## **ORIGINAL RESEARCH**

# When frailty should mean palliative care

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## **Abstract**

There is difficulty for practitioners in recognising frailty and in establishing palliative care. This clinical entity is the sum of several illnesses or syndromes that are curable if taken separately. Practitioners have difficulty integrating the inevitably fatal nature of the situation. The aim of this work is to assist physicians in providing proper care for the frail elderly. It consists in a systematic review of the literature available, intended answer the following questions: Is frailty an appropriate indication for the instatement of palliative care? When is the right moment to instate palliative care for the frail elderly subject? What tools are available to assist care teams? Are there efficient organisational models that integrate the frail elderly into palliative care? A consensus was reached on 12 articles. There are answers to these questions. But the level of evidence is low. It can be concluded that frailty is an indication for the instatement of palliative care. It is possible to envisage a three-stage procedure: First; identification of the frail elderly presenting characteristics that makes them candidates for palliative care. This is the most delicate phase. Then evaluation of symptoms and needs. Here again the GCGA is very useful. Finally, the drafting of a care plan.

## **Key words**

Frailty, Frail elderly, Palliative care, Literature review

### 1 Introduction

The majority of deaths today are related to pathologies other than cancer. However the development of palliative care focused at first on people dying of cancer, and it took some time for it to be extended to age-related illness, and frailty in particular <sup>[1]</sup>. Fried defines frailty as a clinical syndrome in which three or more of the following criteria are verified: unintentional loss of weight, patient-reported feelings of tiredness, slowness walking, muscular weakness and low levels of physical activity. In general, therefore, the frail elderly are the reflection of a clinical reality that is very frequent, and severe stages lead inevitably to death <sup>[2]</sup>.

The last months in the lives of these frail elderly people often cause unnecessary sufferingintensive care <sup>[3]</sup>. Cascade effect is typical of situations of frailty. Yet in the WHO definition, palliative care is not restricted to cancer <sup>[4]</sup>. Any patient with a chronic, evolving disease should have his/her symptoms relieved, receive psychological, social or spiritual support, and be given appropriate therapeutic options. Frailty falls within this definition of a chronic, evolving condition.

For numerous practitioners, the reason behind any interventions by a team specialised in palliative care is the terminal nature of the illness. The functional trajectory of frailty is characterised by a progressive decline over several months or years, punctuated by acute episodes, one of which will result in death <sup>[5]</sup>. There is therefore a genuine difficulty for practitioners in recognising frailty and in establishing palliative care. In the face of a clinical entity that is the sum of several illnesses or syndromes that are curable if taken separately, practitioners have difficulty integrating the inevitably fatal nature of the situation. The other aspect that explains difficulty accessing palliative care for the frail elderly is the lack of expertise among palliative care professionals outside the field of oncology.

There are therefore indications for the development of palliative care among frail elderly people. In recent years there have been advances: in 2011 WHO issued an overview of the situation <sup>[6]</sup> and there was the Australian Palliative Residential Aged Care Project (APRA) in 2006 <sup>[7]</sup> but these undertakings do not address the notion of the frail elderly, but that of palliative care among elderly patients in general.

The aim of this work is to provide an overview of present knowledge on the subject so as to assist physicians in providing proper care for the frail elderly. It consists in a review of the literature available, intended answer the following questions:

- Is frailty an appropriate indication for the instatement of palliative care?
- When is the right moment to instate palliative care for the frail elderly subject?
- What tools are available to assist care teams?
- Are there efficient organisational models that integrate the frail elderly into palliative care?

## 2 Method

A systematic review of the literature was performed using the PubMed and Cochrane Central databases. The search was carried out on articles published since the starting date of the databases up to December 15th 2011. The following keywords were used: "palliative care" AND frailty, "palliative care" AND "frail elderly", "palliative care" AND frailty, pallia\* and tricles as a whole. It was also possible to select an article considered relevant quoted in an article previously selected. Where a literature review was selected, the studies or articles reviewed were not selected.

To select relevant studies, the following inclusion criteria were used:

- The article discusses palliative care AND the notion of frailty or the frail elderly.
- Research studies, (using qualitative, quasi-experimental or qualitative methodologies); articles that were based on personal, expert opinion and literature reviews were also included.

