

Ethical Challenges of Early Identification of Advanced Chronic Patients in Need of Palliative Care: The Catalan Experience

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Abstract

Palliative care must be early applied to all types of advanced chronic and life limited prognosis patients, present in all health and social services. Patients' early identification and registry allows introducing palliative care gradually concomitant with other measures. Patients undergo a systematic and integrated care process, meant to improve their life quality, which includes multidimensional assessment of their needs, recognition of their values and preferences for advance care planning purposes, treatments review, family care, and case management.

Led by the National Department of Health, a program for the early identification of these patients has been implemented in Catalonia (Spain). Although the overall benefits expected, the program has raised some ethical issues. In order to address these challenges, diverse institutions, including bioethics and ethics committees, have elaborated a proposal for the program's advantages. This paper describes the process of evaluation, elaboration of recommendations, and actions done in Catalonia.

Keywords

palliative care, ethics, advance care planning, chronic conditions, palliative care approach

Introduction

In recent years, patients have begun to receive palliative care earlier in the course of their illness. Studies have shown that

early palliative care for patients with advanced chronic diseases is effective and highly beneficial.^{1,2} Clinicians seek to identify patients with palliative care needs in order to provide them with

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Table 1. Potential Benefits of the Program for Early Palliative Care Provision, According to 5 Clinical Ethics Committees.

Benefits for patients	<ul style="list-style-type: none"> • Gradual introduction to the palliative approach: new perspectives and reflexive process on patients' needs and goals for care • A rational and reflexive decision-making process: patient autonomy through advanced care planning • Gradual adjustment to progressive impairment and loss: increase in the intensity and scope of care with a combined curative/palliative focus • Positive identification of individuals in vulnerable situations
Benefits for improving quality of care	<ul style="list-style-type: none"> • Identification of individuals with special needs who might otherwise remain unidentified • Promotion of active team discussion and revision of therapeutic goals • Promotion of integrated and continuing care and a rational approach to emergency care • Focused on improving quality of care

the benefits that such care can provide, but issues such as patient autonomy and nonharm are also very important aspects that should be considered.

Led by the National Department of Health (DoH),^{3,4} a program for early identification of patients with advanced chronic diseases and those with a limited life expectancy has been implemented in Catalonia, Spain. The aim of this program is to establish a new model of care based on a multi-dimensional assessment of needs, advanced care planning, case management, and integrated care pathways across diverse health-care settings. Although the program's primary aim is to improve patients' quality of life, some ethical concerns have been raised by health-care professionals, mainly the risk of stigmatizing patients and potentially missing opportunities for curative treatments.

However, other concerns have also been raised, including privacy issues, misunderstandings about the prognostic value of early identification, and patient involvement in the identification process. Advanced care planning and patient empowerment represent specific challenges that need to be addressed in our social and cultural context.^{5,6} Moreover, in our experience to date, we have found particular barriers to the implementation of the program (mainly training and organizational matters) that also need to be improved.

In order to address these questions, a collaborative, comprehensive process of revision was undertaken. Several additional actions, including creating a core team of professionals, collecting data via a qualitative survey, and providing specific recommendations, were performed. A diverse group of health-care professionals and key institutions—including bioethics and ethics committees—were included in the review process and these same professionals also helped to further the program implementation by highlighting its benefits in terms of quality of life improvement for patients. The Catalan Bioethics Committee had extensive previous experience in drawing up recommendations for professionals who provide care to end-of-life patients.^{7,8} The present report describes the challenges and ethical issues encountered during the implementation process of a new program for early palliative care for individuals with advanced progressive palliative care needs in Catalonia (Spain).

Methods

A multidisciplinary team of health-care professionals from the DoH and the Chair of Palliative Care was constituted. After reviewing existing knowledge, they discussed the ethical aspects of early palliative care provision, agreed on terminology, and produced a preliminary document outlining the conclusions of the meeting. Next, this core team distributed a qualitative survey to 2 groups of 8 primary care professionals (doctors and nurses)⁹ during the pilot phase of implementing the program in primary care services. The professionals were asked to (a) review the utility and feasibility of identifying patients using the proposed instruments, (b) list any ethical aspects related to early identification of such patients, and (c) make recommendations regarding the implementation of the program.

