

### Evidence Summary 18-3 ARCHIVED

## A Quality Initiative of the Program in Evidence-Based Care (PEBC), Cancer Care Ontario (CCO)

## Guidelines for Palliative Care

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## A Quality Initiative of the Program in Evidence-Based Care (PEBC), Cancer Care Ontario (CCO)

### **Evidence Summary**

#### THE PROGRAM IN EVIDENCE-BASED CARE

The Program in Evidence-Based Care (PEBC) is an initiative of the Ontario provincial cancer system, Cancer Care Ontario (CCO). The PEBC mandate is to improve the lives of Ontarians affected by cancer through the development, dissemination, and evaluation of evidence-based products designed to facilitate clinical, planning, and policy decisions about cancer control.

The PEBC is a provincial initiative of CCO supported by the Ontario Ministry of Health and Long-Term Care (OMHLTC). All work produced by the PEBC and any associated Programs is editorially independent from the OMHLTC.

#### INTRODUCTION

There are various definitions for palliative care, but most people would agree that "it focuses on care that addresses both physical and non-physical symptoms. It can be delivered throughout the course of the disease. It involves a team of healthcare providers and supports patients as well as their families."[1]

This evidence summary on palliative care guidelines was requested by the Ontario Palliative Care Network (OPCN). The purpose of this evidence summary is to identify existing palliative care guidelines that could potentially be endorsed or adapted for use in Ontario.

#### **RESEARCH QUESTIONS**

These research questions were developed to direct the search for available evidence on any palliative guidelines in the public domain.

#### TARGET POPULATION

The target population of the guideline search is any individual requiring palliative care.

#### INTENDED PURPOSE

To determine the breadth and scope of palliative care guidelines that are available in the public domain.

#### **INTENDED USERS**

Clinicians and staff involved in the delivery of palliative care.

#### METHODS

This evidence summary was developed by a Working Group consisting of a palliative care physician, a clinical nurse manager, a palliative care specialist, a quality standards lead, and a health research methodologist.

The Working Group was responsible for reviewing the identified evidence and drafting the summary. Conflict of interest declarations for all authors are summarized in Appendix 1, and were managed in accordance with the <u>PEBC Conflict of Interest Policy</u>.

#### Search for Existing Guidelines

A search was conducted for existing guidelines. The search was undertaken in the following databases: Medline, EMBASE, and HeathSTAR. The databases were searched from January 1, 2000 to March 10, 2016. The search terms used included: guideline, consensus, palliative care, palliative medicine, terminal care, hospice, and palliative therapy. A complete literature search strategy is available in Appendix 2. The websites of major international as well as national guideline developers were also searched using the terms "palliative care". These include the National Institute for Health Care and Excellence (NICE), Scottish Intercollegiate Guidelines Network (SIGN), The BC Cancer Agency, Alberta Health Services, National Comprehensive Cancer Network (NCCN), American Society of Clinical Oncology (ASCO), National Guideline Clearinghouse, New Zealand Guidelines Group, Australian Clinical Practice Guidelines.

#### **Study Selection Criteria and Process**

Papers were included if they provided any recommendations on palliative care. Papers were excluded if they only provided guideline or consensus methods and no recommendations.

A review of the titles and abstracts that resulted from the search was conducted independently by one reviewer (NC). For items that warranted full-text review, one reviewer (NC) reviewed each item independently.

#### Data Extraction and Assessment of Study Quality and Potential for Bias

For the selected guidelines, one reviewer (NC) assessed each guideline for quality using the "Rigour of Development" scale from the AGREE instrument [2].

#### RESULTS

#### Search for Existing Guidelines

A total of 4943 potential guidelines were found; 4915 were identified through the electronic search and 28 from searching the websites of major guideline development groups. Articles were chosen for full-text review if they contained any recommendations. The flow diagram can be seen in Appendix 3.

Of the 266 potential guidelines chosen for full-text review, 172 were retained after the full-text review. The guidelines were then sorted into three groups. The first contains guidelines on general aspects of palliative care; the second group contains guidelines that are disease specific (i.e. cancer, diabetes, or amyotrophic lateral sclerosis); and the third contains palliative care guidelines that pertain to children from newborn to 18 years of age. There were 88 guidelines on general aspects of palliative care, 69 disease-specific guidelines, and 15 for children.