The exclusion criterion was as follows:

• The study included only patients with a frailty characteristic already present (for instance only patients with a history of cancer or only with dementia).

The first and second authors of this paper (T. Pialoux and J. Goyard) independently selected the various possible articles. They then compared their selections with a third author (R. Hermet) and, following inclusion and exclusion criteria, agreed on a list of relevant articles (see Figure 1). The initial agreement was determined by means of an agreement score.

In a second step, the authors analysed each article using a non-statistical descriptive approach to assess the findings of each study. Due to the heterogeneity of studies a formal meta-analysis of results was not appropriate. As stated above, all kinds of articles were included in the research. It was therefore impossible to compare them. Similarly, the purpose of this

research was not to evaluate each article in detail, which would be laborious and unproductive. The aim was to review the current literature on the subject, to assess the degree of relevance of each article and to use this research to answer the questions listed above.

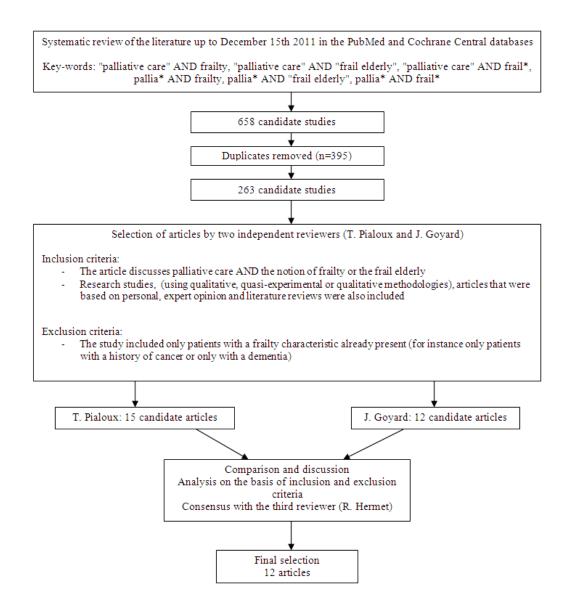


Figure 1. Method

To describe the level of relevance of the studies included, the authors used the level of evidence categories outlined by the CEBM (Centre for Evidence Based Medicine). For other types of article, the level of evidence was difficult to assess and these articles were only described by specifying the type of article; expert opinion, descriptive studies, literature reviews, and qualitative studies.

Each article was then described to provide answers to the questions set out in the introduction (see Table 1).

**Table 1.** Description of the studies

Title of the article	Author, date	Type of article	Main conclusions
Obstacles to Palliation and End-of-Life Care in a Long-Term Care Facility	Travis et al, 2002	Literature review Descriptive retrospective study	Enumerates factors hampering instatement of palliative care among the frail elderly: failure to recognize treatment futility, lack of communication among decision-makers, no agreement on a course for end-of-life care and failure to implement a timely end-of-life care plan
Palliative Care in a Long-term Care Setting : a 25-year French Experience	Sebag-Lanoë et al, 2003	Descriptive study Expert opinion	When is end-of-life care appropriate?  Presentation of the Sebag-Lanoë scale, a decisional tool for the frail elderly in palliative care
The last 2 years of life: functional trajectories of frail older people	Covinsky et al, 2003	Descriptive retrospective study	Functional analysis of the last two years in the lives of frail elderly subjects  No sudden decline predicting death was detected  The end-of-life period for the frail elderly is characterised by progressive aggravation of functional dependency
Scale of levels of care versus DNR orders	Vanpee et Swine, 2004	Expert opinion	Proposal for organisation of care for the frail elderly according to four levels: terminal phase, palliative phase, usual care and intensive car, with description of care provided at each level.
Illness trajectories and palliative care	Murray et al, 2005	Literature review Expert opinion	Description of the three main end-of-life functional trajectories  To plan palliative care it is important to know how the person is likely to die
Prediction of appropriate timing of palliative care for older adults with non-malignant life-threatening disease: a systematic review	Coventry et al, 2005	Literature review	No validated or reliable prognostic tool or model is available for clinical practice
Palliative care for frail older adults	Boockvar and Meier, 2006	Literature review Expert opinion	Procedure for instating palliative care among the frail elderly: 1/diagnose frailty using Fried criteria, 2/recognise and treat symptoms linked to frailty, 3/ Classify frail elderly subjects in three stages (early, middle, late) according to ADL scores, with concrete proposals for each stage
Quality indicators for palliative and end-of-life care in vulnerable elders	Lorenz et al, 2007	Literature review	Overview of knowledge on care provision for various symptoms of discomfort among the frail elderly in palliative care
Improving end-of-life care : a critical review of the Gold Standards Framework in primary care	Shaw et al, 2010	Literature review	The Gold Standards Framework (GSF) improves the practice of GPs multidisciplinary functioning, and the quality of palliative car. The benefit to patients and family is not known
Frailty: an indication for palliative care	Raudonis and Daniel, 2010	Expert opinion	The diagnosis of frailty should lead to envisaging the instatement of palliative care. However"when to begin palliative care is a trouble-some question"
Respecting frailty	Mallery and Moorhouse, 2011	Expert opinion Study presentation	Care organization known as PATH (Palliative and Therapeutic Harmonization): first visit: comprehensive geriatric assessment (CGA), second visit: exchange of expectations and information between patient/care giver and health professional, third visit: decisional stage with the help of a framework of questions for decisions concerning frailty  A study is underway on 100 patients
Interventions for improving palliative care for older people living in nursing care homes	Hall et al with the Cochrane Collaboration Centre, 2011	Systematic review of RCTs	Although certain aspects are encouraging, the statistical evidence is inadequate to conclude on the benefit of interventions of this sort.

