

Mo Li (Orcid ID: 0000-0003-0629-4217)

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Referral Criteria to Specialist Palliative Care for Patients with Dementia: A Systematic Review

Running head: Palliative Care Referral Criteria for Dementia

Li Mo, MD <sup>a, b</sup>, Yimin Geng, MS, MSLIS <sup>c</sup>, Yuchieh Kathryn Chang, DO <sup>a</sup>, Jennifer Philip, PhD, MMed, Grad Dip Pall Med, MBBS, FChPM <sup>d,e,f</sup>, Anna Collins, PhD, MAppSci(Health Psych), BSci <sup>d</sup>, David Hui, MD, MSc <sup>a</sup>

<sup>a</sup> Department of Palliative Care, Rehabilitation and Integrative Medicine, University of Texas MD Anderson Cancer Center, Houston, TX 77030, USA

<sup>b</sup> The Center of Gerontology and Geriatrics, National Clinical Research Center of Geriatrics, Sichuan University West China Hospital, Chengdu, Sichuan, 610041, China

<sup>c</sup> Research Medical Library, The University of Texas MD Anderson Cancer Center, Houston, TX 77030, USA

<sup>d</sup> Department of Medicine, University of Melbourne, Fitzroy, 3010, Australia

<sup>e</sup> Palliative Care Service, St Vincent's Hospital, Fitzroy, 3065, Australia

<sup>f</sup> Royal Melbourne Hospital, Parkville, 3050, Australia

Corresponding author: David Hui, MD, MSc., Department of Palliative Care, Rehabilitation and Integrative Medicine, University of Texas MD Anderson Cancer Center, Unit 1414, 1515 Holcombe Blvd., Houston, Texas 77030, USA. Telephone: 713-606-3376; e-mail: [dhui@mdanderson.org](mailto:dhui@mdanderson.org)

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## Key Points

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1. There is a lack of consensus on palliative care referral criteria for dementia.
2. The most common referral criterion was advanced stage dementia (late referral).
3. Few studies mentioned needs-based criteria to trigger timely referral.

### Why does this paper matter?

This systematic review highlights many reasons for specialist palliative care referrals to better understand the use of palliative care referrals for persons living with dementia. It is the first time to systematically summarize the criteria of palliative care referral for patients with dementia.

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Number of tables: 3 tables

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## Abstract

Background: Patients with dementia often have significant symptom burden and a progressive course of functional deterioration. Specialist palliative care referral may be helpful but it is unclear who and when patients should be referred. We conducted a systematic review of the literature to examine referral criteria for palliative care among patients with dementia.

Methods: We searched Ovid MEDLINE, Ovid Embase, Ovid PsycInfo, Cochrane Library, PubMed, and CINAHL databases for articles from inception to December 3, 2019 related to specialist palliative care referral for dementia. Two investigators independently reviewed the citations for inclusion, extracted the referral criteria and categorized them thematically.

Results: Of the 1788 citations, 59 articles were included in the final sample. We identified 13 categories of referral criteria, including 6 disease-based and 7 needs-based criteria. The most commonly discussed criterion was “dementia stage” (n=43, 73%), followed by “new diagnosis of dementia” (n=17, 29%), “medical complications of dementia” (n=12, 20%), “prognosis” (n=11, 19%), and “physical symptoms” (n=11, 19%). Under dementia stage, 37/44 (84%) articles recommended a palliative care referral for advanced dementia. Pneumonia (n=6, 10%), fall/fracture (n=4, 7%), and decubitus ulcers (n=4, 7%) were most commonly discussed complications to trigger a referral. Under prognosis, the time frame for referral varied from <2 years of life expectancy to <6 months. 3 (5%) of articles recommended “surprise question” as a potential trigger.

Conclusions: This systematic review highlighted the lack of consensus regarding referral criteria for palliative care in patients with dementia and the need to identify timely triggers to standardize referral.

Key words

Dementia; Palliative Care; Referral and Consultation; Selection Criteria; Systematic Review.

