location [1]. Options can include hospice, private residence, nursing home, continuing complex care facility, homeless shelter, and/or hospital. For patients with good symptom control, instrumental support, and a predictable course of illness, decisions regarding place of care are often based on values and expectations [2-5].

Patients frequently experience decisional conflict (personal uncertainty about the best course of action) when considering place for end-of-life care. Personal preferences are weighed against practical considerations and concern for others [2,3,5,6], thus contributing to decisional conflict. Other modifiable factors such as knowledge gaps, unrealistic expectations about outcomes, lack of clarity about what matters most, and feeling pressured to choose a particular option exacerbates the decisional conflict [7]. Unresolved decisional conflict can lead to decisional delay or reversal, dissatisfaction, regret, and blaming the provider [8,9]. Failure to elicit the valued priorities of terminally ill patients and their families can result in missed opportunities, decreased quality of life, unwelcome interventions, and increased risk for complicated bereavement for survivors [3,10-12].

It is generally known that decisional conflict can be reduced with decision support interventions such as decision aids and nurse coaching [7,13]. However, there have been few studies evaluating either of these interventions for decisions at the end-of-life. Although patient decision aids may be useful for some common discrete crossroads decisions with standardized options and outcomes, there may be more payoffs in focusing on coaching interventions that can be applied broadly to care management at the end-of-life. While end-of-life decisions are highly values-sensitive, they also bear a strong resemblance to chronic condition management decisions, which focus on situation monitoring, priority setting, and implementation [14-16].

There is evidence that influencing practitioners' knowledge and attitudes about communication and decision support can strengthen subsequent decision support practices, thus matching care planning to patient preferences and avoiding the use of non-valued interventions [17-20]. Nevertheless few studies have empirically examined the impact of a theoretically informed, decision support training intervention on the quality of decision support knowledge and practices provided by practitioners [21] and

none have been undertaken within the context of palliative care practice.

Patients and families want clinicians to listen to their views and preferences [18] and standard palliative practice calls for patient inclusion in care planning [22,23]. Most patients with advanced cancer want full information and the majority wish to participate actively in decision making [24]. Although seriously ill hospital patients want to discuss end-of-life issues, their preferred decision making role varies and is difficult to predict [25], highlighting the need for active and regular assessment of patients' decision making needs. However, clinicians may avoid raising uncomfortable topics [26-28] and often lack skills and confidence in helping patients in non-directive ways [29].

Systematic review findings confirm that training clinicians in patient centered approaches is an effective strategy for increasing patients understanding of the evidence and implications [30]. For instance, decision coaching by nurses has helped to foster an informed use of resources and avoid the over-use of interventions that patients don't value in urology care [17] and in gynecological care [31]. Practitioners, such as nurses and other professional care coordinators, through their trusted and frequent interactions with patients are well positioned to elicit and explore decisional needs such as decisional conflict and related factors (e.g.: knowledge, values clarity, and support) [32]. Practitioners can then coach patients with information, values clarification, support and links to resources. While a key challenge is the need to strengthen practitioners' decision support skills [29] training interventions have been shown to markedly improve the quality of practitioners' decision support skills for other clinical problems [33].

Accountability to quality patient outcomes and fiscal responsibility confirms the need to practically and pragmatically address patients' end-of-life decision making needs. Systematic and rigorous evaluation of an evidence-based intervention designed to improve the quality of practitioners' decision support could illuminate best practices for decision support and advance the fields of shared decision making, patient-practitioner communication, palliative care, and ultimately improve the lives of those who are living with a terminal illness and their families.

Multifaceted interventions show promise in influencing professional behavior change [34-37]. An exploratory study to identify target variables, choose and refine interventions, and establish their theoretical basis prior to large scale effectiveness trials is a sound research approach [38-40]. The paucity of empirical inquiry, in this area to date, warrants an exploratory study to describe the con-

stant and variable components of a potential intervention and a feasible protocol for intervention delivery.

Guiding Theoretical Models

As the study aims to influence decision support behavior an understanding of factors that can be partially modified, such as attitudes and perceptions of norms that drive actions, is required to inform intervention messages and enhance the potential for behavior change. The pragmatic and conceptual focus of the study also requires an empirically proven, clinically relevant decision support framework to guide intervention content. The Theory of Planned Behavior (TPB) [41,42] and the Ottawa Decision Support Framework (ODSF) [43] fit these criteria. The former predicts the likelihood of behavior change while the latter provides a three step path to optimize quality decision support. The TPB [40,44-46] and the ODSF [3,47,48] are relevant to nursing and have performed well in numerous health-related studies.

Briefly, the TPB proposes that the strength of the intention to change is the primary determinant of actual behavior change. This intention is determined by: (1) a person's attitude to the new behavior (strength of perceived advantages and disadvantages); (2) the extent of self-perceived social pressure to perform or not to perform the new behavior, and (3) degree of perceived control over being able to perform the behavior [49].

According to the ODSF, decision support interventions can be tailored to address modifiable determinants of decisional conflict (knowledge; outcome expectations; values clarity; support factors) resulting in better quality decisions that are informed and consistent with patients' values [50]. In this study, the ODSF will guide decision support skill acquisition interventions and measures of change.

Clinician-identified factors associated with practice change: utility, strong evidence basis, and flexibility to acknowledge the individuality of patients [51] fit well with the ODSF. Historically, the ODSF has been well received by clinicians [3,33,48], has shown robustness in randomized control studies [7,33] and is predicated on a patient-centered approach which recognizes the unique context, circumstance and patient characteristics situated within the decision support encounter. The TPB and ODSF have guided the study design in the following ways:

1. The predictive potential of theory facilitates selection of training intervention components which offers the best probability of success [36,52].
2. The TPB offers a useful lens to examine attitudes, beliefs and perceived control for engaging in decision support

practices and will inform the selection of key messages attached to intervention strategies.

3. Mapping the intervention components onto TPB variables provides a useful template to ensure multiple targets of behavior change are addressed and is consistent with knowledge dissemination best practices [35,53].

4. The ODSF describes a well defined approach to quality decision support provision and provides a practical vehicle to structure components of a knowledge and skill building intervention.

5. Availability of a broad inventory of theoretically grounded and empirically validated, reliable, time tested tools operationalizing ODSF constructs provides a rigorous platform to inform study interventions and will strengthen the trustworthiness of study findings.

