FACULTY OF MEDICINE AND HEALTH SCIENCES

Palliative care within frailty guidelines and recommendations: a narrative review.

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Voorwoord

Tijdens het schrijven van deze masterproef het afgelopen anderhalf jaar kon ik rekenen op begeleiding en ondersteuning van velen.
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List of abbreviations

ACP	Advance Care Planning
ADL	Activities of daily living
BGS	British Geriatrics Society
CGA	Comprehensive Geriatric Assessment
EAPC	European Association for Palliative Care
EuGMS	European Geriatric Medicine Society
FI	Frailty Index
GSF	Gold Standards Framework
IAHPC	International Association for Hospice and Palliative Care Organization
KCE	Kenniscentrum voor de Gezondheidszorg
NECPAL CCOMS-ICO Tool	Tool to identify advanced-terminal patients in need of palliative care within health and social services.
SIPS model	Short-term integrated palliative and supportive care model
SPICT Tool	Supportive and Palliative Care Indicators Tool

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1. Abstract

1.1 Background

An increase in frail older people can be expected because frailty increases in prevalence with age and the western population is rapidly ageing. The integration of a palliative care approach is indicated as frailty advances. As frailty is the most frequent condition among older patients towards the end of life, the introduction of palliative care in guidelines for frail older people is needed. The aim of this review was to provide an overview of current knowledge on palliative care within existing frailty guidelines and recommendations by answering the following questions: "Why and how to identify when frail older people are nearing the end of life?", "When should palliative care be started for frail older people?", "What are the goals and benefits of palliative care for frail older people?" and "What can be found in the existing guidelines regarding palliative care for frailty?".

1.2 Methods

A scopic narrative review was carried out of publications found in gray literature and the electronic databases Pubmed, Embase, Google Scholar and Web of Science. MeSH terms and Emtree terms, in Pubmed and Embase respectively, were used to specify the search query. Twenty-five publications were included, of which ten were deemed eligible for review. The quality of the articles eligible for review was assessed using quality appraisal tools and checklists.

1.3 Results

The studied frailty guidelines and recommendations suggested the following approaches to estimate the closeness to death: the assessment of end-stage frailty, the Frailty Index and the Gold Standards Framework. Additionally, general indicators for the end of life were described. Moreover, instead of using prognosis, it was suggested to identify palliative care needs, using the the Sebag-Lanoë scale, the NECPAL CCOMS-ICO tool and the SPICT^{TM} tool.

Three of the articles presented practical guidance on the management of end of life care for frail older people including the identification of frail older adults eligible for palliative care using comprehensive geriatric assessment, discussing the goals of care and preferences of the patient with the patient and his/her loved ones, and the outlining of an individualised care plan. One report provided additional guidelines regarding pain management, medication, mental health needs, required social and cultural support, care in the last days of life and palliative care in different settings.

The following recommendations regarding the palliative care for frail older people were made by multiple reviewed publications: including the patient and his/her family in the decision-making process to understand their wishes, supporting the caregivers, assessment of needs beyond the

physical aspect, advance care planning, using non-pharmacological approaches for pain management, timely recognition of frailty, medication review, the appointment of a case manager to coordinate care and a multidisciplinary approach.

1.4 Conclusion

In the studied frailty guidelines and recommendations, no consensus could be found on the identification of palliative care needs or on implementation of palliative care for frail older people. However, consensus could be found on multiple important aspects of palliative care for frail older people: mainly a multidisciplinary approach, a holistic assessment of needs, advance care planning, carer support and medication review.

1.5 Keywords

Palliative care, end of life care, guidelines, recommendations, frailty, frail older people, frail elderly

2. Dutch summary

Frailty, of kwetsbaarheid, is een geriatrisch syndroom dat toeneemt in prevalentie bij het ouder worden. De populatie veroudert snel aangezien men in staat is te overleven met meerdere chronische aandoeningen dankzij verbeteringen in de kwaliteit van behandelingen en de gezondheidsinfrastructuur. Een toename in het aantal mensen met kwetsbaarheid is dus te verwachten in de komende jaren. Het is een internationale prioriteit om richtlijnen voor palliatieve zorg voor deze groep patiënten te ontwikkelen aangezien kwetsbaarheid de meest voorkomende aandoening is bij oudere patiënten aan het einde van hun leven. Het doel van deze review was om een overzicht te creëren van de huidige kennis omtrent palliatieve zorgen in de bestaande kwetsbaarheidsrichtlijnen en aanbevelingen.

Deze review bestudeerde publicaties die werden gevonden aan de hand van zoekopdrachten in zowel vrije literatuur als in de elektronische databanken Pubmed, Embase, Google Scholar en Web of Science. In Pubmed en Embase werden respectievelijk MeSH termen en Emtree termen gebruikt om de zoekopdracht te verfijnen. Aan de hand van inclusie en exclusie criteria werden 25 artikels geïncludeerd, waarvan 10 geschikt werden geacht voor review. De kwaliteit van de artikels voor review werd beoordeeld met behulp van instrumenten voor kwaliteitsbeoordeling.

De review werd gebaseerd op 6 artikels omtrent aanbevelingen voor de palliatieve zorg voor kwetsbare ouderen, 1 artikel over de implementatie van vroegtijdige zorgplanning voor kwetsbare ouderen, en ten slotte 3 richtlijnen betreffende palliatieve zorgen voor deze groep.

Verschillende manieren om de overleving en het sterfterisico in te schatten werden voorgesteld in de bestudeerde kwetsbaarheidsrichtlijnen en aanbevelingen: het herkennen van “end-stage frailty”, de Frailty Index score en het gebruik van de Gold Standards Framework. Ook werden algemene indicatoren voor het levenseinde beschreven, maar deze zijn niet specifiek voor de kwetsbare ouderen. Aangezien het maken van een prognose moeilijk bleef op individuele basis, werd aangeraden om de noden te evalueren en zo te besluiten of een palliatieve zorgaanpak moet opgestart worden. De bestudeerde richtlijnen en aanbeveling beschreven dus ook instrumenten zoals de Sebag-Lanoë schaal, de NECPAL CCOMS-ICO tool en de SPICT^{TM} tool, om de palliatieve noden van patiënten in kaart te brengen.

De 3 richtlijnen opgenomen in de review beschreven het beleid omtrent palliatieve zorg voor kwetsbare ouderen. Het “End of life care in frailty” rapport beschreef richtlijnen betreffende pijn behandeling, medicatie, mentale gezondheid van de kwetsbare ouderen, de vereiste sociale en psychologische ondersteuning van zowel de patiënt als zijn naasten, en meer. Het “Fit for frailty”

rapport baseerde de zorg voor kwetsbaren op een uitgebreid geriatrisch onderzoek bestaande uit een globaal medisch nazicht, gevolgd door het opstellen van een geïndividualiseerd zorgplan. De Nederlandse vereniging voor klinische geriatrie beval hetzelfde aan, maar zij benadrukten ook het doorsturen voor verdere onderzoeken indien dit nodig werd geacht, een nazicht van medicatie, vroegtijdige zorgplanning, een multidisciplinaire aanpak, besluitvorming samen met de patiënt en zijn naasten, en zorgcoördinatie.

De verschillende bestudeerde publicaties stelden verscheidene aanbevelingen voor, waaronder het belang van tijdige herkenning van kwetsbaarheid, het opstellen van zorgdoelen in het kader van vroegtijdige zorgplanning, het ondersteunen van verzorgers, het geregeld nakijken van de voorgeschreven medicatie, het beoordelen van pijn bij voorkeur met non-verbale schalen, het coördineren van de zorg met behulp van een case manager en ten slotte het betrekken van de patiënt en zijn naasten in het beslissingsproces.

In de bestudeerde kwetsbaarheidsrichtlijnen en aanbevelingen werd geen consensus bereikt omtrent richtlijnen voor de identificatie van palliatieve noden of voor de implementatie van een palliatieve zorg aanpak voor kwetsbare ouderen. Echter, consensus werd bereikt omtrent belangrijke aspecten van palliatieve zorg voor kwetsbare ouderen zoals een multidisciplinaire aanpak, evaluatie van alle noden, het opstellen van zorgdoelen, ondersteunen van verzorgers en nazicht van medicatie.