## Introduction

Dementia is a rapidly growing public health problem affecting around 50 million people around the world.<sup>1</sup> There are nearly 10 million new cases every year and this figure is set to triple by 2050.<sup>1</sup> Dementia mainly affects older people and is the major cause of disability and dependency among older people. Patients with dementia often experience multiple physical and psychological symptoms, such as pain, weakness, fatigue, appetite loss, dyspnea, constipation, nausea, vomiting, sleep disorder, confusion, agitation, anxiety, and depression.<sup>2-4</sup> They frequently require hospitalization for various complications and complex symptoms, especially in the last months of life.<sup>5,6</sup> The impact of dementia goes beyond people with dementia, but also their caregivers, families and society at large.<sup>1,7</sup>

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness.<sup>8</sup> The World Health Organization has recommended “Specialist palliative care is one component of palliative care service delivery. But a sustainable, quality and accessible palliative care system needs to be integrated into primary health care, community and home-based care, as well as supporting care providers such as family and community volunteers. Providing palliative care should be considered an ethical duty for health professionals.”<sup>9</sup> Early integration of specialist palliative care into routine health care has been found to improve patients’ symptom burden, mood, quality of life, survival and healthcare costs.<sup>10-13</sup> A qualitative systemic review on the incorporation of palliative care principles in dementia care reported benefits in the areas of goals of care and end-of-life conversations, symptom management, emergency room visits, and prescribing behavior.<sup>14</sup> In a qualitative study of 28 hospitalists, Courtright et al.

identified several facilitators and barriers to specialist palliative care consultation for patients with dementia and concluded there was a need for “systematic identification of hospitalized patients with dementia most likely to benefit from palliative care consultation”.<sup>15</sup> Indeed, patients with dementia continue to have low palliative care access and often delayed referrals.<sup>16,17</sup> This is partly due to variable availability of specialist palliative care, lack of awareness of the role of palliative care among patients and families, the misconception among clinicians that specialist palliative care is only appropriate for patients in the last weeks/days of life, and the lack of structure and processes to facilitate timely referrals.<sup>18-20</sup>

Unlike the field of oncology where there is a strong body of literature to support timely palliative care referral, such evidence is mostly lacking for dementia.<sup>21,22</sup> A clearer understanding of the criteria used to initiate a specialist palliative care referral would be helpful towards a) improving the identification of patients with dementia who are likely to benefit from this intervention, b) optimizing the triaging of the precious palliative care resources by streamlining the process of referral, c) allowing programs to develop quality improvement programs by defining a population who would benefit from a referral, d) establishing the eligibility criteria for future clinical trials involving dementia and palliative care, and e) paving the way for policymakers to identify the supply-demand gaps in palliative care for patients with dementia.<sup>23,24</sup> We conducted a systematic review of the literature to examine referral criteria for specialist palliative care among patients with dementia. This represents a first step towards developing a standardized set of referral criteria for patients with dementia.

## Methods

### Literature Search and Review Process

The institutional review board at MD Anderson Cancer Center provided approval to proceed with this systematic review without the need for full committee review. Our clinical librarian searched Ovid MEDLINE, Ovid Embase, Ovid PsycInfo, Cochrane Library, PubMed, and Cumulative Index to Nursing and Allied Health Literature (CINAHL) databases for publications in the English language from the inception of databases to December 3, 2019. The following concepts were searched using subject headings and keywords as needed, “palliative care”, “palliative medicine”, “palliative or palliation”, “terminal care”, “hospice care”, “hospices”, “advance care planning”, “supportive care”, “end-of-life”, “dying”, “referral”, “consultation”, “patient transfer”, “delivery of health care, integrated”, “integrate”, “integrating”, “integration”, “collaborate”, “providing”, “provision”, “needs”, “assessment”, “specialist”, “specialty”, “facilitator”, “barrier”, “initiate”, “decision making”, “dementia”, and “Alzheimer”. The complete search strategies were detailed in Supplementary Table S1 to Supplementary Table S4.