Methods/Design

Aims of the study

The primary aim of this study is to evaluate the efficacy of a theory driven, framework-based training intervention, as compared with a control condition (usual care approach) in enhancing the quality of practitioners' patient decision support skills regarding place of care at end of life. In addition, we plan to assess participants' intention to engage in patient decision support in their practice and to determine the acceptability of the intervention components. Specific objectives include:

1. To identify factors affecting the likelihood of practitioners' integrating decision support principles into their practice
2. To determine the quality of decision support practitioners provide
3. To design and evaluate components of a decision support training intervention

We plan to test the following study hypothesis:

H_1 : A significantly greater proportion of practitioners, who are randomized to a multi-faceted, theory driven, training intervention, will obtain higher scores on quality of decision support following the intervention

H_0 : No change in group means in decision quality following the intervention

Study Design and Methods

A two phase, sequential, mixed method design is planned.

Phase 1 involves a focused needs assessment of key informants (clinicians, educators, administrators) who plan and provide palliative/oncology care. A purposive sample of about 12 key informants representing different levels of experience, responsibility, clinical focus and setting will be interviewed using a semi-structured interview based on the TBP [54].

Phase 2 is a randomized control trial of a brief educational intervention. Consenting/eligible participants will be randomly allocated to an intervention or control group. The intervention, informed by the needs assessment, comprises: an online tutorial; an interactive skills building workshop, a decision support protocol; performance feedback, and educational outreach.

Participants will be assessed: a) at baseline (quality of decision support); b) after the tutorial (knowledge); and 3–6 weeks after the other interventions (quality of decision support; intention to adopt decision support into clinical practice).

Sample Size

The estimated sample size for the Phase 2 study is based on a test for differences in mean scores of decision support quality and knowledge in the intervention versus the control group. An effect size of .70 requires $n = 32/\text{group}$, when alpha error = 0.05 and beta error = 0.20 [55]. This effect size is conservative in that a previous study [17] reported larger effect sizes which required only 18–20 per group.

Participants

Full or part time nurses and care coordinators (i.e.: social worker, case managers, pharmacists) from three Ontario regions (Ottawa, Toronto, Kingston), employed by one of the ten study partner organizations will be invited to participate. Study partners include hospital based institutions [Ottawa Hospital, Queensway-Carleton Hospital, SCO Health Services], community based organizations [Community Care Access Center Care (Toronto Central; South-east Ontario); CareFor Nursing Agency; St. Elizabeth Health Care (Toronto, Kingston); Hospice at May Court; Bayshore Home Health Agency (Cornwall, Toronto, Ottawa)]. Information flyers and information sessions explaining the study will be held at study partner organizations. Interested potential participants will be asked to contact the study coordinator if they have further questions or would like to participate in the study. Participants are considered eligible for study inclusion when they meet the following criteria:

- are a member of a regulated health profession
- care for palliative cancer patients, and/or

- cancer patients with advanced disease, and
- work at least 4 shifts per month,
- in a clinical area where end of life care discussions are likely to be undertaken, and
- are proficient in written and spoken English.

Ethical considerations

The protocol has been approved by the Research Ethics Committees of the University of Ottawa, The Ottawa Hospital and SCO Health Services. Trial registration with the International Standard Randomized Controlled Registry has been obtained (Trial #NCT00614003).

Procedures

Phase 1: Needs Assessment

Semi-structured interviews with a purposive sample of key informants ($n \approx 12$ engaged in direct care, education and/or administration roles) will be used to elicit TPB related factors affecting intentions to provide decision support (personal attitudes, norms, and perceived control). Questions about other barriers to providing decision support will be elicited. Results will inform intervention content and key messages.

Phase 2 Intervention

Consenting practitioners will be randomly allocated to one of two groups. A computer generated randomization list for concealed allocation will be used. To avoid disparate sample sizes permuted blocks will be used. Participants will be allocated by an external statistician, who has no connection to the study team, immediately after collection of baseline data.

Baseline measures of both groups

The quality of decision support skills will be assessed using audio-taped interactions between participants and simulated patients. Simulation scenarios have been created and vetted by a panel of Palliative Advanced Practice Nurses. Simulated patient callers will receive a training and feedback session facilitated by an experienced trainer prior to placing the call to participants. Simulated patient callers will contact each participant and engage in a standardized scenario expressing difficulty related to a place of end-of-life care decision. Calls will be tape recorded and quality scored using the Decision Support Analysis Tool (DSAT) [56].

2. Intervention (experimental) group

Participants assigned to the intervention group will:

- a. Complete an on-line decision support tutorial which introduces the 'When you need extra care decision aid',

case studies and quizzes related to place of care decision support.

b. Participate in a half day skills building workshop. The workshop contains aggregated feedback on baseline simulated calls; opportunities to observe, compare and contrast a traditional patient education approach to a patient decision support approach; role play using the 'When you need extra care decision aid' and peer scoring of the quality of their decision support provision using the DSAT. A determinants of place of care knowledge module will also be delivered. At the end of the workshop, participants will complete a questionnaire eliciting perceived utility/usability of the a) workshop content, and b) decision support protocol.

c. Participate via telephone in an education outreach session to identify areas needing clarification, share problem solving in using the decision support protocol, and to obtain further feedback.

d. Complete a questionnaire eliciting satisfaction with content and process of education program.

3. Post measures of both groups

a. After the auto-tutorial, knowledge tests will be administered.

b. 2–6 weeks following completion of the full intervention a TPB based survey eliciting behavioral intention to integrate decision support in practice and related attitudes, norms, and perceived control will be administered.

c. 2–6 weeks following completion of the full intervention the quality of the participants' decision support skills will be assessed with a different simulated patient scenario using the same methodology as the baseline assessment.

Proposed Intervention Details of the educational intervention follow.

Decision Support Tutorial

Developed by Ottawa Health Decision Centre, Clinical Epidemiology Unit of the Ottawa Health Research Institute (OHRI) this on-line, self-learning resource has been used to train clinicians, graduate students and undergraduate nursing students; US and BC tele-health center nurses; UK urology nurses; and nurses in family practice units in Ontario. Three modules provide 1) an overview of decisional conflict with a three step path to guide decision support, 2) case studies profiling decision support tools (including a decision support protocol) and processes with embedded quizzes to assess comprehension and provide feedback; and 3) a final integrated knowledge test. The original tutorial will be adapted to decisions about

the place of terminal care. The tutorial is hosted by the University of Ottawa and is password protected. Participants will be asked to complete the auto-tutorial one week prior to the workshop.

