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Comprehensive and integrated palliative care for people with advanced chronic conditions: an update from several European initiatives and recommendations for policy

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ABSTRACT

The number of people in their last years of life with advanced chronic conditions, palliative care needs and limited life prognosis due to different causes including multi-morbidity, organ failure, frailty, dementia, and cancer is rising. Such people represent more than 1% of the population. They are present in all care settings, cause around 75% of mortality, and may account for up to one third of total national health system spend. The response to their needs is usually late and largely based around institutional palliative care focused on cancer. There is a great need to identify these patients, and integrate an early palliative approach according to their individual needs in all settings, as suggested by the World Health Organization (WHO).

Several tools have recently been developed in different European regions to identify patients with chronic conditions who might benefit from palliative care. Similarly, several models of integrated palliative care have been developed, some with a public health approach to promote access to all in need.

We describe the characteristics of these initiatives, and suggest how to develop a comprehensive and integrated palliative approach in primary and hospital care, and to design public health and community-oriented practices to assess and respond to the needs in the whole population. Additionally, we report ethical challenges and prognostic issues raised, and emphasize the need for research to test the various tools and models to generate evidence about the benefits of these approaches to patients, their families and to the health system.

Key words: Palliative approach, Palliative care, Public Health Planning, Chronic Care, Comprehensive Care, Integrated Care

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BACKGROUND

Changes in the global needs

In many countries, we face an increasing prevalence of chronic conditions. It is estimated that 69 to 82% of persons who die in high income countries would benefit from palliative care(1), and there is a high prevalence of persons with advanced chronic conditions and limited life prognosis(2). The current response to these challenges is largely specialized palliative care, started at a very late stage of the illness, and designed to meet the needs of people with cancer. There is little integration between primary and secondary care, and lack of training in communication and advance care planning skills for healthcare professionals. Most potential beneficiaries are still not identified for either a generalist or specialist care in all European countries due to the lack of a systematic approach to do so. Although early specialist palliative care has shown benefits to quality of life(3), the processes and outcomes of generalist palliative care are harder to evaluate due to the variety of models integrated in different national health systems.

Innovative concepts

Conceptual research around multi-dimensional illness trajectories of decline and clinical aspects of gradually transitioning from curative to palliative care have also been progressively described in the last decade(4-6). Several organizational and policy frameworks have been developed to respond to these challenges, proposing the integration of the palliative approach for patients with all advanced conditions, in all settings, with changes in the model of care and organization, and adopting Public Health and Population-based policies in all settings(7).

Tools to timely identify persons with palliative care needs

One of the most important barriers for integrated early palliative care is the lack of validated and practical tools to identify patients in need. Recently, several tools have been developed to identify persons with palliative care needs in the population or in specific settings or conditions. Based on the initial experience of the Gold Standards Framework Prognostic Indicator Guidance(8), similar initiatives have combined the so called “surprise question” with several parameters(9,10). There are tools devoted to the identification of persons with specific conditions(11-13), or settings(14,15). Two recent systematic review of tools for identification are available(9,10), but no recent review of the assessment and planning which follows this in different countries exists.

Current experiences of integrated palliative care in Europe

As well as the development of tools to trigger a palliative care approach, there are initiatives to improve the quality of care of patients with all types of advanced chronic conditions in all

settings of care. Such initiatives propose that the doctor (eg, General Practitioner, GP or hospital specialist) starts to gradually introduce a palliative care approach, combining it with the other existing therapies, to improve quality of life and promote adjustment to progressive disease(16-22). The comprehensive and person-centred palliative approach include as main actions a multidimensional needs assessment, followed by the identification of values and preferences and then an advance care planning process. The establishment of an integrated, preventive and continued process of care communicated across all settings is the aim.

The EAPC Task Force

The EAPC Task Force in Primary Palliative Care(23) was set up in 2012 to identify the challenges and promote actions for developing community palliative care in Europe, based on the experience of the International Primary Palliative Care Network(24). The main outcomes included identifying the different initiatives in Europe, and the construction of the EAPC primary care toolkit by a large team of national leaders in this field(25). This EAPC Taskforce is in the process of being transformed into the *EAPC reference group for primary palliative care*, and to include representatives from other settings and a wider social perspective. This review has been elaborated in this context of cooperation.

