

TITLE: Patient- and Family-Centered Care Initiatives in Acute Care Settings: A Review of the Clinical Evidence, Safety and Guidelines

DATE: 31 August 2015

CONTEXT AND POLICY ISSUES

Patient- and family-centered care is an approach that includes patients and their families in decision-making processes and the delivery of health care. It is believed greater patient participation can improve patient satisfaction and health outcomes.¹ Family-centered care is also patient-centered care that involves and supports family members as caregivers.² Within the context of patient participation and involvement, the patient is respected and treated as an autonomous individual, and care is based on patient individual physical and emotional needs.³ In their relationship with health professionals, a genuine patient-clinician relationship and open communication of knowledge and professional expertise are required.³ The Picker Institute outlines eight principles of patient-centered care including: respect for patients' values, preferences, and express needs; coordination and integration of care; information and education; physical comfort; emotional support and alleviation of fear and anxiety; involvement of friends and family; continuity and transition; and access to care.⁴

The delivery of this model of care may take place in institutional settings as well as in the community. In an acute care settings, patient- and family-centered care may be delivered in emergency departments, intensive care units (ICUs), palliative care units, and neonatal or pediatric units, to name a few. Because the effectiveness of this care model in acute care settings is unclear, the present review was undertaken to explore the clinical effectiveness and guidelines for patient- and family-centered care in acute care settings.

RESEARCH QUESTIONS

1. What is the clinical evidence regarding formalized patient- and family-centered care initiatives to support improved service delivery in acute care settings?
2. What is the evidence regarding the safety of structured formalized patient- and family processes or initiatives to support improvements and collaborative practice in acute care settings?

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3. What are the evidence-based guidelines associated with formalized patient- and family-centered care initiatives to support improved service delivery in acute care settings?

KEY FINDINGS

Eight systematic reviews and three randomized controlled trials addressed patient and family-centered care in an acute care setting. While all eight systematic reviews and two of the three randomized trials suggest potential impacts of this model of care on a wide range of health and health care system outcomes, much of the presented evidence is qualitative in nature or has methodological limitations due to lack of blinding or external validity issues of controlled studies, thus making empirically-based conclusions difficult. Data on harms are also limited as are the number of evidence-based guidelines. More high quality empirical research in this area is required.

METHODS

Literature Search Strategy

A limited literature search was conducted on key resources including PubMed, The Cochrane Library, University of York Centre for Reviews and Dissemination (CRD) databases, ECRI, Canadian and major international health technology agencies, as well as a focused Internet search. Methodological filters were applied to limit retrieval to health technology assessments, systematic reviews, meta-analyses, randomized controlled trials, and guidelines. Where possible, retrieval was limited to the human population. The search was also limited to English language documents published between January 1, 2010 and July 31, 2015.

Selection Criteria and Methods

One reviewer screened citation titles and abstracts and selected studies for further review. The selection criteria presented in Table 1 were then applied to the potentially relevant full-text articles.

Population	<ul style="list-style-type: none"> • Adult patients in acute care settings (e.g., hospitals); • Families of adult patients who are in acute care settings
Intervention	<ul style="list-style-type: none"> • Formalized family and patient focused initiatives; • Quality improvement initiatives and/or quality improvement interventions that promote feedback sharing (e.g. patient and family advisory councils, proactive patient rounding, patient experience advisors, patient panels, or patient decision aids)
Comparator	<ul style="list-style-type: none"> • Standard of care (no patient- or family-centered initiatives or interventions); • Any patient- or family-centered initiatives or interventions; • No comparator
Outcomes	<ul style="list-style-type: none"> • Clinical effectiveness <ul style="list-style-type: none"> ○ Consumer driven changes in care (care improvements and/or changes as a result of patient or family input) ○ changes to clinical service delivery

	<ul style="list-style-type: none"> ○ patient and family satisfaction ○ feedback provision (by patients and family) ● Patient safety outcomes (e.g., but no limited to, to reduce falls, better medication management, fewer medications errors) ● Guidelines
Study Designs	Health technology assessments, systematic reviews, meta-analyses, randomized controlled trials, evidence-based guidelines.

Exclusion Criteria

Articles were excluded if they did not meet the selection criteria described in Table 1, if they were duplicate studies, or if they were published prior to 2010. Articles that did not meet minimum requirements for systematic reviews, or guidelines that did not clearly describe their methodology or that were not evidence-based were excluded.

Critical Appraisal of Individual Studies

Included systematic reviews were appraised using the AMSTAR,⁵ randomized trials were appraised using and instrument developed by Downs and Black,⁶ and guidelines were assessed using the AGREE II instrument.⁷ A descriptive summary of the strengths and limitations of each of the included reports was provided.

SUMMARY OF EVIDENCE

Quantity of Research Available

A total of 523 citations were identified in the electronic literature search. From these 495 citations were excluded and 28 potentially relevant reports were retrieved for further assessment. Six potentially relevant reports were identified in the grey literature. From these 34 reports, 20 were excluded either because the intervention, outcomes or setting were not relevant (n=13) or because it was the wrong publication type (n=7). A total of 14 reports were included in this review. A PRISMA flowchart of the study selection process is provided in Appendix 1.

A listing of reports that did not meet the inclusion criteria for systematic reviews or evidence-based guidelines are provided in Appendix 5.

Summary of Study Characteristics

The study characteristics have been summarized in Tables A2.1 to A2.3 of Appendix 2.

Study Designs

The evidence retrieved includes eight systematic reviews,^{2,8-14} three randomized controlled trials,¹⁵⁻¹⁷ and two evidence-based guidelines.^{4,18}

Among the eight systematic reviews, Desai et al. (2015)⁸ included 16 randomized control trials (RCTs) that were published between 2001 and 2012, Pringle et al. (2015)⁹ included 33 studies (RCTs, observational studies, qualitative studies) that were published between 2000 and 2014, Tan et al.(2015)¹⁰ included three qualitative studies published in 2010 and 2011, Cypress et al.

(2012)² included 19 reports (RCTs, quasi-experimental studies, observational studies, qualitative studies, mixed methods, quality improvement reports, anecdotal notes) published between 1988 and 2010, Fawole et al. (2012)¹¹ included 20 prospective controlled studies published between 2000 and 2011, Flynn et al. (2012)¹² included five studies (RCTs and observational studies) published between 1990 and 2010, Kryworuchko et al. (2012)¹³ included four RCTs published between 1992 and 2005, and Scheunemann et al. (2011)¹⁴ included 21 studies (RCTs and non-randomized intervention studies) published between 1995 and 2010.

One evidence-based guideline¹⁸ was published by Cancer Care Ontario (CCO) in 2015 and is intended for patients undergoing cancer therapy. This guideline is an endorsement with adaptation of an existing guideline published by the National Institute for Health and Care Excellence (NICE) in the UK (Clinical guidance 138, 2012)¹⁹ which is also included in this report. The Registered Nurses Association of Ontario (RNAO) guideline (2015)⁴ for person and family-centered care is based on a systematic review of the literature and uses an adapted version of the Scottish Intercollegiate Guidelines Network levels of evidence to grade its recommendations. The guideline published by NICE¹⁹ is based on a systematic review and is intended to improve the experience of care for adults using all National Health Service (NHS) services, including acute care.

Countries of Origin

Three^{4,13,18} of the reports originated in Canada, five^{2,8,11,14,16} were from the United States, five^{9,12,15,17,19} were from European countries, and one¹⁰ was from Singapore.

Patient Populations

Twelve^{2,4,8-16,19} reports were relevant to adult patients, six^{2,4,8,11,12,17} reports were relevant to pediatric patients, and four^{2,4,12,17} related to family members of patients.

A summary of the groups studied in each of the included systematic reviews is provided in Table 2.