Decision Support Protocol

Participants will be introduced to a decision aid in the tutorial. The decision aid guides patients in advanced planning of location of care and is entitled 'When you need extra care decision aid'. The decision aid is based on the Ottawa Decision Support Framework and the Ottawa Decision Support Practitioners Guide (OPDG). The four page decision aid provides a structured approach to assess patients' decisional needs, provide tailored decision support to address needs and evaluate patients' progress in decision making. There are five elements: 1) general information about place of care options and palliative care; 2) self report of functional and symptom status over the past week based on the Palliative Performance Scale [57] and the Edmonton Symptom Assessment Scale [58] respectively; 3) a self-ranking of which reasons for each option are considered most important; 4) an assessment of what else patients need to prepare for decision making; and 5) a summary of next steps.

Content is based on: a) systematic reviews of literature [4,59,60]; b) previous research on women's decision making needs regarding place of care at the end of life [3]; previous research on family members' decision making needs at the end of life [61] and d) the primary investigator's clinical experience in palliative care. Participants will be provided with a hard copy of the protocol as well as access to the online version.

Skill building workshop

Within three weeks of the online tutorial, a half day workshop will be conducted. Content will be based on the pre-intervention TPB needs assessment and also a) practical applications of material learned in the tutorial; b) a video illustrating a clinical application of the decision aid; c) a video contrasting a traditional patient education approach and a decision support approach in a clinical scenario d) role play using the decision support protocol; e) self and peer appraisal during role play and f) discussion about barriers and facilitators to integrating decision support into clinical practice. Use of a facilitator who provides face to face communication and uses a range of enabling techniques has been shown to have some impact on changing clinical practice [62].

Specific workshop objectives are that participants will:

- understand concepts of decisional needs, decision support, and decision quality,

- learn to use decision support tools,
- evaluate decision support skills, and
- analyze barriers and facilitators to implementing decision support in practice.

Performance feedback

Results of the decision quality scored transcripts of baseline simulated calls will be presented and discussed at the workshop. Participants will also be provided with evaluation tools based on the Decision Support Analysis Tool (DSAT) to self appraise their own and workshop peers' quality of decision support during the case studies and role play activities. As well, the facilitator will provide ongoing feedback from case studies and role plays during the workshop. The DSAT self-appraisal tool has been used to train nurses and medical residents in self-appraisal at the University of Ottawa, the Dartmouth Hitchcock Medical Center, and the US Health Dialogue call center.

Education outreach

Two weeks following the workshop intervention group participants will be scheduled for a personal academic detailing session with the workshop facilitator. Based on social marketing approaches educational outreach provides a focused opportunity to personalize learning and behavioral objectives, provide unbiased descriptions of research evidence and opinion leaders' positions, augment educational materials and reinforce positive behavior [63]. Academic detailing using brief, face-to-face interactions has shown promise for modifying physician and dentists practices [64,65] although one study reported initial resistance to the approach [66] and it had no effect as a single intervention [67].

The detailer will provide individualized information and resources, reinforce decision support behaviors, and help participants to identify opportunities for incorporating decision support behaviors into their practice. The one-to-one session will be scheduled at a mutually agreed time, will be conducted by telephone and should last about 15–30 minutes.

Outcome Measures

Primary Outcome Phase 2

Quality of Decision Support Skills will be measured with DSAT modelled on the ODSF and Ivey's Problem Solving Model [68]. The DSAT, with total possible score of 12, assesses the quality of decision support and consists of subscales measuring decision support and communication in a practitioner/patient dyad. The tool demonstrated adequate inter-rater reliability for scoring on both decision support skills (75%, kappa = 0.58) and communication skills (76%, Kappa = 0.68) when it was tested in

physician/patient dyads (n = 34 dyads). Construct validity was demonstrated when the scores were correlated to measures of patient and physician satisfaction[56] The DSAT also discriminates between trained and untrained nurses [33].

Secondary Outcomes Phase 2

Measures include:

- a knowledge test regarding decision support concepts;
- self assessment of decision protocol utility and helpfulness;
- behavioral intention to integrate decision support into clinical practice; and
- acceptability and utility of intervention components in the experimental group.

Analysis Plan

Primary Outcome Phase 2: Quality of nurses' decision support skills

1. Inter-rater reliability of DSAT scores; two raters, who are blind to group allocation, will independently score pre and post intervention simulated call audio tapes.
2. Primary analysis will be undertaken using a repeated measures ANOVA (baseline; post measures). For missing cases an 'intention to treat' approach will be used under the conservative assumption that no change would occur between pre and post testing. Additionally, the impact of missing cases on findings will be explored between groups to provide further direction for the analysis.

Secondary outcomes Phase 2

1. Descriptive measures (frequency; means; range) will describe participant characteristics and acceptability and utility of training intervention components.
2. Descriptive measures (frequency; means; range) of the TPB based survey eliciting behavioral intention to integrate decision support in practice and related attitudes, norms, and perceived control will be undertaken. Between group differences in intention to integrate decision support practices will be analyzed using a t test.
3. Data from qualitative open-ended questions using traditional content analysis techniques [69,70] with the TPB as an organizing framework will be undertaken. Thematic coding, followed by member checking to ensure trustworthiness of final themes, will be undertaken.

Discussion

This will be the first study to evaluate the impact of an educational intervention to improve the quality of deci-

sion support that practitioners provide to dying patients around place of care. This reproducible, portable intervention addresses a key policy mandate regarding choice for end of life care set out by health providers such as the Ontario Ministry of Health in Canada. This is a pragmatic trial with relatively inclusive entry criteria and we anticipate recruiting participants from across a spectrum of care sectors. As well, because we are bringing the intervention to participants in their home regions we are able to include participants who may be unable to access centrally held education due to time and distance pressures in their clinical setting. These features will improve the generalizability of the findings.

Expanding our understanding of how practitioners can best support palliative patients' decision making will help to improve the quality of end-of-life and care for patients and those who share their lives. If findings from this study show promise, a larger effectiveness trial assessing factors such as cost effectiveness, sustainability, and patient and system outcomes will be undertaken

Results will be disseminated via a brief summary prepared for policy makers, a communication flyer for participants, a technical report for the participating organizations, publication in refereed scientific journals, newsletters of palliative care and relevant clinician associations, presentations at scientific and clinical meetings, and clinical rounds. Findings will be available online through the websites of the Canadian Virtual Hospice, Canadian Institutes of Health Research (CIHR) Family Caregiving New Emerging Team, CIHR End-of-Life Care for Seniors New Emerging Team, and the CIHR/NCIC Strategic Training Program in Palliative Care Research.