The WHO WHA67.19 Resolution and the WHO Palliative Care Initiative

After several individual initiatives, the WHO adopted the WHA67.19 Resolution “Strengthening of palliative care as a component of comprehensive care throughout the life course” in 2014(26). This resolution emphasizes the need for Palliative care to be an essential component of public health policies and have universal coverage, with a global, population based and community oriented perspective, in the context of person-centred and integrated systems of care. A global Palliative Care WHO initiative has been designed, including the implementation of specific medical officers, the creation of an internal palliative care group, an experts’ advisory group, proposals of tools and manuals to support the implementation, proposals to develop WHO demonstration projects, and a strategic implementation plan(27).

AIMS OF THIS ARTICLE

This article seeks to describe the status of leading European initiatives in palliative care focused on primary care and the community, to compare the different processes of identifying, assessing and planning, and to propose recommendations to improve the quality of comprehensive and integrated palliative care approach for all patients, in all care settings (see Box).

METHODS

Data came from the authors' experiences in different countries collected by a structured survey, in the context of developing the EAPC Task Force for primary palliative care. This compared different national programmes in 24 European countries.

The recommendations have been built by consensus and are structured in three levels: Actions for the comprehensive care of individual patients in need; proposals for an integrated palliative care approach in health and social care services, and actions for establishing a national/regional policy for a comprehensive and integrated palliative care approach.

RESULTS AND DISCUSSION

Different tools are currently used for identifying patients in need, and also as a screening method to establish the prevalence of people in need of palliative care in services(28). In table 1, we describe the main characteristics, similarities and specific aspects of six European initiatives, including barriers and challenges. Although the identification tools are remarkably similar, there are differences in the scope of these approaches, ranging from a global regional department of health program to screening of patients in individual general practices.

Proposals for the comprehensive and integrated Care of identified persons

The general aims of palliative care are improving the quality of life of patients and families and their adjustment to progressive disease, and to improve the effectiveness and efficiency of care and patient-centred outcomes. A systematic approach is recommended (table 2). This approach must be proposed as more rather than less care, gradually introducing a palliative approach combined with the existing disease-focused therapeutic actions, with the active participation of patients, family and team(s) in shared decision making.

Proposals for improving a palliative approach in services

The general aim consists of improvements of the quality and integration of palliative care in all care settings with a population-based and community oriented perspective (table 3). This is achieved by introducing the palliative approach in chronic care as a major priority, and addressing the educational (training professionals), organizational (adapting to needs and demands), and ethical challenges (promoting benefits for patients).

It is highly recommended that all team members / disciplines are involved in the design and implementation of policies with special emphasis in addressing the clinical and ethical issues of early identification.

Prognostic issues

The main aim of the existing tools and identification processes is to identify persons who might benefit from a palliative care approach in all settings, rather than identifying patients who are likely to die within 12 months. Among diverse parameters(39), the surprise question(40) and most of the individual parameters used in the existing tools, such as advanced frailty(41), functional decline(42), nutritional decline(43), cognitive decline(44), geriatric syndromes(45), multi-morbidity(46), and resource use of acute beds or emergency admissions(47), have shown prognostic implications as tools used in specific diseases(40, 48, 49) or settings(50). In a recent analysis of a cohort of patients identified in the population with the NECPAL tool, and in cancer patients identified with the GSF(51), mortality risks were found associated with the surprise question or other parameters, especially in patients with organ failure. These data suggest that a combination of some of the parameters might be useful for policy-makers in estimating demands for specific services. Further research will define the prognostic value of tools and their components which would be helpful to health service planners.

Ethical issues

Early identification of people with palliative care needs and limited life expectancy has raised some ethical issues in their implementation and there is a need to balance benefits with risks, and to identify barriers and challenges to more systematic implementation of screening(52). In this regard, a thorough process of evaluation(38) has to be carried out during the implementation of this crucial component of integrated palliative care programs, in order to better understand the full implications and impact of generalized early identification(53).