3. Introduction

The population in the western world is rapidly ageing. People are surviving longer even with multiple chronic conditions due to improvements in life-prolonging treatments and health infrastructure (1, 2). Frailty is a geriatric syndrome that increases in prevalence with age (3). It is predicted that one in five people will be aged 60 and over by 2050 (4). In a report published in 2017, the United Nations estimated 962 million people to be aged 60 years old and older (5). A review by Combes et al. states that approximately 10% of those older than 65 are affected by frailty, increasing to approximately 65% of those aged 90 and above (6). An increase in frailty can consequently be expected in the next few years.

This ageing population poses challenges to health systems around the world. To meet the complex needs of these frail older people, a different approach to care is required that is integrated, patient-centred and multidisciplinary (5, 7, 8). The rise in long-term conditions such as frailty, the most frequent condition among older patients towards the end of life, will also challenge the delivery of care at the end of life (9, 10). Because frail older people are projected to become one of the largest users of palliative or end of life care, the establishment of palliative care models for frail older people is an international priority (1).

Interventions with the goal of reducing frailty have the potential for wide benefits. Besides the high prevalence of frailty, the consequences of frailty are not only a burden to the health care services since frail older people are significant consumers of health resources, but also to the older people because it profoundly affects their quality of life and has poor health outcomes (11, 12).

3.1 Defining frailty

Frailty can be regarded as a geriatric syndrome characterised by a decreased reserve and resistance to stressors, resulting from cumulative declines in multiple organ systems. The loss of reserves increases the vulnerability of the older adult and leads to a higher risk of poor health-related outcomes (2, 5, 9, 12, 13). Frailty is the variable vulnerability of people with the same age to these poor health-related outcomes, as a result of the accumulation of health deficits (10). Possible adverse health outcomes include risk of morbidity, delirium, falls, functional dependency, institutionalisation, and death (4, 14).

The concept of frailty contributes to shifting the focus from the disease or the organ to a more integrated approach of the older patients since it includes the assessment of not only their health status, but also of social, cultural and psychological factors (15).

In the assessment of older people, multiple definitions of frailty have been proposed and multiple approaches exist to describe frailty. The two most common definitions are the phenotype based model of Fried et al. and the deficit accumulation model of Rockwood and Mitnitski (table 1) (3, 11).

The Phenotype model of Fried defines frailty as a syndrome based on the presence of 5 core features: unintentional weight loss, weakness, low energy or tiredness, slow walking speed and low physical activity. Based on performance on these 5 variables, the older people are graded as robust, pre-fail or frail. Someone is classified as robust when he/she meets none of these criteria, as pre-frail when he/she meets 1 to 2 criteria, and frail when he/she meets 3 or more criteria (2, 3, 9, 12, 16).

Rockwood and Mitnitski suggest a different model based on the idea of deficit accumulation: in this viewpoint frailty is seen as a state arising from the accumulation of deficits. The number of deficits accumulated determines a Frailty Index (FI): the frailty index is calculated as the number of deficits present in the patient, divided by the number of deficits examined and results in a score from 0 to 1. The more deficits are accumulated, the more vulnerable or frail the patient becomes to adverse health outcomes (9, 13, 16).

Table 1: Most common definitions of frailty

Definition	Author	Based on	Scoring
Phenotype model	Fried et al.	Presence of 5 criteria: • Unintentional weight loss • Weakness • Low energy or tiredness • Slow walking speed • Low physical activity	Robust: 0 criteria Pre-frail: 1-2 criteria Frail: 3 or more criteria
Deficit accumulation model and Frailty Index	Rockwood and Mitnitski	Accumulation of deficits. Frailty Index (FI) = number of health deficits present / number of health deficits measured	0-1

3.2 Identification and assessment of frailty

Frailty might not be recognised unless actively sought for, therefore a standardised approach to the identification and assessment of frailty is recommended (8). The identification of a frail patient consists of an initial screening for frailty. This screening can be followed by a full Comprehensive Geriatric Assessment (CGA). However, performing a full CGA can be time-consuming and expensive (3). The key components of CGA are listed in table 2. Based on the deficits determined in the CGA and the assessment of the degree of frailty, an individualised plan for treatment and follow-up can be developed (3).

Table 2: Key components of Comprehensive Geriatric Assessment (13).

Domain	Assessment
Medical	Review of acute and chronic conditions Medication review Assessment of nutritional status
Psychological	Cognitive assessment Identify anxiety and/or depression
Functional capacity	Ability to perform activities of daily living Gait and balance assessment Ability to exercise
Social circumstances	Formal and/or informal support available Financial situation Entitlement to social and financial support
Home environment	Home facilities and/or equipment Access to local resources and support

A variety of instruments or indices have been developed for the screening and assessment of frailty: the Groningen Frailty indicator, the Tilburg Frailty Indicator, the FRAIL scale, the Edmonton Frail Scale, the Clinical Frailty Scale, PRISMA-7, etc. The choice of instrument depends on the setting, the time available for assessment and the skill level required for administration (2, 4, 16).

Not only the identification of frailty is important, but also the evaluation of the degree of frailty and the remaining functional capacity are vital to understand the needs of the frail older patient and the eventual approach to the end of his/her life. The degree of frailty, from mild to severe or end-stage, can be measured as part of the CGA (3). Frailty can also be divided into 3 stages: early,

middle and late frailty based on impairment of activities of daily living (ADL). The early stage refers to the moment of frailty recognition, the middle stage is the moment when decline in function begins and the late stage indicates an increasing decline, life-threatening illness and imminent death. In those 3 different stages, different geriatric and palliative services are suggested (14). Interventions beneficial to older people in the early stages of frailty might not be beneficial, or even harmful, to older people with late frailty. Therefore, it is important to weigh the benefits of the intervention against the possible harm to the individual patient (3). The assessment of the degree of frailty leads to a more individualised approach to care to ensure that the interventions cover the complex and multidimensional needs of the patient and align with his/her goals of care. It also prevents prolonged suffering due to aggressive non-beneficial interventions (9, 10).

Frailty identification and assessment of the degree of frailty can take place in different settings and has implications on the delivery of care. It helps to determine the appropriate and beneficial care in the different settings. In residential aged care facilities, the assessment of frailty can be a way to identify those patients who benefit more from palliative care services than from hospitalisations. For example, hospitalisation and aggressive medical interventions can be considered as disproportionate care for patients with end-stage frailty. In primary care, early identification of frailty can lead to the establishment of timely multidisciplinary interventions aiming to support and maintain the functional capabilities of the frail older people and thus delay functional dependency. In the emergency department, frailty assessment can contribute to identification of those patients at higher risk of adverse outcomes. In general wards, the identification of the degree of frailty of older patients helps clinicians to decide the appropriate level of care, for example palliative care, and may therefore avoid invasive and harmful treatments (4). On the other hand, the introduction of palliative care may also avoid the undertreatment of older people as their symptoms are often attributed to old age (13).

The identification and assessment of frailty has major implications for clinical practice: first, the prevention of loss of function with the help of early recognition and early treatment such as physical exercise. Second, frailty can also be used as a prognostic indicator. Physical frailty has a good prognostic value for poor health-related outcomes (3, 16). Third, the timely recognition of frailty may allow diagnosis of underlying diseases that are potentially treatable, such as malignancy or an adverse drug effect (14). Additionally, frailty is part of a continuum from non-frail to pre-frail and later on frail and is reversible, therefore early recognition and interventions are crucial (2). Furthermore, early introduction of advance care planning is important to give frail older people the

best chance to be part of the decision making process especially because their cognitive abilities will decrease over time (6).

There are multiple obstacles to the recognition of frailty. The following factors contribute to overlooking frailty in clinical practice. First, frailty does not fit into a classic organ system based disease model. Clinicians often focus on a specific organ system, whereas frailty is a multisystem disease. Second, patients may not seek medical advice because their decline in function is gradual and not acute. Third, because the clinical presentation of frailty is slowly progressive, the declines are often attributed to old age and are not assessed as an indication for the need for medical care. Lastly, there is a lack of geriatric training and knowledge on the existing frailty tools available for the examination of older people (4, 14). These obstacles explain why, even though frailty is an important cause of death, it is often not recognised. Late recognition of frailty can jeopardise the input of the patient in decision-making, for example in the decision regarding the place of care (17).