Design Limitations

Using a similar design in a call center nurses project, contamination was prevented using the following strategies: a) using a private room for simulated calls; and b) requesting that nurses not share or discuss decision support resources or approaches with others. Many of the skills are quite novel (values clarification) and it is unlikely that skills will improve without the workshop and subsequent practice.

Recruitment response may yield an over representation of those more motivated to learn and adopt the intervention than the average adopter. However, this should not pose a threat to internal validity. Moreover, involving early adopters is considered a wise strategy in innovation diffusion [71].

Participants will not be not blinded to the simulated call and know their performance is being monitored. However the use of simulated callers is recognized as a rela-

tively reliable method for assessing professional performance, facilitates a standardized experience across participants, provides a clearer picture of decision support skills in general, is a more accurate measure of current practice compared to self-report or chart audit, and has been used widely [72-77].

The relative impact of each component of the intervention cannot be established with this design [40]. Feasibility constraints preclude a study design using a sequenced addition and evaluation of intervention components or assessing long term sustainability; however, recent studies suggest that evidence based education strategies may trigger long term practice change [78,79].

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

MAM is the initiator of the study and drafted the manuscript. AO'C contributed significantly to the design of the study. AO'C, DS and KGW are providing supervision and mentorship during the implementation of the study and analysis of study data and have contributed to manuscript preparation. All authors read and approved the final manuscript.

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Where the Dying Live: A Systematic Review of Determinants of Place of End-of-Life Cancer Care

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Cancer is the second-leading cause of death in the United States and Canada. About 1.5 million Americans will be diagnosed with cancer in 2009 and, despite increased survivorship, more than 1,500 people will die every day (American Cancer Society, 2008). In Canada, men have a 45% risk of developing cancer during their lifetimes, and women have a 40% risk (National Cancer Institute of Canada [NCIC], 2008). An estimated 29% of Canadian men and 24% of Canadian women will die from the disease (NCIC). Most will receive end-of-life (EOL) care in an institution despite a preference for home palliation (Cantwell et al., 2000; Murray, O'Connor, Fiset, & Viola, 2003; Stajduhar & Davies, 2005; Steinhäuser et al., 2000). This paradox has not been well explained; therefore, this article will investigate the *influencing factors that differentiate preferred and actual place of EOL care for patients with cancer.*

Factors affecting place of EOL care are under reported, limiting the provision of comprehensive, holistic, palliative care (Gomes & Higginson, 2006; Higginson & Sen-Gupta, 2000; Last Acts Palliative Care Task Force, 2002; Romanov, 2000). Increasing awareness of the practical, social, and psychological considerations affecting place of EOL care for patients with cancer would help clinicians and healthcare leaders develop relevant, responsive, evidence-based interventions to better meet the needs of EOL patients and their families. At the healthcare systems level, an enhanced understanding of the factors linked to place of EOL care for patients with cancer could enhance policy and decisions regarding resource allocation.

Establishing what is known about the determinants of place of EOL care for patients with cancer is a starting point. A number of narrative reviews regarding place of EOL care have been published (Grande, Addington-Hall, & Todd, 1998; Tang, 2000; Thomas, 2005); however, information regarding the quality of the studies, scope of the reviews, and potential selection bias is limited and restricts the use and generalizability of the reviews. Because no systematic reviews exclusively focused on patients with cancer and because the shelf life for systematic reviews directly relevant to clinical practice is

Purpose/Objectives: To describe the determinants of place of end-of-life (EOL) care for patients with cancer.

Data Sources: A systematic literature review of primary research studies (1997–2007) was conducted. Studies that investigated place of EOL care or identified place of EOL care in relation to outcomes were examined, their critical quality was appraised, and references were mapped.

Data Synthesis: Of the 735 articles identified, 39 (representing 33 studies) met inclusion criteria. Two main research designs emerged: large-scale epidemiologic reports and smaller descriptive studies. Findings suggest that factors related to the disease, the individual, and the care and social environment influence place of EOL care for patients with cancer. Social support, healthcare inputs (from services and programs and healthcare provider contact), and patient preferences were the most important factors.

Conclusions: Most patients with terminal cancer prefer home palliation; however, most die in an institution. The reasons are complex, with various determinants influencing decisions regarding place of EOL care.

Implications for Nursing: Findings may highlight evidence-based interventions to assist patients and families facing decisions regarding place of EOL care. A clearer understanding of factors that influence place of EOL care for patients with cancer could enhance healthcare policy and guide needs-based modifications of the healthcare system.

relatively short (Shojania, Sampson, Ansari, & Duce, 2007), a systematic review was conducted to identify which factors, under what circumstances, are associated with place of EOL care for patients with cancer. To reflect a more up-to-date context of EOL care, research focused on articles from 1997–2007. To provide insight about knowledge development related to place of EOL care, bibliometric analysis also was undertaken.

Methods

Theoretical Model for Study and Analysis

Gomes and Higginson (2006) modeled a network of influencing factors related to place of EOL care. In the model, variations in place of death are explained by

interactions among three primary characteristics: illness, individual factors, and environment. The model offers a practical means of mapping of a broad set of determinants to a variety of places of EOL care and was used to guide data abstraction, analysis, and results presentation.

Literature Search

Meta-study and -analysis techniques described by Egger and Smith (1998) and Egger, Smith, and Altman (2001) provided the general review methodology. A recognized search strategy from the Centre for Reviews and Dissemination (1996) was used to identify reports that either investigated place of EOL care or identified place of EOL care in relation to outcomes relevant to EOL care for patients with cancer. Inclusion criteria included primary published research (qualitative and quantitative), cancer diagnosis with cancer-related cause of death, reported outcomes including factors that affect place of EOL care, factors affecting place of terminal care stated by the authors or appearing from the published data to be an important element of the study findings, study data collected from 1997–2007, and studies written in English or French.

Previous EOL-related reviews have found that large-scale epidemiologic reports or descriptive, exploratory, and observational studies form the majority of the identified reports (Finlay et al., 2002; Franks et al., 2000; Goodwin et al., 2002; Higginson & Sen-Gupta, 2000; Thomas, 2005). Attrition, recruitment challenges, ethical concerns, and sample selection bias typically limit the use or appropriateness of randomized, controlled trials with EOL patients (Ahlner-Elmqvist, Jordhoy, Jannert, Fayers, & Kaasa, 2004; Goodwin et al.; Higginson & Sen-Gupta); therefore, a broad range of evidence was sought and study design was not an inclusion criteria.