The global benefits of integrating the palliative care approach for all patients in all settings are evident in terms of coverage, equity, and universal access to palliative care as basic principles of a comprehensive and integrated public health approach. There are many benefits for individual patients in gradually introducing an active palliative approach focused on quality of life, including a multidimensional assessment, a review of the state of underlying conditions and treatment options, and starting advance care planning and a case management process. With a shared therapeutic and care plan, there is a clear opportunity to improve the intensity and the quality of care focused on quality of life. From the health care professional's perspective, it helps them to identify patients with specific needs and start an interdisciplinary systematic approach of care. In services with high percentages of patients with advanced chronic conditions, to determine the prevalence and screen the patients in need is a first measure for improving the quality of care and needs to be followed by a set of actions to adapt the organization to these needs with education and training (in methodology issues, clinical care and advance care planning/ethics, communication, and organizational changes to promote accessibility and quality).

Some barriers are related to the lack of training of professionals to identify and start a palliative comprehensive approach: lack of resources to respond to needs, resistances to change the organization of services, and misunderstandings (for example confounding complex, advanced and terminal situations) due to lack of information about the process.

The most important risks are the stigmatization of identified patients, care delivery based on professionals or services without the adequate skills and links to specialized services, the loss of curative opportunities due to death considered inevitable, a lack of participation of patients in the decisions, misuse of the shared information, or the inadequate use of this information to reduce futile and costly treatments.

Based on these statements, we propose some recommendations to consider in implementing such programs. These include outlining the benefits and minimizing the risks, to promote the start of a comprehensive assessment, advance care planning and case management processes, and accompanying the implementation with an active and accessible training in the key components for all professionals, involving the existing palliative care services, other healthcare services, ethical committees and patients.

Establish Public Health Policies

The main purpose of public health policies is to introduce the palliative approach early in chronic care as a priority for all services, in alignment with WHO Resolution, with a person-centred public health and a population-based approach (universal coverage, comprehensive and integrated care, equity, access, quality), with a community perspective.

Actions for establishing a national/regional policy for comprehensive and integrated palliative approach include:

- To establish a formal national or regional policy with participation of patients and all stakeholders (professionals, managers, policymakers, funders)
- To determine (or estimate) the population and setting-specific mortality and prevalence and needs assessment and define target patients
- To elaborate, agree and validate an adapted tool for the identification of these patients in services and to establish protocols to assure good comprehensive person-centred care for the identified patients
- To identify the specific training needs of professionals and insert palliative care training in all settings
- To promote organisational changes in primary care, palliative care specialised, conventional services and integrated care across all settings in districts
- To identify and address the specific ethical challenges

- To establish and monitor indicators and standards of care and implementation plans and generate research evidence

Key Lessons learnt

Identification, assessment and care planning can be practised in most services with specific tools. This should be accompanied by a systematic program addressing the educational, organizational, and ethical challenges and must involve all settings with the participation of professionals, patients and families. The key role of specialized Palliative Care services to be a resource to support care by other professionals and services must be better emphasised and developed, and these specialists need special training in how to train generalists to identify patients for a palliative care approach. Public Health policies with community and hospital perspectives are the frame to develop these initiatives systematically, and should emphasise the strategic training and supporting role of the specialist rather than the delivery of services by the specialist.

CONCLUSIONS AND RECOMMENDATIONS

Due to the increasing needs of people with complex and advanced chronic conditions, the palliative care approach must be a priority for health and social services and public health policies. There are several tools to support timely identification of people with palliative care needs in all care settings, with a community and primary care perspective. These can be used during individual consultations or to identify patients from their electronic medical records(54), and are feasible in all settings. The utility of such tools is that they serve as a screening approach in the general population or in specific settings, to check for unmet needs, to identify people who could benefit from an active palliative care approach.

Good care for people with advanced illnesses is based on a person-centred, multidimensional (physical, emotional, social, spiritual) and respectful care practised by a competent interdisciplinary team. This includes a multidimensional assessment, the identification of values and preferences, starting an advance care planning process, and a systematic preventive and integrated model of care.