# 3 Results

The bibliographic search yielded 658 articles: 576 from PubMed, and 82 from Cochrane Central. After removal of duplicates (n=395), 263 candidate studies were listed. The first author (TP) selected 15 studies, the second (JG) 12 studies. The two raters independently assessed the articles on content and agreed on 85% of the scorings. Disagreement was solved by discussion with the third author (RH). After analysis of the articles for inclusion and exclusion criteria, a consensus was reached on 12 articles.

In an article in 2002, Travis et al. described obstacles to the instatement of palliative care among the frail elderly hospitalised in long-term care facilities [8]. They first of all performed a review of the literature on the subject which highlighted four main shortfalls: failure to recognize treatment futility, lack of communication among decision makers, no agreement on a course for end-of-life care and failure to implement a timely end-of-life care plan. These elements were also found in a descriptive, retrospective study that the same authors conducted on 41 end-of-life situations among frail elderly subjects in nursing homes.

In 2003, Sebag Lanoë et al. developed a decisional tool in palliative care for the frail elderly <sup>[3]</sup>. In the article, which is both an expert opinion and a descriptive study of the palliative care situation for the frail elderly in France, Sebag Lanoë et al. ask the following question: "Identifying the dying elderly patient is not easy. When is end-of-life care appropriate?" They present the beginnings of an answer to this by suggesting the use of their tool, the Sebag-Lanoë scale. This simple tool comprises ten questions to be answered by a multidisciplinary team, which are intended to accompany decisions in the complex situations relating to frailty. These are as follows:

"What is the main diagnosis for the patient? What is the course of disease? Is there any acute disease? Is the acute disease curable? Have there been any recent acute events, or association of several diseases? What does the patient say? What does the patient express through her/his attitude and cooperation with treatment? Is the patient comfortable? What does the patient's family think? What does the nursing staff think?. This tool has not been the subject of any study of its possible contributions.

Covinsky et al., aiming to identify simple functional markers to signal imminent death in the frail elderly, conducted a retrospective descriptive study in 2003 on 970 frail elderly patients who had died, and who were part of the PACE study (Program of All-inclusive Care for the Elderly) [9]. Four measures (independence for personal hygiene, meals, walking, and presence of incontinence) were collected every three months in the two years preceding death. According to the results of this study, it was not possible to detect a particular moment of sudden decline that could signal imminent death. The end-of-life period for the frail elderly is characterised by a gradual deterioration in functional dependency.