Table 2: Characteristics of patient groups in studies included in systematic reviews

Author	Studies	Patient Group	Patient age group		Subjects of interventions		
			Adult	Pediatric	Patients	Family	Health care professionals
Desai ⁸	16	Various	X	X		X	
Pringle ⁹	33	Palliative care	X		X	X	X
Tan ¹⁰	3	Oncology	X		X		
Cypress ²	19	Various	X	X		X	
Fawole ¹¹	20	Various	X	X	X	X	
Flynn ¹²	5	Various - ED	X	X	X	X	X
Kryworuchko ¹³	4	ICU – life support	X		X	X	X
Schuenemann ¹⁴	21	ICU	X		X	X	

ED: emergency department; ICU: intensive care unit

All eight reports included studies with adult patients and four^{2,8,11,12} also included studies with pediatric patients. All reviews except one¹⁰ included studies where the family members were the subjects of the intervention, and all but one²⁰ review included studies where the subjects of the

interventions were the patients themselves. Three reports^{9,12,13} included studies where the subjects of the intervention were health care professionals.

Settings

Settings included hospital acute care wards,^{2,4,8-11,15,16,18} emergency departments,^{8,12} and ICUs,^{11,13,14,17} specifically.

Interventions and Comparators

The intervention in each of the reports was person- or family-centered care or its elements among which were included transition processes,⁸ a patient navigation program,¹⁰ family presence on medical rounds,² communication with patients and/or families,^{11,14,17} shared decision-making,^{12,13} and individualized action plans.¹⁶

The comparator was standard care in five reports^{2,13,15-17} and was not explicitly stated in six.^{8-12,14} Standard care was generally not well described in the included studies.

Outcomes

Outcomes included patient satisfaction,^{2,8,12,16} patient experience,^{2,10} functional assessments,⁸ patient preferences,^{2,12} health related quality of life,^{8,13,15,17} communication,^{12,13,16} missed work or school days,⁸ follow-up with primary care,^{8,12,16} medication adherence,^{8,16} health care utilization,^{8,11-14} impact on dignity,⁹ readmission rates,^{12,15,16} and mortality.¹⁵

Summary of Critical Appraisal

A critical appraisal of the included studies is provided in Tables A3.1 to A3.3 in Appendix 3.

The eight systematic reviews were generally well-conducted and included a priori study design, duplicate study selection, a comprehensive literature search, and provided the characteristics of the included studies. The documentation and use of the scientific quality of the included studies was unclear in six reports.⁹⁻¹⁴ The study by Desai et al⁸ included studies that met criteria for Centre for Evidence-Based Medicine Levels 2 to 4. The study by Tan et al.⁴ used the Joanna Briggs Institute Qualitative Appraisal and Review Instrument and rated two of the included papers to be of high quality (8 out of 10) and one paper to be of moderate quality (6 out of 10). Duplicate study selection or extraction was unclear in four reports,^{2,8,9,14} and a list of excluded studies was also not provided in six.^{2,8,9,11,12,14}

The three randomized trials¹⁵⁻¹⁷ were generally well-conducted with regard to statement of objectives, description of outcomes, description of patient characteristics, interventions, confounders, and reporting, however, all three were unable to blind subjects to the intervention and blinding of the outcome assessors was also unclear in two^{15,17} studies however one study¹⁶ used research assistants that were blind to the study arm and hypotheses to collect patient-reported outcomes 14 days after discharge. Randomization procedures appeared appropriate in all three studies however concealment of allocation was unclear in one study.¹⁷ The external validity of all three studies was also questionable because of high rates of exclusion and patients declining to participate prior to randomization, as well as the fact that two studies^{16,17} were conducted at single centers which may not be representative of the settings at which patients may receive care. None of the trials explicitly reported sample size calculations

however two^{15,16} of the three reported statistically significant findings, and the findings in the third trial¹⁷ were the same in both treatment groups. None of the three trials reported adverse events.

Three evidence-based guidelines^{4,18,19} were critically appraised. The guideline published by Cancer Care Ontario (CCO)¹⁸ was an endorsement and adaptation of an existing guideline¹⁹ that was not intended specifically for cancer patients and that is also reviewed in this report. This guideline clearly stated its objectives, applicable population, target users, conducted a systematic review and quality appraisal of the evidence, and was subjected to external review. Explicit links between recommendations and evidence were not provided. The guideline published by the Registered Nurses Association of Ontario (RNAO)⁴ was based on systematic review and did not have any major limitations however it did not clearly articulate its research questions or consider potential resource implications of its guidance. The guideline published by NICE¹⁹ was based on a systematic review and was of high quality however monitoring and audit criteria were not provided. It was unclear if the content of any of the three guidelines were influenced by their funding bodies. None of the three guidelines were exclusively intended for an acute care setting.

Summary of Findings

The study findings are tabulated in Tables A4.1 and A4.2 of Appendix 4.

What is the clinical evidence regarding formalized patient- and family-centered care initiatives to support improved service delivery in acute care settings?

The review of 16 studies by Desai et al.⁸ reported that family discharge education was associated with better health outcomes compared with control groups, including lower presence of cough at two weeks (13% vs 30%, $P < 0.05$), statistically significantly lower medication name, dosing, and preparation error rates at 12 days, lower non-adherence rates (9.3% vs 38%, $P < 0.001$), higher return to baseline health status at four weeks (82% vs 71%, $P < 0.05$), and a higher rate of follow-up visits post-discharge at four weeks (77% vs 51%, $P < 0.001$). Quality of transition (odds ratio [OR] 2.36, 95% confidence interval [CI] 2.06 to 5.92), knowledge of follow-up plan (99% vs 87%, $P < 0.001$) and of medications (96% vs 87%, $P < 0.01$) at 2-4 weeks post-discharge, as well as patient satisfaction at two weeks (83% vs 75%, $P < 0.001$) were also improved.

Pringle et al.⁹ (33 studies) researched the evidence for the health care settings in which dignity was likely to be violated and discussed models of patient-centered care as a means by which to meet the needs of patients in an acute hospital setting. They concluded that staff need adequate training to provide dignified and person-centered end-of-life care.

A qualitative systematic review by Tan et al.¹⁰ reviewed three papers, and identified three synthesized findings that reflect the experiences of patients with cancer who were exposed to patient navigation programs, specifically, emotional empowerment of patients through the presence of patient navigators through the continuum of cancer care; knowledge empowerment of patients by having the same understanding of treatment goals and plans of the health care team; and continuity of care.

Cypress et al.² reviewed 19 studies and reported that family presence on rounds may lead to better health outcomes for patients as well as improved satisfaction for patients, family members, and health care staff. Positive family member outcomes included positive view of

family inclusion, family satisfaction with family member's care, positive view of participation in parenting role, better communication and information with inclusion on rounds, opportunity to offer input, no feelings of privacy violation, increased feelings of inclusion and respect, and a positive parental attitude toward physicians. Some potential negative outcomes included expression of concerns about privacy and information dissemination, and potential for increased parental confusion and anxiety.

A systematic review 20 papers on communication quality improvement¹¹ reported improvements in health care utilization (between 50% and 100% of studies reviewed, and depending on the intervention) and patient or family satisfaction (22% of studies).

Flynn et al.¹² reviewed five studies and reported that decision support interventions (DSIs) were associated with knowledge and satisfaction with care, preferences for involvement, and engagement in decision-making. A reduction in health care utilization was also demonstrated with two interventions in patients with acute coronary syndrome.

Kryworuchko et al.¹³ did not find evidence for improved communication with shared decision-making in their review of four randomized controlled trials. None of the included studies measured decision quality. There were no between group differences in mortality in any of the included studies, One of the included studies reported decreased post-traumatic stress disorder symptoms, decreased symptoms of anxiety, and symptoms of depression in family members. The impact on intensive care unit length of stay was variable.

Schuenemann et al.¹⁴ reviewed 16 interventions in 21 studies and reported that printed information, palliative care or ethics consultation, or regular structured communication had a positive impact on family distress, comprehension, the use of intensive treatments, as well as length of hospital stay..

