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Palliative medicine and care

Frailty, severity, progression and shared decision-making: A pragmatic framework for the challenge of clinical complexity at the end of life



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ABSTRACT

The current epidemiological context features progressive ageing of the population and an increasing number of multi-morbid persons mostly affected by advanced chronic diseases. This perspective determines an urgency to improve decision-making, which becomes especially difficult due to the clinical uncertainty of life final stages. Usual approaches based on clinical practice guidelines and focused on the prognosis may be useful in a population approach, but will probably be insufficient against the clinical complexity arising from individualized decision-making. For this reason, we propose a pragmatic framework as a more comprehensive base to guide decision-making and helping the dialogue between patient, family and professionals in regards to expectations and objectives in the shared-decision process. This framework requires two stages: (1) an adequate situational diagnosis and (2) the build-up of shared decision-making contexts by involving patients in the process. To determine situational diagnosis, we propose a model that combines elements of background knowledge on geriatrics and palliative care, including the scientific evidence–(from prognostic markers and analysis of frailty based on the accumulation of deficits), and clinical experience (assessment of the variables taking into account both static–severity–and dynamic–progression–behaviour). For decision making, we incorporate the model of person-centred care based on shared decision-making, understood as a collaborative process between patients and professionals to identify needs, set objectives, develop and implement the care plan and monitor its evolution. Future studies will have to evaluate the validity and utility of this framework for decision making in elderly with advanced diseases at end-of-life.

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1. Introduction

In middle and high income countries, the new epidemiological context features progressive ageing of the population and an increasing number of multi-morbid persons mostly affected by advanced chronic diseases with complex care needs. This scenario makes decision-making processes difficult for both healthcare professionals and patients. Professionals need tools to make such usually complex processes easier. As opposed to clinical guidelines, normally focused on disease and with much more academic style,

frameworks establish wider and more personalized ranges, from evidence to teams' expertise and patients' values and preferences.

Given that frailty is the most frequent condition among elderly patients in end-of-life situation [1,2], professionals' expertise needs to have deep background knowledge on geriatrics and palliative care. In fact, these two areas already share methods regarding care process [3]: team work, multidimensional assessment, care provision based on objectives and preferences, psychosocial and caregivers support.

1.1. End of life, clinical complexity and decision-making

End of life–understood as the phase of life that comprises from a few days before dying to some months or even years–is determined by multiple variables and its evolution is entirely

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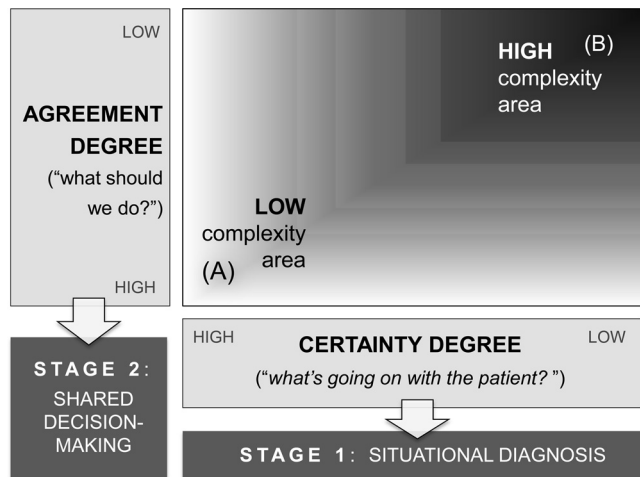


Fig. 1. Clinical Complexity in relation to certainty degree in situational diagnosis with respect to agreement degree on how to act in that situation (adapted from Plsek PE & Greenhalgh T BMJ 2001) and suggested Stages to answer the questions raised. For instance, diagnosis is simple for a young patient with an acute myocardial infarction (A); this is not a high complexity situation regarding decision-making and the plan action is easily elaborated; this is the usual context for protocols and evidence-based guidelines. However, diagnostic uncertainty will be high and decision-making will be difficult if the patient suffers from multiple advanced chronic conditions and presents multisystem impairment before a crisis, sometimes with imprecise clinical performances, such as functional decline, for example (B); these situations can hardly be systematized due to individual singularities. Thus, the origin of clinical complexity in regards to advanced chronic patients in end-of-life situation lies, largely, in such diagnostic and therapeutic uncertainty.

individual. The same clinical scenario and causal heterogeneity can have different manifestations due to individual features. This conveys difficulties for situational diagnosis as well as for decision-making, as shown in Fig. 1.

