Health Quality Ontario
Qualité des services de santé Ontario

Effect of Supportive Interventions on Informal Caregivers of People at the End of Life: A Rapid Review

S Baidoobonso

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Evidence Development and Standards Branch at Health Quality Ontario

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Conflict of Interest Statement

All authors in the Evidence Development and Standards branch at Health Quality Ontario are impartial. There are no competing interests or conflicts of interest to declare.

Rapid Review Methodology

Rapid reviews are completed in 2–4-week time frames. Clinical questions are developed by the Evidence Development and Standards branch at Health Quality Ontario, in consultation with experts, end users, and/or applicants in the topic area. A systematic literature search is then conducted to identify relevant systematic reviews, health technology assessments, and meta-analyses. The methods prioritize systematic reviews, which, if found, are rated by AMSTAR to determine the methodological quality of the review. If the systematic review has evaluated the included primary studies using the GRADE Working Group criteria (http://www.gradeworkinggroup.org/index.htm), the results are reported and the rapid review process is complete. If the systematic review has not evaluated the primary studies using GRADE, the primary studies in the systematic review are retrieved and the GRADE criteria are applied to 2 outcomes. If no systematic review is found, then RCTs or observational studies are included, and their risk of bias is assessed. All rapid reviews are developed and finalized in consultation with experts.

About Health Quality Ontario

Health Quality Ontario is an arms-length agency of the Ontario government. It is a partner and leader in transforming Ontario's health care system so that it can deliver a better experience of care, better outcomes for Ontarians, and better value for money.

Health Quality Ontario strives to promote health care that is supported by the best available scientific evidence. The Evidence Development and Standards branch works with expert advisory panels, clinical experts, scientific collaborators, and field evaluation partners to conduct evidence-based reviews that evaluate the effectiveness and cost-effectiveness of health interventions in Ontario.

Based on the evidence provided by Evidence Development and Standards and its partners, the Ontario Health Technology Advisory Committee—a standing advisory subcommittee of the Health Quality Ontario Board—makes recommendations about the uptake, diffusion, distribution, or removal of health interventions to Ontario's Ministry of Health and Long-Term Care, clinicians, health system leaders, and policy-makers.

Health Quality Ontario's research is published as part of the *Ontario Health Technology Assessment Series,* which is indexed in MEDLINE/PubMed, Excerpta Medica/Embase, and the Centre for Reviews and Dissemination database. Corresponding Ontario Health Technology Advisory Committee recommendations and other associated reports are also published on the Health Quality Ontario website. Visit http://www.hqontario.ca for more information.

About Health Quality Ontario Publications

To conduct its rapid reviews, Evidence Development and Standards and its research partners review the available scientific literature, making every effort to consider all relevant national and international research; collaborate with partners across relevant government branches; consult with expert advisory panels, clinical and other external experts, and developers of health technologies; and solicit any necessary supplemental information.

In addition, Evidence Development and Standards collects and analyzes information about how a health intervention fits within current practice and existing treatment alternatives. Details about the diffusion of the intervention into current health care practices in Ontario add an important dimension to the review. Information concerning the health benefits, economic and human resources, and ethical, regulatory, social, and legal issues relating to the intervention may be included to assist in making timely and relevant decisions to optimize patient outcomes.

Disclaimer

This rapid review is the work of the Evidence Development and Standards branch at Health Quality Ontario, and is developed from analysis, interpretation, and comparison of published scientific research. It also incorporates, when available, Ontario data and information provided by experts. As this is a rapid review, it may not reflect all the available scientific research and is not intended as an exhaustive analysis. Health Quality Ontario assumes no responsibility for omissions or incomplete analysis resulting from its rapid reviews. In addition, it is possible that other relevant scientific findings may have been reported since completion of the review. This report is current as of the date of the literature search specified in the Research Methods section. Health Quality Ontario makes no representation that the literature search captured every publication that was or could be applicable to the subject matter of the report. This rapid review may be superseded by an updated publication on the same topic. Please check the Health Quality Ontario website for a list of all publications: http://www.hqontario.ca/evidence/publications-and-ohtac-recommendations.

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List of Abbreviations

AMSTAR	Assessment of Multiple Systematic Reviews
GRADE	Grading of Recommendations Assessment, Development, and Evaluation
OR	Odds ratio
RCT	Randomized controlled trial
SMD	Standardized mean difference

Background

In July 2013, the Evidence Development and Standards (EDS) branch of Health Quality Ontario (HQO) began work on developing an evidentiary framework for end of life care. The focus was on adults with advanced disease who are not expected to recover from their condition. This project emerged from a request by the Ministry of Health and Long-Term Care that HQO provide them with an evidentiary platform on strategies to optimize the care for patients with advanced disease, their caregivers (including family members), and providers.

