

# How We Should Assess the Delivery of End-Of-Life Care in General Practice? A Systematic Review

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## Abstract

**Background:** The majority of end-of-life (EOL) care occurs in general practice. However, we still have little knowledge about how this care is delivered or how it can be assessed and supported.

**Aim:** (i) To review the existing evaluation tools used for assessment of the delivery of EOL care from the perspective of general practice; (ii) To describe how EOL care is provided in general practice; (iii) To identify major areas of concern in providing EOL care in this context.

**Design:** A systematic review.

**Data Sources:** Systematic searches of major electronic databases (Medline, EMBASE, PsycINFO, and CINAHL) from inception to 2017 were used to identify evaluation tools focusing on organizational structures/systems and process of end-of-life care from a general practice perspective.

**Results:** A total of 43 studies representing nine evaluation tools were included. A relatively restricted focus and lack of validation were common limitations. Key general practitioner (GP) activities assessed by the evaluation tools were summarized and the main issues in current GP EOL care practice were identified.

**Conclusions:** The review of evaluation tools revealed that GPs are highly involved in management of patients at the EOL, but there are a range of issues relating to the delivery of care. An EOL care registration system integrated with electronic health records could provide an optimal approach to address the concerns about recall bias and time demands in retrospective analyses. Such a system should ideally capture the core GP activities and any major issues in care provision on a case-by-case basis.

**Keywords:** end-of-life care; evaluation tool; general practice; palliative care; systematic review

## Background

PROVISION OF HIGH-QUALITY END-OF-LIFE (EOL) care has become a major challenge in most advanced economies because of aging populations, the growing burden of non-communicable disease, and higher risks of comorbidity associated with a longer life expectancy.<sup>1</sup> These trends in population and pattern of disease have necessitated increasing prioritization of EOL care in many healthcare systems. In high-income nations, up to 70% of palliative care occurs in the primary care setting.<sup>2-4</sup> General practitioners (GPs) are well placed and expected to provide and coordinate palliative and EOL care in community settings.<sup>5</sup> Well-coordinated community-based palliative care involving skilled, engaged GPs can reduce the possibility and frequency of emergency department visits in the last stage of life.<sup>6,7</sup>

Improving the quality of a palliative approach to EOL care is a policy priority.<sup>8</sup> Routine assessment and feedback is recognized as an important approach for dynamically monitoring healthcare quality and policy development, and has been widely used in healthcare research.<sup>9</sup> In Australia, the Palliative Care Outcomes Collaboration (PCOC) aims at routinely auditing specialist palliative care.<sup>10</sup> At present, however, there is no routine collection of data about EOL care in general practice.<sup>11</sup> In comparison to specialist palliative care, data collection in general practice are more challenging due to lack of centralized data collection system, less standardized clinical pathways, and unclear delineation of GPs' role in palliative care.

According to Donabedian's healthcare assessment framework, care comprises three elements: "structure," "process," and "outcome." "Structure" refers to the attributes of setting,

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personnel, and regulation relating to care delivery; “process” involves the content and form of care delivery; “outcome” captures the effects of care on the recipients of care.<sup>12</sup> Ideally, a combination of structure, process, and outcome measures would be the best to evaluate healthcare.<sup>12,13</sup>

In palliative and EOL care, however, researchers often prefer process measures, which are often easier to obtain from medical and administrative databases<sup>14–16</sup> and are commonly used to develop indicators of EOL quality of care.<sup>17,18</sup> Previous systematic reviews of palliative care have highlighted process-related and structural barriers, such as insufficient interdisciplinary collaboration, poor doctor–patient communication, limited palliative care training opportunities, and inappropriate funding system.<sup>19–22</sup> In contrast, outcome measures for palliative and EOL care are often not collected due to pragmatic concerns.<sup>17,18</sup> These often have to be obtained directly from patients, which raises the concerns of collection difficulties, the possibility of causing distress, and the subjectivity of data.<sup>23–25</sup>

To our knowledge, no reviews of evaluation tools have been performed, which fully explore the delivery of EOL care in the general practice context. We sought to formally review the published evaluation tools used to assess the delivery of palliative and EOL care from the perspective of GPs, and to provide a summary of major areas of concern in providing EOL care in this context.

### Review aims

- To review the existing evaluation tools used for assessment of the delivery of EOL care from the perspective of general practice;
- To describe how EOL care is provided in general practice;
- To identify major areas of concern in providing EOL care in this context.

### Methods

#### Search strategy

We searched four electronic databases (Medline, EMBASE, PsycINFO, and CINAHL) from their inception to March 2017 with a list of key search terms identified through consensus discussion among the researchers. Both Mesh terms and text words were used. The search strategy used in

Medline is shown in Table 1. Comparable strategies were employed in other three databases. The relevant references from articles included in full-text review were also assessed.

#### Inclusion and exclusion criteria

The following broad screening criteria were used for the title and abstract review: (i) the article must be relevant to the assessment of palliative or EOL/terminal care delivery in primary care; (ii) an evaluation tool used to assess such care formed part of the study (i.e., the tool was used, developed, validated, translated, or updated); (iii) the respondents of the evaluation tool must include a primary care physician, or at least a staff member linked to general practice.

According to the previous summaries developed by Leemans et al. in 2013,<sup>26</sup> palliative and EOL care delivery involves “physical, psychosocial, and spiritual aspects of care,” “communication, care planning, and decision-making,” “continuity and coordination of care,” and “support of family/carers.” In the full-text review, studies of GP activities were included under each of these domains.