We included all original studies, reviews, systematic reviews, guidelines, case reports, editorials, commentaries, book chapters, and letters. Duplicates and conference abstracts were excluded. For our initial screen, one investigator (L.M.), a geriatrician with palliative care training, reviewed all 1770 titles and abstracts to decide if further review was required. Articles that covered topics other than specialist palliative care or had mixed patient population were excluded from further review. For quality control, a senior investigator (D.H.) reviewed the first 100 references independently. The level of agreement was 95% with only 5 discrepancies which were discussed between the two reviewers to arrive at a consensus.

After the initial screen, we retrieved the full text for each article of interest. L.M. read

the entire articles to determine if the authors included any statements on criteria for specialist palliative care referral for patients with dementia. In the dementia literature, the term “palliative care” was used in many different contexts. Given the nature of our research question, we excluded articles that focused on primary palliative care. Palliative care service provided by non-specialist palliative care teams (i.e., primary clinic physician, geriatrician, neurologist) that did not include specialist palliative care were considered as “primary palliative care”. Articles that only discussed the “palliative phase” or “palliative approach” were also considered as “primary palliative care”. We also excluded the studies that involved multiple diseases because it was difficult to identify when or for what the patients with dementia were referred to specialist palliative care. Independent review was provided by D.H. for 50% (88 of 176) of the articles with an agreement of 88%. Any discrepancies were discussed between the two reviewers to arrive at a consensus before proceeding further.

For the final sample of articles, we reviewed each manuscript and retrieved every statement on criteria, triggers, timings or reasons for specialist palliative care referral. Two investigators (L.M. and D.H.) then discussed each statement and categorized them into themes using content analysis.<sup>25</sup> The themes were partly based on our conceptual framework derived from previous systematic reviews on specialist palliative care referral criteria for patients with cancer and heart failure.<sup>24,26</sup> These themes were broadly classified under two domains: disease-based criteria (e.g., diagnosis, prognosis, disease stage, medical complications, or utilization of healthcare resources) and needs-based criteria (e.g., patient/caregiver supportive care concerns). This systematic review followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines for reporting where applicable.<sup>27</sup>

## Statistical Analysis

We summarized the data using descriptive statistics, including counts, frequencies, and percentages.

## Results

### Literature Search

Our literature search identified 1788 articles. Eighteen were excluded as they represented duplicates. A total of 1770 articles were titles and abstracts reviewed. 1594 articles were excluded because they did not discuss dementia or palliative care referral criteria, or discussed multiple diseases. We reviewed the full text of 176 articles, with 59 (34%) publications included in the final sample (Figure 1).

The characteristics of the included articles were summarized in Table 1. A majority of the articles originated from countries in North America and Europe (N=50, 85%) and published after 2010 (N=43, 73%). Thirty (51%) publications were review articles and 20 (34%) were original studies. A large minority (N=25, 42%) of the articles were published in palliative care journals, followed by neurology/dementia journals (N=11, 19%) and geriatric/gerontology journals (N=8, 14%).

The setting of specialist palliative care varied widely among the 34 (58%) articles that reported the referral for dementia, including nursing home (N=10, 17%), hospitalization (N=10, 17%), home palliative care (N=7, 12%), multiple settings (N=7, 12%), outpatient clinic (N=2, 3%), and emergency room (N=1, 2%). Among them, three articles mentioned two different settings. However, twenty-five (42%) articles did not explicitly indicate the specified setting of referral (Table 3).

## Categories of Referral Criteria

We identified 13 categories of referral criteria, which were broadly grouped according to “disease-based” (N=6) and “needs-based” (N=7) criteria (Table 2). The quotes and themes related to palliative care referral in each publication were described in Supplementary Table S5. The most commonly discussed criterion was “dementia stage” (N=43, 73%), followed by “new diagnosis of dementia” (N=17, 29%), “medical complications of dementia” (N=12, 20%), “prognosis” (N=11, 19%), and “physical symptoms” (N=11, 19%) (Table 2). Thirty-five articles (59%) mentioned more than one criteria categories.