After an initial review of research on end-of-life care, consultation with experts, and presentation to the Ontario Health Technology Advisory Committee (OHTAC), the evidentiary framework was produced to focus on quality of care in both the inpatient and the outpatient (community) settings to reflect the reality that the best end-of-life care setting will differ with the circumstances and preferences of each client. HQO identified the following topics for analysis: determinants of place of death, patient care planning discussions, cardiopulmonary resuscitation, patient, informal caregiver and healthcare provider education, and team-based models of care. Evidence-based analyses were prepared for each of these topics.

HQO partnered with the Toronto Health Economics and Technology Assessment (THETA) Collaborative to evaluate the cost-effectiveness of the selected interventions in Ontario populations. The economic models used administrative data to identify an end-of-life population and estimate costs and savings for interventions with significant estimates of effect. For more information on the economic analysis, please contact Murray Krahn at murray.krahn@theta.utoronto.ca.

The End-of-Life mega-analysis series is made up of the following reports, which can be publicly accessed at http://www.hqontario.ca/evidence/publications-and-ohtac-recommendations/ohtas-reports-and-ohtac-recommendations.

- End-of-Life Health Care in Ontario: OHTAC Recommendation
- Health Care for People Approaching the End of Life: An Evidentiary Framework
- Effect of Supportive Interventions on Informal Caregivers of People at the End of Life: A Rapid Review
- Cardiopulmonary Resuscitation in Patients with Terminal Illness: An Evidence-Based Analysis
- The Determinants of Place of Death: An Evidence-Based Analysis
- Educational Intervention in End-of-Life Care: An Evidence-Based Analysis
- End-of-Life Care Interventions: An Economic Analysis
- Patient Care Planning Discussions for Patients at the End of Life: An Evidence-Based Analysis
- Team-Based Models for End-of-Life Care: An Evidence-Based Analysis

Objective of Analysis

Our objective is to determine the effectiveness of supportive interventions in improving coping and reducing burden and distress for informal caregivers of patients who are at the end of life.

Clinical Need and Target Population

More than 50% of people, including those with advanced illness, want to die at home. (1, 2) However, only 30% of Canadians died at home in 2003 (1), and from 2007 to 2009 about 22% of Ontarians died at home and about 18% died in long-term care facilities. (Ba’ Pham, personal communication, February 25, 2014)

A home death is more likely if a person is receiving home-based care. (3) Often, such care is provided by informal caregivers, unpaid individuals who are usually relatives or friends of the care recipient. By definition, people are considered to be at end of life when they have a life-threatening illness from which they are not expected to recover, and their condition continues to deteriorate. (4) Hence, they have an increasing need for assistance with daily tasks.

Informal caregivers sometimes assist with providing care in long-term care facilities as well. The care they provide in these facilities includes, but is not limited to, transportation, food preparation, feedings, grooming, and baths. Sometimes multiple informal caregivers will provide this type of care to a patient residing in a long-term care home.

Providing informal care for people at the end of life can be burdensome, and studies have shown that it can have negative health impacts for the caregivers, such as sleep problems, fatigue, psychosocial distress (i.e., depression and anxiety), burnout, and an increased risk of mortality. (5) Studies have also shown that informal caregivers tend to suffer from financial strain. (6) Furthermore, it is important to recognize that more people are now working outside the home, which may further add to the burden of informal caregiving.

Based on data from IntelliHealth Ontario, about 87,000 Ontarians died each year from 2007 to 2009. Assuming that the 40% of them who died at home or in long-term care facilities had an informal caregiver, that means an estimated 35,000 Ontarians served as informal end-of-life caregivers each year. There is a great need to understand how to better support these individuals as they provide care for people who are at the end of their lives.

Rapid Review

Research Question

What is the effectiveness of supportive interventions in improving coping and reducing distress for informal caregivers of patients receiving palliative/end-of-life care?

Research Methods

Literature Search

Search Strategy

A literature search was performed on February 26, 2014, using Ovid MEDLINE, Ovid MEDLINE In-Process and Other Non-Indexed Citations, and EBM Reviews, for studies published from January 1, 2009, to February 26, 2014. (Appendix 1 provides details of the search strategies.) Abstracts were reviewed by a single reviewer and, for those studies meeting the eligibility criteria, full-text articles were obtained.