Evaluation tools for which English translations could not be obtained or most items were not relevant to structures (in this study referred to as organizational structures/systems for clarity) or processes of care were removed. We also intentionally removed evaluation tools that focused on physician-assisted suicide/euthanasia since it was still not legislated in most countries.<sup>27</sup>

#### Process of assessment

The three authors (all trained in health research methods) independently performed title and abstract assessment for a random selection of 25 records using the broad criteria. A consensus rate of 80% was achieved. After a slight modification to the review procedure, J.D. completed all the title/abstract and full-text reviews. Articles, where inclusion was ambiguous were determined by consensus among the three authors.

#### Evaluation tools request

Authors of selected articles were contacted for any original evaluation tools that were unavailable online. First, contacts were made by J.D. using the email addresses obtained from the included literature, authors’ more recent publications,

TABLE 1. SEARCH STRATEGY IN MEDLINE

Themes	Search terms #
End-of-life care	“Palliative care” [Mesh] OR “Terminal care” [Mesh] OR “Terminally ill” [Mesh] OR “Advance care planning” [Mesh] OR “Advance Directives” [Mesh] OR “Bereavement” [Mesh] OR “Life support care” [Mesh] OR “End-of-Life” OR “Palliat*” OR “advance care plan*” OR “Terminally ill” OR “Terminal care” OR “Advance Directive*” OR “Life support care” OR Bereavement
Instrument	“Surveys and Questionnaires” [Mesh] OR Registries [Mesh] OR Questionnaire* OR Regist* Tool OR Tools OR OR Instrument OR Instruments OR Survey* OR Assessment OR Evaluation
General practitioner	“General Practitioners” [Mesh] OR “Physicians, Family” [Mesh] OR “Physicians, Primary Care” [Mesh] OR “General Practice” [Mesh] OR “primary health care” [Mesh] OR “Family practice” [Mesh] OR Generalist* “general practitioner*” OR “Family doctor*” OR “Family physician*” OR “General practice*” OR “Primary health care” OR “Family practice”

Google searching, or websites of their academic or clinical departments. The second and third requests were sent by A.C. if no response was received after an interval of two weeks.

### **Data extraction and synthesis**

Two tables were designed to extract information. The first table (Table 2) was used to describe the features of the evaluation tool: basic characteristics (author, year and country), components (purposes, respondents, and target population), description (number of items, domains, and format of questions/responses), and process of development, measurement properties, and example of items. Table 3 summarized key EOL activities that were assessed in the evaluation tools and main issues in GP care provision identified from the included studies.

### **Results**

A total of 3423 records were returned. Around 1777 articles remained after removing duplicates, and 225 then entered the full-text review. Of these, 64 studies representing 23 evaluation tools met the full-text review criteria, and 10 English language versions were obtained online or through author contact. We excluded one evaluation tool because the majority of items were not relevant to EOL care delivery. Finally, 43 studies referring to nine evaluation tools were included (Fig. 1). The majority of studies was generated by The SENTI-MELC Registration Form<sup>28</sup> and the Swedish Register of Palliative care (SRPC).<sup>29</sup>

### **Countries in which the evaluation tools were used**

Of the nine evaluation tools included in this report, two were from Belgium<sup>28,30</sup> and the United Kingdom,<sup>31,32</sup> respectively; and one each from Sweden,<sup>29</sup> Canada,<sup>33</sup> the United States,<sup>34</sup> New Zealand,<sup>35</sup> and Germany.<sup>36</sup>

### **Respondent and target population**

The respondents of evaluation tools were primarily GPs, but also included other people, such as nurses, specialists, and relatives of the deceased. For example, the respondents of questionnaire 1 of the SPCR were care providers responsible for the patient's last week of care.<sup>29</sup> For questionnaire 2 of the SPCR<sup>29</sup> and Hughes' study,<sup>31</sup> respondents were mainly practice/unit managers. The study population in each of these included decedents as well as dying patients.

### **Purpose of evaluation tools**

The principal purpose of evaluation tools differed. The SENTI-MELC Registration Form<sup>28</sup> and questionnaire 1 of the SRPC<sup>29</sup> assessed EOL care delivery relatively broadly. Other articles more specifically assessed EOL communication between GPs and patients,<sup>30</sup> resource availability, workload, and barriers for rural GPs,<sup>35</sup> circumstances and symptom management of dying patients,<sup>36</sup> role and activities of GPs in palliative care,<sup>32-34</sup> and adherence to national guidance in EOL care.<sup>31</sup> Questionnaire 2 of the SRPC was specifically designed to measure the participating units' organizational structures and systems of care.<sup>29</sup>

### **Format of items and evaluation tools**

The majority of evaluation tools used both open- and closed-ended questions. The most common question formats were multiple choice based and Likert scales, which were found in almost all evaluation tools. Five evaluation tools assessed the respondents' experience of caring for a particular patient (individual-level data)<sup>28-30,32,36</sup>; whereas others investigated providers' general experience in providing care for a group of patients.<sup>31,33-35</sup> In contrast to other evaluation tools, the SENTI-MELC Registration Form and SRPC were used as part of a registration process to routinely assess and monitor care in the last stage of life.<sup>28,29</sup>

### **Development of evaluation tools**

The evaluation tools were based on a range of resources, but were predominantly based on the integration of previous literature/resources and expert opinion.<sup>28,33-36</sup> For example, the SENTI-MELC Registration Form was based on existing questionnaires, death certificates, a literature review, and expertise in the field.<sup>28</sup> Two evaluation tools referred to guidelines in the development process.<sup>29,31</sup> For instance, the SRPC questionnaires were established with reference to guidelines for palliative and EOL care by the British Geriatrics Society.<sup>29,37</sup> The development process of the two evaluation tools by Vandervoort et al.<sup>30</sup> and Wilson and Cox was not reported.<sup>32</sup>

### **Measurement properties**

Six evaluation tools were reportedly pretested or validated. Commonly reported properties included face and content validity<sup>34</sup>; internal consistency<sup>31</sup>; ease of completion, relevance, clarity, and readability<sup>33</sup>; and feasibility.<sup>28,29</sup> In-depth information about the pretesting and validation of evaluation tools, however, was generally not available.

