Review Article

Are There Differences in the Prevalence of Palliative Care-Related Problems in People Living With Advanced Cancer and Eight Non-Cancer Conditions? A Systematic Review

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Abstract

Context. If access to effective palliative care is to extend beyond cancer patients, an understanding of the comparative prevalence of palliative care problems among cancer and non-cancer patients is necessary.

Objectives. This systematic review aimed to describe and compare the prevalence of seventeen palliative care-related problems across the four palliative care domains among adults with advanced cancer, acquired immune deficiency syndrome, chronic heart failure, end-stage renal disease (ESRD), chronic obstructive pulmonary disease, multiple sclerosis, motor neuron disease, Parkinson's disease, and dementia.

Methods. Three databases were searched using three groups of keywords. The results of the extraction of the prevalence figures were summarized.

Results. The electronic searches yielded 4697 hits after the removal of 1784 duplicates. Of these hits, 143 met the review criteria. The greatest number of studies were found for advanced cancer ($n = 57$) and ESRD patients ($n = 47$), and 75 of the 143 studies used validated scales. Few data were available for people living with multiple sclerosis ($n = 2$) and motor neuron disease ($n = 3$). The problems with a prevalence of 50% or more found across most of the nine studied diagnostic groups were: pain, fatigue, anorexia, dyspnea, and worry.

Conclusion. There are commonalities in the prevalence of problems across cancer and non-cancer patients, highlighting the need for palliative care to be provided irrespective of diagnosis. The methodological heterogeneity across the studies and the lack of non-cancer studies need to be addressed in future research. J Pain Symptom Manage 2014;48:660–677.

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Key Words
Prevalence, palliative care, cancer, acquired immune deficiency syndrome, heart diseases, chronic obstructive pulmonary disease, renal disease, neurodegenerative diseases, dementia

Introduction

The number of deaths from chronic rather than acute diseases is expected to increase worldwide.[1–3] A consequence of the aging population is that the time before death is differentiated by longer dying trajectories, with a higher prevalence of symptoms, resulting in longer and varied care needs at the end of life.[4] To effectively anticipate patients' needs, and plan palliative care services for non-cancer patients, we must understand how prevalent palliative care–related problems are across different diagnostic groups.[5,6] Although individual studies have considered this, only the Solano et al[7] review in 2006 attempted to bring data together across studies. However, only five conditions were appraised, and a considerable amount of data have been published since then. In addition, the review of Solano et al[7] review focused on physical and psychological symptoms, rather than wider palliative care–related problems. Therefore, this systematic review aimed to compare the prevalence of 17 palliative care–related problems within the four World Health Organization (WHO) palliative care domains (the physical, psychological, social, and spiritual domains)[8] among adults with advanced stage cancer, acquired immune deficiency syndrome (AIDS), chronic heart failure (CHF), end-stage renal disease (ESRD), chronic obstructive pulmonary disease (COPD), multiple sclerosis (MS), motor neuron disease (MND), Parkinson's disease, and dementia. We chose to include people living with MS, MND, Parkinson's disease, and dementia in our search because these neurodegenerative diseases show a different disease trajectory in comparison with the other diseases.[9] People living with dementia were included because of the increasing aging population.[10]

Two main objectives were set: 1) to describe and compare the prevalence of palliative care–related problems among advanced cancer and these eight advanced non-cancer diagnostic groups of patients, and 2) to describe and compare the characteristics of the prevalence studies.

Methods

Study Design

This systematic review was conducted in line with the PRISMA 2009 checklist, the PRISMA Flow Diagram, and the Center for Reviews and Dissemination procedures.[11,12] We used the Assessment of Multiple SysTemAtic Reviews (AMSTAR) measurement tool to ensure the methodological quality of our review.[13] The AMSTAR uses 11 questions each of which needs to be answered using the following possibilities: yes, no, cannot answer, or not applicable. To have the highest quality ranking, all applicable questions should be answered with "yes." K. M. conducted the search and the initial screening; R. H. reviewed any articles where there was a question as to whether they met study criteria. I. J. H. adjudicated. The reference lists within the full texts also were searched.

Search Strategy

We searched three electronic medical databases, namely Medline (1966 to February 2013), Embase (1988 to February 2013), and PsycINFO (1985 to February 2013), using three groups of keywords. Within each group of keywords, the words were combined using OR. The three groups of keywords were then combined using AND.