Four bibliographic databases (MEDLINE®, EMBASE®, CINAHL®, and PsychINFO) were searched. Search terms were synonyms for *place of care*, *place of death*, or *placement*; *hospice*, *home*, *hospital*, *nursing home*, *institution*, or *residence*; *dying*, *terminal*, *terminally ill*, *palliative*, or *palliative care*; *terminal illness*, *cancer*, *oncology*, or *neoplasm*; and *demographic factors*.

Given that place of EOL care inquiry is diffusely distributed across broad topic areas such as patient-perceived burden, quality of life (QOL), healthcare services, and symptom management, traditional search protocols described by Greenhalgh and Peacock (2005) were supplemented. The current study's authors used snowball sampling by scrutinizing indexes of journals that contributed the most publications in the electronic search (e.g., *Palliative Medicine*, *Journal of Palliative Care*, *Cancer Nursing*) and scanned reference lists of retrieved articles. In addition, the authors asked experts to recommend relevant papers and were attentive to the possibility of serendipitous findings when searching other related research. Grey literature, generally consisting

of unpublished and unindexed reports that have not been peer reviewed (GreyNet, 2004), were not included because of Cook et al.'s (2001) findings on the minimal contributive value of grey literature to reviews.

Data Extraction and Quality Assessment

Papers were independently screened at three levels (titles, abstracts, full text). Ambiguous citations were retained for additional review, with disagreements resolved by consensus. Reports of a single study were logged as a single entity for data extraction. Two reviewers evaluated studies for validity, methodologic rigor, and relevance to the review's focus.

Papers selected for full-text review underwent quality assessment and content abstraction. Content was abstracted to a standardized tool used in previous systematic reviews (Joanna Briggs Institute, 2004). Critical quality appraisals were conducted independently by two reviewers using previously published quality assessment tools appropriate to specific study designs (Fain, 2004; Goodwin et al., 2002; Joanna Briggs Institute). Quality assessment scores were compared and consensus reached.

Meta-analysis was not attempted because of the heterogeneity among study designs, outcome measures, and findings. However, the included report findings were thematically synthesized and mapped to the Variations in Place of Care Model (Gomes & Higginson, 2006). Basic bibliometric analysis was undertaken to identify the state of knowledge development around place of EOL care. Publication counts, authorship frequency, and dissemination patterns were examined. Details about search strategy, selection decisions, quality assessments, and analysis are available upon request from the primary author.

Findings

Characteristics of Eligible Studies

The search revealed 735 potentially relevant reports. Ninety-four percent were identified via electronic search with an additional 45 reports added from hard-copy searches and colleague referrals. The final sample included 39 reports reflecting 33 different studies (see Figure 1).

The studies represent more than 35 million patients in 15 countries, mostly from Canada, the United States, and the United Kingdom. Considerable heterogeneity existed in study characteristics, such as design, population, sample size, and reported outcome measures. All studies had some weakness. Most common were selection bias, reliance on administrative data, limited use of validated measures, and participant attrition. Quality appraisal, based on included studies' published descriptions, varied considerably (quality scores ranged from 45%–93%). The most frequent gaps were in failing to state a guiding

Potentially relevant studies identified and screened for retrieval (N = 735)

- Papers identified in electronic search (n = 690)
- Papers identified in hand search (n = 45)

Excluded at title or abstract (N = 520)

- Duplicates (n = 63)
- Do not fit inclusion criteria (n = 451)
- Language (n = 6)

Reports retrieved for more detailed evaluation (N = 215)

Excluded after full review (N = 176)

- Do not meet inclusion criteria (n = 162)
- Unable to access (n = 14)

Reports included in the review (N = 39)

- Multiple reports of unique studies (n = 11)
 - Two published reports from a single study (n = 8)
 - Three published reports from a single study (n = 3)

Unique studies included in the review (N = 33)

Figure 1. Flow of Identified Studies Through Review

conceptual or theoretical framework, or in failing to state that ethics board approval had been obtained. Descriptive studies such as retrospective reviews, surveys, and smaller descriptive studies involving patients with a terminal illness, families, or care providers were the most prevalent, followed by large-scale epidemiologic reports. Two systematic reviews and one cluster randomized trial were identified. Figure 2 details the study designs of included reports.

Home was the most common reference point for studies. Several studies dichotomized place of EOL care as home versus nonhome. Hospital was the most frequently identified nonhome location, followed by hospice and nursing home.

Factors Related to Place of End-of-Life Care

Environmental factors were the most frequently identified determinants for place of EOL care, followed by individual and illness factors. Home, as a place of EOL care, was commonly related to personal characteristics, availability and intensity of home care and community-based services, caregiver factors, and preferences. Nonhome places of EOL care were commonly related to cancer diagnosis and symptom intensity, age, gender, and healthcare system factors. Specific results from the included studies are mapped in Table 1.

Environmental factors: Variables within the healthcare system were the most influential and consistently reported determinants. Characteristics of healthcare delivery systems affected place of EOL care, particularly community-based care. Presence of social support emerged as a strong consideration for home as a place of EOL care. The importance of and connections to informal caregivers were striking for home and slightly less so for nonhome locations; geographic influences were variable.

Individual factors: Patient and caregiver views emerged as important determinants. However, a wide range of social determinants mitigated place of EOL care for patients and caregivers. Factors could either enhance or impair decisions regarding place of EOL care, depending on patient characteristics and circumstances. Overall, the evidence pointed to the need for individualized discussions based on patient preferences and context.

Illness factors: A wide range of illness-related factors affect place of care for patients nearing EOL. Overall health, function status, and complexity of care needs were common considerations for patients receiving EOL care in the included studies.

Mapping the Evolution of the Field From 1997–2007

MEDLINE yielded the most electronic citations, followed by EMBASE and CINAHL. Included reports were published in 19 journals. Thirty-four of 39 reports (87%) focused on place of EOL care and were published in the last five years of the review period (2002–2007). The most prolific year was 2005, with 10 reports. Articles had an average of 3.76 authors per paper; six individuals had authorship on three or more included reports, with one having authorship on five. Within the data set, palliative care journals were the most frequent publication venue (see Table 2). Of the papers where the discipline of the first author was identified, nursing was the most frequent, followed by medicine. The most common affiliation of first authors was reported as a university. First authors were more likely to come from the United Kingdom, followed by the United States and Scandinavia (see Figure 3).