### **Key activities assessed in the evaluation tools**

After reviewing the evaluation tools, we categorized key GP activities and organizational characteristics into nine domains based on a framework developed by Leemans et al.<sup>26</sup>: (i) physical treatment, care, and support; (ii) psychological, social, and existential treatment, care, and support; (iii) information, communication, planning, and decision making with patients; (iv) information, communication, planning, and decision making with patients' family; (v) information, communication, planning, and decision making with other care providers; (vi) coordination and continuity of care; (vii) management and type of care; (viii) support of family and other carers; and (ix) organizational structures/systems of care. Overall, GPs' key activities related to some degree to all of the important domains of palliative care,<sup>26</sup> although activities in domains 4, 5, and 8 were less often assessed and reported (Table 3).

### **Main issues identified from the included studies**

The main issues relating to GPs' palliative care delivery were identified through review of the key included studies. These studies mainly described and compared the pattern of palliative care delivered to patients with different diseases (such as cancer, stroke, heart failure, dementia, and chronic

TABLE 2. CHARACTERISTICS OF THE INCLUDED INSTRUMENTS

<i>Evaluation tools</i>	<i>Components</i>	<i>Description</i>	<i>Development</i>	<i>Measurement properties</i>	<i>Example of item</i>
Van den Block et al. <sup>28</sup> (SENTI-MELC Standardized Registration Form) <sup>28</sup> Belgium Evaluation tool was administered in Dutch and French; English copy was obtained	Primary purpose: define the circumstances of death and the care patient received in the last three months of life Respondents: GPs in Sentinel Network Target patient population: Nonsudden death; Part of general practice; Age >1 year	Thirty-three items Domains/sections: Section A (17 items): Key questions <ul style="list-style-type: none"> <li>• Demographic characteristics</li> <li>• Death characteristics</li> </ul> Section B (16 questions) <ul style="list-style-type: none"> <li>• Key questions</li> <li>• Residence trajectory</li> <li>• Care providers' awareness of patients' preferred place of death</li> <li>• Continuity and GP support variables</li> <li>• Social support variables</li> <li>• Main goals of care/treatment</li> <li>• Involvement of specialist palliative care services and other caregivers</li> <li>• End-of-life decisions</li> </ul> Formats of question: closed- and open-ended (choice-based, Likert scale and fill-in-blank question). Summarized based on version 2007	Developed by authors based on various sources: existing questionnaires, death certificate, and literature review. Counseling with Belgian Scientific Institute of Public Health and project Advisory Board Various editions of questionnaires have been developed for different research aims and settings (Belgium, The Netherlands, Italy, Spain)	The feasibility of the evaluation tool was pre-tested in a three-month pilot study in 2004, and slight modification was made based on this pilot study	“What was the main goal of the patient’s treatment (cure, prolonging life, comfort/palliation, unknown) <ul style="list-style-type: none"> <li>– cure</li> <li>– prolonging life</li> <li>– comfort/palliation</li> <li>– unknown”</li> </ul> This Question was answered in three separate time frames (last week before death; second to fourth week before death; second and third before death), respectively

(continued)

TABLE 2. (CONTINUED)

<i>Evaluation tools</i>	<i>Components</i>	<i>Description</i>	<i>Development</i>	<i>Measurement properties</i>	<i>Example of item</i>
Questionnaire 1 of SRPC Lundström et al., 2012 <sup>29</sup> Evaluation tool was administered in Swedish and English copy was obtained	Primary purpose: assess the care provided for patients in their last week of life Respondents: physicians, nurses, or other staff from any care setting (including general practices, inpatient hospices, care homes, and hospitals) responsible for patient care in the last week of life Target patient population: all death in Sweden	Fifty-one items Domains: none identified Key questions: • Information provided to patients and their family • Decision-making capacity • Symptom relief • Prescribed medications • Preferred place of death • Support to family Formats of question: closed-ended (choice-based, and five-scale Likert) Summarized based on the version Launched in 2012 Twenty-three items Domains: none identified Key questions: • Basic facts about the unit • Availability of staff • Existing document routines around end-of-life care • Accessibility of injectable drugs Formats of question: closed and open-ended (choice-based, fill-in-blank question) Summarized based on the version Launched in 2007	First developed by the project group with four members having experience and expertise in palliative care and quality improvement based on the 12 principals of a “good death,” highlighted in guidelines from the British Geriatrics Society <sup>55</sup>	The congruity of data between web-based registration and paper version was 96%–100%; between web-based registration and medical records ranged from 22% to 100%. <sup>54</sup>	“Has an informing ‘breakpoint’ conversation from a doctor with patient about impending death taken place, during the last period in life? – Yes – No – Don’t know”
Questionnaire 2 of SRPC Lundström et al., 2012 <sup>29</sup> Evaluation tool was administered in Swedish and English copy was obtained	Primary purpose: define the characteristics of care units participating in the register Respondents: managers of care units Target population: not applicable	Summarized based on the version Launched in 2012 Twenty-three items Domains: none identified Key questions: • Basic facts about the unit • Availability of staff • Existing document routines around end-of-life care • Accessibility of injectable drugs Formats of question: closed and open-ended (choice-based, fill-in-blank question) Summarized based on the version Launched in 2007	First developed by the project group with four members having experience and expertise in palliative care and quality improvement based on the 12 principals of a “good death,” highlighted in guidelines from the British Geriatrics Society <sup>55</sup>	Not reported	Questions were about organizational structures/systems of care “Do you have written routines for necessary actions at the time of death? – Yes – No”

