


# The challenges of uncertainty and interprofessional collaboration in palliative care for non-cancer patients in the community: A systematic review of views from patients, carers and health-care professionals

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**Ai Oishi and Fliss EM Murtagh**

## Abstract

**Background:** Primary care has the potential to play significant roles in providing effective palliative care for non-cancer patients.

**Aim:** To identify, critically appraise and synthesise the existing evidence on views on the provision of palliative care for non-cancer patients by primary care providers and reveal any gaps in the evidence.

**Design:** Standard systematic review and narrative synthesis.

**Data sources:** MEDLINE, Embase, CINAHL, PsycINFO, Applied Social Science Abstract and the Cochrane library were searched in 2012. Reference searching, hand searching, expert consultations and grey literature searches complemented these. Papers with the views of patients/carers or professionals on primary palliative care provision to non-cancer patients in the community were included. The amended Hawker's criteria were used for quality assessment of included studies.

**Results:** A total of 30 studies were included and represent the views of 719 patients, 605 carers and over 400 professionals. In all, 27 studies are from the United Kingdom. Patients and carers expect primary care physicians to provide compassionate care, have appropriate knowledge and play central roles in providing care. The roles of professionals are unclear to patients, carers and professionals themselves. Uncertainty of illness trajectory and lack of collaboration between health-care professionals were identified as barriers to effective care.

**Conclusions:** Effective interprofessional work to deal with uncertainty and maintain coordinated care is needed for better palliative care provision to non-cancer patients in the community. Research into and development of a best model for effective interdisciplinary work are needed.

## Keywords

Palliative care, primary health care, interprofessional relations, community health services, heart failure, chronic obstructive pulmonary disease

### What is already known about the topic?

- Many people die of non-cancer diseases without enough access to palliative care.
- Many patients want to be cared for at home until the last phase of their life.
- Primary care plays important roles in providing palliative care in the community.

### What this paper adds?

- Non-cancer patients and carers expect general practitioners to provide compassionate care, have appropriate knowledge and play central roles in providing palliative care.

### Corresponding author:

Ai Oishi, c/o Murtagh, Cicely Saunders Institute, King's College London, Bessemer Road, London SE5 9PJ, UK.  
Email: aieye95@gmail.com

- Continuity and coordination of the care are significant gaps in care provision.
- Health-care professionals have reciprocal expectations and concerns that sometimes conflict with each other.
- Uncertainty was recognised by health-care professionals as a great barrier to the provision of good palliative care.

#### Implications for practice, theory or policy

- Effective interprofessional work needs to be enhanced in primary palliative care for non-cancer patients to deal with uncertainty and to assure continuity and coordinated care.
- Research is needed on who should be the coordinators of the care, what kind of care models work and how it works.

## Introduction

Palliative care has been historically developed with the focus on cancer. However, recent rapid global ageing and changes in disease prevalence, which are particularly evident in developed countries, have brought renewed attention to palliative care for chronic non-cancer diseases. Although there are increasing percentages of non-cancer patients among those utilising specialist palliative care services in the United Kingdom and the United States,<sup>1,2</sup> many non-cancer patients are still dying in primary care settings without accessing specialist palliative care services. Considering the fact that more people wish to die at home in most developed countries than in hospitals,<sup>3,4</sup> the role of primary care providers (PCPs) in palliative care for non-cancer patients is significant.

While some studies have shown that general practitioners (GPs) regard palliative care as a part of their responsibilities towards their patients,<sup>5–8</sup> it has been suggested that not many non-cancer patients in the community receive adequate palliative care.<sup>7,9</sup>

The available evidence on the needs and experience of patients suffering from non-cancer diseases has been reviewed mainly in accordance with diagnoses.<sup>10,11</sup> Yet, to our knowledge, this evidence has not been systemically reviewed to allow comparison across different perspectives, for example, those of patients, carers and health-care professionals (HCPs).

Health-care service planning must reflect the needs of service users.<sup>12</sup> It is equally important to know the views of HCPs on the services, as the understanding of conflicts and agreement between HCPs and patients can lead to improvements in the services and clinical practice. The existing evidence regarding the different perspectives on palliative care provision to non-cancer patients in the community needs to be synthesised so as to inform clinicians and policy makers.

This review therefore identifies, critically appraises and synthesises the existing evidence on views on the provision of palliative care for non-cancer patients by PCPs and reveals any gaps in the evidence.

## Methods

The definitions of terms used in this review are given in Table 1.

The methods for this review are structured according to The Centre for Reviews and Dissemination's guidance for undertaking reviews in health care<sup>14</sup> and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement<sup>15</sup> supplemented by guidance on narrative synthesis.<sup>16</sup>

Paper searches were conducted using MEDLINE, Embase, CINAHL, PsycINFO, Applied Social Science Abstract and the Cochrane library (all from inception to September 2012). The searches were conducted in September/October 2012.

Search terms were categorised into four groups:

- Group 1: Disease diagnoses
- Group 2: 'Palliative care'
- Group 3: 'Primary care'
- Group 4: 'Attitude'

(See Appendix 1 for search terms.) These groups were combined with 'AND' to complete the search.

A cited reference search using SCOPUS was conducted for further identification of relevant studies. Reference lists of relevant papers were also manually searched. The content pages of *Palliative Medicine* (1987–1992, and January to November 2012) were hand-searched. Authors of relevant papers and principal researchers of relevant studies identified through UK Clinical Research Network Study Portfolio Database<sup>17</sup> were asked for any further studies related to the review questions. Other search engines such as CareSearch database<sup>18</sup> and Open Grey<sup>19</sup> were searched to identify relevant grey literature.

Selection criteria were set to include studies reporting the views of patients/carers or professionals on primary palliative care provision to non-cancer patients in the community. The SPIDER tool enabled us to conceptualise eligibility criteria (Table 2).<sup>20</sup>

In this review, 'Sample' of the study is patients, carers or professionals. Studies with patients or carers as participants are considered when 50% or more of the participants or the ones they cared for had non-cancer diagnoses. 'Phenomenon of interest' is primary palliative care provision to non-cancer patients at home. 'Evaluation' is participants' views on this phenomenon. Any study designs, both quantitative and qualitative, are considered to be included.

**Table 1.** Definitions of terms.

Palliative care: this review uses the definition of palliative care provided by WHO.<sup>13</sup>

PCPs:

HCPs who are

1. based in the community;
2. taking care of a variety of patients within a certain population regardless of their diagnosis, gender or age;
3. not trained to be specialists in palliative care, despite maybe having had some supplementary training in this area.