Inclusion Criteria

- English-language full-text publications
- published between January 1, 2009, and February 26, 2014
- systematic reviews (SRs), meta-analyses, and health technology assessments
- informal caregivers of adult patients (aged 18 and over) with advanced disease or who are seriously ill and whose health is likely to continue to deteriorate
- informal caregivers of adult patients at the end of life
- supportive interventions that have an effect on informal caregivers

Exclusion Criteria

- primary studies (observational studies and RCTs on the topic)
- non-systematic reviews, case reports, editorials, letters, comments, conference abstracts
- children only (less than 18 years of age)
- related to sudden or violent death

Outcomes of Interest

- informal caregiver coping/burden
- informal caregiver distress (i.e., anxiety and depression)

Statistical Analysis

We divided the primary studies (all RCTs) from the systematic review into subgroups based on the types of interventions they used. Within the subgroups, we pooled the studies to create 1 effect estimate for each intervention type. Using the I^2 statistic, we assessed heterogeneity, and then pooled the results only if the confidence intervals for their effect estimates overlapped. If the I^2 statistic was less than 30% and the confidence intervals overlapped, we used fixed effects models to pool the estimates. If the I^2 statistic was greater than 30% and the confidence intervals overlapped, we used a random effects model to pool the estimates. If the I^2 statistic was greater than 30% and the confidence intervals did not overlap, we did not pool the estimates.

Expert Panel

In August 2013, an Expert Advisory Panel on End-of-Life Care was struck. Members of the panel included physicians, nurses, social workers, health care administrators, health care researchers, and health economists.

The role of the Expert Advisory Panel on End-of-Life Care was to contextualize the evidence produced by Health Quality Ontario and provide advice on end-of-life care in the Ontario health care setting. However, the statements, conclusions, and views expressed in this report do not necessarily represent the views of Expert Advisory Panel members.

Quality of Evidence

The Assessment of Multiple Systematic Reviews (AMSTAR) measurement tool was used to assess the methodological quality of systematic reviews. (7)

The quality of the body of evidence for each outcome was examined according to the Grading of Recommendations Assessment, Development, and Evaluation (GRADE) Working Group criteria. (8) The overall quality was determined to be high, moderate, low, or very low using a step-wise, structural methodology.

Study design was the first consideration; the starting assumption was that randomized controlled trials (RCTs) are high quality, whereas observational studies are low quality. Five additional factors—risk of bias, inconsistency, indirectness, imprecision, and publication bias—were then taken into account. Limitations in these areas resulted in downgrading the quality of evidence. Finally, 3 main factors that may raise the quality of evidence were considered: the large magnitude of effect, the dose response gradient, and any residual confounding factors. (8) For more detailed information, please refer to the latest series of GRADE articles. (8)

As stated by the GRADE Working Group, the final quality score can be interpreted using the following definitions:

High	High confidence in the effect estimate—the true effect lies close to the estimate of the effect
Moderate	Moderate confidence in the effect estimate—the true effect is likely to be close to the estimate of the effect, but may be substantially different
Low	Low confidence in the effect estimate—the true effect may be substantially different from the estimate of the effect
Very Low	Very low confidence in the effect estimate—the true effect is likely to be substantially different from the estimate of the effect

Results of Rapid Review

The database search yielded 191 citations published between January 1, 2009, and February 26, 2014 after duplicates were removed. Articles were excluded based on information in the title and abstract. The full texts of potentially relevant articles were obtained for further assessment, and those that did not meet the inclusion criteria were excluded.

Four systematic reviews met the inclusion criteria, because they all evaluated the effectiveness of supportive interventions in improving coping and reducing distress for informal caregivers of people at the end of life. (1, 5, 6, 9) One systematic review was selected based on its relevance to the research question and AMSTAR rating; it asked a research question that was almost identical to ours and had an AMSTAR rating of 11 out of a possible 11. Table 1 describes that systematic review in further detail.

Table 1: Summary of Included Systematic Review Evaluating Effect of Supportive Interventions on Informal Caregivers of People at the End of Life

Author, Year	Search Dates	Selection Criteria	Study Designs, Number of Studies	AMSTAR (out of 11)
Candy et al, 2011 (6)	1716 to 2010	• Primary quantitative studies, but only included RCTs • Adult informal caregivers for a friend or relative with a disease in the terminal phase • Evaluated intervention that aimed to provide support to the caregiver • Main aim was to assess impact on informal caregiver	RCTs, 11	11

Abbreviation: RCT, randomized controlled trial.

Description of Studies Included in the Systematic Review

Populations

The 11 randomized controlled trials (RCTs) included in the systematic review looked at a total of 1,836 informal caregivers, with 8 of the RCTs looking at more than 100 caregivers each. Typically, the informal caregivers were from 50 to 65 years of age and were spouses or adult children of the people receiving care. In all of the RCTs, the care recipients were adults with diseases in the terminal phase; in all but 1 RCT, the care recipients had cancer. (6)

Settings

Seven of the 11 RCTs were conducted in the United States, 2 were conducted in Australia, and 2 in the United Kingdom. Eight looked at patients who were living at home, 1 looked at patients receiving community-based hospice care, 1 at patients enrolled in a hospice program that included inpatient home care, and 1 at a mix of inpatients and outpatients. (6)

Interventions

Two types of interventions were considered in the studies: those which provided support directly to the informal caregiver, henceforth called “direct interventions”; and those which provided support to the patient, but were expected to have an effect on the informal caregiver, henceforth called “indirect interventions.”