The Fors et al.¹⁵ trial of person-centered care after treatment for acute coronary syndrome events reported a composite endpoint comprised of self-efficacy, return to work or prior activity levels, and re-hospitalization or death. The composite outcome was classified as improved, deteriorated, or unchanged. The authors reported a higher rate of improvement in the intervention group (intervention: 22.3% (n=21), control: 9.5% (n=9), OR: 2.7, 95%CI:1.2 to 6.2, $P = 0.015$)

A trial of a patient-centered community health worker intervention provided in hospital¹⁶ reported significantly better primary care follow-up post-discharge (intervention:60% control:47.9%, $P = 0.02$; OR:1.52, 95%CI:1.03 to 2.23), more high quality communication post-discharge (intervention:91.3%, control:78.7%, $P = 0.002$; OR:2.94, 95%CI:1.5 to 5.8), higher mean SF-12 mental health scores (intervention:6.7, control:4.5, $P = 0.02$), and patient activation scores (intervention:3.4, control:1.6, $P = 0.05$). The authors did not find differences in self-rated physical health, satisfaction with medical care, or medication adherence. While no difference was seen in 30 day readmission, intervention patients were less likely to have multiple 30-day readmissions (not statistically significant), and among a subgroup of 63 readmitted patients, recurrent readmission was lower in the intervention group (15.2% vs 40.0%, $P = 0.03$; adjusted OR:0.27, 95%CI:0.08 to 0.89).

A trial of the effects of person-centered communication on parental stress by Weis et al.¹⁷ reported no significant differences in parental stress using the Parental Stressors Scale as the primary outcome measure (intervention: 2.70±0.67 SD, control: 2.84±0.71 SD, NS)

What is the evidence regarding the safety of structured formalized patient and family processes or initiatives to support improvements and collaborative practice in acute care settings?

A review of a decision support intervention in acute coronary syndrome¹² and one review in shared decision-making¹³ reported that the interventions they studied did not result in any apparent harms.

What are the evidence-based guidelines associated with formalized patient- and family-centered care initiatives to support improved service delivery in acute care settings?

Both guidelines included in this review are Canadian in origin.

The guideline published by Cancer Care Ontario (CCO)¹⁸ is an endorsement with adaptation of an existing guideline published by the National Institute for Health and Care Excellence in the UK (Clinical guidance 138, 2012)¹⁹ and provides extensive guidance with 65 recommendations on providing patient-centered care that are specific to cancer treatment in various health care settings. Due to the large number of recommendations, they are not presented in this review however the reader is directed to pages 5-13¹⁸ of the guideline for their details. The general categories of these recommendations include: knowing the patient as an individual, essential requirements of care, tailoring healthcare services for each patient, continuity of care and relationships, and enabling patients to actively participate in their care. Levels of evidence were reported to be assessed however there is no direct link made with evidence and recommendations.

The RNAO guideline⁴ provides recommendations for person and family-centered care. The general categories of guidance include assessment (which includes guidance recommending establishing a respectful, empowering and therapeutic relationship and understanding a patient's definition of health so as to be able to better deliver care), planning care in collaboration with the patient, implementing tailor-made strategies and care, evaluation of care, and the education of health care providers. The guideline also provides system, organizational, and policy recommendations. Each recommendation was linked explicitly to graded levels of evidence, which were adapted from the method used by the Scottish Intercollegiate Guidelines Network (SIGN, 2011) and Patti (2011), and ranged from levels Ia (evidence obtained from meta-analysis or systematic reviews of randomized controlled trials, and/or synthesis of multiple studies primarily of quantitative research) to V (evidence obtained from expert opinion or committee reports, and/or clinical experiences of respected authorities).

The National Institute for Health and Care Excellence (NICE) guideline¹⁹ provides guidance on improving the experience of care for people using adult NHS services, and is relevant to all levels of care, including acute care. It provides 68 recommendations under general categories of recommendations that are identical to those outlined in the CCO guideline.¹⁸ While the evidence for these recommendations is provided with the guidance, the strength of the recommendations is not graded. Due to the large number of recommendations, they are not reproduced in this review; however the reader is directed to pages 26-32¹⁸ of the guideline for their details.

Limitations

The systematic reviews were generally of good methodological quality however the majority of these reports included a wide variety of study designs including qualitative research reports,

making synthesis difficult. In addition, many did not provide a quantitative summary of their findings. As a result much of the evidence provided from these systematic reviews is qualitative in nature, and difficult to summarize empirically.

Similarly, there is a high degree of heterogeneity in the types of interventions that qualify as patient- and family-centered care, creating challenges for synthesis and interpretation.

Few randomized controlled trials were identified, and those that are included had issues related to blinding of patients and outcome assessors. In addition, the external validity of the trials was questionable because of the large number of exclusions and refusals to participate prior to randomization, as well as possible representativeness of the health care settings in which the studies were conducted.

Some of the reports, particularly the guidelines, were relevant to various health care settings and while this includes acute care, the reports were not specific to the acute care setting.

Standard care was generally not well described in the majority of reports.

There is limited information on harms of patient-centered and family care.

CONCLUSIONS AND IMPLICATIONS FOR DECISION OR POLICY MAKING

Eight systematic reviews and three randomized controlled trials addressed patient and family-centered care in an acute care setting. All eight systematic reviews and two of the three randomized trials reported impacts or potential impacts of this model of care on a wide variety of health and health care system outcomes, suggesting that family and patient-centered care may be effective. Because of the qualitative nature of much of the presented evidence, and because of the few numbers and methodological limitations of controlled studies, it is difficult to draw any empirically-based conclusions regarding the effectiveness of this care model, however based on the findings of this report, it may have impacts on patient and family satisfaction with care, patient and family communication with caregivers, patient and family anxiety, adherence to medications and to follow-up post-discharge, and health care utilization. More quantitative research on the benefits and harms of patient and family-centered care, particularly well-conducted randomized controlled trials, are required.

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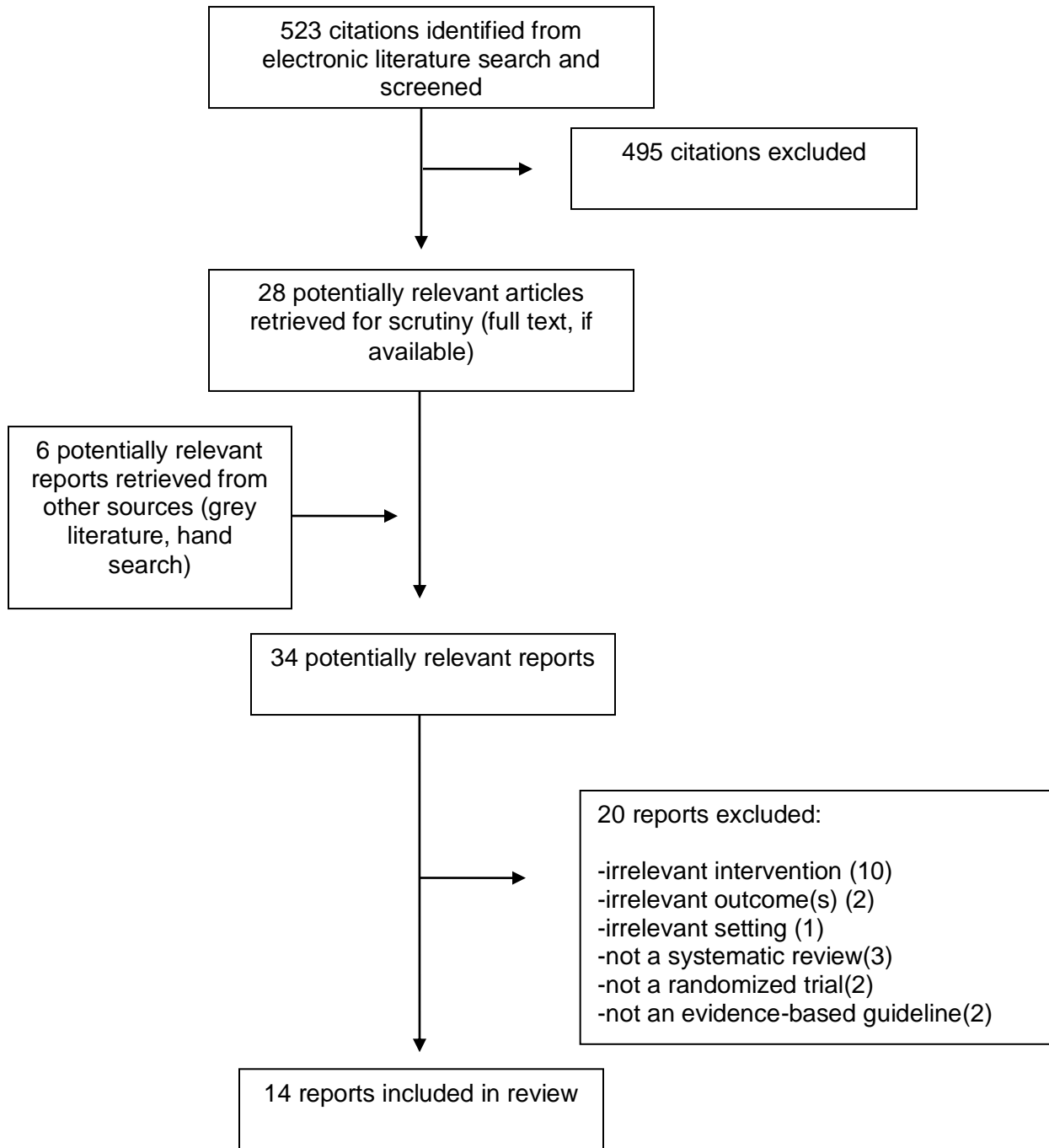
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APPENDIX 1: Selection of Included Studies