For a safe and quality service, the identification of these persons must be accompanied by a process of building the capacity of the professionals to respond to these needs with skills in the main related issues (communication, advance care planning, symptom control, case management) and changing their organization to look after the persons in need, through establishing formal policies that include the determination of their prevalence and increasing

the team approach, accessibility, continuing care, and the coordination with other services involved in the area.

The role of specialized Palliative Care Services needs to be updated and emphasized as referents for training and support, and caring only for particularly complex cases. Flexible, cooperative and partnership models are recommended. In districts, there is a need to assure integrated care across all settings, with special attention to continuity of care, transitions between services, and definition of the diverse roles of all services involved.

All these changes must be part of a national/regional policy for comprehensive and integrated palliative care, with population based and community oriented principles, empowering primary care and other related services to provide generalist palliative care before referral to specialized services. There is an urgent need for research to obtain evidence about the benefits of this new early and generalist approach in improving the quality of life of patients, their perceived experience of the quality of care, and the efficiency of the care system.

Strengths and limits of this paper

This paper integrates national research from many countries in Europe, and highlights similarities and differences, and lessons from these research and development studies. It is timely with lessons for countries in Europe and worldwide in how to best integrate palliative care in all settings. This paper is based on the experiences and cooperation between leading European authors. The data was generated by a structured survey and a series of meetings to build a consensus among authors based on current best practice with its supporting evidence.

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TABLES

Box: Key points of this article

TABLE 1: Characteristics of procedures and implementation processes in countries

TABLE 2: Ten Actions for comprehensive care of the identified patients in services

TABLE 3: Ten Actions for integrated palliative care approach in health and social care services

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TABLES

BOX: Key points of this article

| |
|---|
| <ul style="list-style-type: none"> • What is already known |
| <ul style="list-style-type: none"> - Several tools have been developed and validated to identify persons with palliative care needs and limited life expectancy - Several initiatives have been implemented to deliver a palliative care approach in different care settings, but these innovations have not yet been compared |
| <ul style="list-style-type: none"> • What this paper adds |
| <ul style="list-style-type: none"> - An update of the current status and similarities between existing tools and national initiatives - Proposal of tools with utility in screening at population, service and patient level in order to, listing the needs by dimensions, identifying people with palliative needs to start approach - Agreed recommendations for key aspects of the design and implementation of programmes of a palliative approach at the individual, services, district and regional/national levels - Addressing the need of ethical considerations |
| <ul style="list-style-type: none"> • Implications for policy |
| <ul style="list-style-type: none"> - An integrated timely palliative approach for persons with all types of chronic conditions in all settings of care must be designed and implemented by a systematic program including specific tools, and addressing the clinical, educational, organisational, and ethical challenges - Existing Palliative Care Programs need to be updated with the introduction of timely palliative approach for all patients in need - Palliative care is a global Public Health issue and population based / community oriented policies are needed to make it accessible to all people in need |