Due to the large number of guidelines, the Working Group decided to restrict the review to include only guidelines published in the past five years (2011 to 2016). To identify the best-quality guidelines, the AGREE Instrument Rigour of Development scale was used and only guidelines that scored 28 or above were included in this review. The AGREE Rigour of Development scale is scored out of seven for each of eight questions for a total possible score of 56 [2]. Guidelines that scored 28 or above were considered to have higher AGREE scores and will be discussed below. The Working Group chose this section to use as a screening tool because it shows how rigorous the reported guideline methods were. It was also faster to do this one section than completing the whole AGREE scale for all the large number of identified guidelines.

#### General Palliative Care Guidelines

This section contains guidelines that pertain to palliative care but are not disease or patient specific. This section is the most detailed of the three sections, and the most relevant because it focuses on the whole pathway of palliative care and is related to the guideline objective. Some of the guidelines are broad and cover the entire palliative care path that a patient would follow, while others are narrow in scope and only pertain to a single aspect of palliative care. Of the 172 potential guidelines selected for full-text review, 88 were classified as general palliative care. Of these, 66 guidelines were published before 2011 and, thus, excluded (see Appendix 4). Fifteen guidelines had AGREE Rigour of Development subsection scores lower than 28 [3-17] and seven had high AGREE scores that were 28 or higher [18-24]. The guidelines that could be assessed using the AGREE tool are presented in Table 1.

| Developer  | Title   | Year | Rigour of<br>Development<br>subsection<br>AGREE Score |
|--|---|------|---|
| Lower AGREE scores   |   |      |   |
| McDonald et al. [3]  | Clinical practice guideline on adult domiciliary<br>oxygen therapy: executive summary from the<br>Thoracic Society of Australia and New Zealand       | 2016 | 27  |
| Sinuff et al. [4]  | Improving end-of-life communication and decision<br>making: the development of a conceptual<br>framework and quality indicators                       | 2015 | 26  |
| Hudson et al. [5]  | Guidelines for the psychosocial and bereavement<br>support of family caregivers of palliative care<br>patients  | 2012 | 24  |
| Ministry of Health, New Zealand [6]  | Te Ara Whakapiri principles and guidance for the last days of life  | 2015 | 23  |
| Herndon et al. [7]   | Consensus recommendations from the strategic<br>planning summit for pain and palliative care<br>pharmacy practice                                     | 2012 | 22  |
| American College of Emergency,<br>Physicians<br>American Geriatrics, Society of<br>Emergency Nurses, Association<br>Society for Academic Emergency<br>Medicine [8] | Geriatric emergency department guidelines   | 2014 | 22  |
| National Consensus Project for<br>Quality Palliative Care [9]  | Clinical practice guidelines for quality palliative<br>Care   | 2013 | 19  |
| Gysels et al. [10]   | MORECare research methods guidance<br>development: recommendations for ethical issues<br>in palliative and end-of-life care research                  | 2013 | 19  |
| Mani et al. [11]   | Guidelines for end-of-life and palliative care in<br>Indian intensive care to units: ISCCM consensus<br>ethical position statement                    | 2013 | 18  |
| Mani et al. [13]   | Guidelines for end-of-life and palliative care in<br>Indian intensive care units: ISCCM consensus<br>ethical position statement                       | 2012 | 17  |
| O'Connor et al. [12]   | Developing Organizational guidelines for the<br>prevention and management of suicide in clients<br>and Careers receiving palliative Care in Australia | 2016 | 17  |

| Developer  | Title  | Year | Rigour of<br>Development<br>subsection<br>AGREE Score |
|--|--|------|---|
| Evans et al. [14]                                | The selection and use of outcome measures in<br>palliative and end-of-life care research: The<br>MORECare International Consensus Workshop   | 2013 | 16  |
| Royal College of Physicians [15]                 | Improving end-of-life care: recommendations on professional development for physicians   | 2012 | 13  |
| Weissman and Meier [16]                          | Identifying patients in need of a palliative care<br>assessment in the hospital setting: a consensus<br>report from the Center to Advance Palliative Care  | 2011 | 12  |
| Anonymous [17]                                   | Improving end-of-life care: recommendations on professional development for physicians   | 2012 | 8   |
| Higher AGREE Scores                              |  |      |   |
| NICE [19]  | Palliative care for adults: strong opioids for pain relief   | 2012 | 52  |
| NICE [18]  | Care of dying adults in the last days of life  | 2015 | 52  |
| Registered Nurses Association of<br>Ontario [20] | Risk assessment & prevention of pressure ulcers  | 2011 | 48  |
| Registered Nurses Association of<br>Ontario [21] | End-of-life care during the last days and hours  | 2011 | 48  |
| Wee et al. [22]                                  | Management of chronic cough in patients receiving<br>palliative care: review of evidence and<br>recommendations by a task group of the<br>Association for Palliative Medicine of Great<br>Britain and Ireland  | 2012 | 37  |
| McCusker et al. [23]                             | Palliative Care for adults   | 2013 | 37  |
| Bausewein et al. [24]                            | White paper on outcome measurement in palliative<br>care: Improving practice, attaining outcomes and<br>delivering quality services - Recommendations<br>from the European Association for Palliative Care<br>(EAPC) Task Force on Outcome Measurement | 2016 | 29  |