GPs:

Medical doctors who specialise in primary care; this includes 'family physicians'.

Primary palliative care:

Palliative care provided by PCPs.

Carers:

Carers who are neither professional nor paid. These are usually family members of the patients, but may be friends or anyone who offers to care for the patients. Informal carers, family caregivers and those significant to the patients are included within this term in this review.

WHO: World Health Organization; PCP: primary care provider; HCP: health-care professional; GP: general practitioner.

**Table 2.** SPIDER tool and search term groups.

SPIDER	In this review	Search term
S – sample	Patients with life-limiting diseases other than cancer Carers Any HCPs	Group 1
PI – phenomenon of interest	Primary palliative care for non-cancer patients at home	(Group 1); Group 2; Group 3
D – design	Any designs	
E – evaluation	'Views' of participants	Group 4
R – research type	Any types	

HCP: health-care professional.

Studies that focused on specific topics in palliative care (e.g. decision-making, symptom management, communication, euthanasia, out-of-hours care or identifying patients) were excluded. Papers that only reported patterns of service uses and did not contain any participants' views were also excluded. Studies regarding care for special groups of patients, such as those with severe mental illnesses or those who were incarcerated, and for sexual minorities were also excluded, as the needs of these patients were assumed to be quite different from those of the majority of patients. Papers written in languages other than English, without any new empirical data or not providing sufficient information to judge their eligibility, were also excluded. We also decided to exclude the papers with limited reference to the review questions, as they were considered to have no impact on the overall conclusions.<sup>21–24</sup>

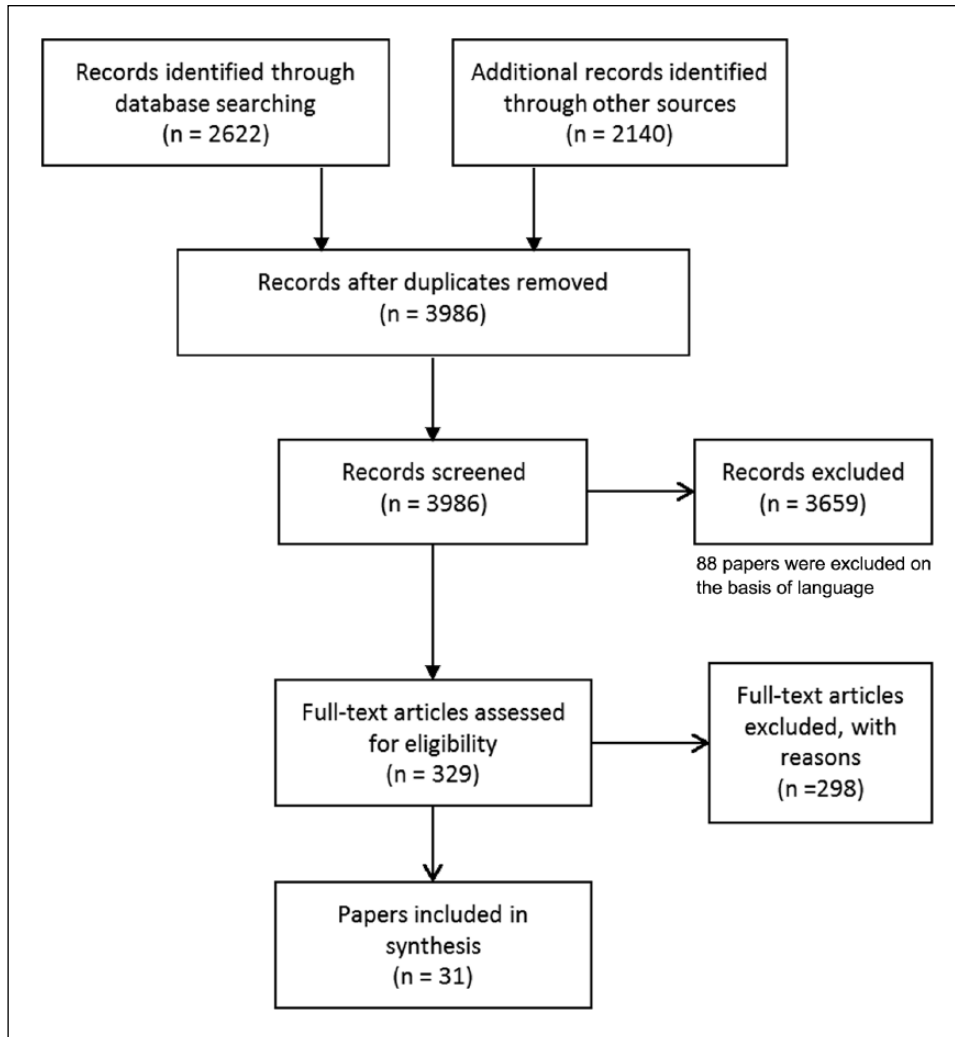
The titles and abstracts of all identified papers were screened by A.O. Of those that were selected for reading of the entire paper, 10% were randomly selected and their agreement with the eligibility requirements was confirmed

by F.E.M.M. Any papers for which inclusion or exclusion was unclear were discussed to reach a consensus.

Information about the studies (e.g. study aims, country, study setting, targeting diseases, participants, sampling methods, types of collected data, analysis methods) was extracted from each paper.

Amended Hawker's criteria<sup>4,25</sup> were used for quality assessment of the included studies. These criteria aim to assess 10 aspects of the study (including aims, method, sampling, data analysis, bias and transferability or generalisability) graded from 1 (very poor) to 4 (very good) and have the advantages of being able to be used for all qualitative, quantitative and mixed-methods studies.

Given the heterogeneity of included studies, Narrative Synthesis<sup>16</sup> is most appropriate for data synthesis in this review. Analysis and synthesis were done by grouping the data by tabulations, thematic analysis and conceptual mapping. Each theme from selected studies was tabulated and then synthesised. The robustness of the synthesis was assessed in the form of a critical appraisal of this review process and is described in the discussion section of this paper.



**Figure 1.** PRISMA flow diagram of study selection.<sup>15</sup>  
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

## Results

After the duplicates were removed, 3986 papers were identified for study selection. A total of 31 papers from 30 studies from 1998 to 2012 met the inclusion criteria. A PRISMA flow diagram<sup>15</sup> of study selection is shown in Figure 1.