(continued)

TABLE 2. (CONTINUED)

<i>Evaluation tools</i>	<i>Components</i>	<i>Description</i>	<i>Development</i>	<i>Measurement properties</i>	<i>Example of item</i>
Vandervoort et al. <sup>30</sup> Belgium	Primary purposes: to determine GPs, nurses, and relatives' experience in advance care planning communication with nursing home patients dying from dementia Respondents: GPs, nurses, and relatives Target population: nursing home residents dying from dementia	9 items Key questions <ul style="list-style-type: none"> <li>• Verbal communication about patient's future medical treatment</li> <li>• Written advance care planning</li> </ul> Formats of question: choice-based closed question	Not reported	Not reported	“FP spoke with the resident concerning medical treatments and the desired direction of care in the last phase of life <ul style="list-style-type: none"> <li>– Yes, once</li> <li>– Yes, more than once</li> <li>– No”</li> </ul>
Hughes et al. <sup>31</sup> United Kingdom Evaluation tool was administered in English	Primary purpose: assess the extent to which United Kingdom Primary Care has implemented national guidance in end-of-life care practice Respondents: senior partner of general practice (GPs, practice managers, district nurses, palliative care coordinators, lead for palliative and cancer care) Target patient population: adult cancer patients	Forty-four items Domains/sections <ul style="list-style-type: none"> <li>• Practice information</li> <li>• Practice organization</li> <li>• Clinical practice</li> <li>• Quality</li> </ul> Formats of question: closed and open-ended questions (four-scale Likert, choice-based, fill-in-blank question, and essay question)	Items were developed by service users, GP colleagues based on principles in the National Institute for Health and Care Excellence guidance and the Scottish Partnership for Palliative Care, and reviewed by academic GPs and palliative care physicians	Internal consistency was tested Domain of clinical Care (Cronbach's $\alpha=0.847$ ; 13 items; $n=1877$ ) Domain of practice Organization (Cronbach's $\alpha=0.684$ ; 12 items; $n=1802$ ) General (Cronbach's $\alpha=0.850$ ; 25 items; $n=1661$ )	“Do care plans appear in the records of palliative care patients? <ul style="list-style-type: none"> <li>– In every case</li> <li>– In most cases</li> <li>– In some cases</li> <li>– Rarely or never”</li> </ul>
Wilson and Cox <sup>32</sup> (GP Activity and Referral Log) <sup>28</sup> United Kingdom Evaluation tool was administered in English	Primary purpose: assess the palliative care activity of the GP with special interests (GPSI) Respondents: GPSI Target patient population: palliative care patient attended by GPSI	Nineteen items Domains/sections <ul style="list-style-type: none"> <li>• Activity log</li> <li>• Patient referral log</li> </ul> Key questions: <ul style="list-style-type: none"> <li>• Who referred</li> <li>• Reason for referral</li> <li>• Diagnosis</li> <li>• Activity undertaken</li> <li>• Time involved</li> <li>• Follow-up plan</li> <li>• Involvement of other services</li> </ul> Formats of question: open-ended questions (fill-in-blank question, and essay question)	Not reported	Not reported	See key questions

(continued)

TABLE 2. (CONTINUED)

<i>Evaluation tools</i>	<i>Components</i>	<i>Description</i>	<i>Development</i>	<i>Measurement properties</i>	<i>Example of item</i>
Brazil et al. <sup>33</sup> Canada Evaluation tool was administered in English	Primary purpose: define the family physicians' role (including direct care and referral) in supportive cancer care Respondents: family physicians (FPs) Target patient population: cancer patients in palliative care stage	Nineteen items Domains/sections: none identified Key questions: <ul style="list-style-type: none"> <li>• Physician characteristics</li> <li>• FP care delivery</li> <li>• FP's role in coordination of care for cancer patients</li> <li>• FP's view on comprehensiveness of care, accessibility to service, and compatibility between providers. (four-scale Likert)</li> </ul> Formats of question: closed- and open-ended questions (four-scale Likert, choice-based, fill-in-blank question, and essay question)	Developed by authors based on previous questionnaires, <sup>40</sup> literature review, feedback from expert and judgment of researchers	Piloted with 10 primary care physicians who were not involved in the survey for clarity, readability, and relevance	“Which (outside) physical supports/services have you referred these cancer patients to? <ul style="list-style-type: none"> <li>– Nursing care</li> <li>– Homemaker support or personal care</li> <li>– Physical rehabilitation services, such as occupational, speech, or physiotherapy</li> <li>– Medical supplies and equipment</li> <li>– Nutritional counseling</li> <li>– Transportation services”</li> </ul>
Farber et al. <sup>34</sup> United States Evaluation tool was administered in English	Primary purpose: evaluate the frequency and perceived competence of primary care physician in providing end-of-life care Respondents: physician (family physicians and internists) Target patient population: patients with terminal disease and their family	Thirty-five items Domains/sections <ul style="list-style-type: none"> <li>• Frequency of providing end-of-life care (four-scale Likert)</li> <li>• Perceived competence in providing end-of-life care (four-scale Likert)</li> <li>• Demographic and other information</li> </ul> Format of question: closed- and open-ended questions (four-scale Likert and choice-based)	Developed by authors with reference to the American Medical Association Education for Physicians on End-of-Life Care (EPEC) Program	Face and content validity was assessed among 25 practicing physicians	“Talking about advance directives (living will, power of attorney) with a terminally ill patient: <ul style="list-style-type: none"> <li>– Always</li> <li>– Frequency</li> <li>– Rarely</li> <li>– Never”</li> </ul>