Due to the low scores, the guidelines that scored in the bottom half of the range in the AGREE, Rigour of Development scale will not be discussed in detail. It should be noted that many of these guidelines scored low because they were lacking details in several of the guideline development methods, such as: no systematic methods were used to search for evidence, there was no criteria for selecting the evidence, and no method for formulating the recommendations was provided [4-17]. The seven guidelines with highest AGREE Rigour of Development subsection scores ranged in topics from specific aspects of palliative care to the general organization of palliative services [18-24].

The "Palliative Care for Adults" guideline by McCusker et al. [23] from the Institute for Clinical Symptoms Improvement covers the palliative care path from the patient's first diagnosis of a serious illness to death. This guideline had an AGREE Rigour of Development subsection score of 37. It provided few details on the systematic review methods, including how the evidence was selected and how the recommendations were developed. This guideline used GRADE [25] to evaluate the evidence but did not provide much information on how the guidelines were chosen for review. Since this is the only broad palliative care guideline, the recommendations are listed below:

- Clinicians should discuss the likelihood of disease progression to death with patients and/or their families.
- Clinicians should initiate or facilitate advance care planning for all adult patients and their families with regular review as the patient's condition changes.
- Clinicians should use a validated assessment tool to assess palliative care needs.
- Care conferences with the patient, family, and an interdisciplinary health care team are recommended on an ongoing basis to discuss patient's condition, course of illness, treatment options, goals, and plan of care.
- Clinicians should engage in ongoing communication with the patient and/or family regarding the dying process and the treatment plan.
- A cultural assessment should be an integral component of the palliative care plan.
- Palliative care should begin at the time of diagnosis of a serious condition and continue through cure, or until death, and then into the bereavement period.
- Clinicians should recognize those patients who are receiving non-beneficial, low-yield therapy.
- Informed consent should be obtained for any treatment or plan of care from either a patient with decision-making capacity or an appropriate surrogate decision-maker.
- The physical aspects of the patient's serious illness should be an integral component of the palliative care plan.
- Clinicians should follow the established best practices of utilizing professional medical interpreters when English is not a patient's first language or when there are gaps in understanding English.
- A psychological assessment should be an integral component of the palliative care plan.
- Palliative care discussion or referral should be considered whenever the patient develops a serious illness. Palliative care discussions should be included whenever a patient with a life-limiting or life-threatening illness presents, including the hospital ICU intensive care unit or emergency department.
- A social assessment should be an integral component of the palliative care plan.
- A spiritual assessment should be an integral component of the palliative care plan.
- Clinicians should utilize clinically trained chaplains as members of the interdisciplinary health care team to provide patient-centered spiritual care and support.

The guideline by Bausewein et al. and the European Association for Palliative Care (EAPC) [24] scored 29 on the AGREE Rigour of Development subsection scale. This guideline did not provide information on the criteria for selecting evidence, the strengths and limitations of the evidence, and updating the guideline. The focus of this guideline was primarily outcome measurement in palliative care services. The guideline makes recommendations as to what kinds of palliative care outcomes should be measured.

The guideline from the Registered Nurses Association of Ontario [21] scored highly in the AGREE Rigour of Development subsection (48 of 56). This is a Canadian guideline about patient care in the last days and hours of life, and the recommendations in this guideline were specific to nurses. The guideline makes recommendations in the following areas:

- Assessment for end of life,
- Decision support at end of life,
- Care and management at end of life,
- Education, and
- Organization and policy recommendations.