### *Dementia stage to trigger referral*

The most prevalent category was “dementia stage”. Overall, 37/44 (84%) articles recommended specialist palliative care referral for advanced stage dementia. Although some articles provided a clear definition for advanced stage disease (e.g., Functional Assessment Staging Test (FAST) stage of 7 [N=5, 8%] and Global Deterioration Scale (GDS) stage of 5-7 [N=4, 7%]), a majority used undefined terms such as “late stage”, “terminal stage”, “end stage”, and “severe stage” (N=19, 32%) or only stated “advanced stage” or “advanced dementia” (N=12, 20%) without further qualifications (Table 2).

Seven articles (12%) recommended specialist palliative care referral for patients with early stage dementia (i.e., “early stage” [N=6, 10%], “GDS stage of 2” [N=1, 2%]). Furthermore, one article (2%) recommended specialist palliative care referral at the time point of “diagnosis of mild cognitive impairment” (Table 2).

### *New diagnosis of dementia to trigger referral*

Seventeen articles (29%) suggested referral initiation from at new diagnosis of dementia, although it was unclear what stage the authors were referring to (Table 2).

#### *Medical complications of dementia to trigger referral*

Twelve (20%) articles suggested medical complications of dementia should lead to a specialist palliative care referral. The most commonly discussed complications were pneumonia (N=6, 10%), fall/fracture (N=4, 7%), and decubitus ulcers (N=4, 7%) (Table 2).

#### *Prognosis as referral criteria*

Prognosis was considered as a criteria for specialist palliative care referral in 11 (19%) articles. The time frame for referral varied widely from <2 years of life expectancy to <6 months. 3 (5%) articles mentioned the use of the “surprise question” to trigger a referral (Table 2).

#### *Physical symptoms and poor nutrition status as referral criteria*

The presence of physical symptom was mentioned as a potential trigger in 11 (19%) articles; however, there did not appear to be a universal consensus on which specific symptom should be considered. Nutritional failure was discussed as a potential trigger for referral in 6 (10%) articles as indicated by hypoalbuminemia (Table 2).

#### *Other referral criteria*

The remaining themes for specialist palliative care referral constituted less than 10% of articles and included the following: two other disease-based referral categories (i.e., “hospitalization” [N=5, 8%] and “no other treatment” [N=5, 8%]), five other needs-

based referral categories (i.e., “functional decline” [N=5, 8%], “psychological needs” [N=2, 3%], “caregiver cannot cope” [N=2, 3%], “goals of care” [N=2, 3%], “social and spiritual needs” [N=1, 2%]), and other reasons that did not clearly fall under the 12 themes (N=8, 14%), including “enteral feeding/feeding tube”, “no verbal communication”, “antibiotics should be withheld”, “prolonging life is no longer meaningful”, and “home-bound people with Medicare Advantage Part B” (Table 2).

## Discussion

In this systematic review, we identified a wide array of reasons for which to refer patients with dementia to specialist palliative care, broadly classified under 13 themes. Although a majority of articles pointed to involving palliative care very late in the disease trajectory, others highlighted a multitude of opportunities earlier in the disease course to refer patients. At the same time, it underscores that tremendous heterogeneity in the literature in reasons for involving specialist palliative care, which may partly explain the variation in patterns of palliative care referral. As such, our goal was to map all the criteria in the literature without preference for one set of criteria over another. Palliative care is fundamental component of medical care for persons living with dementia and may be delivered in a variety of ways. Findings from this study would facilitate further research to identify criteria that would trigger palliative care services. In addition, primary care providers, geriatricians, and others play a critical role in delivering primary palliative services throughout the trajectory of dementia care.<sup>28</sup> The type of palliative care services would be determined by the circumstances of care and access of providers with palliative skills.

Dementia stage was the most commonly mentioned topic. Specialist palliative care referral was more likely to be recommended for patients with advanced dementia which

is late in the disease trajectory, given that these patients often have a life expectancy of less than 2.5 years.<sup>29,30</sup> However, “advanced dementia” was described with variable terms in the included articles without a uniform definition. Indeed, many of the other referral themes also implied advanced dementia even when illness stage was not explicitly stated, such as a short life expectancy, complex medical complications, hospitalizations, no other treatment, poor nutritional status, and impaired function. The focus on what may be considered a late referral may be partly explained by the fact that many of the included publications were in the nursing home or hospital settings that typically involved patients with more advanced diseases.<sup>17,31-35</sup>

“New diagnosis of dementia” was the second most commonly mentioned category for involving palliative care; however, it was unclear if the authors were referring only to patients with advanced stage disease (i.e., late referral) or for any stage of dementia (i.e., early referral). Furthermore, the authors often did not make a clear distinction between a specialist palliative care referral and palliative care approach (i.e., primary palliative care), even though we specifically excluded studies that only discussed primary palliative care.