Keyword Group 1: worry; depression, low mood, sadness, mood; anxiety, adjustment disorders (psychological palliative care domain); wellbeing; peace; spiritual wellbeing; meaning of life; religion; spirituality (spiritual palliative care domain); support; information; family (social palliative care domain); pain; confusion, delirium, cognitive failure; breathlessness, dyspnoea, dyspnea; fatigue, weakness; insomnia, poor sleeping; anorexia; nausea; diarrhea, diarrhea; constipation (physical palliative care domain); symptoms. These words were selected as the most appropriate words to investigate the 17 palliative care–related problems. Because different terms are used to define problems, we used more than one keyword for the following problems: poor sleeping for insomnia; weakness for fatigue;

low mood, mood and sadness for depression; dyspnoea or dyspnea for breathlessness; and delirium and cognitive failure for confusion.

Keyword Group 2: dying, end of life, terminally ill, hospice$, palliative care, terminal care, advanced, terminal disease$. These words were selected to capture samples of patients in advanced disease stage.

Keyword Group 3: terminal disease$, advanced cancer$, metastatic cancer$, AIDS, end stage heart disease$, end stage heart failure, end stage respiratory disease$, end stage chronic obstructive pulmonary disease$, end stage COPD, end stage renal disease$, end stage renal failure, MS, MND, Parkinson disease$, dementia. These words were selected to identify the specified diagnostic groups.

These keywords were derived from those that were successfully used in the reviews of Solano et al[7] and Simms et al.[14] Simms et al[14] used the WHO definition of palliative care[8] to extract keywords identifying each palliative care domain. We refined our keywords using the synonyms for problems reported in the literature on symptom guidance and systematic reviews in palliative care.[15]

Inclusion/Exclusion Criteria

Fig. 1 presents the inclusion and exclusion criteria that were applied in the literature search.

Data Extraction

The data from each study were extracted to a common table with predesigned headings, namely reference, year of publication, country of origin; sample description; study design (measurement methods/tools, point or period

Inclusion criteria

- Studies on adults (aged 18 years or older), with advanced or terminal illness suffering from either cancer, AIDS, HD, COPD, ESRD, MS, MND, Parkinson's disease, or dementia
- Patients in palliative care who deteriorated despite treatment or with poor prognosis (i.e., less than one year)
- Studies reporting the prevalence of specified symptoms
- Original studies (quantitative)
- Articles that included data from at least one of the four palliative care domains

Exclusion criteria

- Case reports of single patients
- Articles not written in English, Dutch, French, or German
- Studies that did not disaggregate the palliative care–related problems within the reported sample
- Randomized controlled trials and other intervention studies (because of the application of selection criteria to the population of study)

Fig. 1. Inclusion and exclusion criteria of search. AIDS = acquired immune deficiency syndrome; HD = heart disease; COPD = chronic obstructive pulmonary disease; ESRD = end-stage renal disease; MS = multiple sclerosis; MND = motor neuron disease.

prevalence); and findings (% prevalence of problems per palliative care domain).

Describing and Comparing the Studies' Characteristics

The characteristics of all the studies are described in Table 1, which presents the total number of studies retained, total combined sample size, the nature of the prevalence measured (period/point), the period prevalence time ranges (minimum-maximum), the countries in which the studies were conducted, and the measurement methods used.

Data Analysis: Describing and Comparing the Prevalence of Problems

The results of the extraction of the prevalence figures of all included studies are summarized using minimum and maximum percentage ranges, and the problems are categorized by palliative care domain in line with the WHO definition[8] (Table 2). Meta-analytic techniques were not appropriate to analyze the prevalence data because of the heterogeneity between studies in terms of measurement tools and study designs. Nevertheless, we reviewed and present the number of studies that showed the prevalence of a problem in a particular diagnostic group of 50% or more.

Results

Retrieval Data

The electronic searches of the three databases yielded 4697 hits after removal of 1784 duplicates. A total of 143 studies[1,5,16–156] met the inclusion/exclusion criteria for the synthesis. The PRISMA flow diagram reports the search strategy and the results yielded (Fig. 2).