Another guideline from the Registered Nurses Association of Ontario was also found [20]. The topic of this guideline was the assessment and prevention of pressure ulcers. This guideline does not focus solely on palliative care, but the treatment and assessment of pressure ulcers in palliative care is a part of the guideline. This guideline is Canadian and is specific to nurses. The guideline makes recommendations in the following areas:

- Assessment,
- Planning,
- Interventions,
- Discharge or transfer or the care arrangements, and
- Education and organization/policy.

The guideline by Wee et al. [22] discusses chronic cough in patients receiving palliative care. This guideline scored 37 using the AGREE Rigour of Development subsection. The systematic review in this guideline was conducted well; however, much of the evidence was from small studies or cohort studies, case reports, and expert opinion pieces. The small studies were randomized but had high heterogeneity and could not be easily compared to each other. The recommendations include use of simple linctus, therapeutic trial of sodium cromoglycate, and then prescription of an opioid or opioid derivative (dextromethorphan, morphine, or codeine).

Two of the guidelines came from NICE [18,19]. They both scored high on the AGREE Rigour of Development subsection (52 of 56, respectively). One focused on strong opioids for pain relief in patients receiving palliative care [19], and the other on care of dying adults in the last days of life [18]. The guideline on strong opioids for pain relief made recommendations in the following areas [19]:

- Communication,
- Starting strong opioids titrating the dose,
- First-line maintenance treatment,
- First-line treatment if oral opioids are not suitable transdermal patches,
- First-line treatment if oral opioids are not suitable subcutaneous delivery,
- Management of constipation,
- Management of nausea, and
- Management of drowsiness.

The care of dying adults in the last days of life guideline made recommendations in the following areas [18]:

- Recognizing when a person may be in the last days of life,
- Communication,
- Shared decision-making,
- Providing individualized care,
- Maintaining hydration,
- Pharmacological interventions, and
- Anticipatory prescribing.

#### Disease-Specific Guidelines

This section contains guidelines that are specific to a group of patients with a disease or condition. The majority of the guidelines pertain to cancer or patients with dementia. Of the 172 papers that were selected for full-text review, 69 were classified as disease-specific palliative care. Of these, 46 guidelines were published before 2011 and excluded (see Appendix 4). Six had AGREE Rigour of Development subsection scores lower than 28 and will not be discussed further [26-31] and 17 had AGREE scores that were 28 or higher [32-48]. The results of the AGREE Rigour of Development assessment can be seen in the table below.

|                              | ease-specific guidelines selected for inclusion   |                              | V    | Diagona - f   |
|------------------------------|---|------------------------------|------|---|
| Developer                    | Title   | Condition                    | Year | Rigour of<br>Development<br>subsection<br>AGREE Score |
| Lower AGREE Scores           |   |                              |      |   |
| Van Der Steen et al.<br>[26] | White paper defining optimal palliative care in older<br>people with dementia: <b>a</b> Delphi study and<br>recommendations from the European Association for<br>Palliative Care                                  | Dementia                     | 2014 | 27  |
| Strachan et al. [27]         | Development of a practice tool for community-based<br>nurses: The Heart Failure Palliative Approach to Care<br>(HeFPAC)   | Heart                        | 2014 | 26  |
| Andersen et al. [28]         | EFNS guidelines on the Clinical Management of<br>amyotrophic lateral Sclerosis (MALS) - revised<br>report of an EFNS task force   | ALS                          | 2012 | 25  |
| Smyth et al. [29]            | European Cystic Fibrosis Society Standards of Care:<br>best practice guidelines   | Cystic<br>Fibrosis           | 2014 | 23  |
| Chow et al. [31]             | Update of the international consensus on palliative<br>radiotherapy endpoints for future clinical trials in<br>bone metastases  | Cancer                       | 2012 | 19  |
| Papamichael et al. [30]      | Treatment of colorectal cancer in older patients:<br>International Society of Geriatric Oncology (SIOG)<br>consensus recommendations 2013   | Cancer                       | 2015 | 19  |
| Higher AGREE<br>Scores       |   |                              |      |   |
| Berger et al. (NCCN)<br>[32] | Cancer-related fatigue, version 1.2016.   | Cancer                       | 2016 | 46  |
| Rayner et al. [35]           | The development of evidence-based European<br>guidelines on the management of depression in<br>palliative cancer care   | Cancer                       | 2011 | 40  |
| Yamaguchi et al. [33]        | Clinical guideline for pharmacological management<br>of cancer pain: the Japanese Society of Palliative<br>Medicine recommendations   | Cancer                       | 2013 | 40  |
| Levy et al. (NCCN) [34]      | Palliative care, version 1.2016.  | Cancer                       | 2016 | 40  |
| Smith et al. [36]            | American Society of Clinical Oncology provisional<br>clinical opinion: The integration of palliative care<br>into standard oncology care  | Cancer                       | 2012 | 39  |
| Lutz et al. [37]             | Palliative radiotherapy for bone metastases: An ASTRO evidence-based guideline  | Cancer                       | 2011 | 37  |
| Rodrigues et al. [39]        | Palliative thoracic radiotherapy in lung cancer: An<br>American Society for Radiation Oncology evidence-<br>based clinical practice guideline   | Cancer                       | 2011 | 36  |
| Mallery et al. [38]          | Evidence-informed guidelines for treating frail older<br>adults with type 2 diabetes: from the Diabetes Care<br>Program of Nova Scotia (DCPNS) and the palliative<br>and therapeutic harmonization (PATH) program | Older adults<br>and diabetes | 2013 | 36  |
| Brajtman et al. [40]         | Developing guidelines on the assessment and<br>treatment of delirium in older adults at the end of life   | Older adults                 | 2011 | 34  |
| Oliver et al. [41]           | A consensus review on the development of palliative   | Neurological                 | 2016 | 33  |