In 2004 Vanpee and Swine suggested that the "do not resuscitate "(DNR) orders should not be used for the frail elderly, but that care should be organised according to a scale of care levels [10]. For these authors, stating what should not be done (compliance with DNR order) results in failing to specify what should be done in terms of active care content for the frail elderly. This is liable to lead to abandonment of care, which is exactly what we want to avoid. The authors suggest a scale with four levels of care for the frail elderly: the terminal phase care level, which is the basic care core applying at all levels (bodily hygiene, pain management, care of the mouth, management of emotions, body position), the palliative care level (during which skin integrity care, mobilisation, transfers, hydration and nutrition by mouth, symptom control by medical or surgical interventions are included); the usual care level (the above mentioned content, and in addition: usual diagnostic procedures, all required medical treatment with intravenous route if necessary, tube or parenteral artificial nutrition if required, surgical or technical procedures required to improve functional capacity); and finally the intensive care level (the above mentioned content, and in addition: advanced required diagnostic and therapeutic procedures, full cardiopulmonary resuscitation with sustained manœuvres when required). The authors do not detail the elements that could enable a given level of care to be allocated to a frail elderly patient, nor is there any study analysing this proposed care model.

In a clinical review (literature review and expert opinion) published in 2005 Murray et al. describe the three main functional end-of-life trajectories and set out their clinical implications <sup>[11]</sup>. The first period is a short period of evident decline (typically cancer), the second is long-term limitations with intermittent serious episodes (organ failure), and the third is prolonged dwindling (frailty). The authors state that the key to satisfactory care provision for the individuals who are going to die is to determine how they are likely to die and to plan care accordingly.

A literature review was published in 2005 aiming to analyse the prognostic tools or models available for the estimation of survival among the frail elderly (older adults with non-malignant life-threatening disease) in order to assist in the establishment of palliative care <sup>[12]</sup>. This work, conducted on the basis of a reliable methodology (using the guidelines and recommendations from the Cochrane Collaboration Centre for Reviews and Dissemination) identified eleven potential candidate studies. The discrimination of the tools was reliable, and a few predictive variables were identified as being useful to identify certain situations requiring palliative care. Nevertheless there is no validated prognostic tool or model available for clinical practice.

In 2006 Boockvar and Meier published an article entitled "Palliative care for frail older adults" [13]. In this article, which was both a literature review and an expert opinion, they suggest procedures in stages for GPs dealing with elderly patients, illustrating what they have to say by way of a concrete situation which is the guiding thread through the article. They first of all recall the definition of frailty and its consequences. The first step is the diagnosis of frailty among elderly patients (using Fried's criteria). The second stage is recognising and treating symptoms relating to frailty (weight loss, weakness, fatigue, pain, depression and falls). The authors recall that recommendations are available for the treatment of each of these symptoms. They then propose a classification of frail elderly subjects into three stages: early (no ADL impairment), middle (onset of ADL impairment) and late (ADL decline or life-threatening illness or death imminent). They note that this staging is based on their "clinical experience and other authoritative reviews". For each of these different stages, proposals are made for palliative care according to four domains: establishing goals for care, programmatic support, financial planning and family support. It is not possible to cite all the measures proposed here, but the authors emphasise the need for GPs to regularly broach the following subjects with patients and their families: the meaning of ongoing therapies, information on the evolution and the consequences of frailty for the patient and anticipation of functional losses. There is no study available analysing this care model.

A literature review was performed in 2007 by Lorenz et al. concerning the management of different symptoms of discomfort in frail elderly subjects in palliative care [14]. Quality indicators were drafted (with an indication on the level of evidence) for the following situations: comprehensive palliative assessment, goals of surrogate discussion, advance care planning, advance directive and surrogate continuity, care-preference documentation, mechanical ventilation preference, decision about life-sustaining treatment, gastrostomy tube placement, dyspnea assessment and treatment, mechanical ventilator withdrawal, management of emergent pain, management of obstruction, caregiver stress and bereavement.