Nine of the 11 RCTs considered direct interventions. In 7 of these, the interventions focused on facilitating coping; in the other 2 they focused on enhancing well-being. None of these interventions provided practical support (e.g., respite care). In 5 of these 9 RCTs, the interventions were delivered by nurses; in 2, by a nurse or social worker; in 1, by social workers; and 1 study did not report who delivered the intervention. Seven of the 9 direct interventions were standardized through the use of a manual or protocol, but 2 studies provided no details about standardization. The direct interventions were tailored to each informal caregiver. They included follow-up sessions and ongoing support, and ranged from 2 to 9 contact sessions. Five of these interventions provided advice and support; 2 interventions were delivered to the entire family; 1 focused on improving sleep and included stimulus control, relaxation, cognitive therapy, and practical advice related to sleep; and 1 intervention provided pain-management education and training. Among the 5 interventions that coupled advice with support, 2 included specific training to improve coping and communication skills (i.e., communicating openly with the patient about illness, and obtaining information to reduce uncertainty); 1 intervention specifically provided support and assistance with caring; and 1 included training for problem solving. (6)

Two studies considered indirect interventions. Both interventions focused on enhancing well-being. One was delivered by nurses who served as care coordinators, and the resulting trial evaluated the effectiveness of care coordinators. The other was delivered by an interprofessional team that included physicians, nurses, a chaplain, social workers, and volunteers. The corresponding trial for that intervention evaluated the effectiveness of inpatient hospice care. Neither indirect intervention was standardized. (6)

Coping

Direct Interventions Versus Usual Care

As shown in Table 2, coping was evaluated in 7 trials that included a total of 738 informal caregivers. The pooled effect of the trials' results showed that direct interventions marginally improved coping, but the effect was not statistically significant (6) and the quality of the evidence was low. None of the intervention types had a significant impact on coping, and the GRADE scores for the trials ranged from very low to moderate.

Table 2: Effect of Direct Supportive Interventions on Improving Coping for Informal Caregivers of People at the End of Life

Type of Direct Intervention	Number of RCTs	Sample Size, Intervention/ Control	SMD[a] (95% CI)	I^2	GRADE
Family intervention	1	17/ 14	0.33 (-0.38 to 1.05)	N/A	Very low
Pain management education and training	1	28/ 28	-0.51 (-1.04 to 0.02)	N/A	Low
Advice and support	2	113/ 98	0.08 (-0.19 to 0.35)[b]	0%	Low
Advice and support + coping strategies and communication skills	2	181/ 188	-0.17 (-0.38 to 0.03)[b]	15%	Moderate
Advice and support + problem solving training + support to assist with caring	1	31/ 40	0.21 (-0.26 to 0.68)	N/A	Moderate
All Direct Interventions	**7**	**370/ 368**	**-0.05 (-0.24 to 0.14)[c]**	**33%**	**Low**

Abbreviations: CI, confidence interval; GRADE, Grading of Recommendations Assessment, Development, and Evaluation; N/A, not applicable; RCT, randomized controlled trial; SMD, standardized mean difference.

[a] Negative (-) SMDs favour the intervention.

[b] Calculated using a fixed effects model.

[c] Calculated using a random effects model.

Indirect Interventions

None of the RCTs assessing indirect interventions evaluated coping as an outcome. (6)

Distress

Direct Interventions Versus Usual Care

As shown in Table 3, based on low-quality evidence from trials that involved 936 informal caregivers, direct interventions had a small (i.e., standardized effect measure of 0.2 or less) but statistically significant effect on decreasing distress. (6) Furthermore, of the various direct interventions that were evaluated, moderate-quality evidence showed that those which provided general advice and support, in addition to strategies to improve coping and communication skills, were associated with a statistically significant decrease in distress among informal caregivers. The quality of evidence for each type of intervention ranged from very low to moderate.