| Developer                         | Title  | Condition | Year | Rigour of<br>Development<br>subsection<br>AGREE Score |
|-----------------------------------|--|-----------|------|---|
|                                   | care for patients with chronic and progressive neurological disease  | diseases  |      |   |
| Kim et al. [42]                   | ACR Appropriateness Criteria® non-spine bone metastases  | Cancer    | 2015 | 32  |
| Dunning et al. [43]               | Developing clinical guidelines for end-of-life care:<br>blending evidence and consensus  | Diabetes  | 2012 | 31  |
| Ubogagu <b>and</b> Harris<br>[44] | Guideline for the management of terminal<br>haemorrhage in palliative care patients with advanced<br>cancer discharged home for end-of-life care   | Cancer    | 2012 | 31  |
| Rodrigues et al. [47]             | Consensus statement on palliative lung radiotherapy:<br>Third international consensus workshop on palliative<br>radiotherapy and symptom control   | Cancer    | 2012 | 30  |
| van Riet Paap et al. [45]         | Consensus on quality indicators to assess the<br>organisation of palliative cancer and dementia care<br>applicable across national healthcare systems and<br>selected by international experts | Dementia  | 2014 | 30  |
| Kloke and Cherny [46]             | Treatment of dyspnoea in advanced cancer patients:<br>ESMO clinical practice guidelines  | Cancer    | 2015 | 30  |
| van der Maaden et al.<br>[48]     | Development of a practice guideline for optimal<br>symptom relief for patients with pneumonia and<br>dementia in nursing homes using a Delphi study  | Dementia  | 2015 | 28  |

Abbreviations: ACR, American College of Radiology; EFNS, European Federation of the Neurological Societies; ESMO, European Society of Medical Oncology; NCCN, National Comprehensive Cancer Network

There are 12 guidelines specific to cancer [32-37,39,42,44-47]. The NCCN guideline by Levy et al. [34] is a comprehensive guideline about the palliative care path in cancer patients. It scored highly on the AGREE Rigour of Development subsection scale (40 of 56). This guideline includes recommendations on screening, assessment, palliative interventions, reassessment, and after-death interventions. It does not begin the palliative assessment with the onset of disease, but further along during disease progression or when the patients inquire about it.

The ASCO guideline [36] has a provisional clinical opinion that relates to integrating palliative care services into standard cancer care. This guideline scored 39 on the AGREE Rigour of Development subsection scale and states that palliative care services should begin when patients are diagnosed with metastatic or advanced cancer.

The other higher AGREE Rigour of Development scoring cancer-related guidelines focused on a single aspect of palliative care. There were four guidelines on the use of radiotherapy, two for palliative radiotherapy for bone metastases [37,42], and two for palliative radiotherapy for lung cancer [39,47]. There was one guideline each on depression [35], terminal hemorrhage in cancer palliative care patients being treated at home [44], cancer pain [33], and dyspnea [46]. There was an additional guideline on cancer fatigue [32]; this NCCN guideline was not exclusively on palliative care, but had sections pertaining to palliative care fatigue.