### Characteristics of included studies

The overview of included studies is shown in Table 3. Apart from four studies, one from each of the United States, Australia, New Zealand and Sweden, all others were from the United Kingdom. These represent the views of 719 patients, 605 carers and over 400 professionals. Only three exclusively collected quantitative data and another three studies used mixed methods. All others were qualitative. Of the three quantitative studies, one was an intervention study<sup>31</sup> and the other two were observational studies.<sup>45,46</sup>

Nine of the included studies were about chronic obstructive pulmonary disease (COPD).<sup>26–30,32,35,43,49</sup> Eight studies had heart failure (HF) as their main topic.<sup>36–39,50–53,55</sup> Three studies investigated the experience of motor neurone disease (MND),<sup>34,40,44</sup> two were on Parkinson's disease (PD)<sup>47,48</sup> and one each was about patients with multiple sclerosis (MS)<sup>33</sup> and dementia.<sup>54</sup> Two survey studies examined stroke patients.<sup>45,46</sup>

More than half of the studies (17 studies) included patients as participants.<sup>26–42</sup> Sixteen included bereaved or current carers.<sup>32–38,40–48</sup>

The average age of patient participants was approximately 70 years, with the exception of the MND and MS studies, which had younger populations.<sup>33,34,40</sup>

Most of the COPD and HF studies recruited participants through general practices while MND and MS studies employed a variety of recruitment methods, which probably reflected the prevalence of the diseases.

**Table 3.** Characteristics of included studies.

Study	Disease	Participants	Relevant findings	Quality score
<i>Studies that have patients as participants</i>				
Skilbeck et al., <sup>26</sup> United Kingdom	COPD	Patients (n = 63)	47% thought the care provided by GPs was excellent, 40% good, 9% fair and 4% poor. 34% received visits from the DN, but the nature of the visit was task-oriented (e.g. dressing or blood sample).	27
Oliver, <sup>27</sup> United Kingdom	COPD	Patients (n = 22)	Some patients remember negative messages such as 'self-inflicted', 'nothing could be done' at the diagnosis. Relationship between HCPs can be strengthened by empathy. There is a reluctance to seek help because 'nothing could be done'. Health-care needs as a direct intervention based on an exacerbation is noted. Patients think they need to be a good patient, not to be a nuisance because doctors hold immense power over decision-making. Primary care nurses are not considered as useful.	28
Jones et al., <sup>28</sup> United Kingdom	COPD	Patients (n = 16)	Participants know when to call, but leave the decision to families. Participants think GPs are too busy. Half of participants want to know more about illness, and the other half does not. Some think visits should be made regularly so as they would not have to ring. Patients attribute their ill conditions to smoking habits.	30
Gysels and Higginson, <sup>29</sup> United Kingdom	COPD	Patients (n = 18)	Patients attribute their conditions to smoking. Some report GPs have lost their interest in patients when they disclose their smoking habit. GPs are considered helpless in treating symptoms. Patients experience difficulty in drawing proper attention from HCPs to their symptoms. DNs rarely visit patients.	32
Shipman et al., <sup>30</sup> United Kingdom	COPD	Patients (n = 16)	Factors related to good relationship with GPs are as follows: - Easy access, GPs' willingness to visit - GPs' understanding the concerns - Continuity of care Barriers to contacting GPs are as follows: - Physical barriers (pain, breathlessness) - Poor relationship with GPs, lack of continuity of care - Not wanting to know too much about the illness - Not knowing when to call - Not wanting to bother doctors 'inappropriately' - Feeling there is little to be done Contact with GPs tends to be made by proxies not by patients. Not much is mentioned about other members of primary care apart from GPs.	32

(Continued)

Table 3. (Continued)

Study	Disease	Participants	Relevant findings	Quality score
Brumley et al., <sup>31</sup> United States	Cancer (47%), HF (33%), COPD (21%)	Patients ( <i>n</i> = 298)	Coordination of care, interdisciplinary team with multi-dimensional approach and earlier involvement (prognosis with 12 months rather than 6 months) can increase the patients' satisfaction, reduce the service use and cost.	34
Seamark et al., <sup>32</sup> United Kingdom	COPD	Patients ( <i>n</i> = 10), carers ( <i>n</i> = 8)	Conscious discussion about condition with HCPs is regarded positive. Many participants deducted their conditions from the contact to HCPs. Specialist services are regarded as inaccessible or useless by some participants. Regular visits by any HCPs are considered to be a reassurance for carers.	26
Edmonds et al., <sup>33</sup> United Kingdom	MS	Patients ( <i>n</i> = 32) and carers ( <i>n</i> = 17)	Lack of continuity and coordination of care both within and between social and health-care services are described as 'compartmentalisation'. Lack of organised information about EOL care is noted.	32
Whitehead et al., <sup>34</sup> United Kingdom	MND	Patients ( <i>n</i> = 24) and carers ( <i>n</i> = 28)	Patients and carers experienced wide range of fears and anxiety regarding the final stages of the diseases. Some participants need more information to help them make decisions regarding EOL care. Many participants wished to die at home. Carers wished to avoid hospital admission. Limited GP involvement and lack of continuity of care and expertise were reported. Accessing supportive care was described extremely difficult.	32
Pinnock et al., <sup>35</sup> United Kingdom	COPD	Patients ( <i>n</i> = 21), carers ( <i>n</i> = 13) and professionals ( <i>n</i> = 18)	Acceptance of disease leads patients not to seek out information about their condition. Chaotic and long story of COPD with no beginning (contrast with HF and lung cancer) is noted. Illness experience is indistinguishable from their natural ageing. Clinicians find it more difficult making formal diagnosis of COPD and discussing about EOL care issues than with cancer patients. Longstanding relationship made discussing EOL care issues even more difficult. Death is not anticipated although some thought they would die during an exacerbation.	37
Murray et al., <sup>36</sup> United Kingdom	HF	Patients ( <i>n</i> = 20), carers ( <i>n</i> = 20) and HCPs ( <i>n</i> = ?)	Cancer care is considered to be more coordinated and resourced than HF care. HF patients are less involved in decision-making. Primary care contacts are made mainly with GP. HF patients have less chance to die at home. GPs are frustrated by their limited role, which is to monitor and adjust the medication. Continuity of key professionals is hard to maintain. Care is based on a medical model focused on treatment.	30