The assessment of the methodological quality of our systematic review using the AMSTAR measurement tool indicated that 10 of the 11 questions could be answered positively, that is, that the following actions are executed and reported in the review: an *a priori* design is provided, a duplicate study selection and data extraction are executed, a comprehensive literature search is performed, the status of publication is used as an inclusion criterion, a list of studies that were included and excluded is provided, the characteristics of the included studies are provided, the scientific quality of the included studies is used to formulate conclusions, the method used to combine the findings of the studies is appropriate, and the conflict of interest is stated at the end of this article. The 11th item or question of the AMSTAR reviews if the likelihood of publication bias is assessed. This was not applicable for our study as we could not use statistical tests to analyze our results because of the heterogeneity across all included studies.

Characteristics of Included Studies

The greatest number of studies by diagnostic group were found for advanced cancer ($n = 57$) and ESRD patients ($n = 47$; Table 1). The lowest number of studies were found for MND ($n = 3$) and MS patients ($n = 2$). The greatest number of studies originated from the U.S. ($n = 57$), the U.K. ($n = 20$), and Canada ($n = 13$). In the advanced cancer diagnostic group, 37 of the 57 studies used a point prevalence to collect data, and in the ESRD patient disease group, 28 of the 47 studies used a period prevalence with a minimum-maximum time range of "past two days" to "the last two months." For all the other diagnostic groups, a period prevalence was primarily used. Considering the measurement tools used across the advanced cancer and non-cancer diagnostic groups, 75 of the 143 studies used validated scales. For data collection among patients with advanced dementia, four of the seven studies used chart reviews.

Describing and Comparing Prevalence Data

The prevalence figures reported in the 143 studies are summarized using minimum and maximum prevalence ranges (Table 2). In this table, the different terms used for each palliative care–related problem across all the studies are presented to highlight the varying definitions. For example, we found studies investigating "shortness of breath" or "respiratory distress" to indicate the study of dyspnea or breathlessness.

Among people living with MND and MS, there were many problems for which we did not find prevalence data, for example, anorexia, delirium, diarrhea, and worry, as well as for all the spiritual and social palliative care–related problems. For certain diseases, we only found one study on the prevalence of a problem (e.g., fatigue in people living with dementia, Parkinson's disease, and MS; Table 2).

Table 1
Characteristics of Included Prevalence Studies ($N = 143$)

Characteristics	Cancer	COPD	CHF	ESRD	Dementia	AIDS	Parkinson	MND	MS
Total number of studies	57	10	8	47	7	8	9	3	2
Total sample (patients), all studies	34,866	2045	1310	11,140	868	1864	25,941	221	214
Total number of point prevalence studies[a]	37, of which two studies presented both a point and a period prevalence	1	1	11, of which one study presented both a point and a period prevalence	2	—	—	—	—
Total number of period prevalence studies	17, of which two studies presented both a point and a period prevalence	8	7, of which one study presented both a point and a period prevalence	28, of which one study presented both a point and a period prevalence	—	5	6	1	1
Period prevalence time ranges (minimum-maximum)	Three Days-past week	Last three days-final year of life	Last year of life	Past two days-last two months	—	Last two days-last two weeks	Past two weeks-last month	Last month of life	Last three days
Total number of studies of which the point or period of prevalence was not specified	7	1	1	10	5	3	3	2	1
Total number of studies conducted in the following countries									
The Netherlands, $n = 6$	3	1	1	1					
Germany, $n = 5$	4	1							
Austria, $n = 1$				1					
France, $n = 3$				2		1			
Italy, $n = 7$	5			1	1				
Spain, $n = 5$	3		1		1				
Switzerland, $n = 2$	1				1				
United Kingdom, $n = 20$	7	3	2	5			1	1	1
Ireland, $n = 1$				1					
China, $n = 6$	4			2					
Korea, $n = 1$				1					

Japan, $n=3$	2			1					
India, $n=1$	1								
Australia, $n=5$	2						1	1	1
New Zealand, $n=2$	2								
Canada, $n=13$	2	1		10					
Sweden, $n=3$	1		1				1		
Norway, $n=1$	1								
Denmark, $n=1$	1								
Romania, $n=1$	1								
Hungary, $n=1$				1					
South Africa, $n=2$	1					1			
Israel, $n=3$				2	1				
Africa, $n=1$				1					
U.S., $n=57$	16	4	3	18	3	6	6	1	
Number of studies using the following symptom/problem measurement methods:									
Validated assessment scales	24	7	2	29	1	4	5	1	2
Self-developed items list or checklist	22	2	4	13	1	2	2	1	
Medical records or patient reports	10		2	5	4	2		1	
Minimum data set review					1		1		
Method not specified	1	1					1		

COPD = chronic obstructive pulmonary disease; CHF = chronic heart failure; ESRD = end-stage renal disease; AIDS = acquired immune deficiency syndrome; MND = motor neuron disease; MS = multiple sclerosis.