Table 3: Effect of Direct Supportive Interventions on Reducing Distress for Informal Caregivers of People at the End of Life

Type of Direct Intervention	Number of RCTs	Sample Size, Intervention/ Control	SMD[a] (95% CI)	I^2	GRADE
Family intervention	2	166/106	0.00 (-0.24 to 0.25)[b]	0%	Low
Pain management education and training	1	28/28	-0.42 (-0.95 to 0.11)	N/A	Low
Advice and support	2	110/99	-0.16 (-0.43 to 0.11)[b]	0%	Low
Advice and support + coping strategies and communication skills	2	181/188	-0.24 (-0.45 to -0.04)[b]	0%	Moderate
Strategies to improve sleep	1	15/15	0.07 (-0.64 to 0.79)	N/A	Very low
All Direct Interventions	**8**	**500/436**	**-0.15 (-0.28 to -0.02)[c]**	**0%**	**Low**

Abbreviations: CI, confidence interval; GRADE, Grading of Recommendations Assessment, Development, and Evaluation; N/A, not applicable; RCT, randomized controlled trial; SMD, standardized mean difference.

[a] Negative (-) SMDs favour the intervention.

[b] Calculated using a fixed effects model.

[c] Calculated using a random effects model.

Indirect Interventions

Two studies evaluated the effect of indirect interventions on informal-caregiver distress. However, the authors of 1 of these failed to provide full details about their analyses and results. Hence, it was not possible to pool the information from the 2 studies; the results are described in-text, as follows:

The intervention that included a care coordinator appeared to reduce depression (odds ratio [OR], 0.89; 95% confidence interval [CI], 0.42–1.86) and anxiety (OR, 0.61; 95% CI, 0.29–1.26), which are 2 dimensions of psychological distress. The results were not significant, however, (6) and the evidence produced by the corresponding RCT was of very low quality. The other RCT looked at the effectiveness of inpatient hospice care on decreasing distress among informal caregivers. It found no significant difference in depression between the intervention and control groups, but it did find a statistically significant reduction in anxiety for caregivers in the intervention group ($P < 0.01$). (6) However, the authors did not provide details about their results. Also, the evidence from this trial, like the evidence from the trial evaluating the effectiveness of care coordinators, was of very low quality.

Summary of Results

A summary of the results from this rapid review is presented in Table 4.

Table 4: Effects of Supportive Interventions on Informal Caregivers of People at the End of Life—Summary of Results

Type of Intervention	Coping		GRADE	Distress		GRADE
	Favours Intervention	**Favours Usual Care**		**Favours Intervention**	**Favours Usual Care**	
Direct Interventions						
Family intervention		✓	Very low[a]			Low
Pain management education and training	✓		Moderate[a]	✓		Moderate[a]
Advice and support		✓	Low	✓		Low
Advice and support + coping strategies and communication skills	✓		Moderate	✓[b]		Moderate
Advice and support + problem solving training + support to assist with caring		✓	Moderate[a]	N/A	N/A	N/A
Strategies to improve sleep	N/A	N/A	N/A		✓	Very low[a]
All Direct Interventions	✓		**Low**	✓[b]		**Low**
Indirect Interventions						
Care coordinator	N/A	N/A	N/A	✓		Very low
Inpatient hospice care	N/A	N/A	N/A	✓		Very low
All Indirect Interventions	N/A	N/A	N/A	✓		**Very low**

Abbreviations: GRADE, Grading of Recommendations Assessment, Development, and Evaluation; N/A, not applicable.

[a] Based on 1 RCT with fewer than 100 participants.

[b] Statistically significant ($P \le 0.05$).

Conclusions

Overall, low-quality evidence shows that *direct interventions* have a small effect on reducing distress for informal caregivers of people at the end of life, but no effect on helping them cope. Among the different types of direct interventions, moderate-quality evidence shows which ones are associated with reduced distress—those which combine general advice and support with educational strategies to help the caregivers improve their coping and communication skills (i.e., helping them to communicate openly about illness with the dying person, and to obtain information to reduce uncertainty). However, despite their aim to improve coping skills, these interventions had no impact on coping. The evidence regarding direct interventions comes from 9 fairly recent RCTs.

Evidence of very low quality suggests that the *indirect interventions* included in the systematic review did not have an effect on informal caregivers' distress. These interventions were evaluated in 2 RCTS, 1 published in 1992 and the other in 1984; and there were no studies that evaluated the effect of indirect interventions on the caregivers' ability to cope. This points to a need for more-recent RCTs to study the effects of indirect supportive interventions on informal caregivers' coping and distress.

Some of the major limitations of this rapid review:

- Although the systematic review that we relied on—the review by Candy and colleagues—has a high AMSTAR rating and asks a research question similar to ours, it missed a large proportion of the relevant body of evidence. For instance, we identified 3 other systematic reviews on the topic, and there was little overlap between the primary studies they included and the studies Candy et al included. (1, 5, 6, 9) This was true after considering both included and excluded studies.
- Some types of supportive interventions, such as respite care, were not considered in the RCTs included in the Candy et al review. Hence, there is a gap in the types of interventions that were considered in this rapid review.
- Lastly, 10 of the 11 RCTs in the systematic review were conducted with informal caregivers of cancer patients. Hence, the results of this rapid review might have limited generalizability to informal caregivers of non-cancer patients.