3.3 Frailty and palliative care

Palliative care can be delivered in all care settings, from primary care to hospitals and long-term care residences. Both specialists and general practitioners can deliver palliative care. Initially, it focused on people dying of cancer, but its value to patients with life-threatening diseases other than cancer has become apparent and palliative care services are no longer restricted to patients with cancer (1). The World Health Organisation states that “all patients with a chronic evolving disease should have their symptoms relieved, receive psychological, social and spiritual support, and be given appropriate treatment options.” (18). This definition is applicable to older people living with frailty. Palliative care should be offered to all patients in need, regardless of their age, illness or care setting, and consequently also to frail older people (13).

The key principles of palliative care are addressing the complex physical, psychosocial and spiritual needs, protecting the autonomy and dignity of the patient, and symptom control (19). Symptom control is relevant, as it can be associated with higher functional status, improved quality of life, and greater patient and family satisfaction (13). The introduction of palliative care is beneficial to sustain the quality of life in the last phase of life (19).

Frailty is associated with long-term disease, decline in function, and higher risk of death. Because frailty is associated with a limitation of the life expectancy, integrating a palliative care approach is indicated as frailty advances (12, 14) . However, the end of life period of frail older people is defined by a gradual decline in function and a slowly progressive increase in functional dependency. This trajectory of functional decline is presented in figure 1. This has an impact on the implementation of palliative care for the frail older people, as it is difficult to pinpoint a particular moment of abrupt decline that could predict impending death and therefore the moment to start palliative care (13, 20).

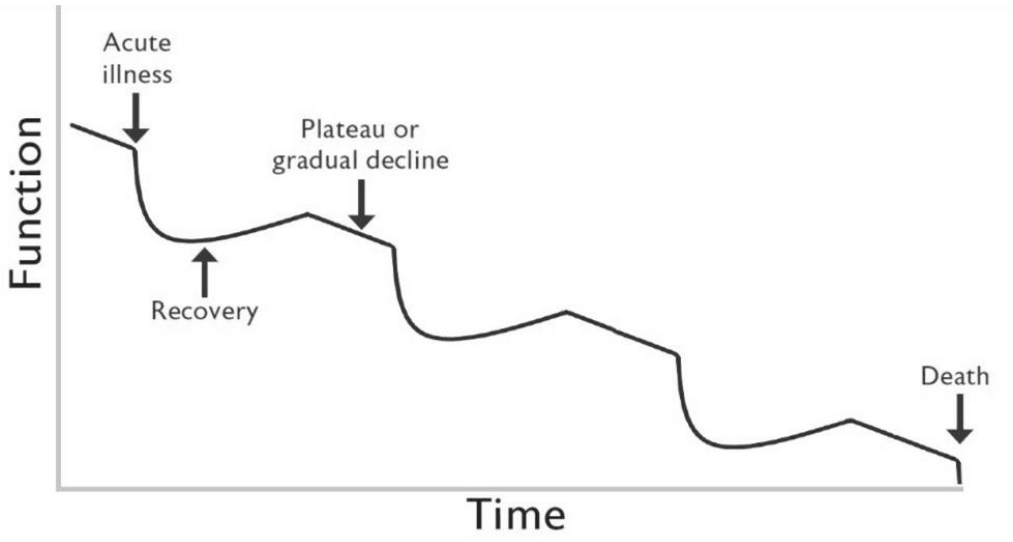

Fig. 1: Trajectory of functional decline in frail older people according to the British Geriatrics Society (17).

In conclusion, palliative care should be available to patients with non-malignant, life-limiting diseases such as frailty even though it was initially developed to care for patients with non-curable cancer. Providing this care for patients with frailty is a challenge because of the complex needs of these patients and the difficulty in recognising the onset of the palliative phase. Therefore guidelines and recommendations for palliative care focused on frail older people are needed (16). Especially because the population of frail older adults is projected to become one of the largest users of palliative care services, due to the demographic changes described earlier (6).

This research paper aimed to provide an overview of recommendations on palliative care within frailty guidelines and frailty recommendations. It is a scopic narrative review intended to answer the following questions:

- Why and how to identify when a frail older person is nearing the end of his/her life?
- When should palliative care be started for frail older people?
- What are the goals and benefits of palliative care for frail older people?
- What are the existing guidelines regarding palliative care for frail older people?

4. Method

A review of the literature was performed using the following electronic databases: Pubmed, Embase, Google Scholar and Web of Science. The search was carried out without restrictions regarding the year of publication, therefore articles published since the starting date of the databases up to December 2019 were included in the search. There was no restriction on the language of the publication.

In Pubmed and Embase we started by screening on free text because the most recent articles have not been indexed and would not be found through searching solely with MeSH or Emtree terms, respectively. The following MeSH terms were used to identify the most relevant articles: “Guideline (publication type)”, “practice guideline (publication type)”, “practice guidelines as topic”, “frail elderly”, “palliative care”, “terminal care” and “health services for the aged”. The subheadings “organization and administration” and “standards” were added to specify the MeSH term “health services for the aged”. To combine different terms we used the Boolean terms ‘OR’ and ‘AND’ and the use of the truncation symbol helped to include variations in the terminology.

As we did in Pubmed, we started by searching free text in Embase. The filters “aged” and “very elderly” narrowed the results. Next, Emtree terms “frail elderly”, “frailty”, “palliative therapy”, “terminal care”, “practice guideline” and “health care policy” were combined in a query. The functions “explode” and “as major focus” were applied where useful.

In Google Scholar, the keywords “guidelines”, “frail older people” or “frail elderly”, and “palliative care”, “terminal care” or “end of life care” were combined. Searches in Google Scholar obtained a high number of results, so only the first 10 pages of results were screened on title and abstract, after sorting the results based on relevance. Lastly, Web of Science was consulted and the query “frail elderly guidelines palliative care” resulted in 23 articles.

In total, 1059 citations were found through database searching. The review of title and abstract resulted in the selection of 53 citations. The other citations were excluded based on the screening of title and abstract: the study was focused on a specific drug or disease, the article did not include frailty but focused solely on palliative care, or the study population was not aged.
After excluding the duplicates, 42 records remained. The full texts of these articles were obtained and assessed for eligibility with the help of selection criteria (table 3). This resulted in a final selection of 20 records.

Table 3: Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
- Availability of full text - Every language - No time limit - Age: aged or very elderly - Worldwide - Different settings: primary care, hospitals, long-term residences, hospice care,… - Frailty and palliative care or frailty and care model/ guidelines/ recommendations	- Not about frailty - A specific disease or drug - Age: not aged

In addition to electronic databases, gray literature was screened. Different websites were browsed. On the website of the Dutch association for geriatrics, Verenso, a variety of guidelines was found relating to palliative care and frailty. A report by the "Kenniscentrum voor de Gezondheidszorg" (KCE) was found regarding the organisation of palliative care in Belgium. National guidelines from different European countries are gathered on the website of the European Association of Palliative Care (EAPC). On the websites of the national palliative care organisation of Australia, the International Association for Hospice and Palliative Care Organization (IAHPC), the American Geriatrics Society and the Canadian Geriatrics Society, guidelines regarding palliative care could be found. A variety of NICE guidelines exist relating to frailty and palliative care. The search query "Guideline frail elderly" in Google resulted in 1 relevant guideline, published by the regional health council of Tuscany, Italy. The website of the Gerontological society of America, the Indian Geriatrics society, the National Health Services of the UK, the European geriatric medicine society (EuGMS) and British gerontology were browsed, but this did not result in relevant guidelines or articles. The British geriatrics society (BGS) published a guidance report on living with frailty and on the website of the society for geriatric medicine in Australia and New Zealand, a variety of position statements was published, including one about frailty. Lastly, a guideline was found on the website of Guideline central. After excluding the duplicates and applying the selection criteria as stated in table 3, the initial screening of gray literature resulted in the inclusion of 4 additional citations.