[a]Point prevalence time points include measurements at the moment and those over the last 24 hours.

Table 2

Prevalence Summary Grid Derived From 143 Studies

Domain	Problems and Number of Different Studies for Each Problem for All Diagnostic Groups (n)	Minimum-Maximum Prevalence % of Each Problem[References] Total Sample of Patients (N) for Each Problem Total Number of Studies (n) for Each Problem Number of Studies That Report Prevalence for a Problem as ≥50% ($n_{\geq 50\%}$)								
		Cancer	COPD	CHF	ESRD	Dementia	AIDS	Parkinson	MND	MS
Physical:	Fatigue/ tiredness/ weakness $n = 58$	23–100%[5,17,18,21,23–26,28,31,34,37,38,40,43,45,47–50,52–54,56–59,64,65,67–71] $N = 23{,}825$ $n = 34$ $n_{\geq 50\%} = 25$	32–96%[1,74,75,77,79,a] $N = 500$ $n = 5$ $n_{\geq 50\%} = 3$	42–82%[79,83,84] $N = 212$ $n = 3$ $n_{\geq 50\%} = 2$	13–100%[87,88,90,91,93,100,101,106,117,128,129] $N = 1403$ $n = 11$ $n_{\geq 50\%} = 7$	22%[137] $N = 50$ $n = 1$	43–95%[141,143,145] $N = 528$ $n = 3$ $n_{\geq 50\%} = 2$	42%[149] $N = 101$ $n = 1$	-	80%[156] $N = 52$ $n = 1$
	Anorexia $n = 10$	76–95%[63,67,70] $N = 1098$ $n = 3$	64–67%[1,a] $N = 87$ $n = 1$	-	38–64%[95,103,106,128] $N = 788$ $n = 4$ $n_{\geq 50\%} = 3$	-	82%[145] $N = 52$ $n = 1$	13%[154] $N = 123$ $n = 1$	-	-
	Pain (including different origins) $n = 86$	30–94%[5,16–19,21–25,27–29,31,32,34,35,37–40,42–52,54–60,63–65,67–71] $N = 29{,}966$ $n = 47$ $n_{\geq 50\%} = 4$	21–77%[1,72–75,77,79,a] $N = 1730$ $n = 7$ $n_{\geq 50\%} = 3$	14–78%[73,79,81–85] $N = 1230$ $n = 7$ $n_{\geq 50\%} = 2$	11–83%[86–88,93,94,100,101,103,131,b] $N = 814$ $n = 9$ $n_{\geq 50\%} = 6$	14–63%[85,132–135,137] $N = 745$ $n = 6$ $n_{\geq 50\%} = 1$	30–98%[138,139,142–145,c] $N = 1325$ $n = 6$ $n_{\geq 50\%} = 5$	42–85%[147,148,152,154] $N = 327$ $n = 4$ $n_{\geq 50\%} = 2$	52–76%[152,155,d] $N = 102$ $n = 2$	68%[156] $N = 52$ $n = 1$
	Nausea-vomiting $n = 67$	2–78%[5,16–25,27–35,40–50,52,54,56–60,63,65,67–71] $N = 31{,}743$ $n = 48$ $n_{\geq 50\%} = 3$	4%[79] $N = 81$ $n = 1$	2–48%[79,81,83,84] $N = 812$ $n = 4$	8–52%[86,87,90,91,101,103,106,117,128,b] $N = 1176$ $n = 9$ $n_{\geq 50\%} = 1$	8%[137] $N = 50$ $n = 1$	41–57%[138,139,143,145,c] $N = 914$ $n = 4$ $n_{\geq 50\%} = 1$	-	-	26%[156] $N = 52$ $n = 1$
	Breathlessness/ dyspnea/ shortness of breath/respiratory distress $n = 73$	16–77%[5,16–21,23–35,37–54,56–60,63,65,67–71] $N = 33{,}175$ $n = 40$ $n_{\geq 50\%} = 16$	56–98%[1,72–75,77,79,80,a] $N = 1835$ $n = 8$	18–88%[73,79,81–85] $N = 1230$ $n = 7$ $n_{\geq 50\%} = 5$	11–82%[86–88,90,91,93,95,100,101,117,131,b] $N = 1031$ $n = 11$ $n_{\geq 50\%} = 4$	12–52%[85,132–134,137] $N = 674$ $n = 5$ $n_{\geq 50\%} = 1$	43–62%[138,139,145,c] $N = 811$ $n = 3$ $n_{\geq 50\%} = 3$	-	81–88%[155,d] $N = 52$ $n = 1$	26%[156] $N = 52$ $n = 1$