Acknowledgements

Editorial Staff
Sue MacLeod, BA

Medical Information Services
Corinne Holubowich, BEd, MLIS
Kellee Kaulback, BA(H), MISt

Health Quality Ontario's Expert Advisory Panel on End-of-Life Care

Panel Member	Affiliation(s)	Appointment(s)
Panel Co-Chairs		
Dr Robert Fowler	Sunnybrook Research Institute University of Toronto	Senior Scientist Associate Professor
Shirlee Sharkey	St. Elizabeth Health Care Centre	President and CEO
Professional Organizations Representation		
Dr Scott Wooder	Ontario Medical Association	President
Health Care System Representation		
Dr Douglas Manuel	Ottawa Hospital Research Institute University of Ottawa	Senior Scientist Associate Professor
Primary/ Palliative Care		
Dr Russell Goldman	Mount Sinai Hospital, Tammy Latner Centre for Palliative Care	Director
Dr Sandy Buchman	Mount Sinai Hospital, Tammy Latner Centre for Palliative Care Cancer Care Ontario University of Toronto	Educational Lead Clinical Lead QI Assistant Professor
Dr Mary Anne Huggins	Mississauga Halton Palliative Care Network; Dorothy Ley Hospice	Medical Director
Dr Cathy Faulds	London Family Health Team	Lead Physician
Dr José Pereira	The Ottawa Hospital University of Ottawa	Professor, and Chief of the Palliative Care program at The Ottawa Hospital
Dean Walters	Central East Community Care Access Centre	Nurse Practitioner
Critical Care		
Dr Daren Heyland	Clinical Evaluation Research Unit Kingston General Hospital	Scientific Director
Oncology		
Dr Craig Earle	Ontario Institute for Cancer Research Cancer Care Ontario	Director of Health Services Research Program
Internal Medicine		

Panel Member	Affiliation(s)	Appointment(s)
Dr John You	McMaster University	Associate Professor
Geriatrics		
Dr Daphna Grossman	Baycrest Health Sciences	Deputy Head Palliative Care
Social Work		
Mary-Lou Kelley	School of Social Work and Northern Ontario School of Medicine Lakehead University	Professor
Emergency Medicine		
Dr Barry McLellan	Sunnybrook Health Sciences Centre	President and Chief Executive Officer
Bioethics		
Robert Sibbald	London Health Sciences Centre University of Western Ontario	Professor
Nursing		
Vicki Lejambe	Saint Elizabeth Health Care	Advanced Practice Consultant
Tracey DasGupta	Sunnybrook Health Sciences Centre	Director, Interprofessional Practice
Mary Jane Esplen	De Souza Institute University of Toronto	Director Clinician Scientist

Appendices

Appendix 1: Literature Search Strategies

Search date: February 26, 2014
Databases searched: Ovid MEDLINE, Ovid MEDLINE In-Process, All EBM Databases (see below)

Limits: 2009-current; English
Filters: Systematic reviews, meta-analyses, health technology assessments

Database: EBM Reviews - Cochrane Database of Systematic Reviews <2005 to January 2014>, EBM Reviews - ACP Journal Club <1991 to February 2014>, EBM Reviews - Database of Abstracts of Reviews of Effects <1st Quarter 2014>, EBM Reviews - Cochrane Central Register of Controlled Trials <January 2014>, EBM Reviews - Cochrane Methodology Register <3rd Quarter 2012>, EBM Reviews - Health Technology Assessment <1st Quarter 2014>, EBM Reviews - NHS Economic Evaluation Database <1st Quarter 2014>, Ovid MEDLINE(R) <1946 to February Week 2 2014>, Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations <February 25, 2014>
Search Strategy:

#	Searches	Results
1	exp Terminal Care/	40195
2	exp Palliative Care/	40423
3	exp Terminally Ill/	5287
4	((End adj2 life adj2 care) or EOL care or (terminal* adj2 (care or caring or ill* or disease*)) or palliat* or dying or (Advanced adj3 (disease* or illness*)) or end stage*).ti,ab.	149715
5	or/1-4	190042
6	exp Day Care/	4856
7	exp Home Nursing/	8858
8	exp social support/	51634
9	exp Caregivers/	21412
10	exp Adaptation, Psychological/	103004
11	exp Family Nursing/	1031
12	(daycare* or day care* or respite or caregiver* or care giver* or carer* or ((non-professional or nonprofessional) adj home care*) or supportive intervention* or social support* or psychosocial support* or social network* or support* system* or home nursing* or ((care* or caregiver* or caring) adj2 (family or families or spouse* or friend* or relative* or peer* or parent* or husband* or wife or wives or child or children or significant other*)) or ((coping or adapt* or adjust*) adj2 (skill* or behavio?r* or psych*)) or (family adj2 (nursing* or centred or centered or focus*)) or ((family or families or spouse* or friend* or relative* or peer* or parent* or husband* or wife or wives or child or children or significant other*) adj5 (support* or information or help* or assist* or service* or train*or educat* or teach* or advis* or advice* or counsel* or intervention* or therap* or program*))).ti,ab.	296473
13	or/6-12	412570
14	5 and 13	12623
15	Meta Analysis.pt.	44724
16	Meta-Analysis/ or exp Technology Assessment, Biomedical/	53695
17	(meta analy* or metaanaly* or pooled analysis or (systematic* adj2 review*) or published studies or published literature or medline or embase or data synthesis or data extraction or cochrane).ti,ab.	194964
18	((health technolog* or biomedical technolog*) adj2 assess*).ti,ab.	2658

19	or/15-18	211058
20	14 and 19	378
21	limit 20 to (english language and yr="2009 -Current") [Limit not valid in CDSR,ACP Journal Club,DARE,CCTR,CLCMR; records were retained]	198
22	remove duplicates from 21	195

Appendix 2: Evidence Quality Assessment

Table A1: AMSTAR Scores of Studies Meeting the Inclusion Criteria for This Rapid Review

Author, Year	AMSTAR Score[a]	(1) Provided Study Design	(2) Duplicate Study Selection	(3) Broad Literature Search	(4) Considered Status of Publication	(5) Listed Excluded Studies	(6) Provided Characteristics of Studies	(7) Assessed Scientific Quality	(8) Considered Quality in Report	(9) Methods to Combine Appropriate	(10) Assessed Publication Bias	(11) Stated Conflict of Interest
Gomes et al, 2013 (1)	11	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Harding et al, 2011 (9)	5	No[b]	No	Yes[c]	No[d]	No	Yes	Yes	Yes	N/A[e]	No[f]	Yes
Candy et al, 2011 (6)	11	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Hudson et al, 2010 (5)	7	No[b]	Yes	Yes	Yes[g]	No	Yes	Yes	Yes	N/A[e]	No	Yes

Abbreviations: AMSTAR, Assessment of Multiple Systematic Reviews.

[a] Maximum possible score is 11. Details of AMSTAR score are described in Shea et al. (7)

[b] Current review was an update to an earlier systematic review, but protocol for current review was not published.

[c] Searched 2 databases, which is the minimum number specified by AMSTAR.

[d] Only included peer-reviewed reports.

[e] Not applicable, because the results were not pooled.

[f] Authors commented on publication bias, but there was no evidence that publication bias was assessed by the authors.

[g] No indication that non-peer reviewed articles were excluded.

Table A2: GRADE Evidence Profile for RCTs Comparing Family Intervention Versus Usual Care

Number of Studies (Design)	Risk of Bias	Inconsistency	Indirectness	Imprecision	Publication Bias	Upgrade Considerations	Quality
Coping							
1 (RCT)	Very serious limitations (–2)[a,b]	No serious limitations	No serious limitations	Serious limitations (–1)[c]	Undetected	None	⊕ Very Low
Distress							
2 (RCTs)	Very serious limitations (–2)[a,b]	No serious limitations	No serious limitations	No serious limitations	Undetected	None	⊕⊕ Low

Abbreviations: GRADE, Grading of Recommendations Assessment, Development, and Evaluation; RCT, randomized controlled trial.

[a] Could not assess the risk of selection, reporting, or detection bias, because the information was not provided.

[b] Risk of attrition bias was unclear from the information provided.

[c] Very wide confidence interval.

Table A3: GRADE Evidence Profile for RCTs Comparing Education and Training Intervention Versus Usual Care

Number of Studies (Design)	Risk of Bias	Inconsistency	Indirectness	Imprecision	Publication Bias	Upgrade Considerations	Quality
Coping							
1 (RCT)	Serious limitations (–1)[a]	No serious limitation	No serious limitations	Serious limitations (–1)[b]	Undetected	None	⊕⊕ Low
Distress							
1 (RCT)	Serious limitations (–1)[a]	No serious limitation	No serious limitations	Serious limitations (–1)[b]	Undetected	None	⊕⊕ Low

Abbreviations: GRADE, Grading of Recommendations Assessment, Development, and Evaluation; RCT, randomized controlled trial.

[a] There was not enough information to guide the assessment of the risk of selection or reporting bias.

[b] Very wide confidence interval.