Descriptive Retrospective Reviews

Back et al., 2005; Carlsson & Rollison, 2003; Chvetzoff et al., 2005; Grande et al., 2003; Howat et al., 2007; Izquierdo-Porrera et al., 2001; Maida, 2002; Tang, 2002

Surveys

Cantwell et al., 2000; Choi et al., 2005; Fukui et al., 2003; Gyllenhammar et al., 2003; Kessler et al., 2005; Tang, 2003a; Tang et al., 2005

Small Descriptive Studies

Ahlner-Elmqvist et al., 2004; Hirai et al., 2006; McCall & Rice, 2005; Murray et al., 2003; Tang, 2003b; Tang & McCorkle, 2003; Teirnan et al., 2002; Thomas, 2005; Thomas et al., 2004

Large-Scale Epidemiologic Reports

Aabom et al., 2005; Bruera et al., 2002, 2003; Burge et al., 2003; Fiory et al., 2004; Fukui et al., 2004; Gatrell et al., 2003; Lackan et al., 2004; Lock & Higginson, 2005; Neurel et al., 2005; Tang, 2003b

Cluster Randomized Trial

Jordhoy et al., 2000, 2003

Systematic Reviews

Gomes & Higginson, 2006; Higginson & Sen-Gupta, 2000

Figure 2. Reports Categorized by Study Designs

Table 1. Factors Related to Home, Nonhome, Hospital, Hospice, and Nursing Home Venues for End-of-Life Care

Venue	Illness Factors	Individual Factors	Environmental Factors
Home	Tumor related • Solid tumors (Howat et al., 2007; Maida, 2002; Tang, 2002) General health • Higher functional status across trajectory or dying phase (Fukui et al., 2003, 2004) • Less complex care needs (Fukui et al., 2004; Thomas, 2005) • Longer survival (Tang, 2003a) • Low functional status (Chvetzoff et al., 2005; Gomes & Higginson, 2006; Tang, 2002, 2003b) • Pain on admission to homecare service (Tang, 2002)	Demographic variables • Cultural concerns (Tang et al., 2005) • Home ownership (Maida, 2002) Personal variables • Attitude toward healthcare providers (Tang, 2003b; Thomas et al., 2004; Thomas, 2005) • Being informed (Gyllnehammar et al., 2003) • Female (Tang, 2003a) • Male (Carlsson & Rollison, 2003; Jordhoy et al., 2000) • Older age (Fukui et al., 2003, 2004) • Past experience with death (McCall & Rice, 2005; Thomas et al., 2004) • Perceived quality of life (Tang, 2003b) • Personal preference (Gomes & Higginson, 2006; Gyllnehammar et al., 2003; Higginson & Sen-Gupta, 2000; Hirai et al., 2006; McCall & Rice, 2005; Tang, 2003a, 2003b; Teirman et al., 2002; Thomas et al., 2004) • Younger age (Bruera et al., 2003; Howat et al., 2007; Jordhoy et al., 2000)	Healthcare input • Culture of practice (Thomas 2005) • Distance to services (Carlsson & Rollison, 2003; Howat et al., 2007; Jordhoy et al., 2000; Maida, 2002; Tang, 2003b) • Homecare use (Gomes & Higginson, 2006; Howat et al., 2007; Jordhoy et al., 2000; Maida, 2002; Tang, 2003b) • Intensity/type of home care (Ahlin-Elmqvist et al., 2004; Fukui et al., 2003; Gomes & Higginson, 2006; Grande et al., 2003; Howat et al., 2007; Jordhoy et al., 2000; Maida, 2002; Tang, 2002; Tang 2003a; Tang & McCorkle, 2003) • Less hospitalization (Fukui et al., 2004; Tang, 2002, 2003a; Tang & McCorkle, 2003) • Multidisciplinary team support/visits (Chvetzoff et al., 2005; Fukui et al., 2003, 2004; Jordhoy et al., 2000; Tang 2003b; Thomas, 2005) • Rural (Choi et al., 2005; Gomes & Higginson, 2006) • Service infrastructure (Jordhoy et al., 2000; Thomas, 2005) Social support • Caregiver factors (Cantwell et al., 2000; Fukui et al., 2003, 2004; Maida, 2002; Tang, 2003a, 2003b; Tang & McCorkle, 2003; Tang et al., 2005) • Caregiver support (Fukui et al., 2003, 2004; Izquierdo-Porrera et al., 2001; McCall & Rice, 2005; Tang, 2003b; Tang et al., 2005; Thomas et al., 2004; Thomas, 2005) • Financial support (Bruera et al., 2002; Choi et al., 2005; Thomas, 2005) • Living with someone (Carlsson & Rollison, 2003; Fukui et al., 2003; Gomes & Higginson, 2006; Gyllnehammar et al., 2003; Jordhoy et al., 2000; Thomas et al., 2004) • Married (Aabom et al., 2005; Bruera et al., 2003; Choi et al., 2005; Fukui et al., 2003; Howat et al., 2007; Jordhoy et al., 2000) Macrosocial factors • Historical trends (Gomes & Higginson, 2006)
Nonhome	Tumor related • Longer time from diagnosis to death (Burge et al., 2003) • Nonsolid tumors (Aabom et al., 2005; Bruera et al., 2002, 2003; Gatrell et al., 2003; Gomes & Higginson, 2006; Lock & Higginson, 2005; Maida, 2002) • Palliative radiation (Burge et al., 2004) • Solid tumors (Lackan et al., 2004; Lock & Higginson, 2005) • Short survival (Aabom et al., 2005) General health • Comorbidities (Grande et al., 2003; Gyllnehammar et al., 2003; Izquierdo-Porrera et al., 2001)	Demographic variables • Higher education (Gatrell et al., 2003; Lackan et al., 2004) • Higher social class (Kessler et al., 2005; Lackan et al., 2004) • Lower social status (Gatrell et al., 2003) Personal variables • Ethnicity (Bruera et al., 2002, 2003; Fiory et al., 2004; Lackan et al., 2004) • Female (Burge et al., 2003; Carlsson & Rollison, 2003; Jordhoy et al., 2000; Thomas et al., 2005) • Male (Bruera et al., 2003; Neurel et al., 2005) • Older age (Burge et al., 2004; Gatrell et al., 2003; Jordhoy et al., 2000, 2003; Neurel et al., 2005)	Healthcare input • Admitted to palliative care program (Burge et al., 2003) • Homecare agency affiliation with hospital (Fukui et al., 2003) • Nonacute care setting (Back et al., 2005) • Previous home care (Jordhoy et al., 2000) • Previous experience (Higginson & Sen-Gupta, 2000) • Prior enrollment in managed care (Lackan et al., 2004) • Proximity to hospital (Bruera et al., 2003; Gatrell et al., 2003; Kessler et al., 2005) • Rural (Burge et al., 2003) • Visiting general practitioners and nurses (Aabom et al., 2005) Social support • Active caregiver/support seeking (Kessler et al., 2005) • Caregiver attitude/anxiety/ability (Kessler et al., 2005; Tang & McCorkle, 2003) • Living alone (Carlsson & Rollison, 2003) • Married (Lackan et al., 2004) • Not living with spouse (Jordhoy et al., 2000, 2003) • Practical concerns (Tang et al., 2005) • Trust relationship with providers (Tang, 2003a)