	Insomnia/ poor sleeping/ difficulty sleeping/ sleep disturbance $n=65$	3–67%[5,16–18,20,21,23–25,27,29,31,32,34,35,37,38,41,43,45,47–50,52,56–59,63,65,67,70] $N=21{,}725$ $n=33$ $n_{\geq 50\%}=11$	15–77%[1,74,75,77,a] $N=419$ $n=4$ $n_{\geq 50\%}=3$	36–48%[81,83,84] $N=746$ $n=3$	1–83%[87,88,91,93,98,101,103,117–120,122–127,131] $N=2265$ $n=18$ $n_{\geq 50\%}=7$	14%[136] $N=123$ $n=1$	40–74%[138,139,145,c] $N=811$ $n=3$ $n_{\geq 50\%}=3$	43–50%[149,154] $N=224$ $n=2$ $n_{\geq 50\%}=1$	24–33%[155,d] $N=52$ $n=1$	-
	Confusion/ delirium/ cognitive failure/ cognitive symptoms $n=31$	2–68%[18,22,23,27,29,31–34,38,40,41,44,46–52,56,57,62,65,71] $N=18{,}768$ $n=25$ $n_{\geq 50\%}=3$	14–33%[1,73,a] $N=309$ $n=2$	15–48%[73,82,83] $N=433$ $n=3$	35–70%[86,b] $N=32$ $n=1$	-	-	24%[154] $N=123$ $n=1$	-	-
	Constipation $n=60$	4–64%[5,18–25,29,30,32–38,40–50,52,54,56–60,63,65,67,69–71] $N=30{,}841$ $n=42$ $n_{\geq 50\%}=10$	12–44%[1,75,a] $N=150$ $n=2$	12–42%[81,83,84] $N=746$ $n=3$	8–65%[87,88,92,101,106,130,131] $N=1136$ $n=7$ $n_{\geq 50\%}=3$	40%[137] $N=50$ $n=1$	19–35%[138,139,c] $N=759$ $n=2$	24%[153] $N=123$ $n=1$	52–56%[155,d] $N=52$ $n=1$	46%[156] $N=52$ $n=1$
	Diarrhea $n=33$	1–25%[5,20,21,23–25,27,29,32,34,37,40–42,44,46–48,56–60,69] $N=17{,}813$ $n=24$	-	12%[83,84] $N=146$ $n=2$	8–36%[86–88,131,b] $N=105$ $n=4$	-	29–53%[138,139,143,c] $N=862$ $n=3$ $n_{\geq 50\%}=2$	-	-	-
Psychological:	Depression/ depressive mood/sadness/ low mood $n=71$	4–80%[5,16,18–20,23,27–29,32,34,37,38,41,47,48,50,52,56,57,63,65,68–71] $N=16{,}200$ $n=26$ $n_{\geq 50\%}=10$	17–77%[1,74,76–80,a] $N=752$ $n=7$ $n_{\geq 50\%}=4$	6–59%[79–81,83,84] $N=892$ $n=5$ $n_{\geq 50\%}=1$	2–61%[87–89,91,96–100,102,104–116] $N=7644$ $n=23$ $n_{\geq 50\%}=3$	46%[136] $N=123$ $n=1$	17–82%[138–140,142,143,145] $N=1211$ $n=6$ $n_{\geq 50\%}=4$	15–50%[146,149–151,153] $N=24{,}759$ $n=5$ $n_{\geq 50\%}=1$	23%[153] $N=119$ $n=1$	15%[153] $N=162$ $n=1$
	Anxiety/ nervousness/ agitation $n=50$	3–74%[5,16,20,28,32,38,47,48,50,52,56,57,63,65,66,68–71] $N=14{,}724$ $n=19$ $n_{\geq 50\%}=7$	23–53%[74,77,79,80] $N=455$ $n=4$ $n_{\geq 50\%}=1$	2–49%[79–81,83,84] $N=892$ $n=5$	7–52%[86–88,91,96,99,100,106,107,109,b] $N=818$ $n=10$ $n_{\geq 50\%}=1$	8–72%[133–137] $N=708$ $n=5$ $n_{\geq 50\%}=2$	13–76%[138–140,145] $N=923$ $n=4$ $n_{\geq 50\%}=2$	5–62%[146,149,151,153,154] $N=24{,}842$ $n=5$ $n_{\geq 50\%}=2$	19%[153] $N=119$ $n=1$	24%[153] $N=162$ $n=1$
	Worry $n=12$	3–71%[16,23,27,29,32,57,69] $N=1500$ $n=8$ $n_{\geq 50\%}=3$	65%[77] $N=60$ $n=1$	-	32–55%[87,88] $N=30$ $n=2$ $n_{\geq 50\%}=1$	-	51–86%[138,139,c] $N=759$ $n=2$	-	-	-