In October 2020, following an additional search in gray literature, a series of clinical guidelines titled “End of life care in frailty” was found. These guidelines were published by the British Geriatrics Society in May of 2020 and were also included for review. In these guidelines, the BGS refers to the Gold Standards Framework, the NECPAL CCOMS-ICO tool, and de SPICT^{TM}. These were consulted through the link on the website of the British Geriatrics Society. In total, 5 citations were included by screening gray literature.

Of the 25 included articles, 15 were suitable for background information and understanding of the concept of frailty, but not included for review as they consisted of opinion articles, publications about care models for frail older people not including palliative care or the publications focused on the decision making process instead of guidelines or recommendations. Only the 10 articles including palliative care for frail older people were used for review. As only 3 frailty guidelines touching on the subject of palliative care especially for frail older people could be found, publications such as narrative reviews and qualitative studies describing recommendations for the palliative care for frail older people were also included in the review. The process of the selection of articles included in the review is presented in a PRISMA flow diagram (fig. 2).

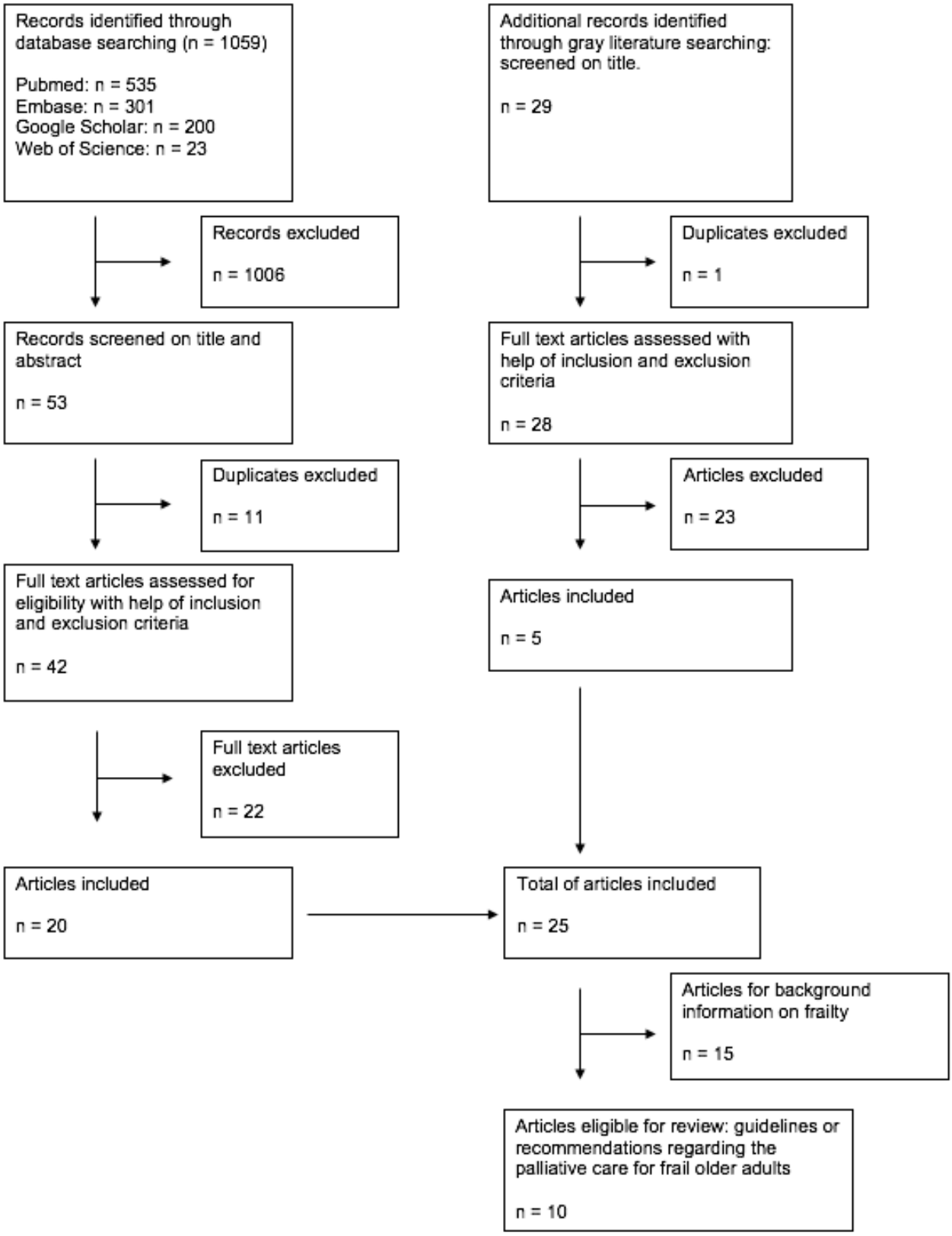

Fig. 2: PRISMA flow diagram

In a next step, the 10 articles eligible for review were assessed with the help of quality appraisal tools to describe their level of relevance and evidence. The following quality appraisal tools were applied: the AGREE tool for guidelines/recommendations, the PRISMA checklist for systematic reviews, the JBI critical appraisal checklist by the Joanna Briggs Institute for text and opinion papers, the SANRA scale for narrative reviews and the quality appraisal tool by the CEBM (Centre for Evidence Based Medicine) for qualitative studies. The quality was scored using +, ++ and – to display the extent in which the article meets the criteria of the used tool or checklist. The results of the quality appraisal are summarised in table 4.

Table 4: Quality appraisal

++: article fully meets the criteria

+: article partially meets the criteria

-: article does not meet the criteria

SANRA scale						
	Justification of the article's importance	Statement of concrete aims	Description of literature search	Referencing	Scientific reasoning	Appropriate presentation of data
Cardona-Morell et al. (4)	+	++	-	++	+	+
Koller and Rockwood (16)	+	+	-	++	+	+

CEBM tool for critical appraisal of qualitative studies								
	Appropriate qualitative approach	Sampling strategy	Data collection methods	Data analysis	Position of re-searcher	Credibility of the results	Justification of the conclusions	Trans-ferability of the findings
Bone et al. (1)	++	++	++	++	-	++	++	-
Lloyd et al. (21)	++	++	++	++	-	+	+	-

PRISMA checklist The full checklist consists of 27 items, divided into 7 topics.							
	Criteria regarding title	Criteria regarding abstract	Criteria regarding introduction	Criteria regarding methods	Criteria regarding results	Criteria regarding discussion	Criteria regarding funding
Combes et al. (6)	+	++	+	+	+	++	++
Pialoux et al. (18)	-	-	+	+	+	++	++

AGREE checklist The full checklist consists of 23 items, divided into 6 domains.						
	Scope and purpose	Stakeholder involvement	Rigour of development	Clarity of presentation	Applicability	Editorial independence
Fit for frailty. (22)	+	+	-	+	-	-
Zorgpad kwetsbare ouderen (23)	++	++	-	+	+	++
End of life care in frailty. (17)	+	+	-	+	-	-

JBI critical appraisal checklist for text and opinion papers The checklist consists of 6 questions.						
	Clearly identified source	Standing in the field of expertise	Interests of the relevant population are the central focus	Analytical process	Reference to the extant literature	Incongruence logically defended
Boockvar and Meier (14)	++	++	++	+	++	+

5. Results

Ten publications were reviewed. Six of these publications were articles recommending or describing palliative care approaches. One review studied the implementation of advance care planning for frail older people. Three articles, consisting of two articles published by the British Geriatrics Society and one by the Dutch association for clinical geriatrics, were guidance reports regarding the end of life care for frail older people.

Through review of the included publications, guidelines and recommendations regarding palliative care for frail older people could be distinguished. The guidelines offered step-to-step procedures on palliative care for the population of frail older people. The recommendations presented more general suggestions for the palliative care approach. The main conclusions are presented in table 5.

Table 5: Description of the included studies

Title	Author(s), Date	Main conclusions
Fit for frailty (22)	British Geriatrics Society, 2017	Guideline published by the BGS describing frailty and how frailty can be identified and recognised, followed by practical guidance on how care for these frail older patients can be provided. The management of frailty is based on comprehensive geriatric assessment and consists of a holistic medical review and the development of an individualised care and support plan, including an advanced care or end of life care plan.
Zorgpad kwetsbare ouderen over de keten en in het ziekenhuis (23)	Nederlandse vereniging voor klinische geriatrie, 2018	This guidance report describes 6 different trajectories of care. Among other things, the 6th trajectory describes temporary stay in the context of palliative end of life care. It recommends a multidisciplinary approach and comprehensive geriatric assessment of all patients, followed by the drawing of a care plan in the 4 domains: functional, social, psychological and somatic. Additionally, referral for treatment and more examination, a medication review, and advance care planning to establish the wishes of the patient regarding treatment and care are suggested.