(Continued)

Table 1. Factors Related to Home, Nonhome, Hospital, Hospice, and Nursing Home Venues for End-of-Life Care (Continued)

Venue	Illness Factors	Individual Factors	Environmental Factors
Nonhome (continued)	- Low functional status (Jordhoy et al., 2000) - Poor global overall health (Jordhoy et al., 2000, 2003) - Symptoms (Howat et al., 2007; Jordhoy et al., 2000; Teirman et al., 2002) - Weight loss (Izquierdo-Porrera et al., 2001)	- Perceived burden (Murray et al., 2003) - Perceived safety (Kessler et al., 2005) - Tang, 2003a; Tang et al., 2005) - Poor function (Jordhoy et al., 2000) - Younger age (Gatrell et al., 2003; Kessler et al., 2005; Lackan et al., 2004; Neurel et al., 2005)	Macrosocial factors - National and community policies (Thomas et al., 2004) - Regional trends (Neurel et al., 2005)
Hospital	Tumor related - Nonsolid tumors (Aabom et al., 2005; Bruera et al., 2002, 2003; Gatrell et al., 2003; Gomes & Higginson, 2006; Maida, 2002; Neurel et al., 2005) - Solid tumors (Lackan et al., 2004; Lock & Higginson, 2005) General health - Palliative radiation (Burge et al., 2003) - Short survival (Aabom et al., 2005) - Symptom control (Howat et al., 2007; Teirman et al., 2002) - Weight loss and comorbidities (Izquierdo-Porrera et al., 2001)	Demographic variables - Higher education (Gatrell et al., 2003; Lackan et al., 2004) - Higher social class (Kessler et al., 2005; Lackan et al., 2004) - Lower social status (Gatrell et al., 2003) Personal variables - Ethnicity (Bruera et al., 2002, 2003; Fiory et al., 2004; Lackan et al., 2004) - Male (Bruera et al., 2003; Neurel et al., 2005) - Older age (Gatrell et al., 2003) - Women living alone (Carlsson & Rollison, 2003) - Younger age (Gatrell et al., 2003; Kessler et al., 2005; Lackan et al., 2004)	Healthcare input - Geographic proximity (Bruera et al., 2003; Gatrell et al., 2003; Kessler et al., 2005) - Previous experience (Higginson & Sen-Gupta, 2000; Lackan et al., 2004) - Prior enrollment in managed care (Lackan et al., 2004) Social support - Active caregiver information/support seeking (Kessler et al., 2005) - Caregiver attitude/anxiety (Kessler et al., 2005) - Homecare agency affiliation with hospital (Fukui et al., 2003) - Married (Lackan et al., 2004) - Trust relationship with providers (Tang, 2003a) Macrosocial factors - Regional trends (Neurel et al., 2005)
Hospice	Tumor related Solid tumors (Lackan et al., 2004; Lock & Higginson, 2005)	Demographic variables - Higher education (Gatrell et al., 2003; Lackan et al., 2004) - Higher social class (Kessler et al., 2005; Lackan et al., 2004) - Non-Hispanic (Lackan et al., 2004) Personal variables - Living alone (Carlsson & Rollison, 2003) - Younger age (Gatrell et al., 2003; Kessler et al., 2005; Lackan et al., 2004)	Healthcare input - Geographic proximity (Gatrell et al., 2003; Kessler et al., 2005) - Prior enrollment in managed care (Lackan et al., 2004) - Previous experience (Higginson & Sen-Gupta, 2000) Social support - Active caregiver information/support-seeking (Kessler et al., 2005) - Married (Lackan et al., 2004)
Nursing home	Tumor related - Solid tumors (Lock, 2005) General health - Low functional status (Jordhoy et al., 2000, 2003) - Poor global overall health (Jordhoy et al., 2000, 2003) - Symptoms (Jordhoy et al., 2000)	Personal variables - Female (Gatrell et al., 2003; Jordhoy et al., 2000) - Older (Gatrell et al., 2003; Jordhoy et al., 2000, 2003) - Poor cognitive/social functioning (Jordhoy et al., 2000)	Healthcare input - Nonproximity to a hospital (Gatrell et al., 2003) - Previous homecare functioning (Jordhoy et al., 2000) Social support - Not living with spouse (Jordhoy et al., 2000, 2003)

Table 2. Publication Venue of Included Reports

Characteristic	n
Specialty journals (N = 26)	
Palliative care	15
Oncology	6
Symptom specific	5
General medicine or nursing journals (N = 13)	
Medicine	7
Nonspecific	5
Nursing	1

Discussion

The evidence in this review comes from several different countries, cultures, and clinical settings, confirming that place of EOL care is a common concern. Overall, findings from the review reinforce that individual, contextual, and practical considerations shape how people deal with place of EOL care and how healthcare systems respond. Findings from this review have major policy implications for decision makers interested in reforming EOL care for patients with cancer and for clinicians in their daily practice.

Patient-centered coordinated care is pivotal to quality of EOL care (Bircumshaw, 1993). Findings suggest that illness factors and characteristics of the healthcare system, rather than patient preferences and needs, often drive decisions about place of EOL care. Patient preferences have been linked to psychological and social health as much as to physical health (Sherbourne, Strum, & Wells, 1999); therefore, patient-centered EOL care planning should incorporate strategies to elicit patient preferences in a timely and effective manner.