(continued)

TABLE 2. (CONTINUED)

<i>Evaluation tools</i>	<i>Components</i>	<i>Description</i>	<i>Development</i>	<i>Measurement properties</i>	<i>Example of item</i>
Smyth et al. <sup>35</sup> New Zealand and Evaluation tool was administered in English	Primary purpose: assess the palliative care provided by rural GPs and their barriers in providing palliative care Respondents: rural GPs Target patient population: palliative care patient attended by rural GPs	30 items Domains/sections: none identified Key questions <ul style="list-style-type: none"> <li>• Access to hospital beds, specialist palliative care advice, knowledge of palliative care, nursing care, and equipment</li> <li>• Number of patients, places of death, charge of care, patient referral</li> <li>• Demographic information</li> </ul> Formats of question: closed and open-ended (choice-based, fill-in-blank question, and essay question)	Originally developed through literature search and used in Australia by Pereira et al., <sup>52</sup> then adapted to New Zealand by Smyth et al. <sup>35</sup>	Not reported	“On average how many times per week do you see your palliative care patients? _____”
Gágyor et al. <sup>36</sup> Germany Evaluation tool was administered in German and English copy was obtained	Primary purpose: evaluate care provided by GPs in the last stage of life Respondents: GPs Target patient population: adult patients who died in the last 12 months and were cared by GP at least three months	Thirty-five items Domains/sections <ul style="list-style-type: none"> <li>• Details regarding your patient</li> <li>• Details relating to primary care</li> <li>• Details of clinical picture of the patient</li> <li>• Details regarding the patient circumstance at the time of death</li> </ul> Formats of question: closed- and open-ended (choice-based and fill-in-blank question)	Developed by a team of professionals from multiple disciplines (including healthcare and sociology) based on previous studies	Tested by a team of professional from multiple disciplines (including healthcare and sociology)	“How often did you see or have contact with your patient in the 4–6 months preceding their death? <ul style="list-style-type: none"> <li>– 2–3× per week</li> <li>– 1× per week</li> <li>– Every 2 weeks</li> <li>– 1–2× in the last 4–6 weeks</li> <li>– Not at all”</li> </ul>

GP, general practitioner; SRPC, Swedish Register of Palliative care.



TABLE 3. GENERAL PRACTITIONER PRACTICE TABLE

<i>Domains</i>	<i>Key items in each domain</i>	<i>Main issues identified in literature</i>	<i>Relevant studies</i>
Processes of EOL care in general practice			
1. Physical treatment, care, and support	<ul style="list-style-type: none"> <li>• Assessment of pain and other symptoms</li> <li>• Prescribing for pain and other symptoms (e.g., palliative medication, chemotherapy, antibiotics)</li> <li>• Provision of nonmedication treatment/aids (e.g., parenteral fluids/nutrition or internal tube feeding, transfusions)</li> <li>• Assessment of adequateness and appropriateness of interventions provided</li> </ul>	<ul style="list-style-type: none"> <li>• Validated scales are not commonly used in the assessment of pain, and even less often for other symptoms (including psychological symptoms).</li> <li>• Patients with noncancer diagnosis and older patients are less often provided with medications for physical symptom control.</li> <li>• Relief of physical symptoms in the last stage of life may be less than ideal. Pain and shortness of breath are often reported as the symptoms with the highest and lowest level of complete relief, respectively.</li> <li>• GPs do not regularly assess the overall combination of EOL care they provide for patients.</li> </ul>	Ko et al., <sup>38</sup> Meeussen et al., <sup>39</sup> Brazil et al., <sup>33</sup> Gágyor et al., <sup>36</sup> Hughes et al., <sup>31</sup> Brännström et al., <sup>40</sup> Martinsson et al., <sup>41</sup> Lindskog et al., <sup>42</sup> Eriksson et al., <sup>43</sup> Årestedt et al., <sup>44</sup> Smedbäck et al., <sup>45</sup> Vandervoort et al., <sup>30</sup> Axelsson et al. <sup>46</sup>
2. Psychological, social and existential treatment, care and support	<ul style="list-style-type: none"> <li>• Management of psychological and cognitive symptoms</li> <li>• Addressing cultural/social/spiritual needs</li> <li>• Support in preparing and accepting death/Addressing patient's expectations and preferences</li> <li>• Assessment of the adequateness and appropriateness of care provided</li> </ul>	<ul style="list-style-type: none"> <li>• Limited reporting on management of psychological problems, except for anxiolytic drugs.</li> <li>• GP-based support in this domain are often restricted to psychological and cognitive symptoms. Problems in social, existential, and spiritual care are rarely assessed and reported.</li> </ul>	Ko et al., <sup>38</sup> Meeussen et al., <sup>39</sup> Gágyor et al., <sup>36</sup> Brännström et al., <sup>40</sup> Martinsson et al., <sup>41</sup> Lindskog et al., <sup>42</sup> Eriksson et al., <sup>43</sup> Årestedt et al., <sup>44</sup> Smedbäck et al., <sup>45</sup> Vandervoort et al., <sup>30</sup> Axelsson et al.
3. Information, communication, planning, and decision making with patients	<ul style="list-style-type: none"> <li>• Recognition of dying patients</li> <li>• Breaking bad news (e.g., diagnosis and prognosis)</li> <li>• Providing information about available treatment and care</li> <li>• Discussion about care options/plans (e.g., transition to palliative care or EOL care)</li> <li>• Communication and recording of care preferences/wishes (including preferred places of death and care)</li> <li>• Assistance in preparing advance care planning (living will, advance directive, and power of attorney)</li> <li>• Assessment of patients' capacity in decision making</li> </ul>	<ul style="list-style-type: none"> <li>• Often late recognition that patient is dying, especially for patients with a noncancer diagnosis.</li> <li>• EOL discussions are often restricted to primary diagnosis and physical complaints. Psychological, social, and spiritual problems are discussed less frequently.</li> <li>• EOL discussions often involve family/caregivers rather than the patients themselves.</li> <li>• Patient's preferences for care and places of death are often not known by GPs, especially for patients with a noncancer diagnosis.</li> <li>• GPs are often not involved in preparing advance care planning. Written advance care planning (including advance care directive and proxy for EOL decision making) is only conducted for a minority of patients.</li> </ul>	Abarshi et al., <sup>47,48</sup> Evans et al., <sup>49-51</sup> De Roo et al., <sup>52</sup> Ko et al., <sup>38</sup> Meeussen et al., <sup>39,53,54</sup> Penders et al., <sup>55</sup> Gágyor et al., <sup>36</sup> Hughes et al., <sup>31</sup> Lundquist et al., <sup>56</sup> Brännström, <sup>40</sup> Martinsson et al., <sup>41</sup> Lindskog et al., <sup>42</sup> Eriksson et al., <sup>43</sup> Årestedt et al., <sup>44</sup> Smedbäck et al., <sup>45</sup> Axelsson et al., <sup>46</sup> Vandervoort et al., <sup>30</sup>