**Table 3.** (Continued)

Study	Disease	Participants	Relevant findings	Quality score
Boyd et al., <sup>37</sup> United Kingdom	HF	Patients ( <i>n</i> = 20), carers ( <i>n</i> = 20) and HCPs ( <i>n</i> = 16)	<p>GPs were regarded as the main contact and sometimes offer emotional and practical support.</p> <p>Patients and carers are not sure about raising EOL care issues and GPs are awaiting for cues from them.</p> <p>Continuity of GPs' care is hardly maintained.</p> <p>GPs frustrated as little could be done to help patients.</p> <p>Professionally led approach is not recognised as a partnership by patients and carers. Some GPs are not approachable for patients.</p> <p>Professionals were considered to have power over treatment and some patients prefer to leave decision-making to the professionals.</p> <p>A few patients actively avoided information.</p> <p>Information needs vary depending on patients' preference.</p> <p>Professionals' interest in the well-being of patients and carers was appreciated.</p> <p>Some patients thought GPs were not quick enough to prevent hospital admissions.</p> <p>HF nurse specialist home visit was considered useful, but some GPs were ambivalent, wanting the specialist nurses to have an advisory role.</p>	32
Boyd et al., <sup>38</sup> United Kingdom	HF	Patients ( <i>n</i> = 36), carers ( <i>n</i> = 30) and professionals ( <i>n</i> = 32)	<p>Professionals, who are supportive, continue the relationships and coordinate the care proactively, are highly valued.</p> <p>Offering personalised information, fostering self-management, regular monitoring and holistic assessment are considered to be important.</p> <p>Tension between primary or secondary care was noted.</p> <p>It is recognised that primary care should function as a coordinator of the services.</p> <p>A lack of understanding specialists' advisory role among HCPs is pointed out.</p> <p>Time constraints can compromise effective primary care.</p> <p>Prognostic uncertainty causes difficulty in introducing palliative care at the right timing.</p> <p>HF nurse specialists' concerns about quality of care provided by non-specialists.</p>	31
Waterworth et al., <sup>39</sup> United Kingdom and New Zealand	HF	United Kingdom: patients and professionals ( <i>n</i> = 120); New Zealand: patients and GPs ( <i>n</i> = 25+?)	<p>Time constraints at consultations are noted by both GPs and patients.</p> <p>HF nurses are seen to be able to have more time with patients.</p> <p>Accessing GPs without appointment or during out-of-hours is possible for some patients, but this varies.</p> <p>Patients consider that GPs are busy. They do not want to waste GP's time, but they also feel that their own time is wasted if their needs are not met.</p>	29

(Continued)

Table 3. (Continued)

Study	Disease	Participants	Relevant findings	Quality score
Hughes et al., <sup>40</sup> United Kingdom	MND	Patients (n=9), carers (n = 5) and professionals (n = 15)	<p>Some GPs have noticed patients' notion of wasting GPs' time.</p> <p>All GPs experience difficulty in prognostication and managing time to have the 'difficult conversation'.</p> <p>Palliative care services were used to ensure 'emotional' time.</p> <p>Continuity of care is highly regarded.</p> <p>Conflicted views on service availability and usefulness among HCPs and patients are noted. (HCPs think MND patients are prioritised, while patients do not think so).</p> <p>Lack of HCPs' knowledge about MND and lack of coordination are perceived by patients.</p> <p>HCPs show their understanding of impacts of illness.</p>	33
Exley et al., <sup>41</sup> United Kingdom	Cancer (47%) and cardiorespiratory diseases (53%)	Patients (n = 27), carers (n = 7) and professionals (n = ?)	<p>Little information is conveyed to GPs from hospital professionals, and GPs feel sidelined.</p> <p>Patients and carers generally show their positive impression to their GPs.</p> <p>Non-cancer patients hesitate to ask for help to avoid 'bothering' GPs and DNs.</p> <p>More episodic care is provided to non-cancer patients.</p> <p>GPs are considered unable to do much to help them.</p> <p>GPs' prompt response to 'emergency calls' is highly valued.</p> <p>DNs are absently referred by patients and carers.</p> <p>DNs think they are called only at a 'crisis point' from non-cancer patients.</p> <p>Disorganisation of out-of-hours care is pointed out by GPs.</p> <p>GPs think it is much harder to recognise the non-cancer patients dying, which leads to less communication on EOL care issues.</p> <p>Patients rely on lay understandings and interpretations to make sense of their symptoms.</p>	29
Fitzsimons et al., <sup>42</sup> United Kingdom	HF (n = 6), RF (n = 6), respiratory disease (n = 6)	Patients (n = 18), carers (n = 17) and professionals (n = 18)	<p>Specialist nurses are cited as the main source of professional support and few patients cited other professional as beneficial.</p> <p>Carers view resource availability as limited, and GPs' time as constrained.</p> <p>Poor access to community service including appliances and financial benefits.</p> <p>Many patients show their acceptance of illness and insight to their poor prognosis. The longstanding relationship with HCPs enhances this trend.</p> <p>Some clinicians expressed difficulties in communicating poor prognosis; being afraid of taking away hope.</p> <p>Many participants have concerns about the uncertainty of the future.</p>	31



**Table 3.** (Continued)

Study	Disease	Participants	Relevant findings	Quality score
<i>Studies that have only carers as participants</i>				
Elkington et al., <sup>43</sup> United Kingdom	COPD	Bereaved carers (n = 25)	<p>Patients do not necessarily seek help or accept offers of help.</p> <p>Patients do not perceive there is a health problem.</p> <p>Health service provision at community level is valid in the last year of life.</p> <p>Respiratory nurses act as a link between primary and secondary care.</p> <p>Having someone who cares about (GPs or any other HCPs) and is willing to spend time with patients is appreciated.</p> <p>GPs' attitudes (e.g. carrying on writing) and the lack of regular and active monitoring were criticised.</p>	28
Herz et al., <sup>44</sup> Australia	MND	Bereaved and current carers (n = 11)	<p>Some participants view the GP as 'an ally' in the search for a cure.</p> <p>The emotional cost is acknowledged by bereaved carers to be greater than physical burden.</p> <p>Lack of GPs' knowledge about MND and their time are reported.</p> <p>Need for respite and not seeking help for emotional needs are reported by bereaved carers retrospectively.</p>	30
Addington-Hall et al., <sup>45</sup> United Kingdom	Stroke	Bereaved carers (n = 237)	<p>More than three quarters of participants think that the GPs' treatment for constipation and nausea/vomiting had relieved these symptoms 'a lot' or 'some' (88% and 79%, respectively), but smaller proportions report this degree of control of pain and breathlessness (55% and 66%, respectively).</p> <p>82%–90% think GPs have tried hard enough to control symptoms.</p>	34
Young et al., <sup>46</sup> United Kingdom	Stroke	Bereaved carers (n = 183)	<p>83% of participants report it is very or fairly easy to get an appointment with the GP urgently.</p> <p>50% discuss with GPs about worries as much as they wanted, 18% discussed but not as much as they wanted, 12% do not discuss although they had tried.</p> <p>28% think GPs' care is excellent, 39% good, 22% fair, 11% poor.</p>	27
Hasson et al., <sup>47</sup> United Kingdom	PD	Bereaved carers (n = 15)	<p>Respite care is viewed as essential.</p> <p>Lack of communication between primary and secondary caregivers is noted.</p> <p>Access to palliative care and services is thought to be patchy and uncoordinated.</p> <p>GPs are generally highly rated by participants; home visits and information access on carers' behalf are particularly appreciated.</p> <p>Some suggest GPs' lack of detailed knowledge of disease.</p>	31