Table A4: GRADE Evidence Profile for RCTs Comparing Advice and Support Intervention Versus Usual Care

Number of Studies (Design)	Risk of Bias	Inconsistency	Indirectness	Imprecision	Publication Bias	Upgrade Considerations	Quality
Coping							
2 (RCTs)	Serious limitations (–1)[a]	Serious limitations (–1)[b]	No serious limitations	No serious limitations	Undetected	None	⊕⊕ Low
Distress							
2 (RCTs)	Serious limitations (–1)[a]	No serious limitations	No serious limitations	Serious limitations (–1)[c]	Undetected	None	⊕⊕ Low

Abbreviations: GRADE, Grading of Recommendations Assessment, Development, and Evaluation; RCT, randomized controlled trial.

[a] There was not enough information to guide the assessment of the risk of detection, attrition or reporting bias.

[b] One result favoured the intervention and the other favoured the control.

[c] Very wide confidence interval.

Table A5: GRADE Evidence Profile for RCTs Comparing Communication, Coping, Advice, and Support Intervention Versus Usual Care

Number of Studies (Design)	Risk of Bias	Inconsistency	Indirectness	Imprecision	Publication Bias	Upgrade Considerations	Quality
Coping							
2 (RCTs)	Serious limitations (–1)[a]	No serious limitations	No serious limitations	No serious limitations	Undetected	None	⊕⊕⊕ Moderate
Distress							
2 (RCTs)	Serious limitations (–1)[a]	No serious limitations	No serious limitations	No serious limitations	Undetected	None	⊕⊕⊕ Moderate

Abbreviations: GRADE, Grading of Recommendations Assessment, Development, and Evaluation; RCT, randomized controlled trial.

[a] There was not enough information to guide the assessment of the risk of selection or reporting bias.

Table A6: GRADE Evidence Profile for RCT Comparing Advice, Support, Problem Solving, and Support to Assist with Caring Intervention Versus Usual Care

Number of Studies (Design)	Risk of Bias	Inconsistency	Indirectness	Imprecision	Publication Bias	Upgrade Considerations	Quality
Coping							
1 (RCT)	No serious limitations	No serious limitations	No serious limitations	Serious limitations (–1)[a]	Undetected	None	⊕⊕⊕ Moderate

Abbreviations: GRADE, Grading of Recommendations Assessment, Development, and Evaluation; RCT, randomized controlled trial.

[a] Wide confidence interval.

Table A7: GRADE Evidence Profile for RCT Comparing Sleep-Related Intervention Versus Usual Care

Number of Studies (Design)	Risk of Bias	Inconsistency	Indirectness	Imprecision	Publication Bias	Upgrade Considerations	Quality
Distress							
1 (RCT)	Very serious limitations (–2)[a]	No serious limitations	No serious limitations	Serious limitations (–1)[b]	Undetected	None	⊕ Very Low

Abbreviations: GRADE, Grading of Recommendations Assessment, Development, and Evaluation; RCT, randomized controlled trial.

[a] Could not assess selection, detection, attrition, or reporting bias based on the information provided.

[b] Wide confidence interval.

Table A8: GRADE Evidence Profile for RCT Comparing Care Coordinator Intervention Versus Usual Care

Number of Studies (Design)	Risk of Bias	Inconsistency	Indirectness	Imprecision	Publication Bias	Upgrade Considerations	Quality
Distress							
1 (RCT)	Very serious limitations (–2)[a]	No serious limitations	No serious limitations	Serious limitations (–1)[b]	Undetected	None	⊕ Very Low

Abbreviations: GRADE, Grading of Recommendations Assessment, Development, and Evaluation; RCT, randomized controlled trial.

[a] Could not assess selection, attrition, or reporting bias based on the information provided.

[b] Wide confidence interval.

Table A9: GRADE Evidence Profile for RCT Comparing Inpatient Hospice Care Intervention Versus Usual Care

Number of Studies (Design)	Risk of Bias	Inconsistency	Indirectness	Imprecision	Publication Bias	Upgrade Considerations	Quality
Distress							
1 (RCT)	Very serious limitations (–2)[a]	No serious limitations	No serious limitations	Serious limitations (–1)[b]	Undetected	None	⊕ Very Low

Abbreviations: GRADE, Grading of Recommendations Assessment, Development, and Evaluation; RCT, randomized controlled trial.

[a] Could not assess selection, detection, attrition, or reporting bias based on the information provided.

[b] Could not assess using the information provided.

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Health Quality Ontario
130 Bloor Street West, 10th Floor
Toronto, Ontario
M5S 1N5
Tel: 416-323-6868
Toll Free: 1-866-623-6868
Fax: 416-323-9261
Email: EvidenceInfo@hqontario.ca
www.hqontario.ca