TABLE 1: Characteristics of implementation processes

| | <i>Dimension</i> | <i>Catalonia, Spain</i> | <i>Scotland, UK</i> | <i>England, UK</i> | <i>Nijmegen, Netherlands</i> | <i>France</i> | <i>Belgium</i> |
|---|----------------------------------|--|---|---|---|--|--|
| <i>General aspects</i> | <i>Scope</i> | Formal Program at the Department of Health inserted in the Chronic Care Program. It includes clinical, epidemiological and services research and education and training on advanced chronic care and advance care planning | Supportive and Palliative Care Indicators Tool (SPICT) developed by literature review and experts consensus offered to General practitioners and more hospital doctors | Gold Standards Framework (GSF) is now a comprehensive training program for a range of settings which includes training, tools, measures and support leading to formal quality assurance | Tool to help GPs to identify patients with cancer, chronic obstructive pulmonary disease (COPD) or congestive heart failure (CHF) in need of palliative care | Pilot project in a Multi-professional Primary Healthcare Centre (MPHC), supported by the Regional Health Authority (SCoP3) (19) | A Care Pathway for Primary Palliative Care (CPPPC) has been developed (<i>Pro-Spinoza</i>)(18) |
| | <i>Tool</i> | NECPAL CCOMS-ICO (7,29) | SPICT (17,30) | GSF PIG (8) | RADPAC (16) | SQ + SPICT_FR (31) | SQ + SPICT |
| <i>Main results Quantitative & Qualitative approach</i> | <i>Main results</i> | Up to 130,000 persons identified mostly in primary care services. Development of implications for public health and geriatrics Qualitative assessment currently ongoing | Various research studies providing evidence base. Most patients in Scotland now die with anticipatory care in place, supported by a Key Information Summary. | Up to 80% patients on primary care: 70% with advance care planning (ACP) halving hospital deaths. In hospitals: 85% ACP, Reduction length stay, more discharged home Less hospital use | Used in a randomised controlled trial (RCT) Despite a negative result in a RCT, the post-hoc analysis indicates that this has the potential to improve the quality of palliative care | No results at the present moment. A mixed-methods research and a RCT are ongoing (funded by the French Ministry of Health) | Care plan defined: Identification of palliative care needs. A quasi-experimental study of the implementation of the CPPPC is currently recruiting GPs and patients, motivating participants to apply |
| | <i>Difficulties and barriers</i> | <ul style="list-style-type: none"> - Lack of training - Ethical debate on benefits/risks - Low implementation in Hospitals | <ul style="list-style-type: none"> - Time, identifying the trigger - Lack of training and confidence | Cultural barriers e.g. reframing from dying to active supportive care especially in hospitals, time to plan, some staff issues | Communicating the 'marking moment' still difficult regarding organ failure Indicators that are quite 'terminal' | Lack of time and training to initiate ACP Fear of destroying hope / "loss of chance" | Taboo of palliative care GPs lack time Many single-handed practices. Poor linkages with other services |
| | <i>Proposals</i> | The ACP training program General training program District-based care pathways Registry must be accompanied by proposal of therapeutic plan Ethical issues must be addressed | <ul style="list-style-type: none"> - Trials of use to identify primary care patients for anticipatory care - Hospital trials in different wards - Use in many countries where developed spict.org.uk | <ul style="list-style-type: none"> - Impact of the full approach /GSF program better than just use of the tool - The concept of early recognition and proactive planning matters more | <ul style="list-style-type: none"> - Intensive training in communication skills - Including secondary care to identify patients during unplanned hospitalizations | Use experiential and active learning methods Form agreements between primary and secondary care Involve volunteers Anticipate and coordinate across settings. | Stimulate quality improvement Whole system approach to foster the development of long-term improvement plans shared by all stakeholders of given health care regions (32) |

TABLE 2: Ten Actions for comprehensive care of the identified patients in services