APPENDIX 2: Characteristics of Included Publications

Table A2.1 – Characteristics of Included Systematic Reviews					
Author Year Country	Primary studies included Research question /objective	Population characteristics Setting	Intervention	Comparators	Outcomes
Desai 2015 ⁸ United States	16 RCTs “...to evaluate the effectiveness of specific family-patient centered transition processes on health outcomes during hospital- and ED-to-home transitions.” (p.220) ⁸	Pediatric, adult, or elderly populations Hospital wards, EDs	Contained elements of transition processes involving the patient and/or the family	Not explicitly stated	Patient health outcomes including satisfaction, discharge readiness, functional assessments, HRQOL, missed school or work days knowledge of the care plan, adherence to follow-up with primary care physician, medication adherence, health care utilization.
Pringle 2015 ⁹ United Kingdom	33 studies including observational studies, qualitative studies, and randomized controlled trials “To examine international evidence relating to dignity and person-centered care for people with palliative care needs in the acute hospital setting.” (p.1) ⁹	Adults ≥18 years of age with palliative care needs Acute care setting	Person-centered care	Not explicitly stated	Impact on dignity
Tan 2015 ¹⁰ Singapore	Three qualitative studies “...to understand the experiences of adult patients in patient navigation programs and how patient navigators impact the challenges patients encounter in the cancer care continuum.” (p.136) ¹⁰	Adults ≥18 years of age who are receiving or have received cancer care Hospital	Patient navigation program	Not explicitly stated	Patient experiences

Table A2.1 – Characteristics of Included Systematic Reviews

Author Year Country	Primary studies included Research question /objective	Population characteristics Setting	Intervention	Comparators	Outcomes
Cypress 2012 ² United States	19 reports including randomized controlled trials, quasi-experimental studies, observational studies, qualitative studies, mixed methods, quality improvement reports and anecdotal notes. “To review research studies related to family presence on medical rounds.”(p.54) ²	Family members of adult and pediatric patients Critical and non-critical care setting	Family presence on medical rounds	Non-inclusion of family members	Patient, family, and health care staff outcomes
Fawole 2012 ¹¹ United States	20 prospective controlled studies “To systematically review the evidence for effectiveness of communication-related quality improvement interventions for patients with advanced and serious illness and to explore the effectiveness of consultative and integrative interventions”.(p.570) ¹¹	Patient populations with life-limiting or severe life-threatening illness Thirteen of the 20 studies were conducted in an ICU and the remaining seven studies were conducted in non-ICU settings	Communication with patients and/or families	Not explicitly stated	Health care utilization
Flynn 2012 ¹² United Kingdom	Five studies including RCTs and observational studies “...to conduct a systematic review to evaluate the	Adults or children and their surrogates Emergency	Shared decision-making (SDM)	Not explicitly stated	Patient preferences, decision-making, patient satisfaction, patient knowledge, follow-up visits, readmission rates, length of stay, testing

Table A2.1 – Characteristics of Included Systematic Reviews					
Author Year Country	Primary studies included Research question /objective	Population characteristics Setting	Intervention	Comparators	Outcomes
	approaches, methods, and tools used to engage patients or their surrogates in SDM in the ED” (p.959) ¹²	department (ED)			
Kryworuchko 2012 ¹³ Canada	Four randomized controlled trials “To explore the effectiveness of interventions to improve communication between the health care team, patients, their family members, and surrogate decision-makers about the decision to use life support in the ICU.”(p.4) ¹³	Patients in ICU requiring life support ICUs	Shared decision-making interventions	Usual care or any alternative intervention for end-of-life decision-making	Improvements in communication, patient health outcomes, anxiety and distress, harms, resource utilization
Schuenemann 2011 ¹⁴ United States	21 studies including RCTs and non-randomized intervention studies Are interventions to improve family communications in the adult ICU setting effective In improving patient- or family-centered outcomes, or in reducing costs or resource use?	Patients ≥18 years ICUs	Communication via printed information or structured family conferences with or without additional family support	Not explicitly stated	Any outcome measure including patient or family-centered outcomes, resource utilization, costs

ED: emergency department; HRQOL: health related quality of life; ICU: intensive care unit; RCT: randomized controlled trial; SDM: shared decision-making

Table A2.2 – Characteristics of Included Randomized Controlled Trials

Author Year Country	Research question / objective	Population characteristics (N)	Setting Follow-up period	Intervention Comparators	Outcomes
Fors 2015 ¹⁵ Sweden	“To evaluate of person-centered care can improve self-efficacy and facilitate return to work or prior activity level in patients after an event of acute coronary syndrome.”(p.693) ¹⁵	Patients hospitalized for an acute coronary syndrome event N=199	Hospital followed to outpatient and to primary care Six months	Person-centered care Conventional care	Self-efficacy (General Self-Efficacy Scale), return to work or prior activity level, (Saltin Grimby Activity Level Scale), re-hospitalization, death
Kangovi 2014 ¹⁶ United States	“To determine if a tailored community health worker intervention would improve post hospital outcomes among low SES patients.”(p.535) ¹⁶	Patients aged 18 to 64 years who were under observation or inpatients and were expected to be discharged to home N=466	Hospital One month	Individualized action plans for achieving patients’ stated goals for recovery for a minimum of 14 days Routine hospital care	Patient-reported completion of a follow-up with a primary care physician within 14 days of discharge. Quality of discharge communication, self-rated health, satisfaction, patient activation, medication adherence, 30-day readmission rates
Weis 2013 ¹⁷ Denmark	“To investigate the effect of a Guided Family-Centered Care intervention...on parental stress in a neonatal intensive care unit (NICU).”(p.1130) ¹⁷	Parents of infants born ≤34 weeks gestational age N=134	NICU To discharge	Guided Family-Centered Care (GFCC) through person-centered communication techniques Standard care	Parental stress (Nurse Patient Support Tool and the Parental Stressor Scale)

ED: emergency department; GFCC: guided family-centered care; MRS: medication therapy management and reconciliation service; NICU: neonatal intensive care unit; SES: socioeconomic status