The category “medical complications of dementia” also denotes late referral because patients with dementia who developed pneumonia, urinary tract infections, decubitus ulcers, falls and fractures often have a poor prognosis.<sup>17,34,36-39</sup> Many of these patients may require hospitalization and referral to an inpatient specialist palliative care team would be appropriate.

Prognosis was another major category to trigger palliative care referral. For dementia, some investigators have mentioned 6-24 months of expected survival as an appropriate timepoint for referral.<sup>40-46</sup> Prognostication is filled with uncertainty and particularly

difficult to the patients with dementia.<sup>47</sup> The Gold Standard Framework Proactive Identification Guidance that included several prognostic factors has been proposed to identify the people who are likely to die within the next 12 months<sup>44,48</sup>, but needs to be further validated to facilitate earlier identification of patients appropriate for a specialist palliative care referral.<sup>49</sup>

The NICE guideline recommended that “from diagnosis, offer people living with dementia flexible, needs-based palliative care that takes into account how unpredictable dementia progression can be.”<sup>50</sup> Similar, the EAPC recommended that “perceived problems in caring for a patient with dementia should be viewed from the patient’s perspective, applying the concept of person-centered care. Responding to the patient’s and family’s specific and varying needs throughout the disease trajectory is paramount.”<sup>28</sup>

We were surprised that only a minority of articles mentioned those needs of physical and psychological symptoms as a reason for specialist palliative care referral. This may partly be explained by the interest among geriatrician, neurologist and primary care teams to provide good symptom management as part of primary palliative care. There is also significant stigma associated with a specialist palliative care referral.<sup>51</sup> However, few studies have been conducted in the dementia patient population specifically and their interpretations were limited by methodologic issues.<sup>17,52</sup> Furthermore, because of limited ability to self-report, symptoms are typically under-reported in patients with advanced dementia.<sup>53</sup> Systematic assessment of symptoms is important to identify patients who may benefit from a specialist palliative care referral. Specifically, patient-reported outcomes may be appropriate for patients with early dementia who could still self-report, and surrogate or observational measures may be considered for patients who

have difficulty expressing their concerns. Thus, delivery of good primary palliative care should not exclude involvement of specialist palliative care. By routinely screening symptoms, clinicians could use specific cutoff as triggers to initiate automatic timely palliative care referral.<sup>10,23,54,55</sup> Few studies to date have examined what symptom intensity cutoff would be most appropriate to trigger a referral; more research is needed in this area.

We were also surprised that very few included studies explicitly mentioned the need for goals of care discussions as a criterion for specialist palliative care. This may be partly because many geriatricians believe that this is part of their responsibility in the primary palliative care setting.<sup>56</sup> More recent studies, however, are starting to recognize that specialist palliative care teams may be helpful to facilitate serious illness conversations for hospitalized patients with dementia.<sup>15</sup>

### Implications

As we move towards a more personalized approach to medical care, it is important to refer the right patient to the right service at the right time. Akin to mutation analysis for targeted therapies, the referral criteria identified here may help to formulate system-based criteria that would allow identification of patients most appropriate for specialist palliative care referral while minimizing referrals for patients who may not yet require specialist palliative care input.<sup>10,57,58</sup> This would help to triage the limited available palliative care resources, while concurrently maximize patient outcomes. Referral criteria are being examined in cancer patients but few studies have been conducted in dementia patients. The themes identify here may form the basis for a Delphi study to identify consensus criteria for palliative care referral for patients with dementia.