The Gold Standards Framework (GSF) is a primary healthcare programme in the UK that enables GPs and community nurses to improve their practice in palliative care, in particular for the frail elderly. This programme is backed up by a manual (practical tools, orientation documents, examples of good practice). It proposes a care provision model with the appointment of a reference physician or nurse for each patient, regular multidisciplinary coordination meetings, and advance care planning. To detect frail elderly subjects who should benefit from this palliative care programme, three "triggers" are suggested: 1/ to the question "would you be surprised if this patient were to die in the next 6-12 months" the practitioners replies "no", 2/ the elderly patient expresses a clear desire to receive solely care to make him/her comfortable, and 3/ the patient presents: a) numerous comorbidities, in association with dependency in most activities of daily living, b) deteriorating functional scores for WHO or Karnosfsky performance status (<50%), c) the combination of at least three symptoms among the following: weakness, slow walking speed, low physical activity, weight loss, self-reported exhaustion. In 2010 Shaw et al. published a critical review of the Gold Standards Framework in primary care [15]. Its aim was to determine whether the GSF improved end-of-life care. Fifteen articles were reviewed. The authors concluded that

despite methodological difficulties restricting the level of evidence, the GSF improved GP practice, multidisciplinary functioning, and the quality of palliative care. However the benefits to patients and their families are not documented. It should be noted that the authors are members of the national GSF team, and hence had funding to evaluate the GFS.

Raudonis and Daniel, who are both nurses, published an article in 2010 in the form of an expert opinion entitled: "Frailty: an indication for palliative care" [16]. In this article published by the National Gerontological Nursing Association, the authors give considerable attention to the definition of the frail elderly and their care, aiming to show that the diagnosis of frailty should suggest the need to instate palliative care. Their opinions as nurses and academics are backed up in the article by numerous publications. Nevertheless the authors conclude that in the particular instance of the frail elderly, the determination of "when to begin palliative care is a troublesome question for patients, families and healthcare providers", without offering any concrete suggestions.

In 2011 Mallery and Moorhouse in a brief report (expert opinion) presented an organisation of palliative car provision for the frail elderly set up in their facility [17]. They started from the observation that curative treatments can trigger major unwanted effects in the frail elderly, that palliative care teams have well-standardised protocols within single-illness systems, but not for frailty, and that guidelines published for much younger populations are often applied to the frail elderly without any tailoring. Further to this the frail elderly population is not included in studies on the subject. The authors underline the lack of information concerning frailty intended specifically for the elderly people concerned, their families and their caregivers. They also underline the importance of the Comprehensive Geriatric Assessment (CGA) in the evaluation and care of the frail elderly. Their intervention programme, named PATH (Palliative and Therapeutic Harmonisation) consists in three visits by a healthcare provider trained in the method: first visit: administration of the CGA; second visit: exchange of expectations and information between patient/care giver and health professional (education about each illness, its impact on health and what to expect in the future, with a review of prognosis and expected decline); third visit: decision-making with the help of a framework questions for decision-making in frailty: which health conditions are easily treatable? Which are not? How far will frailty make treatment risky? Will the proposed treatment improve or worsen function and memory? Will the proposed treatment require time in hospital? If so, for how long? Will the treatment allow more good quality years, especially at home? What can we do to promote comfort and dignity in the time left? A study on 100 patients is underway. The authors do not detail the way in which patients are diagnosed as being frail, and which are included in the consultations.

In 2011, with the Cochrane Collaboration Centre, Hall et al. published review of the literature entitled "Interventions for improving palliative care for older people living in nursing care homes (review)" [18]. The level of relevance of this study (according to the CEBM) is 1 (Systematic review of RCTs). A meta-analysis was not possible because of the heterogeneity of the studies reviewed. The only genuine studies included (two randomised controlled trials and a before-and-after study) were all three performed in the United States. The results reported are as follows: improvement of satisfaction with care, improvement in comfort observed in patients with dementia in terminal phase, a decrease in terminal phase hospital-lisations, an increase in the number of DNR orders, and more frequent presence of a care plan. However the authors noted that there were few studies, they was not very good quality, biased, did not include cost-efficiency data, and were derived from a single country. This is statistically inadequate to conclude on the benefits provided by these interventions.

### 4 Discussion

In the light of the above results, the first observation is that the literature on the subject is fairly sparse. It can also be remarked that the level of evidence in the conclusions provided by these articles is rather low. Three descriptive studies <sup>[3, 8, 9]</sup>, six literature reviews <sup>[8, 11-15]</sup>, six expert opinions <sup>[3, 10, 11, 16, 17]</sup> and only one systematic review of RCTs are available <sup>[18]</sup>. Nevertheless the content of these various articles does enable the questions set out at the start to be partially answered:

#### Is frailty an indication for the instatement of palliative care?

Numerous authors are convinced that a frail elderly subject should have palliative care <sup>[3, 10, 13-15-17]</sup>. What is interesting is that geriatricians <sup>[3, 13, 17]</sup>, General Practionners <sup>[15]</sup>, palliative care teams <sup>[3]</sup> and nurses <sup>[16]</sup> are all represented. The end-of-life functional trajectory of the frail elderly is now well-known <sup>[9,11]</sup>. Frailty is indeed a chronic, evolving pathology that leads to death.