Clinical complexity is closely linked to uncertainty, even inherent, in end-of-life care and patients. Such uncertainty comes from the difficulties on diagnosis and decision-making. This paper provides a proposal for a pragmatic conceptual framework aimed at complex decision-making processes for patients at the end of life. This requires two stages, as described in Table 1.

2. Stage 1: situational diagnosis

The first stage for decision-making is based on situational diagnosis. We have adopted such concept to refer to the evaluation and assessment of patients that allows healthcare professionals determine patients' health degree and or possible closeness to end-of-life situation. Certainly, not a simple diagnosis.

2.1. The paradox of end-of-life identification

Because end-of-life diagnosis is so complex, healthcare professionals have looked for answers in prognostic models in order to

identify patients likely to die within a short period of time. Such models are reliable to estimate survival of a population group from an epidemiological point of view. However, they are not conceived for individual decision-making, therefore contrasting with the benefits of early identification of patients likely to be in end-of-life situation [4].

In summary, despite the need of early identification, definite indicators to allow such early identification have not been consistently defined. We suggest two conceptual changes to give answer to this paradox.

2.1.1. From prognosis to need

If care provision is focused on patients' needs rather than on prognosis, identifying—ideally at early stages—those patients reasonably likely to die shortly and aiming at covering their needs would be appropriate. We advocate for a progressive approach, then, in which palliative care is provided as long as patients' needs evolve, those being related to disease, individual personal characteristics or social context.

2.1.2. From population screening models to individual clinical assessment

The need for specific population strategies that include the screening of patients with palliative care needs is clear. Different tools have been designed and validated with that purpose. Some of them include the Prognostic Indicator Guidance (PIG) of the Gold Standards Framework (GSF) [5], the Supportive & Palliative Care Indicators Tool (SPICT) [6] or the NECPAL CCOMS-ICO® [1]. However, such screening should be complemented by an exhaustive multidimensional assessment in order to: (I) validate the identification of advanced situation by ruling out potentially treatable or reversible factors and (II) elaborate a specific care plan for each patient's evolutionary situation.

2.2. Bases for situational diagnosis and end-of-life identification: Severity, progression and frailty

Professionals' skills have to include appropriate knowledge of the physiopathology process involved in end-of-life situations. Such process has been traditionally understood as an organ-centred one, in which severe criteria of specific diseases are trying to be identified. These criteria, as being individually determined, have been proved to have low prognostic capacity at mid-term, particularly regarding geriatric patients [7]. At the same time, the presence of more general conditions (functional, nutritional and cognitive status, geriatric syndromes, and social vulnerability) with solid death predictive values have been proved to be reliable indicators of 'advanced situation' [8].

In order to clarify the conceptual approach of end-of-life indicators, we suggest the terms severity and progression [9] as central axis when measuring the different variables; end-of-life situation is determined by the severity degree and the progression of both the main disease and other additional general conditions.

Table 1
Stages of the conceptual framework for complex decision making at the end of life.

Stage	Based on	How to do it?
Stage 1	Situational diagnosis	Frailty degree
		Healthcare professionals carry out an assessment of the variables/prognostic markers taking into account both its static (severity) and dynamic (progression) behaviour to determine frailty degree and evaluate potential reversibility Frailty index can be a good tool to measure it
Stage 2	Shared decision-making	Patients' and healthcare professionals' expertise
		Both professionals and patients establish a cooperative process to identify needs, agree on objectives, develop and implement a collaborative care plan and monitor the evolution

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