| Action | Method | Comment/terms |
|--|---|---|
| 1. Multidimensional assessment | Use validated tools | <ul style="list-style-type: none"> - Suffering/wellbeing/adjustment - Psychosocial and Functional - Assessment of caregivers burden, needs, and demands |
| 2. Explore worries, fears, values and preferences of patients and families | Start: Advance care planning <ul style="list-style-type: none"> - Shared decision making - Start discussion about the future | <ul style="list-style-type: none"> - Explore the emotional experience of the patient (and its evolution in time)(33) - Consider the illness narratives and life stories told by the patient (34) |
| 3. Review state of diseases and conditions | Review Disease: <ul style="list-style-type: none"> - Stage and Prognosis - Aims and Recommendations to prevent or respond to crisis or possible complications | <ul style="list-style-type: none"> - Do not forget non-specific items and general indicators of functional decline in frail elderly (35) - Given that end of life is a trajectory (dynamic) and not a situation (static), consider the temporal evolution of these general indicators - Identify the current Palliative Care Phase(36) |
| 4. Review treatment | <ul style="list-style-type: none"> - Update aims - Adequacy - De-prescribing, if needed | <ul style="list-style-type: none"> - Discussing goals of care (short-/mid-/long- term) with the patients may be a good opportunity to initiate anticipatory care planning |
| 5. Identify and support family carer | <ul style="list-style-type: none"> - Assessment - Education and support | Promote: Capacity of care, adjustment and prevention of complex bereavement |
| 6. Involve the team | Joint: <ul style="list-style-type: none"> - Assessment - Plan | <ul style="list-style-type: none"> - Define role in conventional follow up, shared care, emergencies, and continuing care - Define referent professional (s) |
| 7. Define, agree and start a Comprehensive Multidimensional Therapeutic Plan | <ul style="list-style-type: none"> - Respecting patients' preferences - Addressing all the needs identified - Use the square of care model - Involving all team(s) | Including: <ul style="list-style-type: none"> - Needs assessment - Aims - Decisions |
| 8. Organize care with all services involved, including the specialized Palliative Care Services | <ul style="list-style-type: none"> - Case management - Shared care and decision making - Therapeutic pathways across settings - Look at care and setting transitions - Therapeutic Conciliation between services | <ul style="list-style-type: none"> - Contact Palliative Care services for care of complex needs - Encourage continuing collaboration between services and develop partnership agreements - Involve patients and family carers patients when designing programs |
| 9. Register and share key information with all involved services | <ul style="list-style-type: none"> - In clinical charts - In shared information - In anticipatory care planning booklet - In reports of multi-disciplinary team meetings | <ul style="list-style-type: none"> - State of diseases, symptoms, emotional adjustment, family support - Patients' priorities and preferences (goals of care,) - Possible crisis (Out of hours handover forms, anticipatory prescribing) - Decisions made (e.g. referral to specialist palliative care service, treatment withdrawal / withholding) - Recommendations for care in all settings - Record, communicate and coordinate the care plan across all settings |
| 10. Evaluate / monitor outcomes | <ul style="list-style-type: none"> - Frequent review and update - After death, clinical audit | <ul style="list-style-type: none"> - Consider NICE quality standard(37) - Design research and generate evidence |

TABLE 3: Ten actions for integrated palliative care approach in health and social care services

| Action | Methods |
|--|--|
| 1. Establish and document a formal policy for palliative approach | <ul style="list-style-type: none"> - Evidence-based - Involve patients in the design and implementation of the policy |
| 2. Determine the prevalence and identify patients in need | <ul style="list-style-type: none"> - Stratify the population at need/risk (Complex and Advanced chronic patients) |
| 3. Establish protocols, registers, and tools to assess patients' needs and respond to most common situations | <ul style="list-style-type: none"> - Evidence-based |
| 4. Train professionals and insert palliative care training and review in the conventional training process (sessions, etc.) | <ul style="list-style-type: none"> - Basic and intermediate level - Carry out process evaluation during programme's implementation(38) |
| 5. Identify the primary carers of patients and give support and care, including bereavement | <ul style="list-style-type: none"> - Validated tools - Assess needs and demands - Increase access - Give education and support - Plan bereavement |
| 6. Increase team approach | <ul style="list-style-type: none"> - Joint Interdisciplinary approach |
| 7. In services with high prevalence: devote specific times and professionals with Advanced training to take care of palliative care patients (Basic Palliative Care) | <ul style="list-style-type: none"> - Trained referent professionals - Specific times in outpatients - Specific devoted areas in inpatients |
| 8. Increase the offer and intensity of care for identified persons focused in quality of life | <ul style="list-style-type: none"> - Improve access and equity in the provision of palliative care - Increase offer of home care (if, primary care services) - Plan follow up and continuity of care - Prevent and respond to crisis, plan emergency care |
| 9. Integrated care: Establish links, joint information system, criteria intervention and access to Palliative Care Specialized services and all services in the area | <ul style="list-style-type: none"> - Establish sectorized policies - Establish and/or update the role of Palliative Care specialized services - Establish partnerships between services - Define clinical care pathways - Clinical information available for all settings |
| 10. Address the ethical challenges of early identification and involve society | <ul style="list-style-type: none"> - Promote benefits (Shared decision-making, ACP, improved intensity and quality of care, palliative approach) and reduce risks (stigma, loss of curative opportunities, reduction in care) |