Table A2.3 – Characteristics of Included Guidelines

Author Year Country	Intended users Target population Setting	Evidence collection and synthesis	Appraisal of evidence quality and strength	Recommendations development and evaluation	Guideline validation
CCO 2015 ¹⁸ Canada	Clinicians and staff in oncology settings, patients (and/or family members and caregivers) and their care providers Adults (≥18 years) in Ontario using oncology services and their care providers Adult oncology service setting	Systematic review	AGREE II used to assess endorsed guideline	Single guideline endorsed and adapted using results from systematic literature search and guideline working group	Not indicated
RNAO 2015(46) Canada	Practice recommendations are directed toward nurses and other health care providers who provide direct care to persons in health-system settings and in the community Individuals and their family members Various health care settings including acute care	Systematic review, quality appraisal and data extraction	Levels of evidence adapted from Scottish Intercollegiate Guidelines Network (2011) and Pati (2011)	Update of <i>Client Centred Care</i> (RNAO, 2002), and the revision supplement (RNAO, 2006a), based on systematic review and supported by five clinical questions, conducted by RNAO expert panel.	Extensive review by stakeholders
NICE 2012 ¹⁹ United Kingdom	All providers of healthcare in NHS Patients using the NHS All NHS services, including primary and community care, e.g. NHS dentistry services as well as district nursing and health visitor services, and hospital inpatient and outpatient care.	Systematic review	Based on NICE Guidelines Manual for appraising studies	Guidelines Development Group used existing guidelines and evidence obtained from systematic review and quality rating	Four week public consultation

CCO: Cancer Care Ontario; NHS: National Health Service; NICE: National Institute for Health and Care Excellence; RNAO: Registered Nurses Association of Ontario

APPENDIX 3 – Critical Appraisal of Included Publications

Table A3.1 – Strengths and Limitations of Systematic Reviews using AMSTAR⁵		
Author Year Country	Strengths	Limitations
Desai 2015 ⁸ United States	<ul style="list-style-type: none"> • A priori design provided • Duplicate study selection • Comprehensive literature search • Characteristics of included studies provided • Scientific quality of included studies assessed and documented • Scientific quality of included studies used appropriately to formulate conclusions • Conflict of interest stated 	<ul style="list-style-type: none"> • Single data extraction • Restricted to published literature and English language • List of excluded studies not provided
Pringle 2015 ⁹ United Kingdom	<ul style="list-style-type: none"> • A priori design provided • Comprehensive literature search • Characteristics of included studies provided • Scientific quality of included studies assessed and documented • Conflict of interest stated 	<ul style="list-style-type: none"> • Duplicate study selection and extraction unclear • Restricted to published literature • Unclear if scientific quality of included studies used appropriately to formulate conclusions • List of excluded studies not provided
Tan 2015 ¹⁰ Singapore	<ul style="list-style-type: none"> • A priori design provided • Duplicate study selection and data extraction • Comprehensive literature search • Scientific quality of included studies assessed and documented • List of excluded studies provided • Conflict of interest stated 	<ul style="list-style-type: none"> • Restricted to published literature and English language • Unclear if scientific quality of included studies used appropriately to formulate conclusions
Cypress 2012 ² United States	<ul style="list-style-type: none"> • A priori design provided • Duplicate study selection • Comprehensive literature search • Characteristics of included studies provided • Scientific quality of included studies assessed and documented • Scientific quality of included studies used appropriately to formulate conclusions • Conflict of interest stated 	<ul style="list-style-type: none"> • Duplicate study data extraction unclear • Restricted to published literature and English language • List of excluded studies not provided
Fawole 2012 ¹¹ United States	<ul style="list-style-type: none"> • A priori design provided • Duplicate study selection and extraction • Comprehensive literature search • Characteristics of included studies provided • Scientific quality of included studies assessed 	<ul style="list-style-type: none"> • Restricted to published literature • Scientific quality of included studies not documented • List of excluded studies not provided

Table A3.1 – Strengths and Limitations of Systematic Reviews using AMSTAR⁵		
Author Year Country	Strengths	Limitations
	<ul style="list-style-type: none"> • Scientific quality of included studies used appropriately to formulate conclusions • Conflict of interest stated 	
Flynn 2012 ¹² United Kingdom	<ul style="list-style-type: none"> • A priori design provided • Duplicate study selection and extraction • Comprehensive literature search • Characteristics of included studies provided • Scientific quality of included studies assessed and documented • Conflict of interest stated 	<ul style="list-style-type: none"> • Restricted to published literature and English language • Unclear if scientific quality of included studies used appropriately to formulate conclusions • List of excluded studies not provided
Kryworuchko 2012 ¹³ Canada	<ul style="list-style-type: none"> • A priori design provided • Duplicate study selection and extraction • Comprehensive literature search • Characteristics of included studies provided • List of excluded studies provided 	<ul style="list-style-type: none"> • Restricted to published literature • Scientific quality of included studies not assessed or documented • Scientific quality of included studies not used to formulate conclusions • Conflict of interest not explicitly stated
Schuenemann 2011 ¹⁴ United States	<ul style="list-style-type: none"> • A priori design provided • Duplicate study selection • Comprehensive literature search • Characteristics of included studies provided • Scientific quality of included studies assessed and documented • Conflict of interest stated 	<ul style="list-style-type: none"> • Duplicate study data extraction unclear • Restricted to published literature and English language • Unclear if scientific quality of included studies used appropriately to formulate conclusions • List of excluded studies not provided

Table A3.2 – Strengths and Limitations of Randomized Controlled Trials using Downs and Black⁶

Author Year Country	Strengths	Limitations
Fors 2015 ¹⁵ Sweden	<ul style="list-style-type: none"> • Aim of study clearly described • Main outcomes clearly described • Patient characteristics described • Interventions clearly described • Distribution of principle confounders described • Main study findings clearly described • Estimates of random variability for main outcomes provided • Characteristics of patients lost to follow-up described • Actual probability values reported • Staff, places, facilities representative • No data dredging apparent • Comparable group follow-up • Appropriate statistical tests • Reliable compliance • Main outcome measures accurate • Patient groups recruited from same population • Patient groups recruited over same time period • Randomization to intervention • Concealed allocation • Adequate adjusting for confounders • Losses to follow-up reported • Sufficient power for primary outcome but not for subgroup analyses 	<ul style="list-style-type: none"> • Adverse events not reported • Subjects not representative of entire population • Unclear if subjects who were prepared to participate were representative of entire population • Blinding of study subjects not possible • Blinding of outcome assessors unclear
Kangovi 2014 ¹⁶ United States	<ul style="list-style-type: none"> • Aim of study clearly described • Main outcomes clearly described • Patient characteristics described • Interventions clearly described • Distribution of principle confounders described • Main study findings clearly described • Estimates of random variability for main outcomes provided • Characteristics of patients lost to follow-up described • Actual probability values reported • No data dredging apparent • Comparable group follow-up • Appropriate statistical tests • Reliable compliance • Main outcome measures accurate • Patient groups recruited from same population 	<ul style="list-style-type: none"> • Adverse events not reported • Unclear if staff, places, facilities representative • Unclear if subjects not representative of entire population • Unclear if subjects who were prepared to participate were representative of entire population • Blinding of study subjects not possible •

Table A3.2 – Strengths and Limitations of Randomized Controlled Trials using Downs and Black⁶

Author Year Country	Strengths	Limitations
	<ul style="list-style-type: none"> • Patient groups recruited over same time period • Randomization to intervention • Concealed allocation • Blinding of outcome assessors • Adequate adjusting for confounders • Losses to follow-up reported • Sufficient power 	
Weis 2013 ¹⁷ Denmark	<ul style="list-style-type: none"> • Aim of study clearly described • Main outcomes clearly described • Patient characteristics described • Interventions clearly described • Distribution of principle confounders described • Main study findings clearly described • Estimates of random variability for main outcomes provided • Actual probability values reported • No data dredging apparent • Comparable group follow-up • Appropriate statistical tests • Reliable compliance • Main outcome measures accurate • Patient groups recruited from same population • Patient groups recruited over same time period • Randomization to intervention • Losses to follow-up reported • Sufficient power 	<ul style="list-style-type: none"> • Adverse events not reported • Characteristics of patients lost to follow-up not clearly described • Unclear if staff, places, facilities representative • Unclear if subjects not representative of entire population • Unclear if subjects who were prepared to participate were representative of entire population • Blinding of study subjects not possible • Blinding of outcome assessors unclear • Concealed allocation unclear • Blinding of outcome assessors unclear • Inadequate adjusting for confounders