(*Continued*)

Table 2
Continued

Domain	Problems and Number of Different Studies for Each Problem for All Diagnostic Groups (n)	Minimum-Maximum Prevalence % of Each Problem[References] Total Sample of Patients (N) for Each Problem Total Number of Studies (n) for Each Problem Number of Studies That Report Prevalence for a Problem as ≥50% ($n_{\geq 50\%}$)								
		Cancer	COPD	CHF	ESRD	Dementia	AIDS	Parkinson	MND	MS
Spiritual:	Well-being $n=2$	91%[70] $N=406$ $n=1$	14%[79] $N=81$ $n=1$	5%[79] $N=66$ $n=1$	-	-	-	-	-	-
	Spiritual pain $n=1$	44%[61] $N=91$ $n=1$	-	-	-	-	-	-	-	-
	Spiritual wellbeing $n=1$	-	-	6%[84] $N=66$ $n=1$	-	-	-	-	-	-
	Peace $n=0$	-	-	-	-	-	-	-	-	-
Social:	Support $n=1$	49%[71] $N=4035$ $n=1$	-	-	-	-	-	-	-	-
	Information $n=0$	-	-	-	-	-	-	-	-	-
	Psychosocial distress $n=0$	-	-	-	-	-	-	-	-	-

COPD = chronic obstructive pulmonary disease; CHF = chronic heart failure; ESRD = end-stage renal disease; AIDS = acquired immune deficiency syndrome; MND = motor neuron disease; MS = multiple sclerosis.
A dash indicates that no data were found for this specific problem in this specific diagnostic group.
[a]This study included a period prevalence measurement on two time points: in the final year of life and in the final week of life.
[b]This study included a point and a period prevalence measurement in the same sample of patients.
[c]This study took place in three different sites and contains data for three different samples of patients.
[d]This study contains the data of two groups of patients: one group who died at home and one group who died in a hospice.