The other large group of disease-specific guidelines pertained to dementia. The guideline by van Riet Paap et al. [45] is a consensus guideline that centres on quality indicators to assess the organization of palliative cancer and dementia care. This guideline scored 30 on the AGREE Rigour of Development subsection scale. This guideline identified 23 quality indicators covering the following areas: the availability of palliative care teams; the availability of special facilities to provide palliative care for patients and their relatives; and

the presence of educational interventions for professionals, such as documentation of pain and other symptoms, communication with patients in need of palliative care and their relatives, and end-of-life decisions.

An additional two guidelines were found that focused on dementia or delirium. The first is a Canadian guideline by Brajtman et al. [40], which pertained to delirium in older adults at the end of life in various healthcare settings. The guideline by van der Maaden et al. [48] focused on reliving symptoms of pneumonia and dementia in patients in nursing homes.

Two guidelines centred on treating diabetes in the palliative setting. The first is a Canadian guideline by Mallery et al. [38] for the Diabetes Care Program of Nova Scotia (DCPNS) and the Palliative and Therapeutic Harmonization (PATH), and focuses on frail older adults with type 2 diabetes. This guideline scored a 36 on the AGREE Rigour of Development subsection scale. The goal of this guideline was to create a more appropriate standard of care regimen for frail patients and makes clinical recommendations for care. The second diabetes guideline is by Dunning et al. [43] This guideline scored 31 on the AGREE Rigour of Development subsection scale and describes the process used to develop a clinical practice guideline for managing diabetes at the end of life. The recommendations are guiding philosophies and not clinical recommendations.

#### **Pediatric Guidelines**

This section contains guidelines that pertain to palliative care and are specific to children. This group includes children from newborns to 18 years of age. Of the 172 papers that were selected for full-text review, 15 pertained to children. Six guidelines were published before 2011 and therefore excluded (see Appendix 4). Six had lower AGREE Rigour of Development subsection scores (lower than 28) and will not be discussed further [49-54] and three had higher AGREE Rigour of Development subsection scores [55-57]. The assessed guidelines can be seen in Table 3 below.

| Developer                | Title  | Year | Rigour of<br>Development<br>subsection<br>AGREE<br>Score |
|--------------------------|--|------|--|
| Lower AGREE Scores       |  |      |  |
| Tsai et al. [52]         | Withholding and withdrawing artificial nutrition and hydration   | 2011 | 21   |
| Warrick et al. [54]      | Guidance for withdrawal and withholding of intensive care as part of neonatal end-of-life care   | 2011 | 25   |
| Feudtner et al. [50]     | Pediatric palliative care and hospice care commitments, guidelines, and recommendations  | 2013 | 15   |
| Mendes and Da Silva [53] | Neonatal palliative care: Developing consensus among<br>neonatologists using the Delphi technique in Portugal                                      | 2013 | 23   |
| Bradford et al. [51]     | Components and principles of a pediatric palliative care consultation: results of a Delphi study   | 2014 | 18   |
| Kenner et al. [49]       | Recommendations for palliative and bereavement care in the NICU: <b>a</b> family-centered integrative approach.                                    | 2015 | 8  |
| Higher AGREE Scores      |  |      |  |
| Berger et al. [55]       | Perinatal care at the limit of viability between 22 and 26 completed weeks of gestation in Switzerland: 2011 revision of the Swiss recommendations | 2011 | 30   |
| Coccia et al. [57]       | Adolescent and young adult oncology clinical practice guidelines in oncology   | 2012 | 40   |

Table 3. Pediatric guidelines selected for inclusion.

| Developer         | Title  | Year | Rigour of<br>Development<br>subsection<br>AGREE<br>Score |
|-------------------|--|------|--|
| Knops et al. [56] | Paediatric palliative care: recommendations for treatment of symptoms in the Netherlands | 2015 | 33   |

There were three guidelines that had AGREE Rigour of Development subsection scores that were 28 or over. The first guideline by Berger et al. [55] focused on palliative care of preterm infants delivered between 22 and 23 weeks' gestation. The second guideline by Coccia at al. [57] was an NCCN guideline that focused on adolescent and young adults through their cancer journey and had a section on palliative care. The third guideline by Knops et al. [56] was a thorough guideline on palliative care for children.