Finally, the core team distributed a semistructured survey to 5 relevant clinical ethics committees. These committees were asked to review the initial document, paying particular attention to possible benefits, risks, barriers, and challenges, and to elaborate a list of proposals to be implemented. Their comments were sent to the Catalan Bioethics Committee for assessment, which produced a final version with recommendations to be implemented.

Results—Findings

Information Collected From the Surveys and Focus Groups

Respondents highlighted the value of the multidisciplinary recruitment process of patients to identify non-cancer patients with chronic illnesses who require palliative care interventions. Additionally, the respondents identified significant areas related to the health-care professionals that needed to be addressed, including communication skills, emotional support, a team approach, and ethical issues (mainly advanced care planning and shared decision-making strategies). They also emphasized the importance of creating policies to establish integrated care pathways involving all health-care settings (hospital, home, and hospices) and common information systems. Most of the contributions underscored how this program offered an excellent opportunity to substantially improve the quality of palliative care provision (Table 1). However, this review process also revealed numerous possible risks and challenges (Table 2).

Table 2. Potential Risks of the Program for Early Palliative Care Provision, According to 5 Clinical Ethics Committees.

Risks for patients	<ul style="list-style-type: none"> • Stigmatization: Loss of care and curative options (“negative discrimination”) due to confusion between advanced and terminal disease • Negative impact: Lack of involvement and permission of patients, with a possible impact due to prognosis awareness
Risks and barriers for improving care quality	<ul style="list-style-type: none"> • Training deficits of health-care professionals: Lack of knowledge or resources to adequately meet patient needs • Resistance of professionals due to the “dichotomy perspective” (antagonism: curative vs palliative) • Changes in the role of palliative care services in the early palliative approach and the need to establish new criteria for intervention • Potential misuse of the program to reduce costs of care at the end of life

Table 3. Questions and Answers on Implementation of the Program for Early Identification of Patients in Need of Palliative Care.

Frequent Asked Questions (By Professionals)	Answers and Recommendations
Program aims	<ul style="list-style-type: none"> • To improve the quality of care of patients with advanced chronic conditions in all departments
Aims of identifying patients	<ul style="list-style-type: none"> • Provides valuable clinical information to screen patients with advanced conditions and palliative care needs in primary care and other conventional treatment areas
Who identifies patients? Where?	<ul style="list-style-type: none"> • Patients must be identified by a competent team (preferably a multidisciplinary team) who knows the patient. Careful assessment must be performed. • Primary care services are the preferred place for identification
Patient involvement	<ul style="list-style-type: none"> • Identifying patients in emergency services without previous contact is not advisable • Patients must be actively involved in the process. They should be given sufficient information about the program, advanced care planning, and they should lead decision-making. Patient should be gradually informed about their situation and the purpose, meaning, benefits, and goals of being identified
Family involvement	<ul style="list-style-type: none"> • Family caregivers must also be involved in the process
Prognostic value of identification	<ul style="list-style-type: none"> • Recent data show higher mortality rates for patients with early identification (suggesting these are “at risk” patients) • The prognostic value needs to be interpreted cautiously in individual patients
What does being NECPAL+ mean?	<ul style="list-style-type: none"> • It means that the patient suffers from one or more advanced chronic conditions and that a palliative approach should be incorporated into the existing care plan
What to do after identification	<ul style="list-style-type: none"> • Gradually implement a palliative care approach (reflexive process of assessment) accompanied by other perspectives (advanced care planning and case management) • The patient should be registered through shared information systems and all available clinical data should be accessible for all departments, including information on patients’ needs, established and agreed goals, and recommendations for future expected scenarios
How to improve the palliative approach in all settings?	<ul style="list-style-type: none"> • Implementation of early palliative care needs to be accompanied by training strategies for health-care professionals and organizational changes in all departments
Do NECPAL+ patients need to be referred to a specialist palliative care service?	<ul style="list-style-type: none"> • Not necessarily. Specialist intervention should depend on the complexity of needs and agreements between departments
What is the role of specialist palliative care services in the care of NECPAL+ patients?	<ul style="list-style-type: none"> • As the primary reference for complex cases • To provide advice and support to other departments to improve the quality of palliative care
Do NECPAL+ patients need curative measures?	<ul style="list-style-type: none"> • Yes, the use of a palliative approach must be concomitant with all other measures that could benefit patient survival and quality of life
Is the aim to reduce the cost of care?	<ul style="list-style-type: none"> • No. Palliative care programs could reduce resource usage and related costs, but only as a side benefit related to improved efficiency. However, this is not the primary aim of the program