## Limitations

Our systemic review has several limitations. First, only 59 articles met the inclusion criteria. Second, 34% of articles were narrative reviews based on expert opinion rather than original research. Third, many articles discussed palliative care without making a clear distinction between primary and specialist palliative care. Although we made every attempt to exclude studies that only focused on primary palliative care, some of the criteria highlighted here may not be intended for specialist palliative care. Fourth, we only focused on published literature and did not search the grey literature such as society guidelines. Further research is needed to determine if there were additional themes beyond those identified in this study.

## Conclusions

We identified 13 categories of specialist palliative care referral criteria for patients with dementia. This diversity highlights the many reasons to involve specialist palliative care and simultaneously the lack of consensus on who and when patients should be referred. A majority of referral criteria were late and the patients were predominated from institutionalized settings. Given the growing recognition of unmet supportive and palliative care needs in patients with dementia, a set of consensual referral criteria may facilitate timely specialist palliative care referral to enhance patient and caregiver outcomes.

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Figure 1. Study Flowchart

Supplementary Material (Online Publication)

Supplementary Table S1. MEDLINE Search Strategy

Supplementary Table S2. Embase Search Strategy

Supplementary Table S3. PsycInfo Search Strategy

Supplementary Table S4. Cochrane Library Search Strategy

Supplementary Table S5. Quotes and Themes Related to Specialist Palliative Care

Referral in Publications

Table 1. Publication Characteristics

Article characteristics	Number of articles (N=59), N (%)
<b>Publication year</b>	
2010-2019	44 (75)
1993-2009	15 (25)
<b>Article type</b>	
<b>Review</b>	30 (51)
Review-narrative	19 (32)
Review-systematic	11 (19)
<b>Original studies</b>	20 (34)
Retrospective studies	6 (11)
Qualitative studies	5 (8)
Cross-sectional surveys	4 (7)
Prospective non-randomized studies	3 (5)
Prospective randomized trials	1 (2)
Clinical trials	1 (2)
<b>Others</b>	9 (15)
Book chapters	5(8)
Letters	2 (3)
Commentaries	1 (2)
Editorials	1 (2)
<b>Journal type</b>	
Palliative care journals	25 (42)
Neurology and dementia journals	11 (19)
Geriatric and gerontology journals	8 (14)
Other journals *	15 (25)
<b>Continents and countries</b>	
<b>North America</b>	25 (42)
United State of America	22 (37)
Canada	3 (5)
<b>Europe</b>	25 (42)
United Kingdom	13 (22)
Ireland	4 (7)
Netherlands	3 (5)
Bulgaria	1 (2)
Italy	1 (2)
Belgium	1 (2)
German	1 (2)
France	1 (2)
<b>Asia</b>	7 (12)
Japan	3 (5)
Singapore	3 (5)
Iran	1 (2)
<b>South America</b>	1 (2)
Brazil	1 (2)
<b>Australia</b>	1 (2)

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\* Other journals: indicated other types of journals include nursing, psychiatry, general medicine, family medicine, surgery, social work, etc.

Table 2. Palliative Care Referral Criteria for Dementia

Domain	Categories of criteria	Number of article (N=59), N (%)**
Disease- based referral	Dementia stage	43 (73)
	Late/terminal/end/severe stage	19 (32)
	Advanced stage/advanced dementia	12 (20)
	Early stage	6 (10)
	Functional assessment staging test (FAST) stage of 7	5 (8)
	Global deterioration scale (GDS) stage of 5-7	4 (7)
	GDS stage of 2	1 (2)
	Middle/moderate stage	1 (2)
	Diagnosis of mild cognitive impairment	1 (2)
	New diagnosis of dementia	17 (29)
	Medical complications of dementia	12 (20)
	An episode of pneumonia in the past 1 year	6 (10)
	Fall/fracture	4 (7)
	Decubitus ulcers	4 (7)
	Urinary tract infection	3 (5)
	Bowel and bladder incontinence	3 (5)
	Unspecified infections	2 (3)
	Agitation	1 (2)
	Acute abdominal emergency *	1 (2)
	Unspecified †	3 (5)
	Prognosis	11 (19)
	“Surprise question” ‡	3 (5)
	Gold standard framework	2 (3)
	Life expectancy ≤ 6-months	2 (3)
	Life expectancy ≤ 1 year	1 (2)
	Life expectancy ≤ 2 year (machine learning model)	1 (2)
	Unspecified §	3 (5)
Hospitalization	5 (8)	
Hospitalized with an acute illness	3 (5)	
Intensive Care Unit admission	1 (2)	
Hospitalized with falls, fractures, and bedsores	1 (2)	
No other treatment	5 (8)	
For co-morbidity and complication of dementia	4 (7)	
For dementia disease	1 (2)	
Unspecified	1 (2)	
Needs- based referral	Physical symptoms	11 (19)
	Fever	3 (5)
	Pain	2 (3)
	Behavioral problems	2 (3)
	Nausea	1 (2)
	Coughs	1 (2)
	Anorexia	1 (2)
	Catatonia	1 (2)
	Weakness and fatigue	1 (2)
	Severe myoclonic jerks	1 (2)
Pronounced parkinsonian symptoms	1 (2)	