(Continued)

**Table 3.** (Continued)

Study	Disease	Participants	Relevant findings	Quality score
McLaughlin et al., <sup>48</sup> United Kingdom	PD	Carers (n = 26)	Lack of communication between primary and secondary caregivers is noted. The role of GPs is highly evaluated. Neurologists' involvement is also considered as important by some carers implying the GPs' lack of knowledge. Communication with and access to health and social care professionals are often ad hoc. Carers think that they only need palliative care when they are unable to cope. They want open communication with professionals. Need for respite is reported.	28
<i>Studies that have only professionals as participants</i>				
Disler and Jones, <sup>49</sup> United Kingdom	COPD	DNs (n = 43)	Nursing role is reported as task-oriented, but they think the relationship is based on emotional support. Some feel sidelined or roles taken over by specialists' involvement. Patients' reluctance of seeking help/ignorance of health-care needs is noted. Historical background of cancer-focused palliative care is noted. Lack of knowledge/self-confidence is reported as a barrier to get involved in EOL care. Unpredictable illness trajectory makes them fail to see COPD as a progressive life-limiting illness.	31
Hanratty et al., <sup>50</sup> United Kingdom	HF	Doctors (GPs, cardiologists, geriatricians and one palliative care doctor) (n = 34)	Three types of barriers to palliative care for HF patients are identified: 1. Organisational barriers (e.g. no support for GPs, need for key workers, poor support in the community). 2. Prognostication (e.g. bad impact of giving bad news too soon). 3. Doctors' roles (e.g. GPs are considered as a centre of care, GPs think SPC inaccessible or liable to steal their patients and cardiologist often fail to recognise palliative care needs).	32
Hanratty et al., <sup>51</sup> United Kingdom	HF	Doctors (GPs, cardiologists, geriatricians and one palliative care doctor) (n = 36)	Palliative care for HF is seen as not very medical and expectation of nurses is greater than of doctors. The balance between care and survival and the transition from rescue to comfort may not be clear-cut. It is noted that permission to fail is given in palliative care remit. Elusive role of palliative care specialists and doctors is reported. There is a need for support of GPs.	28
Waterworth et al. <sup>52</sup> and Waterworth and Gott, <sup>53</sup> New Zealand	HF	GPs (n = 30)	The amount of information given to patients varies. GPs are reluctant to use the word 'failure'. GPs tend to be protective and they attribute it to patients' old age. Illness trajectory is recognised as slow in decline, with multiple comorbidities, complex and unpredictable. Need for support for carers is noted.	27/30

**Table 3.** (Continued)

Study	Disease	Participants	Relevant findings	Quality score
Brännström et al., <sup>55</sup> Sweden	HF	Doctors (cardiologists and internists) (n = 15)	<p>Referral to palliative care is regarded as a sensitive issue.</p> <p>Hospital admissions are considered as an indication for more support input.</p> <p>Conversation about prognosis and EOL care issues is recognised as difficult.</p> <p>Support system in the community is variable.</p> <p>Practice nurses' role is considered as follows by GPs:</p> <ul style="list-style-type: none"> <li>- First contact, telephone communication is key</li> <li>- Education, team approach, coordinator of the care</li> <li>- Doing home visit</li> </ul> <p>GPs' attitudes can limit practice nurses' role.</p> <p>HF specialists' actual involvement is viewed as minimal because of lack of organisation, time and available HF programme.</p>	31
Grisaffi and Robinson, <sup>54</sup> United Kingdom	Dementia	GPs (n = 10)	<p>Lack of follow-ups and continuity of care are reported.</p> <p>Refuting opinions are conveyed in whether generalists or specialists should take responsibility of patients with severe conditions.</p> <p>Potential of HF nurses being a part of follow-up is suggested.</p> <p>Unpredictable illness trajectory is thought to make decisions about ICDs, resuscitation and active treatment difficult.</p>	27
Field, <sup>5</sup> United Kingdom	General	GPs (n = 25)	<p>Definition of 'end of life' is thought to be vague.</p> <p>Fluctuating illness trajectory at the end of life is noted.</p> <p>Prior knowledge of the person and eliciting wishes from patients themselves are thought to be important.</p> <p>Clinical assessment of patients with multiple comorbidities is viewed as an essential skill.</p> <p>Communication issues, discontinuity of care and low awareness of professionals are raised as dementia-related issues.</p> <p>Needs for education and raising awareness are noted.</p>	26
			<p>Terminal care is thought to be equated with care of cancer patients.</p> <p>Patients with long-term conditions are viewed as different from those dying from cancer in many ways; progression of their disease and the continuing treatment options are available.</p> <p>It is harder for GPs to define non-cancer patients as 'terminally ill' because of unpredictable illness trajectory.</p> <p>It is thought that it takes longer for non-cancer patients to accept that they are dying.</p> <p>It is thought to be easier for cancer patients to access palliative care.</p> <p>Non-cancer patients are viewed as unlikely to be construed as terminally ill.</p>	

The results of the quality assessment of all included studies are displayed in Table 3. The mean score was 30.1 (range from 26 to 37).

### *Expectations of GPs*

The identified themes were categorised as follows: service users' expectations of GPs, roles of professionals and barriers to effective primary palliative care provision to non-cancer patients.

Patients and carers expressed various expectations of GPs based upon their experience and understanding of illness either explicitly or indirectly.