Table A3.3– Strengths and Limitations of Guidelines using AGREE II⁷

Author Year Country	Strengths	Limitations
CCO 2015 ¹⁸ Canada	<ul style="list-style-type: none"> • Overall objectives of guideline described • Applicable population described • Guideline development group includes individuals from all relevant professional groups • Target users clearly defined • Systematic methods used for search • Criteria for selecting evidence described • Methods for formulating recommendations described • Guideline externally reviewed by experts • Procedure for guideline update provided • Recommendations specific and unambiguous • Different management options presented • Key recommendations easily identifiable • Competing interests declared 	<ul style="list-style-type: none"> • Health questions covered not specifically described • Views and preferences of target population not sought • Strengths and limitations of body of evidence not clearly described • Unclear if health benefits, side effects, and risks considered in formulating recommendations • Explicit link between evidence and recommendations not made (endorsement) • No description of facilitators and barriers • No implementation advice or tools • Potential resource implications not considered • No monitoring or auditing criteria • Unclear if funding body influenced content
RNAO 2015(46) Canada	<ul style="list-style-type: none"> • Overall objectives of guideline described • Applicable population described • Views and preferences of target population sought • Guideline development group includes individuals from all relevant professional groups • Target users clearly defined • Systematic methods used for search • Criteria for selecting evidence described • Strengths and limitations of body of evidence described • Methods for formulating recommendations described • Health benefits, side effects, and risks considered • Explicit link between evidence and recommendations • Guideline externally reviewed by experts • Procedure for guideline update provided • Recommendations specific and unambiguous • Different management options presented • Key recommendations easily identifiable • Description of facilitators and barriers • Implementation advice or tools • Monitoring/auditing criteria • Competing interests declared 	<ul style="list-style-type: none"> • Health questions covered not specifically described • Potential resource implications not considered • Unclear if funding body influenced content

Table A3.3– Strengths and Limitations of Guidelines using AGREE II⁷

Author Year Country	Strengths	Limitations
NICE 2012 ¹⁹ United Kingdom	<ul style="list-style-type: none"> • Overall objectives of guideline described • Applicable population described • Health questions covered specifically described • Views and preferences of target population sought • Guideline development group includes individuals from all relevant professional groups • Target users clearly defined • Systematic methods used for search • Criteria for selecting evidence described • Strengths and limitations of body of evidence described • Methods for formulating recommendations described • Health benefits, side effects, and risks considered • Explicit link between evidence and recommendations • Guideline externally reviewed by experts • Procedure for guideline update provided • Recommendations specific and unambiguous • Different management options presented • Key recommendations easily identifiable • Description of facilitators and barriers • Potential resource implications considered • Implementation advice or tools • Competing interests declared 	<ul style="list-style-type: none"> • Monitoring/auditing criteria • Unclear if funding body influenced content

CCO: Cancer Care Ontario; NICE: National Institute for Health and Care Excellence; RNAO: Registered Nurses Association of Ontario

APPENDIX 4 – Main Study Findings and Summary of Guideline Conclusions

Table A4.1 – Summary of Findings of Included Studies		
Author Year Country	Main study findings	Authors' conclusions
Systematic Reviews		
Desai 2015 ⁸ United States	<p>Four studies evaluating pediatric ED-to-home transitions reported that family discharge education was associated with better health outcomes compared with control groups, including lower presence of cough at two weeks (13% vs 30%, p<0.05), better MDIS use (95% vs 72%, p<0.05), statistically significantly lower medication name, dosing, and preparation error rates at 12 days, lower non-adherence rates (9.3% vs 38%, p<0.001), a higher rate of return to baseline health status at 4 weeks (82% vs 71%, p<0.05), and a higher rate of completed follow-up visits at four weeks (77% vs 51%, p<0.001).</p> <p>Twelve adult trials evaluating hospital-to home transitions using transition needs assessments or individualized transition records found better patient health outcomes and health care utilization among the intervention groups. Outcomes showing statistically significant improvement in the intervention groups compared with the control groups included post-discharge visit rates (>1 study), quality of transition reported at 1 week (OR:2.36, 95%CI:2.06-5.92), feeling better than before hospitalization at 30 days (OR:2.36, 95%CI:1.41-3.95) knowledge of who to call with questions at 1 week (Or:15.87, 95%CI:2.05-125.00), satisfaction with follow-up plan (97% vs 76%, p<0.001), knowledge of follow-up plan at 2-4 weeks (99% vs 87%, p<0.001), knowledge of medications at 2-4 weeks (96% vs 87%, p<0.01); feeling prepared for discharge (65% vs 55%, p<0.05), and patient satisfaction at two weeks (83% vs 75%, p<0.001).</p> <p>All included studies met the criteria for Centre for Evidence-Based Medicine Levels of Evidence two to four.</p>	<p>“Patient-tailored discharge education is associated with improved patient health outcomes in pediatric ED patients.”(p.220)⁸</p> <p>“Conducting a needs assessment during hospitalization and providing patients and families with an individualized transition record is associated with improved outcomes in adult patients and further investigation is needed to evaluate the effectiveness of these transition processes in pediatric hospital-to-home transitions.”(p.230)⁸</p>
Pringle 2015 ⁹ United Kingdom	<p>“Papers highlighted the many and varied potential threats to dignity for people with palliative care needs in acute settings, including symptom control and existential distress, approaches and models in care provision and healthcare settings and design”(p.1)⁹</p>	<p>“Acute hospital staff require training, including symptom control, and the correct environment in which to deliver dignified and person-centered end-of-life care. Specific models/approaches to care can be</p>

Table A4.1 – Summary of Findings of Included Studies

Author Year Country	Main study findings	Authors' conclusions
		beneficial, if adequate training regarding implementation is given, The needs of family members also require consideration, particularly following bereavement.”(p.1) ⁹
Tan 2015 ¹⁰ Singapore	“The three synthesized findings from the 17 findings extracted from the papers were: (1) Emotional empowerment: patient navigators need to be present with patients at key phases of the cancer care continuum and assure patients of their accessibility; (2) Knowledge empowerment: patient navigators need to explore and manage the needs and expectations of patients so that the healthcare team and patient have the same understanding of treatment goals and plans; and (3) Bridging the gaps: patient navigators need to ensure practical assistance is provided for patients to ensure continuity of care even at the completion of the treatment regimen.”(p.137) ¹⁰	“The presence of a patient navigator provides strong support to the patients when experiencing disruption from cancer diagnosis and treatment. The emotional isolation they experience lessens with the assurance that there is always a consistent and constant contact point they can fall back on. The logistic and practical help given by the navigators allows patients to take time to process information and make sense of what is happening.”(p.138) ¹⁰
Cypress 2012 ² United States	<p>“Parents and family members from 3 prospective observational studies reported satisfaction with participation in rounds.”(p.56)²</p> <p>“Inclusion of parents on rounds was also seen positively by parents in an inpatient medical unit at a large academic children’s hospital.”(p.57)²</p> <p>“One nonrandomized trial conducted in an adolescent ward found that FCRs affected the medical decision-making discussion in 90% of the cases from the multidisciplinary staff members.”(p.57)²</p> <p>“Jarvis and colleagues found that parents were very supportive of involvement in decision making for their child because they learned more about their child’s history and health and had a greater opportunity to offer input (96%), ask questions, and be a part of the discussion. Nurses responded that family presence on medical rounds increased communication with families and increased sense of parent education.” (p.57)²</p> <p>In a study that aimed to discover parental preferences about being present during ward rounds, most parents (73%) wanted to be present at rounds and viewed their participation to be an important dimension of their parenting</p>	<p>“In summary, compared with noninclusion of family members, family presence on rounds may lead to positive outcomes and increased satisfaction among patients, family members, and the health care staff. Most study results reported by investigators were positive, although some research findings are negative (refer to Tables 5 and 6 for summary of findings). Quality improvement reports yielded positive results as well.”(pg. 61)²</p> <p>“Family-centered rounds hold a potential to create a patient centered environment, enhance medical and nursing education, and improve patient outcomes. Further research on family presence on rounds is warranted.”(pg.63)²</p>