	Specific deterioration in feeding or breathing	1 (2)
	Unspecified <sup>¶</sup>	4 (7)
	Poor nutrition status	6 (10)
	Albumin level in serum < 35g/L	4 (7)
	Weight loss <sup>#</sup>	3 (5)
	Albumin level in serum < 25g/L	2 (3)
	Reduced oral intake	2 (3)
	Body mass index < 21 kg/m <sup>2</sup>	1 (2)
	Functional decline	5 (8)
	Palliative performance scale < 40	2 (3)
	Karnofsky performance status < 50	2 (3)
	Barthel index < 3	2 (3)
	General physical decline	2 (3)
	Dependence in most activities of daily living	2 (3)
	Poor quality of life	1 (2)
	Psychological needs	2 (3)
	Caregiver cannot cope	2 (3)
	Goals of care	2 (3)
	Social and spiritual needs	1 (2)
Others	Enteral feeding/feeding tube	3 (5)
	No verbal communication	1 (2)
	Home-bound people with Medicare Advantage Part B	1 (2)

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\* Acute abdominal emergency: indicated the cases that needed for surgical intervention and a diagnosis of intestinal ischemia.

<sup>†</sup> Medical complications of dementia \_ unspecified: included multiple comorbidities, active and progressive life-threatening illness.

<sup>‡</sup> “Surprise question”: this question was “Would you be surprised if this patient were to die within the next 6-12 months?” in 2 articles. In another article, it was described as “Would you be surprised if this patient were to die within 1 year?”

<sup>§</sup> Prognosis \_ unspecified: indicated no clear life expectancy was given and described with vague concepts, such as “the last days of life”, “a short life expectancy”, and “very last moments of life”.

<sup>¶</sup> Physical symptoms \_ unspecified: indicated no special symptom was mentioned and described with vague concepts, such as “after the first symptom”, “at the advance of symptoms”, “dementia symptoms seriously hamper a person’s autonomy”, and “complex symptom control issues”.

<sup>#</sup> Weight loss indicated that unintentional weight loss of greater than 10% in the previous six months.

\*\* An article could mentioned more than one palliative care referral criteria for dementia. So the sum of all sub-categories exceeded 100%.

Table 3. Setting of Palliative Care Referral for Dementia

Setting	Number of articles (N=59), N(%) <sup>§</sup>
Unspecified *	25 (42)
Nursing home	10 (17)
Hospitalization	10 (17)
Home palliative care <sup>†</sup>	7 (12)
Multiple settings <sup>‡</sup>	7 (12)
Outpatient clinic	2 (3)
Emergency room	1 (2)

\* Unspecified: the articles did not explicitly mention the setting of dementia.

<sup>†</sup> Home palliative care: indicated that palliative care services for home-dwelling patients with dementia, including multidisciplinary palliative homecare team, Admiral Nurse within a specialist community palliative care team, community palliative homecare program, etc.

<sup>‡</sup> Multiple settings: indicated more than one setting of palliative care referral for dementia, including any residential or health-care setting.

<sup>§</sup> Three articles mentioned more than one setting of palliative care referral for dementia. So the sum of all sub-categories exceeded 100%.