Five studies (on stroke, COPD, HF and renal failure) reported high satisfaction with GPs' care.<sup>26,41,42,45,46</sup> The same number of studies were interested in physicians' views on palliative care for non-cancer patients.<sup>5,51,52,54,55</sup> Three studies on COPD attempted to depict patients' and carers' views on professionals other than GPs in the primary care setting, but neither patients nor carers responded.<sup>27,28,30</sup> For this reason, expectations of GPs – that is, compassionate care, knowledge and skills, central role and quick response – are presented in this section.

A compassionate attitude toward care is highly valued by patients and carers.<sup>30,37,38,42,43</sup> In these studies, the willingness of GPs to spend time with patients and to understand their concerns is greatly welcomed. In contrast, dismissive attitudes (e.g. 'carrying on writing') are severely criticised.<sup>43</sup>

All three MND, two PD and one of the COPD studies convey the concerns of patients or carers over GPs' lack of knowledge about the disease in question.<sup>29,34,40,44,47,48</sup> The patients and carers attribute this lack of knowledge to either low prevalence of the disease<sup>40</sup> or GPs' time constraints.<sup>44</sup> Lack of knowledge on the part of GPs leads to a lack of information for patients about available services<sup>40</sup> or hinders patients from accessing general practices when needed.<sup>29</sup> While some participants insist that GPs should have sufficient knowledge and skills, one carer of PD patients puts an emphasis on maintaining contact with neurologists for symptom management, doubting the ability of GPs in this area.<sup>48</sup> In studies investigating HF care, some hospital doctors<sup>55</sup> and specialist palliative care nurses<sup>38</sup> are concerned about the quality of care provided by primary care teams.

Patients and carers report that GPs play a central role in their care.<sup>37,43</sup> Some even convey their perceptions of GPs as partners in their journey with illness.<sup>44,47</sup> This notion, of the GP as the central person in the care, is also shared by other HCPs including GPs themselves.<sup>37,50,51</sup>

Quick responses to urgent needs, including out-of-hours, are considered highly important by patients and carers.<sup>37,41</sup> GPs are expected to be able to prevent unnecessary hospital admissions by responding to emergency needs. This may be related to some patients' negative impressions

of hospital admissions<sup>37</sup> and carers' beliefs that admission to hospital should be avoided.<sup>34,37</sup>

### *Roles of professionals*

The unclear boundaries of the roles of each professional are recognised by HCPs themselves, as well as by patients and carers.

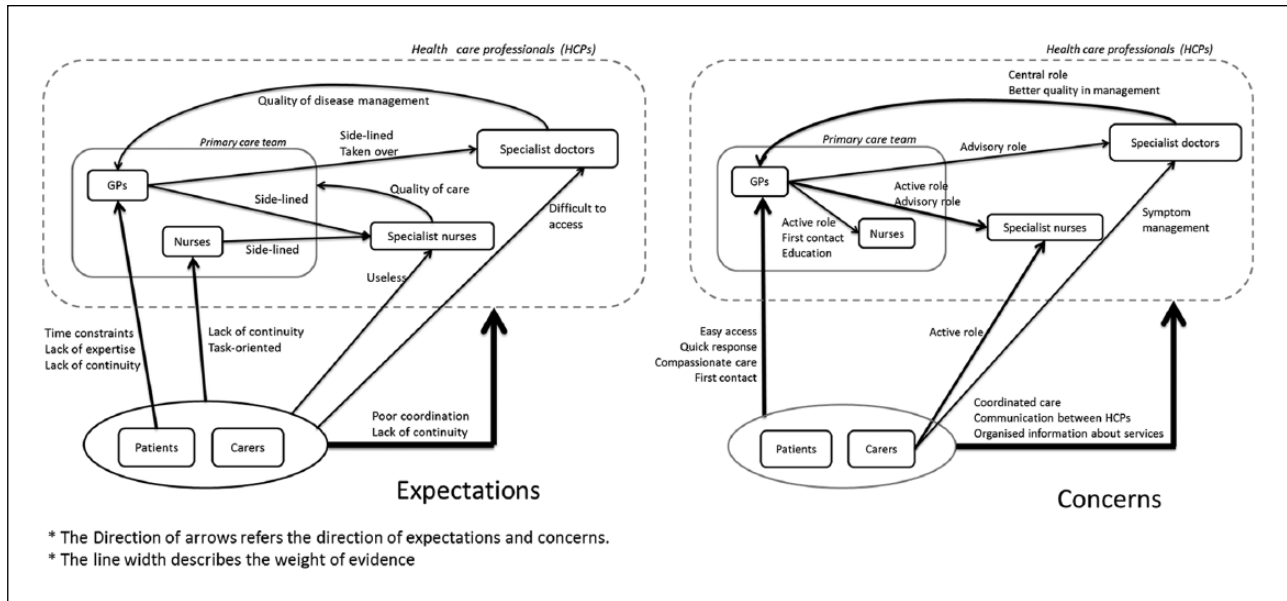
Both patients and nurses consider the nurses' role to be task-oriented.<sup>26,49</sup> However, one of the studies supporting this was ranked as relatively low in quality.<sup>26</sup> Carers appreciate having nurses with good technical skills,<sup>34</sup> which can be contrasted to their expectation of doctors to have a compassionate attitude. Moreover, primary care nurses think of themselves as lacking experience in end-of-life care for cardiorespiratory diseases.<sup>41,49</sup> GPs, on the other hand, expect nurses to act as coordinators and to provide education and holistic care to patients with HF.<sup>53</sup>

Various views on the role of specialist nurses are shown across the studies. In one study conducted in a rural area, patients saw specialist respiratory nurses as less useful.<sup>32</sup> Other studies report that nurses specialising in HF or COPD are seen as linking primary and secondary HCPs and as potentially useful.<sup>37,39,42,43,55</sup> This disparity may be caused by the difference in settings, but it should be noted that the former study<sup>32</sup> was assessed as low in quality and conducted by GPs, which potentially leads to bias towards generalists. Some studies show particular expectations of other HCPs for specialist HF nurses to take more active roles in the regular monitoring and coordination of care.<sup>52,55</sup>

Ambivalent feelings of PCPs towards specialist services are described in some studies, using words such as 'sidelined' and 'taken over' to express their feeling of specialist services taking over care of the patients.<sup>41,49</sup> Those who have such feelings consider that specialist nurses should be restricted to an advisory role rather than providing direct care to the patients.<sup>41</sup> While the importance of the role of specialist doctors in symptom management is cited by a PD carer,<sup>48</sup> in other studies, patients cite specialist doctors as inaccessible.<sup>32</sup> However, again, the latter study was conducted by GPs, and it is unclear whether they recruited participants from their practice, which could impact the results of the study.