Table A4.1 – Summary of Findings of Included Studies

Author Year Country	Main study findings	Authors' conclusions
	<p>role. Some families expressed concerns about violations of privacy. The authors also suggested a mixture of concerns about communication, practicalities, issues of ethics, and confidentiality, but the authors concluded that family presence on rounds was an opportunity to communicate with the health care team. Confidentiality was also a matter of concern for some family members, but many parents expected some sharing of information between families in the unit. In contrast, family members in another study did not perceive a violation of their privacy by participating in rounds. The same study also concluded no significant difference between time spent on rounds in the presence or absence of family members. Other study findings were varied when viewing the perceptions of the health care staff regarding family presence on rounds in pediatrics. (pgs. 57-58)²</p> <p>“Only 2 studies of 17 reviewed that investigated family presence on rounds were conducted in the adult patient population. Authors from 1 study conducted in an internal medicine department suggested that nurses, physicians, patients, and relatives expressed positive attitude toward participation of family members in rounds after having undergone the experience. Positive attitude referred to improvement in receiving information regarding the disease, participation in decision making, formal discussions with physicians, family stress, communication with staff, and staff’s attitude toward the patient. The only study conducted in medical ICU queried whether family attendance at interdisciplinary family rounds would enhance communication. The findings indicated that certain elements of satisfaction were improved but not overall satisfaction. Structured interdisciplinary rounds can improve some families’ satisfaction, but some families feel rushed to make decisions.”(pgs. 58-61)²</p>	
Fawole 2012 ¹¹ United States	“We found four intervention types: (1) family meetings with the usual team (11 studies, 77 % found improvement in healthcare utilization), (2) palliative care teams (5 studies, 50 % found	“Communication in the care of patients with advanced and serious illness can be improved using quality improvement interventions,

Table A4.1 – Summary of Findings of Included Studies

Author Year Country	Main study findings	Authors' conclusions
	<p>improvement in healthcare utilization), (3) ethics consultation (2 studies, 100 % found improvement in healthcare utilization), and (4) physician-patient communication (2 studies, no significant improvement in healthcare utilization).</p> <p>Among studies addressing the outcomes of patient/family satisfaction, 22 % found improvement; among studies addressing healthcare utilization (e.g., length of stay), 73 % found improvement. Results suggest that consultative interventions, as opposed to integrative ones, may be more effective, but more research is needed.”(p.570)¹¹</p>	<p>particularly for healthcare utilization as an outcome. Interventions may be more effective using a consultative approach.”(pg.570)¹¹</p>
<p>Flynn 2012¹² United Kingdo</p>	<p>“Overall, DSIs were associated with improvements in patients’ knowledge and satisfaction with the explanation of their care, preferences for involvement, and engagement in decision-making and demonstrated utility for eliciting patients’ preferences and values about management and treatment options. Two computerized DSIs (designed to predict risk of ACS in adults presenting to the ED with chest pain) were shown to reduce health care use without evidence of harm. None of the studies reported lack of feasibility of SDM in the ED.”(pg.959)¹²</p>	<p>“Early investigation of SDM in the ED suggests that patients may benefit from involvement in decision-making and offers no empirical evidence to suggest that SDM is not feasible. Future work is needed to develop and test additional SDM interventions in the ED and to identify contextual barriers and facilitators to implementation in practice.”(p.960)¹²</p>
<p>Kryworuchko 2012¹³ Canada</p>	<p>“Of four trials, three interventions were evaluated. Two studies of interventions including three of nine elements of SDM did not report improvements in communication. Two studies of the same ethics consultation, which included eight of nine elements of SDM, did not evaluate the benefit to communication. The interventions were not harmful; they decreased family member anxiety and distress, shortened intensive care unit stay, but did not affect patient mortality.”(p.3)¹³</p>	<p>“Few studies have evaluated interventions to improve communication between healthcare professionals and patients/families when facing the decision about whether or not to use life support in the ICU. Interventions that include essential elements of SDM need to be more thoroughly evaluated in order to determine their effectiveness and health impact and to guide clinical practice.”(p.3)¹³</p>
<p>Schuenemann 2011¹⁴ United States</p>	<p>“Printed information, palliative care or ethics consultation, or regular, structured communication by the usual ICU team reduced family distress, improved comprehension, and decreased the use of intensive treatments.”(p.543)¹⁴</p>	<p>“The evidence supports the use of printed information and structured communication by the usual ICU team, ethics consultation, or palliative care consultation to improve family emotional outcomes and to reduce ICU length of stay and treatment intensity. Evidence that these</p>

Table A4.1 – Summary of Findings of Included Studies		
Author Year Country	Main study findings	Authors' conclusions
		interventions reduce total costs is inconclusive. A comprehensive research agenda should ensure the future study of a full range of patient-centered outcomes.”(p.543) ¹⁴
Randomized Controlled Trials		
Fors 2015 ¹⁵ Sweden	<p>A composite endpoint at six months (self-efficacy [GSE scale], return to work or prior activity level [SGPALS], re-hospitalization or death) was classified as improved, deteriorated, or unchanged</p> <p>Improved: Intervention: 22.3% (n=21) Control: 9.5% (n=9) OR: 2.7 95%CI:1.2-6.2, p=0.015</p>	“A person-centered care approach emphasizing the partnership between patients and health care professionals throughout the care chain improves general self-efficacy without causing worsening clinical events.”(p.693) ¹⁵
Kangovi 2014 ¹⁶ United States	<p>Primary care follow-up post-discharge: Intervention:60% Control:47.9% P=0.02 OR:1.52, 95%CI:1.03-2.23</p> <p>High quality of post-discharge communication: Intervention:91.3% Control:78.7% P=0.002 OR:2.94, 95%CI:1.5-5.8</p> <p>Mental health (SF-12): Intervention:6.7 Control:4.5 P=0.02</p> <p>Patient activation: Intervention:3.4 Control:1.6 P=0.05</p> <p>No differences were seen in self-rated physical health, satisfaction with medical care, or medication adherence. No difference was seen in 30 day readmission however intervention patients were less likely to have multiple 30-day readmissions (NS), and among a subgroup of 63 readmitted patients, recurrent readmission was lower in the intervention group (15.2% vs 40.0%, p=0.03; adjusted OR:0.27, 95%CI:0.08-0.89).</p>	“Patient-centered community health worker intervention improves access to primary care and quality of discharge while controlling recurrent readmissions in a high risk population.”(p.535) ¹⁶

Table A4.1 – Summary of Findings of Included Studies

Author Year Country	Main study findings	Authors' conclusions
Weis 2013 ¹⁷ Denmark	PSS: Intervention: 2.70±0.67 SD Control: 2.84±0.71 SD (NS)	"Our study was unable to demonstrate the effect of person-centered communication using the Guided Family-Centered Care intervention."(p.1130) ¹⁷

ACS: acute coronary syndrome; CI: confidence interval; DSI: decision support interventions; ED: emergency department; FCR: family-centered rounds; GSE: General Self-Efficacy Scale; ICU: intensive care unit; MDIS: metered dose inhaler and spacer; NS: not statistically significant; OR: odds ratio; PSS: Parental Stressors Scale; SF-12: Short-Form 12-Item Health Survey; SD: standard deviation; SGPALS: Saltin Grimby Physical Activity Level Scale; SDM: shared decision-making