End of life care in frailty (17)	British Geriatrics Society, 2020	A series of clinical guidelines concerning different aspects of end of life care for frail older people. Included are guidelines about identification and prognostication, advance care planning, urgent care needs, pain, continence care, falls, delirium, nutrition, dysphagia, medicines management, psychological support, spiritual and cultural issues, rehabilitation, social support, dementia, care in different settings, and care in the last days of life.
Developing a model of short-term integrated palliative and supportive care for frail older people in community settings: perspectives of older people, carers and other key stakeholders (1)	Bone et al., 2016	Potential benefits of the SIPS model include holistic assessment, the opportunity to inform the older people better about choices with the possibility to plan future care, opportunity for end of life discussion, symptom management and carer reassurance and inclusion. Regarding the timing of referral to palliative care, the older people and their carers advocated for early referral whereas service providers proposed referral based on the symptom burden. The assignment of a key worker to coordinate care and function as a single point of contact is recommended, but it remains uncertain which professional should be assigned.
Palliative care for frail older adults "There are things I can't do anymore that I wish I could…" (14)	Boockvar and Meier, 2006	Proposals on the management of the common symptoms that frail older people experience and different geriatric and palliative approaches appropriate for the 3 frailty stages, defined based on impairment in activities of daily living (ADL): timely recognition of frailty, establishing goals of care, programmatic support, financial planning, family support and avoidance of iatrogenic harm.
Recognising older frail patients near the end of life: what next? (4)	Cardona-Morrell et al., 2017	Frailty should be identified because it is a good prediction of mortality, and recognising the beginning of the dying trajectory is essential to transition to palliative care. There is no consensus on how to measure it and various frailty indices exist, but the CGA is considered gold standard for identification and assessment. The British guidelines recommend the use of CGA at every encounter with an older patient to assess frailty, diagnosing chronic illnesses to

		optimise care, deprescribing, and conversations with the patient, followed by the drawing of an individualised care plan. The Asia-Pacific guidelines do not only suggest the use of CGA and addressing polypharmacy, but also referral to an individualised physical activity program because there is evidence that it can delay the onset of frailty. Additionally, investigation of reversible causes of fatigue and weight loss is proposed so that these can be treated with protein and caloric supplementation. The Geriatric Emergency Department Guidelines suggest a screening for frailty on all older patients in the emergency department.
Implementing advance care planning with community-dwelling frail elders requires a system-wide approach: an integrative review applying a behaviour change model (6)	Combes et al., 2019	The following key elements for successful implementation of advance care planning (ACP) are identified: • Capability: education, training and early engagement. • Opportunity : ACP needs to be part of everyday practice, recognition of triggers, provision of relevant resources. • Motivation: starting conversations on death, not only living day to day but also future planning, acknowledging that personal beliefs can change over time, and that relationships of frail older people are an important factor in ACP decision-making.
Frailty in older adults: implications for end-of-life care (16)	Koller and Rockwood, 2013	Description of how frailty is defined, how it affects the end of life care, and suggestions to better the end of life care for frail older people. The following actions are suggested: • Pain management • Examination of the medication list for possible adverse drug effects • Managing symptoms with appropriate doses: “start low and go slow, but get there”. • Adjunctive therapies to optimise pain control • Establishing goals of care

Physical, social, psychological and existential trajectories of loss and adaptation towards the end of life for older people living with frailty: a serial interview study (21)	Lloyd et al., 2016	Dying is four dimensional and consists of physical, psychological, social and existential changes. Understanding these multi-dimensional needs can help to develop palliative care interventions desirable for frail people. To improve the end of life for frail older people it is beneficial to: • Recognise needs beyond the physical aspect • Enable the maintenance of a sense of self • Support carers • Involve community networks • Address greatest fears
When frailty should mean palliative care (18)	Pialoux et al., 2013	A proposal of a procedure of implementation of palliative care for frail older people. 1. Identification of the frail older people eligible for palliative care. 2. Evaluation of symptoms and needs, using CGA. 3. Outlining a care plan, depending on the degree of frailty. Various care models exist and recurring aspects are geriatric evaluation of the frail older people using CGA, informing the patient and family, reflecting on care according to the frailty stage, and multidisciplinary working.

5.1 Identification of frail older people nearing the end of their lives

The identification of a person living with frailty is of great importance because frailty and the stage of frailty are good predictors of impending mortality, better than comorbidity or biological age (4, 17). Four articles stated that frail older people are at greater risk of death compared to fit older adults (4, 6, 14, 16).

However, predicting the risk of death or survival time of frail older people to determine when a frail patient is nearing the end of his/her life remains a challenge. No validated tools to exactly determine survival time or risk of death of an individual patient were described in the reviewed publications. Nevertheless, different approaches to estimate the closeness to death were suggested.

First, it was described that the degree of frailty is correlated with survival time or the risk of death of the frail older person. Therefore, it is important to not only identify patients living with frailty, but to also assess the degree of frailty and thus recognise end-stage frailty (4, 17). According to the BGS, older people with end-stage frailty are five times more likely to die in a year than non-frail older people and patients with end-stage frailty have a higher risk of death within 6 months. Consequently, the assessment of the severity of frailty is an essential part in the assessment of the risk of death (17). To distinguish the various stages of frailty, including end-stage frailty, the comprehensive geriatric assessment or a classification based on the impairment in activities of daily living (ADL) were suggested (17, 18). Koller and Rockwood described how the Frailty Index can also be a good tool to assess the frailty degree as it is associated with the physiologic reserve and the accumulation of deficits. A high Frailty Index score is correlated with a higher risk of death. The concept of accumulating deficits can help to visually define the functional decline (16).

Next, the review by Pialoux et al. and the “End of life care in frailty” guidelines suggested the Gold Standards Framework (GSF) to support the early identification of patients likely to die within a short period of time (17, 18). It consists of the following 3 elements: identification of patients nearing the end of life, assessment of their needs, and planning current and future care with the goal of “living well and dying well”. According to the Gold Standards Framework, the process of identification of frail older people nearing the end of life consists of 3 steps : Step 1 is the surprise question: “Would you be surprised if the patient were to die in the next year, months, weeks, days?”. Step 2 regards the presence of general indicators of decline and increasing needs, such as repeated unplanned hospital admissions, presence of significant multi-morbidities or serum albumin < 25g/l. Step 3 consists of the assessment of specific clinical indicators related to the frailty trajectory (table 6) (24).

These indicators for frailty were not only presented by the Gold Standards Framework, but were also referred to in the “Fit for Frailty” guidelines by the British Geriatrics Society (22). Additionally, the Supportive and Palliative Care Indicators Tool (SPICT^{TM}) listed clinical indicators for frailty (table 6) (25). The 7 other publications included in the review did not describe specific indicators for the recognition of frailty.

Table 6: Clinical indicators for frailty in tools identifying patients for palliative care approach (22, 24, 25)

According to the Gold Standards Framework and the Fit for Frailty report
Multiple morbidities
Deteriorating performance score
Weakness and weight loss exhaustion
Slow walking speed: it takes more than 5 seconds to walk 4 m.
TUGT: the time it takes to stand up from chair, walk 3 m, turn and walk back > 10 s
PRISMA, at least 3 of the following: aged over 85, male, health problems that limit activity, regular need for help, health problems that require the patient to stay at home, the availability of someone in case of need, the use of a stick, walker or wheelchair.
According to SPICT^{TM}
Unable to dress, walk or eat without help
Eating and drinking less; difficulty with swallowing
Urinary and faecal incontinence
Not able to communicate by speaking; little social interaction
Frequent falls; fractured femur
Recurrent febrile episodes or infections; aspiration pneumonia

Lastly, it was proposed in the “End of life care in frailty” guidelines that the identification of people nearing the end of their lives can also be based on general clinical indicators indicating the end of life. These indicators are listed in table 7 but are not specific to the frail population (17). The other reviewed publications did not list general indicators for the end of life.