Note. with the tool NECPAL CCOMS-ICO*

(*)Accssible at: http://ico.gencat.cat/en/professionals/serveis_i_programes/observatori_qualy/programes/programa_necpal/index.html

Final Recommendations of the Ethics Committee

With all the information collected, the core team elaborated a second draft document which was sent to the Catalan Bioethics Committee for formal evaluation. After evaluation, the

Committee drew up a final document that included relevant comments and recommendations¹⁰ (Table 3). Finally, the definitive proposal was presented to the DoH for approval and subsequent implementation. The main actions adopted by the

DoH included strengthening policy strategies, such as developing protocols for care organizations, as well as creating a formal document on good ethical practices.

Discussion

We provide a description of the ethical aspects, benefits, risks, and challenges identified in the process of implementation of systematic procedures for early identification of patients with palliative needs in conventional primary care services in Catalonia, Spain. Several different methods were used to identify these issues, including focus groups of relevant professionals, sessions in primary care services, and reviews performed by ethics committees to develop conclusions and recommendations.

One important finding was that implementation of timely identification of patients in need of palliative care should be accompanied by an improvement in the model of care. This model should be improved based on a consensus among multidisciplinary clinical experts, including ethicists, policy makers, and patients. This comprehensive approach has shown benefits for patients, as it provides care to patients according to their needs rather than according to their specific diagnosis. However, providing such care is among the most relevant recent challenges of palliative care.

Another important challenge is related to providing sufficient quality training for the professionals involved. This is essential to ensure delivery of the highest quality of care while minimizing the risks of harming patients. Advanced care planning is one of the major areas that must be addressed after early identification.¹¹⁻¹⁵ To cover the needs of professionals in our region, a project has been developed to improve the performance of advanced care planning. That project is in the early phases of implementation at present, with an initial focus on primary care and nursing homes. In this sense, an expert panel of 60 professionals has been created to develop a conceptual framework adapted to our culture and health-care system. These professionals are elaborating training material and activities at the time of the writing of the present document.

Evaluation of this early palliative care program is currently in process. This evaluation includes both quantitative assessments and qualitative surveys of professionals to investigate relevant ethical issues, and outcomes of this assessment process should be available soon.

The strengths of the review process described here include a strong awareness of the ethical perspectives involved in the implementation process and the close participation of relevant professionals and ethics committees in developing specific proposals to improve the program. In contrast, the lack of a systematic evaluation and rigorous methodology is a limitation.

Conclusions

Evaluating health-care systems and applying new policies is a complex undertaking due to the need to assess and account for a multitude of different factors and inputs. Even though the main

aim is to benefit a diverse group of participants (primarily patients, but also health-care professionals and policy makers, among others), it is inevitable that many challenges will arise when any new program is implemented. For this reason, it is essential to identify the ethical challenges that are encountered during program implementation. It is even more important to eliminate, to the extent possible, any ethical issues that are identified.

An integral feature of this program is the innovative initiative of involving ethics committees to draw up proposals on how to address the ethical issues raised by early palliative care provision. By facing and resolving these ethical issues, the implementation of new policies is strengthened. Furthermore, the experience described here could be adopted in other contexts to improve the approach to palliative care, both in primary care services and in the community. This experience can be helpful to address ethical aspects, assure benefits, and prevent some of the risks described here related to the timely identification of patients in need of palliative care in conventional services.

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