Table A4.2 – Summary of Findings of Included Guidelines

Author Year Country	Recommendations	Strength of evidence
CCO 2015 ¹⁸ Canada	<p>This guideline outlines a series of 65 recommendations for person-centered care in the delivery of oncology services. Due to the length and detail of this information, only the general categories for the recommendations are provided here:</p> <ul style="list-style-type: none"> • <u>Knowing the patient as an individual</u> (recommendations 1-7) (pg.5) • <u>Essential requirements of care</u> (pgs. 6-7) Respect for the patient (recommendations 8-9) Patient concerns (recommendations 10-12) Nutrition, pain management and personal needs (recommendations 13-15) Patient independence (recommendation 16) Consent and capacity (recommendations 17-18) • <u>Tailoring healthcare service for each patient</u> (pgs.7-9) An individual approach to services (recommendations 19-21) Patient views and preferences (recommendations 22-27) Involvement of family members and caregivers (recommendations 28-29) Feedback and complaints (recommendations 30-31) • <u>Continuity of care and relationships</u> (recommendations 32-37) (pg. 9) • <u>Enabling patients to actively participate in their care</u> (pgs.10-13) Communications (recommendations 38-47) Information (recommendations 48-56) Shared decision-making (recommendations 57-64) Education programs (recommendation 65) 	Strength of evidence not explicitly linked to recommendations

Table A4.2 – Summary of Findings of Included Guidelines		
Author Year Country	Recommendations	Strength of evidence
RNAO 2015(46) Canada	<p>“1.0 Assessment</p> <p>Recommendation 1.1: Establish a therapeutic relationship with the person using verbal and non-verbal communication strategies to build a genuine, trusting, and respectful partnership.</p> <p>Recommendation 1.2: Build empowering relationships with the person to promote the person’s proactive and meaningful engagement as an active partner in their health care.</p> <p>Recommendation 1.3: Listen and seek insight into the whole person to gain an understanding of the meaning of health to the person and to learn their preferences for care.</p> <p>Recommendation 1.4: Document information obtained on the meaning and experience of health to the person using the person’s own words.” (pg.9)⁴</p> <p>“2.0 Planning</p> <p>Recommendation 2.1: Develop a plan of care in partnership with the person that is meaningful to the person within the context of their life.</p> <p>Recommendation 2.2: Engage with the person in a participatory model of decision-making, respecting the person’s right to choose the preferred interventions for their health, by: 1) Collaborating with the person to identify their priorities and goals for health care; 2) Sharing information to promote an understanding of available options for health care so the person can make an informed decision; and 3) Respecting the person as an expert on themselves and their life.” (pg. 10)⁴</p>	<p>III - Synthesis of multiple studies primarily of qualitative research</p> <p>Ia - Evidence obtained from meta-analysis or systematic reviews of randomized controlled trials, and/or synthesis of multiple studies primarily of quantitative research</p> <p>Ia - Evidence obtained from meta-analysis or systematic reviews of randomized controlled trials, and/or synthesis of multiple studies primarily of quantitative research</p> <p>V - Evidence obtained from expert opinion or committee reports, and/or clinical experiences of respected authorities</p> <p>Ia - Evidence obtained from meta-analysis or systematic reviews of randomized controlled trials, and/or synthesis of multiple studies primarily of quantitative research</p> <p>Ia - Evidence obtained from meta-analysis or systematic reviews of randomized controlled trials, and/or synthesis of multiple studies primarily of quantitative research</p>

Table A4.2 – Summary of Findings of Included Guidelines		
Author Year Country	Recommendations	Strength of evidence
	<p>“3.0 Implementation Recommendation 3.1: Personalize the delivery of care and services to ensure care is not driven from the perspective of the health care provider and organization, by collaborating with the person on: 1) Elements of care; 2) Roles and responsibilities in the delivery of care; and 3) Communication strategies.</p> <p>Recommendation 3.2: Partner with the person to tailor strategies for self-management of care that are based on the person’s characteristics and preferences for learning.” (pg. 10)⁴</p> <p>“4.0 Evaluation Recommendation 4.1: Obtain feedback from the person to determine the person’s satisfaction with care and whether the care delivered was person and family-centred.” (pg. 10)⁴</p> <p>“5.0 Education Recommendation 5.1: Educate health care providers at a minimum on the following attributes of person- and family-centered care to improve the person’s clinical outcomes and satisfaction with care: 1) Empowerment; 2) Communication; and 3) Shared decision-making.</p> <p>Recommendation 5.2: Educational institutions incorporate this Guideline into the curricula for nurses and, as appropriate, for other health care providers.”(pg. 11)⁴</p> <p>This guideline also provides system, organizational, and policy recommendations for person-centered care (not presented here, pages 11-12)⁴</p>	<p>Ia - Evidence obtained from meta-analysis or systematic reviews of randomized controlled trials, and/or synthesis of multiple studies primarily of quantitative research</p> <p>V - Evidence obtained from expert opinion or committee reports, and/or clinical experiences of respected authorities</p> <p>Ia - Evidence obtained from meta-analysis or systematic reviews of randomized controlled trials, and/or synthesis of multiple studies primarily of quantitative research</p> <p>Ia - Evidence obtained from meta-analysis or systematic reviews of randomized controlled trials, and/or synthesis of multiple studies primarily of quantitative research</p> <p>V - Evidence obtained from expert opinion or committee reports, and/or clinical experiences of respected authorities</p>
NICE 2012 ¹⁹ United Kingdom	<p>This guideline outlines a series of 68 recommendations for person-centered care in the delivery of National Health Service services. Due to the length and detail of this information, only the general categories for the recommendations are provided here:</p> <ul style="list-style-type: none"> • <u>Knowing the patient as an individual (recommendations 1-7) (pg.26)</u> 	<p>Evidence is presented with recommendations however strength of evidence not provided</p>

Table A4.2 – Summary of Findings of Included Guidelines		
Author Year Country	Recommendations	Strength of evidence
	<ul style="list-style-type: none"> • <u>Essential requirements of care</u> (pgs. 26-28) Respect for the patient (recommendations 8-9) Patient concerns (recommendations 10-12) Nutrition, pain management and personal needs (recommendations 13-16) Patient independence (recommendations 17-18) Consent and capacity (recommendations 19-20) • <u>Tailoring healthcare service for each patient</u> (pgs.28-29) An individual approach to services (recommendations 21-23) Patient views and preferences (recommendations 24-29) Involvement of family members and caregivers (recommendations 30-31) Feedback and complaints (recommendations 32-33) • <u>Continuity of care and relationships</u> (recommendations 34-39) (pg.29) • <u>Enabling patients to actively participate in their care</u> (pgs.29-32) Communications (recommendations 40-49) Information (recommendations 50-58) Shared decision-making (recommendations 59-66) Education programs (recommendations 67-68) 	

CCO: Cancer Care Ontario; NICE: National Institute for Health and Care Excellence; RNAO: Registered Nurses Association of Ontario

APPENDIX 5 – Reviews and guidelines that did not meet selection criteria

Reviews

Gabrielsson S, Savenstedt S, Zingmark K. Person-centred care: clarifying the concept in the context of inpatient psychiatry. *Scand J Caring Sci*. 2015 Sep;29(3):555-62.

Levin TT, Moreno B, Silvester W, Kissane DW. End-of-life communication in the intensive care unit. *Gen Hosp Psychiatry*. 2010 Jul-Aug;32(4):433-42.

Guidelines – Not clearly evidence-based

Mason KE, Urbansky H, Crocker L, Connor M, Anderson MR, Kissoon N, et al. Pediatric emergency mass critical care: focus on family-centered care. *Pediatr Crit Care Med*. 2011 Nov;12(6 Suppl):S157-S162.

Greenwald JL, Halasyamani L, Greene J, LaCivita C, Stucky E, Benjamin B, et al. Making inpatient medication reconciliation patient centered, clinically relevant and implementable: a consensus statement on key principles and necessary first steps. *J Hosp Med*. 2010 Oct;5(8):477-85.