Table 7: General clinical indicators indicating the end of life according to the "End of life care in frailty" guidelines (17).

- Two or more unplanned hospital admissions in the past 6 to 12 months
- Persistent and recurrent infections
- Weight loss of 5-10% in the last 6 months
- Multiple morbidity in addition to frailty
- Combined frailty and dementia
- Delirium
- Exacerbation of falling
- Rapidly rising frailty score
- Escalating patient, family or service provider distress
- Older person asking for palliative care support and/or withdrawal of active treatment

The difficulty in recognising when a frail older patient is nearing the end of his/her life was described as one of the challenges for the implementation of palliative care among frail older people. As stated above, it is impossible to detect a specific moment of sudden decline in the trajectory of end of life of frail older people that can forecast imminent death. Therefore, it is difficult to recognise the onset of the palliative phase and decide when to start palliative care (17, 18). Further, it was emphasised that the risk of death of the individual patient is not necessarily identical to the risk of death of all frail older people. This uncertainty of outcome and of proximity of death is an important factor in the prognostication for frail older people and contributes to the challenges regarding the start of palliative care (17). The following additional reasons for the difficulties were described: the lack of expertise and knowledge among professionals concerning palliative care outside the field of oncology, and the perception that the end of life is a certain point in time instead of a process over time. The end of life trajectory often begins years before the actual death of the patient takes place (4, 18).

5.2 When to start palliative care for frail older people

Because the prediction of the survival time of a frail older individual remains challenging, the assessment of needs of the frail older patient was recommended to decide when to start palliative care. The importance of the holistic assessment of not only physical, but also of social, psychological and existential needs was emphasised in four reviewed articles (1, 17, 21-23). Several tools to assess palliative care needs were described in the reviewed publications.

First, Sebag Lanoë et al. developed a decisional tool “The Sebag-Lanoë scale” to help decide when palliative care is appropriate, based on ten questions a multidisciplinary team has to answer. However, this tool has not been validated (18). Second, the British Geriatrics Society referred to the NECPAL CCOMS-ICO Tool and the Supportive and Palliative Care Indicators Tool (SPICT) as tools designed to screen for patients with palliative care needs (17).

The NECPAL CCOMS-ICO Tool is a tool for the identification of patients who require palliative care, including geriatric patients with frailty. A patient can be identified as in need of palliative care if the answer is “No” to the question “Would you be surprised if this patient dies within the next 12 months?”, and the answer is “Yes” to at least one of the questions regarding the following criteria: choice/request or need of palliative care, general clinical indicators of severity and progression (for example nutritional or functional markers, signs of emotional distress, and comorbidities), and specific clinical indicators of severity and progression per disease (26).

The SPICT is a useful tool for the identification of people with deteriorating health. They need to be assessed for care needs, including palliative care needs, in order to plan appropriate care. The general indicators of deteriorating health are listed in table 8 (25).

Table 8: SPICT indicators of deteriorating health (25).

Indicators of deteriorating health
Unplanned hospital admissions
Performance status is poor or deteriorating, with limited reversibility.
Depends on others for care due to increasing physical and/or mental health problems.
The persons’ carer needs more help and support.
Progressive weight loss, patient remains underweight, low muscle mass.
Persistent symptoms despite optimal treatment of underlying conditions.
The person or family asks for palliative care, chooses to reduce, stop or not have treatment, or wishes to focus on quality of life.

Next to the difficulty in recognising when frail older people are nearing the end of their lives and consequently when to start palliative care, the implementation of palliative care itself also comes along with challenges. According to Pialoux et al. four main obstacles could be identified for the establishment of palliative care among frail older people: difficulty to recognise treatment ineffectiveness, lack of communication among decision makers, no agreement on an approach to palliative care and failure to start the palliative care at the right time (18).

5.3 Goals and benefits of palliative care for frail older people

Frailty is associated with symptomatic long-term disease, decline in function and health, and imminent death (14). Therefore, a care approach aiming to relief suffering, to provide spiritual and psychosocial support, and to optimise quality of life is important for frail older people (14, 16). Palliative care intends a patient-centred care through a multidisciplinary approach of symptoms and psychological, social and spiritual needs (17).

The BGS stated that the goals of palliative care (table 9) are different from the geriatric care goals, as the geriatric care team focusses on quality of life by restoring and optimising function whereas the main focus of palliative care is the improvement of quality of life by adding life to days (17).

Table 9: The goals of palliative care (14, 16, 17).

- Relief of suffering
- Improving the quality of life
- Providing spiritual, psychological and social support
- Symptom control

Five of the reviewed publications described recommendations for the palliative care of frail older people. These articles offered general suggestions on aspects and organisation of palliative care to achieve the goals of the palliative care approach.

First, two articles emphasised the importance of timely recognition of frailty to be able to introduce the palliative approaches in appropriate time. This allowed timely end of life discussion and building relationships with the palliative care team (1, 14).

Next, Koller and Rockwood underlined that appropriate doses of medication should be used for symptom control, keeping in mind the key concept of “start low and go slow, but get there”, meaning the therapeutic goals should still be reached even though doses are lower than those used for younger patients. Medication lists need to be examined on the possibility of adverse drug effects that may worsen symptoms (16). Pain management as a part of symptom control for frail older patients was also described in the article by Boockvar and Meier (14, 16). However, only in the article by Koller and Rockwood it was emphasised that pain management can be challenging if communication with the patient is compromised, for example due to dementia. To prevent undertreatment or underassessment of pain, the use of non-verbal pain scales, looking for behavioural signs of pain and including family in the assessment process were recommended (16).

The role of advance care planning was described in the article by Combes et al. This article reported that ACP can improve the end of life care quality by providing medical care according to the personal values and preferences of the patient. The following key elements for a successful advance care planning implementation were described: early engagement to give frail older people the chance to engage physically and cognitively, including ACP in everyday practice, recognising the importance of relationality as an important factor in the decision-making process because frail older people want to make decisions within relationships, and lastly being aware that personal beliefs of the patient can change over time (6). Not only the article by Combes et al. reported the importance of ACP, the articles by Boockvar and Meier, Koller and Rockwood and Bone et al. also described the importance of establishing and later reassessing goals of care of the frail older patient (1, 14, 16).

Further, family support such as support groups or counselling for caregivers was of great importance according to Boockvar and Meier (14). Lloyd et al. added that supporting carers and involving community networks can help to minimise social alienation. This article also stated that palliative care should not only concern the patients, but also their families as their quality of life suffers as well due to the imminent death and decline of their loved one (21). Bone et al. emphasised that the assessment of the needs of the carers is beneficial in order to provide them with support and reassurance which in its turn reinforces them in their caring role, especially with increasing care needs of the frail older people as they approach death (1).

Financial planning and programmatic support such as housekeeper assistance were suggested in the article by Boockvar and Meier as important palliative care services (14). However, this was the only reviewed publication that described these aspects of care.

Besides recommendations on important aspects of palliative care, two of the reviewed articles made suggestions regarding the organisation of the end of life care for frail older people. Boockvar and Meier emphasised the importance of coordination and continuity of care to avoid iatrogenic harm and complications such as adverse drug effects. These complications often occur following inadequately monitoring or inappropriately prescribing of drugs during transitions between care settings (14). In the study by Bone et al., it was recommended to assign a key worker, or case manager, to coordinate care and function as the contact person for the patient and their carers (1).

Next to the goals of palliative care, the introduction of palliative care in the care for frail older patients has a variety of benefits. Two of the reviewed publications explained that palliative care programs were not only beneficial for the relief and control of symptoms and improvement of the quality of life, but also for reducing hospital expenses by preventing frequent hospitalisations. Additionally, it caused a greater likelihood of death at home, increased health care utilisation, improved shared decision-making, and a higher level of patient and family satisfaction (4, 14). The articles by Cardona-Morell et al. and Boockvar and Meier were the only reviewed publications that described these benefits of palliative care (table 10).

Table 10: The benefits of a general palliative care approach (4, 14).