Delays in identifying transition points in goals of care, such as a changing focus from curative to supportive approaches, can limit patients' opportunities to benefit from such approaches. Prognostic uncertainty, funding issues, lack of relevant expertise, and boundary issues between providers and services have been identified as troublesome issues (Addington-Hall, Fakhoury, & McCarthy, 1998). In response, several researchers (Fins et al., 1999; Lynn, 2005), policy makers (Romanov, 2000; World Health Organization, 2006), and professional organizations (Canadian Strategy on Palliative and End-of-Life Care Working Group, 2005; Institute of Medicine, 2001) advocate models that combine life-prolonging care with palliative approaches. Typically, within these models, disease-modifying approaches that focus on QOL and respect for patient autonomy and choice begin at diagnosis and continue throughout the illness trajectory.

As cancer is increasingly considered a chronic condition, principles from chronic condition management models (Wagner et al., 2005), which acknowledge the patients as experts in their situations and emphasize a patient/practitioner partnership, may be more conducive to

meeting the needs and preferences of patients and families considering place of EOL care (Murray, 2007). A randomized, controlled trial by Lorig et al. (1999) supported this philosophy when a chronic condition management approach was used with patients diagnosed with stroke, arthritis, heart disease, or lung disease.

The findings also reinforce that place of EOL care emerges from a complex set of relations and preparations that occur when a patient is diagnosed with terminal cancer. Arrangements and characteristics of healthcare services emerge as an important influence on place of EOL care. The importance of social and healthcare system factors is consistent with other non-cancer-specific reviews of place of EOL care (Gomes & Higginson, 2006; Higginson & Sen-Gupta, 2000). Other studies confirm that patients consider trust in their healthcare team, avoidance of unwanted life support, effective communication, continuity of care, having time with loved ones, and having a sense of completing life tasks to be the most important elements of quality EOL care (Heyland et al., 2006; Singer, Martin, & Kellner, 1999). Given the pressure to strengthen the links among evidence, policy, and practice, policy makers may use these findings to plan healthcare systems that are responsive to patient preferences, circumstances, and needs.

Many studies used home as the primary reference point. The current review's findings suggest that place of EOL care is less important than how patients experience that care. Modeling the complexities and interconnections between determinants of place of EOL care for patients with cancer is difficult. The authors' approach was to abstract the details, make a number of simplifications, and hope the resulting low-resolution model would capture the essence of the underlying dynamics. Additional qualitative studies may provide

Discipline

Not specified (n = 18)
Nursing (n = 11)
Medicine (n = 10)

Affiliation

University (n = 25)
Clinical practice (n = 11)
Other (n = 3)

Country of Study's Origin

United Kingdom (n = 10)
United States (n = 8)
Scandinavia (n = 6)
Canada (n = 5)
Taiwan (n = 4)
Japan (n = 3)
France (n = 1)
South Korea (n = 1)
Australia (n = 1)

Figure 3. Demographic Characteristics of Studies' First Authors

new insights; however, they will not capture the tension between what happens at the level of the individual and what is transferable to other patients and situations.

A quality EOL decision is consistent with an informed patient's values and preferences, is acted upon, and results from shared decision making where patients are involved in the process, are informed of options and the uncertainty of outcomes, participate in the actual decision to the extent desired, and are satisfied with the process (Levy & Curtis, 2006; Murray, Miller, Fiset, O'Connor, & Jacobsen, 2004). Given this definition, place of EOL care is not a measure of a quality decision; therefore, healthcare providers should be cautious about presenting death at home as the gold standard. Favoring one location over another may disregard the multiplicity of factors considered by patients, create unrealistic expectations, and not benefit patients or healthcare service planning. Clinicians should be mindful to think in therapeutic terms rather than geographic landscapes.

Another finding of this review is that preferences matter. Several studies showed that stating and sharing preferences with others influenced place of EOL care. When patients and caregivers acknowledge the possibility of death and discuss options in an open, sensitive manner, the chances of dying in a preferred location increase. Although patients are frequently thinking about place of EOL care (Voltz, Akabayashia, Reese, & Hans-Martin, 1998), clinicians may avoid raising the topic (Chang, Hwang, Feueman, & Kasimis, 2000; Higginson & Romer, 2000; Zhukovsky, Abdullah, Ricardson, & Walsh, 2000), feel unprepared to engage in palliative conversations (Docherty, Miles, & Brandon, 2007), and often lack skills and confidence in helping patients in nondirective ways (Murray, Fiset, & O'Connor, 2004). In addition, families and practitioners often misjudge patients' wishes regarding EOL care (Ditto et al., 2001; Miura et al., 2006); therefore, advance-care planning discussions should include a range of goals considered important to patients. Opportunities for skills development and practice in conversations about death and dying should be included in professional pre- and postlicensure education programming (Epstein & Street, 2007; Fitch, 2007).

Bibliometric Analysis

Preliminary bibliometrics were conducted. Analysis of publication patterns, frequency, and author contribution citations provides a proxy measure of how knowledge is developed and disseminated within and outside a field of study (Estabrooks, Winther, & Derkson, 2004). The bibliometric analysis showed that studies were predominantly published in palliative care journals. Given that few patients at EOL receive specialty palliative care, implications for knowledge exchange are evident (Carstairs & Beaudoin, 2000). Gaining access to a wider audience of healthcare professionals is necessary to ensure that emerging strategies to address place

of EOL care are relevant and meaningful. Knowledge translation encompasses both knowledge creation and application. Using planned action theories and frameworks and proven knowledge-transfer strategies could foster a broader understanding of the determinants of place of EOL care and the subsequent implications.

Limitations

Completeness of the literature search, language limitations, and inconsistencies in terminology and idiosyncrasies in database indexing influenced the final data set and ultimately limited the review. Study design diversity and outcome measures made it impossible to synthesize findings with meta-analysis techniques or to fully capture the impact of individual determinants on place of EOL care. However, efforts to conduct a transparent, comprehensive review characterized by careful searching, multiple levels of critical appraisal, reviewer reflexivity, and implementation of quality control mechanisms to minimize bias and error represent a useful contribution to the knowledge about determinants of place of EOL cancer care.

Conclusion

Home, as a place of EOL care, often is preferred by patients. However, the presence of caregivers and contact patterns with healthcare services influence place of EOL care. The findings of this article suggest that home versus nonhome as the preferred site for EOL care may not capture the multiple determinants affecting place of EOL care. This review contributes to the discourse about the state of the evidence from 1997–2007, how the published evidence is disseminated, and the salient methodologic implications that affect the knowledge related to place of EOL care. This review strengthens the understanding of place of EOL care and may lead to the identification of best practices to meet the needs of patients who entrust healthcare professionals with their care; the ultimate *raison d'être* of palliative care research and praxis.

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