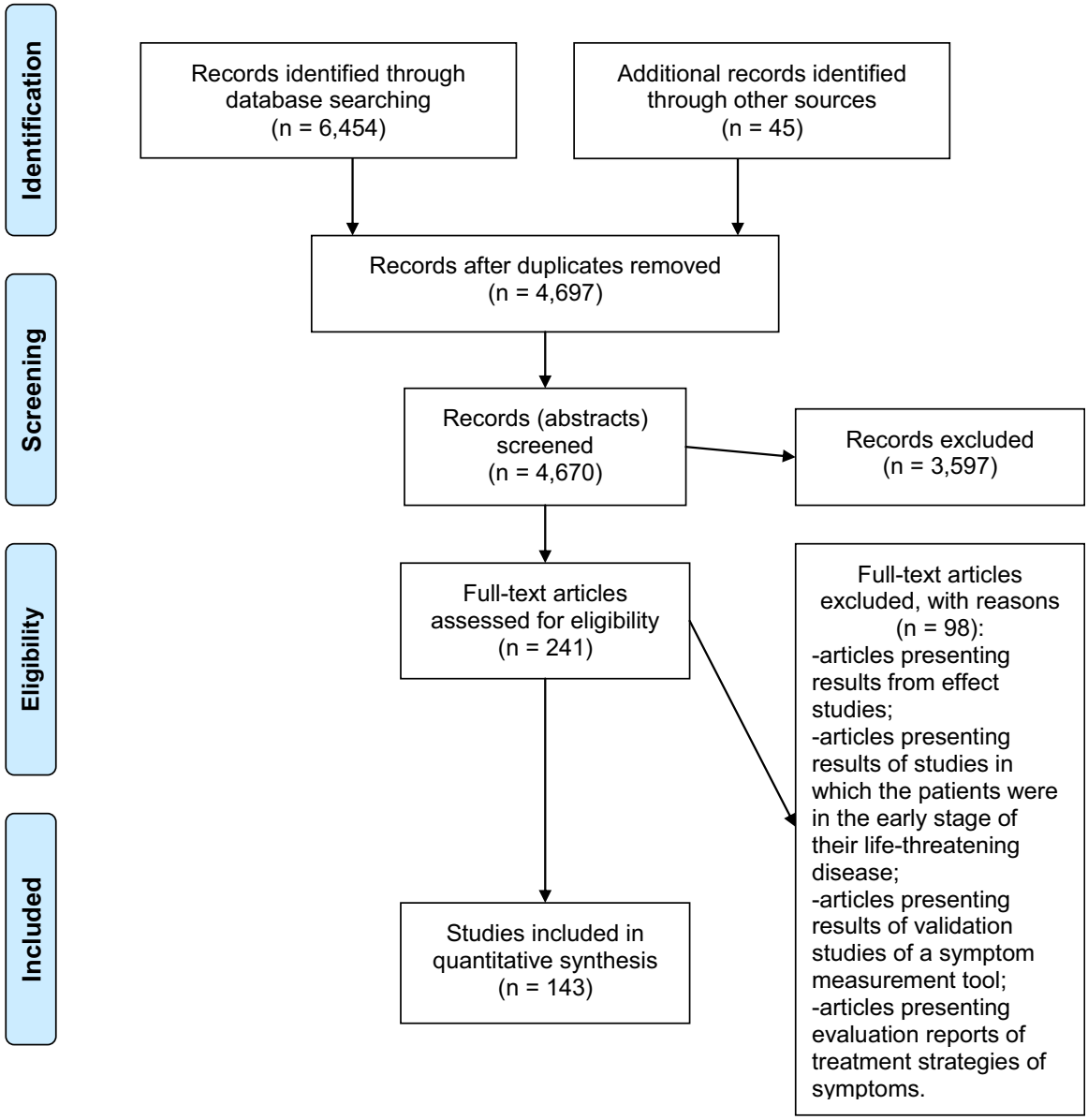

Fig. 2. PRISMA flow diagram of search process.

We found only four studies on spiritual,[61,70,79,84] and one study on social palliative care–related[71] problems. In people living with advanced cancer, lack of well-being and support were the problems that were considerably prevalent (91% and 49%, respectively).

The problems for which we found the widest minimum (<10%) and maximum (≥50%) prevalence ranges were: nausea-vomiting in advanced cancer and ESRD; insomnia in advanced cancer and ESRD; delirium in advanced cancer; constipation in advanced cancer and ESRD; depression in advanced cancer, CHF and ESRD; anxiety in advanced cancer, ESRD, dementia, and Parkinson's disease; and worry in advanced cancer.

Looking at most studies that presented a prevalence of 50% and more in comparison with the total number of studies for each problem per diagnostic group, the following problems showed a prevalence of 50% or higher: fatigue in advanced cancer, COPD, CHF, ESRD, AIDS, and MS; anorexia in advanced cancer, COPD, ESRD, and AIDS; pain in advanced cancer,

COPD, ESRD, AIDS, Parkinson's disease, MND, and MS; dyspnea in COPD, CHF, ESRD, AIDS, and MND; insomnia in COPD, AIDS, and Parkinson's disease; constipation in ESRD and MND; diarrhea in AIDS; depression in COPD and AIDS; anxiety in AIDS and Parkinson's disease; worry in advanced cancer, COPD, ESRD, and AIDS; and lack of well-being in advanced cancer.

Within the group of 143 articles, there were only five studies that directly compared the prevalence of palliative care–related problems with another diagnostic group while using the same measurement tool.[73,79,80,152,153] In these five studies, COPD patients were compared with CHF and dementia patients,[73,79,80] and Parkinson's disease patients to MND and MS patients.[152,153] In these studies, the range of the minimum and maximum prevalence ranges was not wide.