- Symptom relief
- Improved quality of life
- Reduced hospital costs
- Greater likelihood of death at home
- Increased health care utilisation
- Improved shared decision-making
- Higher level of patient and family satisfaction

5.4 Palliative care services for frail older people: existing guidelines

Three guidance reports regarding the end of life care for frail older people were reviewed: 2 guidelines published by the British Geriatrics Society, and 1 by the Dutch Association for Clinical Geriatrics.

“Fit for frailty” is a report by the British Geriatrics Society on care for older people. It provides practical guidance on the management of frailty and the care for frail older people. The first step in the care of frail older people is the recognition of frailty. Once recognised, the best management strategy for frail older people is comprehensive geriatric assessment. The holistic medical review consists of a review of medication, looking for underlying diagnoses, cognitive impairment and new medical problems. Lastly, a discussion with the frail older patient about individual goals and aspirations takes place resulting in the outlining of an individualised care and support plan including an advanced care or end of life care plan (22).

The Dutch Association for Clinical Geriatrics issued a guidance report that describes 6 different trajectories of care. The 6th trajectory illustrates the care for frail older people in institutions for temporary and long-term stay, including palliative end of life care. This trajectory of care recommended comprehensive geriatric assessment of all patients, followed by the drawing of a care plan in the 4 domains: functional, social, psychological and spiritual. It was recommended to outline these plans together with the patient and his/her loved ones, using shared decision-making. Additionally, referral for treatment and more examination, a medication review, and advance care planning to establish the wishes of the patient regarding treatment and care were suggested. Lastly, coordination of care with the help of a case manager was also recommended (23).

In May of 2020, the British Geriatrics Society published a series of clinical guidelines on their website, touching on different aspects of end of life care for frail older people (17).

Regarding the pain management for frail older people nearing the end of their lives, the BGS recommended a comprehensive pain assessment, preferably based on self-reporting tools such as a visual analogue scale, because pain is subjective. The BGS listed the following recommendations regarding pharmacological treatment: “start slow and go slow” but also frequent reviews of the prescribed medications and their indications. Better compliance can be achieved when using modified release preparations or transdermal patches. Additionally, non-pharmacological approaches were described. On one hand to treat chronic pain and on the other hand because frail older people are susceptible to adverse drug effects, interactions, and the risks associated with polypharmacy (17).

Because there is a significant influence of medication on adverse health outcomes for frail older people, it was recommended to regularly review medication and identify potential drug related harm. Medication review consists of the establishment of goals, a review of how a patient uses his/her medicines, a review of each individual medicine for appropriateness, a check of possible interactions and side effects, and additionally a confirmation of medical history to determine appropriateness of the prescribed medications (17).

Next, people with frailty are a high-risk group for mental health problems such as depression or anxiety because they may lose their purpose and social support, and they often feel like they are a burden. Additionally, they might struggle with the anticipation of death. It is vital to be aware that frailty and physical decline increases the probability of mental health issues. Identification and assessment of psychological needs can be based on validated tools such as the Geriatric

Depression Scale. Offering psychological support is a task of all health professionals and involves listening well, reassuring and offering practical advice. It is important to recognise depression and anxiety because it is treatable. Interventions consist of medication such as antidepressants, psychological and psychosocial interventions, cognitive behavioural therapy, peer support and physical activity (17).

Further, it was described that spiritual and cultural support may be crucial to maintain pleasure and optimism and therefore improve quality of life and wellbeing of the frail older people. Spiritual and cultural support may consist of religious activities, nature, pets, art, etc. Recognising the spiritual needs, values and beliefs of the individual is important for a patient-centred approach to care (17).

Social support was also reported as incredibly important at the end of life of frail older people. Progressive frailty affects the social wellbeing of the patients because the dependence on others and uncertainty of prognosis can impact relationships. Consequences of loss of social support are not only social isolation and a decrease in quality of life of the patient, but there are additional financial and practical consequences. To assess the social care needs and available support, the social surroundings of the patient should be included in comprehensive end of life assessment. Further, information regarding resources available should be collected and provided to the patient. Financial needs should be assessed as well because they are often a source of anxiety and concern for the frail older people and their carers, and people may be eligible for financial support or funding. Additionally, carers should be supported: they are often unrecognised but play an important role in the care for the frail older people and may experience anticipatory grief or physical and emotional distress. The carers' needs can be assessed using the Carer Support Needs Assessment Tool. Various resources exist to provide support for carers, either personally, in groups or online (17).

Identification and recognition of the last days of life is important to adapt communication, interventions and treatments: unnecessary interventions and investigations should be avoided. No test to predict when exactly someone will die was described. However, there are certain signs and symptoms that can be identified in most dying people: weakness, drowsiness, confusion, not eating and drinking, loss of urine output, apnoea, withdrawal from social interactions, retreating into him/herself, a sense of calm acceptance, etc. Close follow-up of the patient and frequent bedside examination is key to monitor for the smallest signs of change (17).

Lastly, the “End of life care in frailty” guidelines described how end of life care of frail older people can take place in different settings such as community settings or care homes. Community care involves a multidisciplinary team of paramedics, social carers, local authorities, family and friends. Recommendations for community-based end of life care include: a 24-hour access number for help, prescribing anticipatory medication to be used to ensure comfort in case of sudden deterioration, and involving the social carers. On the other hand, frail older people can receive end of life care in care homes. In these long-term facilities, care is principally provided by social care workers. All patients should be considered for end of life care when they transition to a care home, but most residents and families do not want to discuss end of life care at the time of admission because they are still adjusting to the overwhelming changes. A specific challenge in care homes is that the multidisciplinary team consists of members with different work schedules causing assessment at different points in time and difficulties to sit down as a team. This requires careful and thorough documentation and case management. A recommended approach to end of life care in care homes was the Gold Standards Framework. It was also suggested to review medication at time of admission and every 6 months thereafter (17).

Other guidelines in the series of “End of life care in frailty” described urgent care needs, continence care, falls, delirium, nutrition, dysphagia, rehabilitation, dementia, prison settings and law and ethics and can be consulted on the website of the British Geriatrics Society (17). They were not described in this review as they fall outside the scope of this global review.

A variety of aspects of care, beneficial to quality palliative care for frail older people, could be identified in the guidelines described above. These elements of care are summarised in table 11.

Table 11: Elements of a quality palliative care for frail older people as described in the reviewed guidelines (17, 22, 23).

Guidance report	Guidelines for the palliative care of frail older people
Fit for frailty report by the BGS	1. Comprehensive geriatric assessment
	2. Holistic medical review: review of underlying diagnoses, cognitive impairment, new medical problems, all medication, previous diagnoses and chronic conditions and their management, a complete physical examination of the patient and discussing individual goals and aspirations.
	3. Outlining an individualised care plan

Dutch Association for Clinical Geriatrics	Comprehensive geriatric assessment
	Drawing of a care plan in the 4 domains: functional, social, psychological and spiritual.
	Referral for treatment and more examination
	Medication review
	Advance care planning to establish the wishes of the patient
	Shared decision-making
	A multidisciplinary approach
	Coordination of care: a case manager
End of life care in frailty report by the BGS	Pain management: - comprehensive pain history and assessment - functional assessment - the use of self-reporting tools - start slow and go slow - frequent medication reviews and monitoring - modified release preparations or transdermal patches for better compliance - non-pharmacological approaches for chronic pain
	Medication: - regular medication review - regular identification of potential adverse drug effects
	Mental health needs: - identification and assessment of psychological needs

	- treating depression and anxiety: antidepressants, psychological and psychosocial interventions, cognitive behavioural therapy, peer support, physical activity
	Spiritual and cultural support: religious activities and communities, nature, pets, art, etc
	Social support: - assessment of available support - assessment of strength and capabilities of the patient - providing information on available resources - assessment of financial needs and possible funding - support of carers
	Recognition of the last days of life: - adaption of communication and interventions - parallel care
	Community-based end of life care: - a 24 hour access number for help - prescription of anticipatory medication - involvement of the social carers
	End of life care in care homes: - careful documentation and case management - considering all patients for end of life care at the time of admission to the care home - Gold Standards Framework - medication review every 6 months

6. Discussion and conclusion

Ten publications regarding palliative care within frailty guidelines and recommendations were reviewed. The content of the publications included in the review provided means for the questions set out at the start to be partially answered:

The importance of identification of frail older people nearing the end of their life to determine when to initiate palliative care was emphasised (4, 17). However, predicting survival time or risk of death to determine when a frail patient is nearing the end of his/her life remained a challenge. No validated tools to exactly determine survival were described in the reviewed frailty guidelines and recommendations. Nevertheless, different approaches to estimate the closeness to death were suggested. First, the degree of frailty is correlated with survival time or the risk of death of frail older people and thus CGA or a classification based on impairment in activities of daily living were suggested to recognise end-stage frailty (17, 18). The concept of accumulating deficits can help to visually define the functional decline and estimate survival. The frailty index can be used as a tool to assess the degree of frailty and is strongly correlated with the risk of death (16). Next, the Gold Standards Framework was referred to, to support the early identification of patients nearing the end of their lives, and can be applied to frail older people (24). Both the Gold Standards Framework and the SPICT^{TM} provided clinical indicators for frailty. Additionally, general indicators for the end of life were listed in the “End of life care in frailty" report by the BGS, but these are not specific to the frail population (17).