### *Barriers to effective primary palliative care*

Along with expectations, many barriers to effective primary palliative care have been identified in the included studies. The impacts of an uncertain and unpredictable illness trajectory are most frequently cited across studies.<sup>35,36,40–42,50,54,55</sup> It is more evident that COPD starts without a clear onset and is punctuated by sporadic periods of exacerbation.<sup>26,27,35</sup> HF and dementia, on the other hand, are conveyed as a rather gradual deterioration.<sup>39,54</sup> The punctuated illness trajectory results in ad hoc care,



**Figure 2.** Expectations and concerns between patients, carers and health-care professionals.  
GP: general practitioner; HCP: health-care professional.

which is prominent in COPD and HF.<sup>26–28,32,35,38,43,55</sup> All HF, COPD, PD and MS patients and their carers expressed the need for continuity of care and regular monitoring.<sup>27,28,32,33,38,41,43,47,48,55</sup>

The uncertain illness trajectory results in difficulty in identifying the right timing for the transition of care.<sup>35,38,41,50,52,54</sup> This is also related to difficulty in accepting their dying conditions for patients and carers.<sup>27,41,54</sup>

The lack of communication between care providers is also frequently pointed out.<sup>33,38,41,42,47,48,54</sup> Not only are the boundaries of the roles of professionals unclear,<sup>38,47,50,51,55</sup> but carers are often required to act as the coordinators of the care.<sup>33</sup> One randomised controlled trial confirms that coordinated care can raise levels of satisfaction of patients.<sup>31</sup>

A lack of access to services for non-cancer patients is often cited across the disease groups.<sup>5,26,33,34,36,40–42,49,52</sup> The importance of home visits to compensate for the limited access is also pointed out in the highest quality study exploring the access to general practices for people with advanced COPD.<sup>30</sup> Some studies suggest that there are only a few existing available services,<sup>41,49</sup> while others point out that information to access the service is not well organised.<sup>33,40</sup>

Some studies convey the patients' notion that 'GPs are busy'.<sup>28,38,39,44</sup> Patients regard GPs' time constraints as a reason for their not having received enough information or care from GPs.<sup>44</sup> MND patients also claim that this situation has even hindered patients from seeking help from GPs.<sup>30,44</sup> Some patients, particularly those from a COPD/HF cohort, think little or nothing could be done by HCPs to improve their situation, which is why the patients end up not seeking help.<sup>27,29,36,37,41</sup> Some are anxious about

bothering HCPs inappropriately, for fear this may have a negative impact on their treatment decision.<sup>27</sup> Two studies respond to this notion of patients with comments from GPs, admitting that they indeed lack adequate time for sufficient care.<sup>38,52,53</sup>

## Discussion

### Principal findings of the review

A majority of the 30 included studies are on HF or COPD with small numbers of other diseases, for example, MND, stroke, PD, MS and dementia. In all, 27 of the studies use qualitative methods, 3 use mixed methods and another 3 are quantitative. In all, 27 studies are from the United Kingdom. The review represents the views of 719 patients, 605 carers and over 400 professionals.

First, patients and carers highly value PCPs' compassionate care, appropriate knowledge and skills, quick responses to urgent needs and maintenance of the coordination and continuity of care. Second, the unclear boundaries of the roles and responsibilities of each professional are recognised by HCPs themselves, as well as by patients and carers. HCPs also report their reciprocal expectations and concerns, which sometimes conflict with each other (Figure 2). While many patients, carers and other HCPs regard GPs as having a central role, GPs are juggling competing priorities with a limited amount of time, expecting nurses to take more active roles. In addition, uncertainty caused by unpredictable illness trajectory, lack of available resources and PCPs' lack of expertise are listed as additional barriers to palliative care for non-cancer patients.

**Table 4.** Expectations and barriers in palliative care in primary care settings.

	Expectations	Barriers
Common in generic palliative care in primary care settings	Willingness to spend time with patient <sup>42</sup> Continuity of care <sup>30,33,34,40,41,43,48,55</sup>	Time constraints <sup>28,38,40,42,44,52,53</sup>
Prominent in non-cancer conditions	Regular monitoring <sup>32,38,47,55</sup>  Coordinated care <sup>33,36,37,40,42,47</sup> Information needs <sup>28,33,34,36–38,40,41,48</sup> Sufficient knowledge about diseases <sup>40,44,48</sup>	Unpredictable illness trajectory <sup>26,27,35–37,40–42,50–53,55</sup> Unclear roles of specialists Conflict between care and cure <sup>50,51,55</sup> Patients' lack of insight for severity <sup>27,41</sup> Less available services <sup>26,33,34,36,37,40–42,49,52,53</sup> Lack of expertise <sup>41,49</sup>

### How the results fit in

There are two main challenges identified in this review, one is how to maintain continuity and coordination of care as a multiprofessional team and the other is how to deal with uncertainty. Patients' expectations of GPs such as a compassionate attitude, availability for home visits and out-of-hours care to maintain continuity of care are consistent with those identified in previous studies.<sup>56–58</sup> What has been newly added in this review is that uncertainty in non-cancer diseases makes meeting these expectations more difficult.

Uncertainty is likely to contribute to other barriers to effective care, for example, provision of care on an ad hoc (rather than planned) basis and failure to identify dying. This has been recognised as a challenge in palliative care for non-cancer patients.<sup>59–61</sup> While many efforts have been made to develop a model to predict the right timing to introduce palliative care to non-cancer patients, there are as yet no definite tools.<sup>54,62</sup> In COPD patients, for example, the gradual deterioration punctuated with exacerbations leads to ad hoc care.

Less available services and resources for non-cancer patients in the community aggravate the situation. In general, PCPs are required to achieve more with fewer resources. Table 4 summarises these expectations and barriers.

Figure 2 shows the reciprocal expectations and concerns between patients, carers and HCPs. What is notable is that no expectations of primary care nurses were directly expressed by patients, while concerns over their lack of continuity were voiced. This is supported by other evidence showing the low prevalence of access to community nurses.<sup>63</sup> Moreover, no other primary care team members were discussed in the included studies. In one study, the interviewers attempted to draw out opinions about other professionals but participants did not respond,<sup>41</sup> showing that they minimally consider other professionals in the primary care team. It is hence plausible that patients and carers predominantly consider GPs to be the main professional of their care in primary palliative care.