Discussion

This study showed that there are commonalities in problem prevalence across diagnostic groups. Some problems were rarely studied, for example, social and spiritual problems; and for certain diagnostic groups, we found a very limited number of problem prevalence studies, for example, for people living with MND and MS.

There are a balanced number of strengths, weaknesses, or limitations in this systematic review. One of the limitations of our study is that each disease group we selected has its specific pathology process with its specific (other) symptoms occurring throughout the trajectory. For example, muscle cramps, dry skin, muscle soreness, headaches, and restless legs are specific for people living with ESRD, but these are not included in this review as we aimed to summarize the generally prevalent problems across all our studied diagnostic groups. We also recognize publication bias while looking at certain domains of interest; for example, social and spiritual problems may receive lower priority from peer-reviewed publications. Hence, problems for which we could not find (sufficient) evidence does not mean that these problems are not present. Another limitation is that systematic reviews rely on a broad yet accurate search strategy to identify relevant evidence. We tried to limit this by implementing a search strategy using synonyms for specific palliative care–related problems. Lastly, from the beginning of our study, we were aware that by collecting data on our research topic, we had to deal with presenting a heterogeneous amount of information. This, for example, resulted in our presenting the data in a very descriptive way using minimum and maximum prevalence ranges.

We believe that this review has the following strengths: using the PRISMA 2009 flowchart to execute our search in a stepwise way, giving us a structured overview of which studies were correctly excluded; assessing the quality of the review using the PRISMA 2009 checklist and the AMSTAR measurement tool; reviewing the evidence on palliative care–related problems not only focusing on the physical and psychological problems but also using a total care view and including prevalence studies of spiritual and social palliative care–related problems; using several search or keywords to describe the same single problem; and excluding intervention studies to prevent selection bias. We expanded the variety of palliative care–related problems and non-cancer conditions in comparison with the review of Solano et al,[7] allowing us to provide a broader view on the palliative care–related problems in palliative care patients in accord with the WHO definition of palliative care.[8]

One of the study's objectives was to review the prevalence studies across all palliative care domains, but only two studies investigated well-being,[70,79] one study the presence of spiritual pain,[61] one study the lack of spiritual well-being,[84] and one study the problems with receiving support.[71] We can understand this situation given the current availability and accessibility of spiritual outcome measurement tools. There are only nine spiritual outcome measurement tools that have been validated in cross-cultural palliative care populations.[157]

The variations in the minimum and maximum prevalence ranges were likely caused by the differences in time points of data collection (point vs. period prevalence, or a mix of both), the period prevalence time ranges, the varying definitions for a problem, the sample size proportions, and the various different measurement methods used across studies. In light of the wide variations in the minimum and maximum prevalence

ranges and the methodological heterogeneity across studies, and the insights gained by looking at the five direct comparison studies, we can state that there is as much variation in prevalence between diagnostic groups as there is similarity. Also, understanding the prevalence of palliative care–related problems of non-cancer patients in comparison with cancer patients is complex as a result of the varying trajectories of functional decline and dependency in non-cancer diagnostic groups,[158] and their comorbidities and changing disease stages. Therefore, although there are commonalities in prevalence across diagnostic groups, the methodological heterogeneity across studies and the limited number of non-cancer studies must be taken into consideration when interpreting our results.

Our review identified some gaps that need to be addressed in future research. More research is needed that directly compares palliative care–related problems between cancer and non-cancer patients using the same measurement tools and time points. Our results also call for an intensification of the measurement and reporting of spiritual and social palliative care–related problems.

We also found that pain, fatigue, anorexia, dyspnea, and anxiety were highly prevalent problems across advanced cancer and non-cancer diagnostic groups. Health care providers should be aware of these problems and be more sensitive to their assessment and treatment.

Future prevalence studies should build on the findings of our review in terms of the most often used measurement methods across studies, and our identified evidence gaps, particularly in the under-researched non-cancer patient groups.

In conclusion, our study reveals that there is as much variation within diagnostic groups as between groups in relation to prevalence of palliative care–related problems. Our study can be considered as an epidemiological needs assessment while using the summarized prevalence data of palliative care–related problems among advanced cancer and non-cancer patients indicating that both are in need of palliative care. These summarized prevalence figures across diagnostic groups support the conclusion that palliative care should be made available based on the problems and needs patients exhibit, and not based on the diagnostic group to which a patient belongs.

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