(continued)

TABLE 3. (CONTINUED)

<i>Domains</i>	<i>Key items in each domain</i>	<i>Main issues identified in literature</i>	<i>Relevant studies</i>
4. Information, communication, planning, and decision making with patients' family	<ul style="list-style-type: none"> <li>Identifying family/carers with whom patient care can be discussed and coordinated</li> <li>Giving appropriate written information to family carers</li> <li>Documenting family/carers' insight into the patient's condition</li> <li>Discussing care/treatment with family</li> </ul>	<ul style="list-style-type: none"> <li>Information on this domain is not often assessed and reported.</li> <li>Only around half of general practices provide the family/carer with written information about patient's condition and record their responses.</li> </ul>	Hughes et al., <sup>31</sup> Brännström et al., <sup>40</sup> Lindskog et al., <sup>42</sup> Eriksson et al., <sup>43</sup> Arestedt et al., <sup>44</sup> Smedbäck et al., <sup>45</sup> Axelsson et al., <sup>46</sup> Vandervoort et al. <sup>30</sup>
5. Information, communication, planning, and decision making with other care providers	<ul style="list-style-type: none"> <li>Exploring patient and carer satisfaction with communication with other services (hospitals, hospices, care homes...)</li> <li>Availability of handover form for out-of-hours care</li> <li>Use of multidisciplinary consultation</li> </ul>	<ul style="list-style-type: none"> <li>Information on this domain is not often assessed and reported.</li> <li>Lack of timely and effective communication with specialists is a common issue.</li> </ul>	Brazil et al., <sup>33</sup> Wilson and Cox, <sup>32</sup> Hughes et al. <sup>31</sup>
6. Coordination and continuity of care	<ul style="list-style-type: none"> <li>Actual places of death and care (care trajectory)</li> <li>Availability of GPs (e.g., out of hours, home visits, and on-call duties)</li> <li>Referral patterns (destinations and purposes)</li> <li>Involvement of other disciplines/persons in patient's care (e.g., specialists, nursing services, allied health, psychological services, spiritual services, relatives, volunteers)</li> <li>GPs' perceived role in care coordination</li> </ul>	<ul style="list-style-type: none"> <li>The majority of GPs do not consider themselves as the primary coordinators of palliative care. Often GPs identify themselves as part of a wider team or hand over the coordination role by referral.</li> <li>Only a minority of GPs report providing out-of-hours care for terminally ill patients.</li> <li>Home deaths occur in less than half of patients, although this option is often reported as being preferred by the majority of patients. Patients in urban areas are less likely to die at home than rural patients.</li> <li>Frequent care setting transitions in the last stage of life prevent patients from dying at home.</li> </ul>	<p>Abarshi et al.,<sup>47,57</sup> Evans et al.,<sup>51</sup> Houttekier et al.,<sup>58</sup> De Roo et al.,<sup>52</sup> Ko et al.,<sup>38</sup> Meeussen et al.,<sup>59,53</sup> Penders et al.,<sup>55,59</sup> Van den Block et al.,<sup>60</sup> Brazil et al.,<sup>33</sup> Wilson and Cox,<sup>32</sup> Hughes et al.,<sup>31</sup> Smyth et al.,<sup>35</sup> Brännström et al.,<sup>40</sup> Martinsson et al.,<sup>41</sup> Lindskog et al.,<sup>42</sup> Eriksson et al.,<sup>43</sup> Arestedt et al.,<sup>44</sup> Smedbäck et al.,<sup>45</sup></p>

(continued)

TABLE 3. (CONTINUED)