Regarding the role of primary care nurses, the results of the present review are by and large consistent with a previous systematic review.<sup>64</sup> One exception is that while primary care nurses regarded palliative care as holistic care in the previous review, this was not clearly shown in the present review. Moreover, the unpredictability of illness trajectory and a lack of expertise and awareness were identified as additional barriers to provision of palliative care to non-cancer patients. This is concordant with the findings in Table 4.

From GPs' point of view, they expect nurses to take more active roles.<sup>50–53</sup> This might be a reflection of GPs' excessive workloads and the expectations placed upon them. In fact, it seems impossible for GPs to take on all responsibilities given the multi-dimensional principle of palliative care.<sup>13</sup> Taking these findings into account, it seems that collaborations between GPs and primary care nurses are not efficiently undertaken, with primary care nurses roles being minimally considered by patients.

GPs also expect specialists to play advisory roles rather than to take full responsibility for the patients. GPs expressed discomfort about their role towards the patients being completely taken over, and this discomfort was also shared by primary care nurses. On the whole, interprofessional work in primary palliative care settings is relatively ineffective despite the importance of collaboration having been repeatedly emphasised.<sup>65–67</sup> This is even more relevant for non-cancer patients because the fluctuating trajectory of their illnesses can cause frequent exacerbations and admissions.<sup>68</sup>

This raises an issue as to how we can promote coordinated care and who should be the coordinator of the care. In the United Kingdom, the National Gold Standard Framework has been introduced as a systematic approach to enhance coordinated care.<sup>69</sup> While its effectiveness has been shown,<sup>70–73</sup> it is also suggested that an adequate amount of time to maintain shared vision, mutual respect and inclusive decision-making are important for its successful implementation.<sup>74</sup> Moreover, good networks are usually based on personal liaison rather than on a systematic approach.<sup>75</sup>

Allocating key care workers has been suggested to be important to maintain the continuity of care;<sup>76</sup> however, it is difficult from the present review to conclude who should be the coordinator of the care. While GPs are usually seen as the multidisciplinary team lead in the present review, they obviously lack time and resources. Some evidence within and outside of this review supports specialist nurses can possibly be the key workers.<sup>37,39,42,43,52,53,76</sup> The decision is probably better made locally, however, according to available resources and local preference.

### **Strengths and limitations**

This review, to our knowledge, is the first systematic review of views on palliative care provided by PCPs to non-cancer patients in community. It combines both qualitative and quantitative evidence with a wide range of views from different perspectives across the diseases. The completeness of the search with expert consultation and hand searching maximised the identification of the studies.

However, there are some limitations that should be considered in included studies. Many studies lacked detailed information about their participants, for example, patients' medical conditions or specialties of HCPs and the settings in which they were working.<sup>35–38,40–42,49</sup> Second, reporting by whom the findings are conveyed was also often missed. Despite the fact that having interviewed patients and carers together may affect the data, reports often failed to mention if they had interviewed them together or separately.<sup>34,38</sup> Only Edmonds et al.<sup>33</sup> mentioned this issue in their discussion.

At the review level, a majority of the included studies are from the United Kingdom, which may impact the generalisability of the findings. Cultural impacts on end-of-life care issues have to be considered when interpreting the results of this review. However, we believe our findings are useful to other nations with similar care models to that in the United Kingdom.

Another potential bias is that only one reviewer conducted the review process, with appraisals of a second reviewer at each step. As narrative synthesis is still regarded as a somewhat subjective method, having more reviewers would be preferable, but was not possible due to the limited resources available for this review.

Finally, excluding some papers with only a limited reference to the review questions<sup>21–24</sup> can be considered a weakness. This approach was adopted to make the review more feasible and the synthesis more appropriate. Furthermore, because the synthesis does not rely on quantitative concepts, and the contents extracted from included studies were sufficient, we believe excluding these papers did not affect the overall results.

### **Implications for practice, policy and research**

Continuity and coordination of care seemed to be significant gaps in care provision along with the great challenge

of uncertainty. The important point is to acknowledge uncertainty of illness trajectory – and for HCPs to share this acknowledgement with patients and carers – and develop a joint strategy or care plan to help manage it. To accept and deal with uncertainty has in fact been suggested as being a part of medical generalist services.<sup>77</sup> Paying attention to detail, being sensitive to patients' and carers' concerns and creating innovative solutions that are pertinent to compassionate care are ways to overcome the challenges caused by uncertainty.<sup>61,78</sup>

Enhancing interdisciplinary work not only increases the capacity as a team to support patients with a great extent of uncertainty in their illness trajectory but also enables more coordinated care to assure continuity. It is necessary to develop a better framework or better ways to utilise existing frameworks to achieve effective collaboration particularly in relation to palliative care for non-cancer patients. The existing care models should receive more in-depth evaluation in terms of how they work and what impact they have on multidisciplinary teams to inform future policymaking. Based on the findings of this review, as Barclay mentioned,<sup>79</sup> palliative care specialists should probably concentrate on short-term intensive input to more complicated cases rather than maintaining long-term relationships with patients.

### **Conclusion**

Our review found that patients expect GPs to provide compassionate care, have appropriate knowledge and play central roles in coordinated care. Uncertainty of the illness trajectory, unclear definition of the role of professionals and lack of collaboration between professionals are identified as barriers to effective primary palliative care provision to non-cancer patients. It is crucial to increase the capacity to deal with uncertainty as a team through effective interdisciplinary work. Clear role definitions of each professional and effective interprofessional collaboration will help to manage many challenges encountered in delivering palliative care to non-cancer patients in the community. Research into and development of a best model for effective interdisciplinary work are needed for better primary palliative care provision for non-cancer patients.

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#### Appendix I. Selected search terms.

Group 1	non-malignant* non-cancer* non-oncolog*. mp. stroke cerebrovascular* pulmonary emphysema chronic obstructive pulmonary disease/COPD neurodegenerative diseases motor neuron* disease/MND amyotrophic lateral sclerosis/ALS parkinson* disease multiple sclerosis/MS multiple system atrophy progressive supranuclear palsy acquired immunodeficiency syndrome/AIDS human immunodeficiency virus infection/HIV dementia huntington* heart failure chronic kidney failure end stage liver disease
Group 2	palliative care terminal care terminally ill end of life
Group 3	family practice/family medicine/family physician general practice/general practitioner primary health care community health services community health nursing public health nursing
Group 4	attitude of health personnel attitude to death delivery of health care health service accessibility clinical competence