#### DISCUSSION AND CONCLUSION

The goal of this evidence summary was to determine the breadth and scope of available, recent, palliative care guidelines to see if there were any that could potentially be endorsed or adapted. The 172 guidelines found in this review ranged in topic and quality. Comparison among guidelines was challenging due to marked heterogeneity. Many of the guidelines included in this review scored low on the Rigour of Development AGREE scale. This was only one subsection of the AGREE scale and the guidelines that scored low in this area may have scored higher in other areas.

#### INTERNAL REVIEW

The evidence summary was reviewed by the Director of the PEBC. The Working Group is responsible for ensuring the necessary changes are made.

#### Approval

After internal review, the report was presented to the working group. The working group reviewed the document at a meeting on June 16<sup>th</sup> 2016, and formally approved the document.

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## Appendix 1: Members of the Working Group and their COI declaration

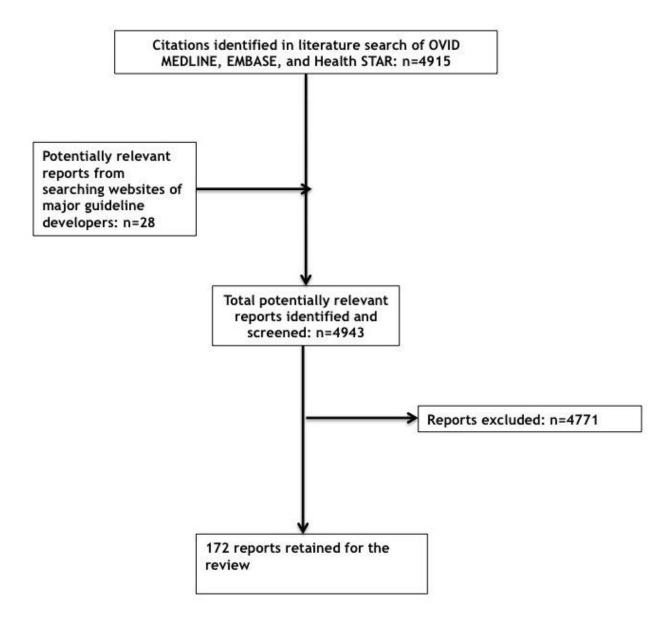
| Name                          | Affiliation                      | Declarations of interest |
|-------------------------------|----------------------------------|--------------------------|
| Tara Walton                   | Ontario Palliative Care Network, | None declared            |
| Specialist, Palliative Care   | Toronto, Ontario                 |                          |
| Ahmed Jakda                   | Grand River Regional Cancer      | None declared            |
| Physician                     | Centre, Kitchener, Ontario       |                          |
| Melody Boyd                   | North Simcoe Muskoka Hospice     | None declared            |
| Clinical Nurse Manager        | Palliative Care Network          |                          |
|                               |                                  |                          |
| Lacey Phillips                | Health Quality Ontario, Toronto, | None declared            |
| Lead, Quality Standards       | Ontario                          |                          |
| Nadia Coakley                 | Program in Evidence-Based Care   | None declared            |
| Health Research Methodologist | McMaster University              |                          |
|                               | Hamilton, Ontario                |                          |

#### Appendix 2: Literature Search Strategy

Medline, EMBASE and HealthSTAR

- 1. (guideline or practice guideline).pt.
- 2. exp consensus development conference/
- 3. consensus/
- 4. (guideline: or recommend: or consensus or standards).ti.
- 5. consensus development conference/
- 6. practice guideline/
- 7. \*consensus development/ or \*consensus/
- 8. \*standard/
- 9. (guideline: or recommend: or consensus or standards).kw.
- 10. (guideline: or recommend: or consensus or standards).ti.
- 11. or/1-10
- 12. limit 11 to yr="2000 -Current"
- 13. palliative care.mp.
- 14. palliative medicine.mp.
- 15. (Hospice and Palliative Care Nursing).mp. [mp=ti, ab, tx, kw, ct, hw, tn, ot, dm, mf, dv,
- nm, kf, px, rx, ui]
- 16. terminal care.mp.
- 17. hospice.mp.
- 18. hospice care.mp.
- 19. palliative therapy.mp.
- 20. or/13-19
- 21. 12 and 20
- 22. limit 21 to english language
- 23. limit 22 to yr="2000 2010"
- 24. remove duplicates from 23
- 25. limit 22 to yr="2011 2016"
- 26. remove duplicates from 25
- 27. 24 or 26

Appendix 3: PRISMA Flow Diagram



#### Appendix 4: References from Older Guidelines

### General Palliative Care Guidelines from 2000-2010

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Appendices