<i>Domains</i>	<i>Key items in each domain</i>	<i>Main issues identified in literature</i>	<i>Relevant studies</i>
7. Management and type of care	<ul style="list-style-type: none"> <li>• Referrals and involvement of other services (e.g., specialist palliative care service, hospital)</li> <li>• Defining goals/levels of EOL care</li> <li>• Determination of whether patient is considered as requiring palliative care</li> </ul>	<ul style="list-style-type: none"> <li>• Up to half of patients do not receive GP-provided palliative care in the last stage of life. Patients with a noncancer diagnoses are less often provided with palliative care by GPs.</li> <li>• Cure-aimed treatments are common for many patients in their last stage of life.</li> <li>• Hospital admissions are provided to more than half of patients in the last stage of life.</li> </ul>	<p>Abarshi et al.,<sup>47,61</sup> Bossuyt et al.,<sup>62</sup> Claessen et al.,<sup>63</sup> Evans et al.,<sup>50</sup> Ko et al.,<sup>38</sup> Meeussen et al.,<sup>39,53</sup> Penders et al.,<sup>55,59</sup> Pivodic et al.,<sup>2,64</sup> Van den Block et al.,<sup>65</sup> Lindskog et al.<sup>42</sup></p>
8. Support of family and other carers	<ul style="list-style-type: none"> <li>• Assessment of physical and emotional burden of family/carers</li> <li>• Assessment of financial burden of family/carers</li> <li>• Bereavement support/counseling</li> </ul>	<ul style="list-style-type: none"> <li>• Burden of family/carers in caring EOL patients is not often assessed and reported.</li> <li>• Patients' family/carers may not be offered bereavement follow-up.</li> </ul>	<p>Wilson and Cox,<sup>32</sup> Ko et al.,<sup>38</sup> Brännström et al.,<sup>40</sup> Martinsson et al.,<sup>41</sup> Lindskog et al.,<sup>42</sup> Eriksson et al.,<sup>43</sup> Årestedt et al.,<sup>44</sup> Axelsson et al.</p>
Organizational/system structure of EOL Care in general practice	<ul style="list-style-type: none"> <li>• Number of palliative care patients</li> <li>• Human resources (GPs and other employees) in practice</li> <li>• Location and type of practice</li> <li>• Resource availability and accessibility (e.g., specialist palliative care support, community nurse, inpatient palliative care service, allied health, medical equipment)</li> <li>• Availability of palliative care improvement initiatives (e.g., palliative care guidelines/protocols, patient and care register/record system, symptom assessment tools, system for care coordination, continuity, and planning)</li> <li>• Type of charge for palliative care</li> <li>• Palliative care training of GPs</li> </ul>	<ul style="list-style-type: none"> <li>• Limited availability of nursing care, specialist advice, support in psychological and social aspects, hospital and hospice beds, and necessary equipment in provision of EOL care.</li> <li>• High proportion of GPs have not received training in palliative care.</li> </ul>	<p>Brazil et al.,<sup>33</sup> Gágyor et al.,<sup>36</sup> Hughes et al.,<sup>31</sup> Smyth et al.<sup>35</sup></p>
9. Organizational structures/systems of care			

EOL, end of life.

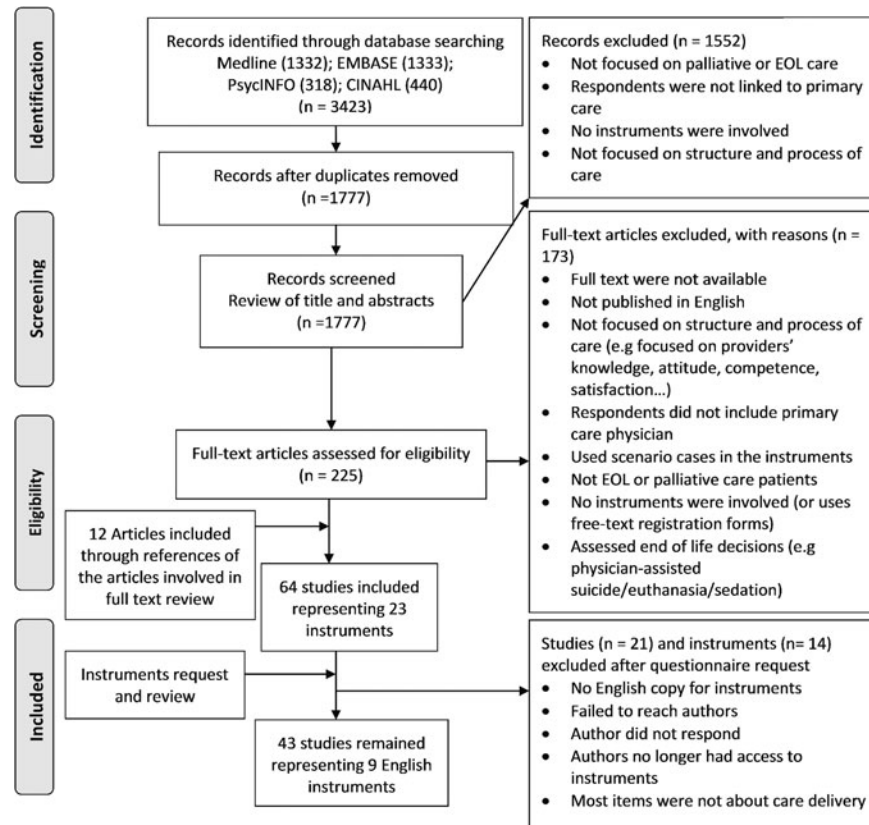


FIG. 1. PRISMA flow chart.

kidney disease), age groups, in different countries, and care settings. In almost all domains, cancer patients and their family received higher levels of palliative care and support than patients with other diseases. Significant discrepancies in the palliative care delivery pattern among countries were also identified. Specific issues in each domain were also presented. In the organizational structures/systems of care, limited availability in nursing care, specialist advice, support in psychological and social aspects, hospital and hospice beds, and necessary equipment were often reported as major barriers in providing EOL care. These issues are summarized in Table 3.