## When should palliative care be instated among the frail elderly?

Travis (2002) accurately describes the problems that are regularly encountered for the instatement of palliative care among the frail elderly, in particular the difficulty recognising the moment when the palliative phase begins <sup>[8]</sup>. This aspect is mentioned by several authors <sup>[3, 8, 9, 16]</sup>. It is a central issue for which there is no simple answer. One of the reasons for this difficulty in defining the period of palliative care for these patients is indeed the absence of a "gold standard" to classify the various stages in frailty. Certain authors suggest methods: Boockvar (2006) classifies the frail elderly into three groups (with palliative care suited to each) according to ADL <sup>[13]</sup>. The Gold Standard Framework (GSF) suggests a procedure that depends on the patient's opinion, Fried criteria and WHO status <sup>[15]</sup>, and Mallery uses the CGA to decide whether or not to instate palliative care <sup>[17]</sup>. A number of authors recommend an evaluation using a CGA rating which enables the recognition and treatment of the main geriatric symptoms, and also the establishment of the degree of frailty of the patient, so as to adapt the care offered, in particular palliative care <sup>[3, 10, 13, 15-17]</sup>.

#### What tools are available to assist healthcare teams?

The first response to his question is that there is no validated prognostic tool or model available to help in determining whether or not to instate palliative care <sup>[12]</sup>. Covinsky (2003) even concluded that it is not possible to determine a point of sudden decline announcing the imminent death of the frail elderly subject <sup>[9]</sup>. This is a reality in geriatric practice that has to be integrated, and it is rather new for palliative care teams. There are nevertheless certain tools available: decisional questionnaires <sup>[3, 17]</sup>, and scales defining palliative care according to the degree of frailty <sup>[10, 13, 17]</sup>. However none has been validated by appropriately designed studies.

#### Are there efficient care organisation models that integrate the frail elderly?

Several models are proposed <sup>[10, 13, 15, 17]</sup>. While they differ one from another, there are several recurrent aspects: a geriatric evaluation using the CGA, clear information to the patient and family, reflection upstream on the meaning of therapies and care according to the frailty stage, and multidisciplinary functioning. However, even if the first results appear encouraging for some of these models, further more robust research is required <sup>[18]</sup>.

### 5 Limitations of this review

Certain relevant studies may not have been quoted despite the care taken by the authors. The inclusion and exclusion criteria were wide, and the subjectivity of the authors probably had some effect. There are probably other studies that contribute to the subject without explicitly referring to "frailty" and "palliative care". The heterogeneity of the articles reviewed did not enable the comparison among studies.

### 6 Conclusion

Following this work, it can be concluded that frailty is indeed an indication for the instatement of palliative care. It is important to cite the work of sentinel researchers in this subject area. Despite the low level of evidence in the literature, it is possible to envisage a three-stage procedure:

First, identification of the frail elderly presenting characteristics that makes them candidates for palliative care. This is the most delicate phase. Using prognosis as the sole decision criterion for instating palliative care is liable to exclude a large number of patients from palliative care. The training of GPs and palliative care teams in geriatric syndromes and CGA administration seems essential. Several decisional tools, non-validated, are available.

Then, evaluation of symptoms and needs. Here again the GCGA is very useful. There are also clear recommendations for the way in which to cater for the different symptoms causing discomfort in frail elderly patients.

Finally, the drafting of a care plan. This means specifying the objectives, the type of care to be provided, and the type of care to be avoided, according to the degree of frailty. Communication with the patient and his/her family, and the information they are given (in particular concerning the end-of-life trajectory in the frail elderly) are essential.

There are many models for palliative care of the frail elderly. It could be worthwhile for practitioners to become acquainted with them, so as to establish an organisation that is suited their particular practice and culture, remembering that none of these models has been validated using a statistically sound methodology.

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