Moreover, instead of using prognosis, it was suggested to identify palliative care needs. The following instruments were proposed to assess the palliative care needs of a certain patient and consequently help to decide when palliative care is appropriate: the NECPAL CCOMS-ICO tool, the SPICT^{TM} tool and the Sebag-Lanoë scale, but this last tool has not been validated (18, 25, 26).

The main goals of palliative care were described as relief of suffering, improvement of the quality of life, provision of spiritual, psychological and social support, and symptom control (14, 16, 17). The benefits of a palliative care approach not only consisted of symptom relief and an improved quality of life, but also of reduced hospital costs, a greater likelihood of death at home, an increased health care utilisation, improved shared decision-making and a higher level of patient and family satisfaction (4, 14).

The review by Pialoux et al., the “Fit for frailty” report by the British Geriatrics Society, the Dutch Association for Clinical Geriatrics and the article by Lloyd et al. suggested a similar procedure: first, the identification of the frail older people eligible for palliative care using comprehensive

geriatric assessment, followed by a holistic medical review for the evaluation of symptoms and needs, and lastly the outlining of an individualised care plan. Not only the functional, but also the social and psychological needs beyond the physical aspect need to be assessed (18, 21-23). The other reviewed publications did not propose a procedure for the implementation of palliative care for frail older people.

On one hand, consensus regarding multiple elements of palliative care could be found. This underlines their importance as part of the palliative care approach for frail older people. First of all, several publications emphasised the importance of the timely recognition of frailty to be able to introduce the palliative care in good time. The timely recognition leads to an early establishment of the goals of care, and this ensures that the patient is still capable of taking part in the decision-making process (1, 14). Timely conversations about the wishes of the patient ensure a care centred around the values of the patient (17). Next, the importance of including the patient and his/her family in the decision-making process was reported (4, 16, 23). Understanding their preferences and wishes is critical for the drawing of an individualised care plan. The family does not only need to be included, but also needs support in the care of their loved one. Support for caregivers is important because they may experience anticipatory grief or physical and emotional distress (1, 14, 17, 21). Further, the importance of advanced care planning including the establishment and later reassessment of the goals of care was described in multiple reviewed articles (1, 6, 14, 16, 23). Both the article by Koller and Rockwood and the “End of life care in frailty” guidelines by the BGS suggested non-pharmacological approaches to pain management because frail older people are sensitive to adverse drug effects and interactions. By using adjunctive therapies for pain control, side effects of pain medication can be avoided (16, 17). Finally, multiple articles highlighted the importance of medication review, because of the significant influence of medication on adverse health outcomes. There is a fine line between the appropriate doses needed for symptom control, and occurring of complications like adverse drug effects (16, 17, 23).

Not only on certain elements of palliative care, but also on recommendations for the organisation of palliative care, consensus could be found: three articles suggested the appointment of a case manager to coordinate care and support continuity of care (1, 14, 23). A multidisciplinary approach was also suggested for the care of the multidimensional needs of the patient (14, 21, 23).

On the other hand, only the “End of life care in frailty” guidelines compared the different settings where end of life care can take place and described the different approaches in these settings. In community settings, a 24-hour access number for help, prescribing anticipatory medication to be

used to ensure comfort in case of sudden deterioration, and involving the social carers were recommended. In care homes, the Gold Standards Framework was suggested for the approach of end of life care, and a review of medication at time of admission and every 6 months thereafter (17). The “End of life care in frailty” guideline by the BGS was also the only reviewed publication that described the importance of assessment and treatment of mental health needs such as depression and anxiety, and the importance of spiritual and cultural support to improve the quality of life of frail older people. This publication was the only reviewed publication touching on care in the last days of life (17). Additionally, financial planning and programmatic support such as housekeeper assistance were suggested in the article by Boockvar and Meier as important palliative care services (14). However, this was the only reviewed publication that described these aspects of care.

6.1 Strengths and limitations

The quality of the articles was assessed using validated quality appraisal tools and checklists. The quality was scored using +, ++ and – to display the extent in which the article meets the criteria of the used tool or checklist. The allotment of +, ++ or – to the article, benefits a visual overview and easy comparison of the articles, but is subject to the subjectivity of the reviewer. However, there were no consequences to the quality appraisal for the inclusion of the article in the review. Overall, the reviewed articles were assessed as partially or fully meeting the criteria. Minority of the criteria of the quality appraisal tools were not met.

The first observation is that the existing literature on this subject is fairly sparse. Only 25 publications were included based on the inclusion and exclusion criteria, and only 10 were deemed eligible for review. A variety of publications could be found regarding models of care for frail older people, but frequently these did not focus on palliative care and were thus not included for review. Even though only a limited amount of publications was found, the search was carried out in electronic databases and in gray literature, and there were no restrictions regarding the year of publication. Though, the language of the articles may have been a barrier as only English keywords were used for the query. The limited amount of included publications in this review and the fact that certain relevant studies may not have been included because of language barriers are possible limitations of this review.

A second observation is that the guidelines and recommendations that could be found were often similar. Additionally, the publications regularly referred to other publications also included in the review. This can be explained by the low amount of information and sources available.

Additionally, a lot of complexity and uncertainty surrounds the concept of the end of life. The end of life can be understood as the phase in the trajectory of life that starts from a few days to a couple of months or even years before death (9). There is no strict outlining of this concept, and the end of life trajectory is different for each individual. This may contribute to the complexity of the development of palliative care approaches. Because of the difficulty in defining the end of life, publications relevant to this review may not have been found in the search query as the allotment of the keywords “end of life care” or “palliative care” may have been ambiguous.

6.2 Implications for clinical practice, education and further research

Because only 10 eligible articles for review could be found and multiple publications referred to each other, it can be concluded that more research regarding this topic is needed. Further research is also necessary to reach consensus on the best palliative care approach for frail older people. The limited amount of articles regarding the subject can also imply that more education regarding palliative care outside of the cancer model is necessary, especially in the field of frailty. It is vital that palliative care for frail older people is part of the medical training of all health care professionals. Because frailty is the most frequent condition among older people at the end of their lives and majority of frail older people are cared for by their general practitioner, general practitioners should have sufficient knowledge on this topic. The development of a standardised approach would benefit future quality of care. Tools to recognise end-stage frailty should be used, and the needs of this group of patients need to be accurately assessed to timely introduce palliative care. Finally, studies to further validate existing tools such as the Sebag-Lanoë scale are needed.

6.3 Conclusion

It can be concluded that trajectories of end of life of frail older people differ from other conditions such as cancer. Frail older people also have complex and multidimensional needs. For these reasons, other palliative approaches than the cancer-based model are needed for frail older people. Most of the existing literature focuses on identification and consequences of frailty, and there is a gap in knowledge on guidelines regarding the identification of palliative care needs in the group of frail older people with complex needs and consequently on guidelines regarding when to initiate palliative care. A variety of recommendations for palliative care services were proposed and possible approaches were recommended, but no standardised approach to implement palliative care in clinical practice exists. Thus, further research is needed to establish guidelines based on evidence regarding the palliative care for frail older people.

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