## Discussion

This review provides an overall picture of the scope of palliative and EOL care delivery in general practice. In this report, we identified nine evaluation tools in the peer-reviewed literature, which focus on the delivery of palliative and EOL care in general practice. These evaluation tools used various formats and included a diverse range of items relating to care, in part reflecting the particular context of the healthcare providers and countries. Some domains and activities were less often assessed and reported, such as the process of communication between GPs and other care providers. However, it is important to note that lower levels of assessment and reporting does not suggest that GPs provide less care in these domains, and may relate to gaps or biases in the tool itself, collection difficulties, or time constraints in completing questionnaires.<sup>28,66</sup>

This review identified a range of issues in palliative and EOL care delivery in general practice, which are largely consistent with previous studies.<sup>19–22,67</sup> One major issue related to the inequity of palliative care among patients with different illnesses. Patients diagnosed with cancer often received a higher level of palliative care, and their families were more fully involved in such care. Other specific areas of concern included the infrequent use of validated scales in symptoms assessment, suboptimal symptom relief, and limited support in social and spiritual aspects of EOL. Amongst some groups of doctors, there was limited awareness of patient's preferences for care and preferred place of death. Limited resource availability and lack of palliative care training opportunities were also reported as areas of concern.

Interestingly, many GPs did not consider themselves as the primary coordinators of palliative care even though they were often highly involved in most of the aspects of palliative care for their patients. This could be explained by the unclear role delineation of GPs due to the increasing "specialization" of palliative care and role fluctuation during illness trajectory.<sup>68–70</sup> This may also suggest that GPs are providing more palliative care than they realize.<sup>70–72</sup> These findings highlight priority areas for any future evaluation tool of palliative and EOL care in general practice.

One of the major weaknesses of the evaluation tools was lack of validation. Pretesting or expert consultation was discussed for six tools, but there was limited reporting of the results. Questionnaire 1 of the SRPC was one of the tools for which validity was reported for items.<sup>73,74</sup> Using medical records as the benchmark, agreement levels for around one

third of the items (such as diagnosis, symptom control, EOL communication with patients and family, and use of scales for symptom assessment) failed to meet the standard of 0.8 predefined by the researchers<sup>73,74</sup> or the criterion validity of 0.7 set by Terwee et al.<sup>75</sup> One reason for the lack of formal validity assessment is that most of the identified studies did not focus on the development of tools, but on the assessment of palliative and EOL care using the tools. The use of a mixture of various formats and structures of questions in most tools makes many of the measurement properties difficult to evaluate and compare.<sup>75,76</sup>

Most evaluation tools identified in this review had a narrow and discrete focus, which rendered them less suitable for comprehensive assessment of palliative care in general practice. Marked variation across centers also suggested a lack of international consensus on how this care should be assessed. These findings indicate that a degree of integration and adaptation of these evaluation tools is necessary to fully capture the range of EOL care provided in general practice.

Although retrospective data collection is widely used in EOL care studies, there are concerns over recall bias and excessive time demands, even using web-based registration evaluation tools.<sup>28,66,77</sup> The growing uptake of computerized health records in general practices may allow some of these problems to be circumvented.<sup>78,79</sup> Much of the core EOL care data (such as causes and places of death, prescribing, and referral patterns) is reasonably standardized in electronic medical records and could be populated by a data extraction tool integrated with electronic health records.<sup>80–82</sup> This approach could routinely provide ongoing individual-level EOL care data, which are more detailed, reliable, and up to date compared with the information on GPs' general experience intermittently collected by traditional GP surveys.<sup>83,84</sup>

This review focuses on the tools to assess EOL care from the perspective of general practice. There are existing initiatives, which evaluate EOL care from different perspectives that may serve as useful models or may potentially be adapted for the GP context. In Denmark, for example, the Danish Palliative Care Database registers cancer patients referred to and/or in contact with specialized palliative care and measures the quality of care they received against several indicators.<sup>85</sup> In Australia, PCOC provides a system to prospectively and routinely collect patient-reported outcomes and use pre-established benchmarks to measure performance and quality of specialist palliative care.<sup>10</sup> The approach of retrospective family survey on care received by patient at EOL was applied in the United States,<sup>77</sup> Japan,<sup>24</sup> South Korea,<sup>86</sup> and Spain.<sup>87</sup>

To our knowledge, this is the first systematic review focusing on evaluation tools measuring the processes and organizational structures/systems in palliative and EOL care from the general practice perspective. Our generic search strategy and strict use of inclusion and exclusion criteria in this review helped to ensure that the majority of evaluation tools we identified were applicable for palliative and EOL patients in the general practice setting.

However, there may have been a degree of selection bias in this review. To address this problem, we pretested the inclusion criteria for the title and abstract review and achieved a consensus rate of 80% across three trained assessors. A more serious limitation was that of the 23 evaluation tools from 64 studies identified after full-text review, only nine were finally included because of failure to obtain certified

English translations. These might have resulted in omissions of some relevant evaluation tools. Furthermore, many studies that assessed the delivery of primary palliative care using more qualitative approaches were not included in this review, and this may have resulted in gaps in the analysis of the key GPs' activities and issues in this study.

## Conclusion

This study involved the review of nine evaluation tools used to assess GP EOL care delivery. Lack of formal validation and a relatively narrow focus of these tools were identified as common problems. Future research should focus on the development of more comprehensive and fully validated assessment tools for EOL care in general practice. It is crucial to capture the range of GP activities and major issues in current GP EOL care practice highlighted in this study. Any new tools should routinely record aspects of EOL care on a case-by-case basis instead of using traditional surveys that examine GPs' overall experience in providing EOL care.

To address the concerns about recall bias and time demands, an optimal data collection approach may involve an EOL care registration system integrated with electronic health records. Such advances in assessment would help to capture the scope and quality of EOL care delivered in general practice and inform the development of health policy. However, this approach will possibly involve ethical issues around privacy of patients, data confidentiality, and intellectual property, which will require close communication with the families of patients, GPs, and the companies involved in developing clinical software and electronic registries.

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## Author Disclosure Statement

No competing financial interests exist.

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