Building systems to address functional decline and dependence in ageing populations

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A Framework for guidance on End-of-life Care

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Background paper

Background, problems

Palliative Care is defined as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (Sepulveda et al. 2002).

Palliative care has demonstrated that it improves quality of life, provides comfort for patients and care givers and even may reduce costs of end-of-life care. Modern palliative care started forty years ago in the UK, and has become an international success story in the last decades, moving from isolated pioneers and specialist centres to full integration in mainstream health care in some European countries.

Palliative care is not only useful for patients with cancer (who find access to palliative care more easily in developed countries) or patients with HIV/AIDS (who receive palliative care in many resource-poor countries as part of the antiretroviral treatment strategy). It may also be beneficial for patients with neurological diseases (motorneuron disease, multiple sclerosis, Parkinson's disease or stroke), patients with chronic heart, lung or renal failure and, more important, also multimorbid elderly patients, patients living in nursing homes and patients with dementia.

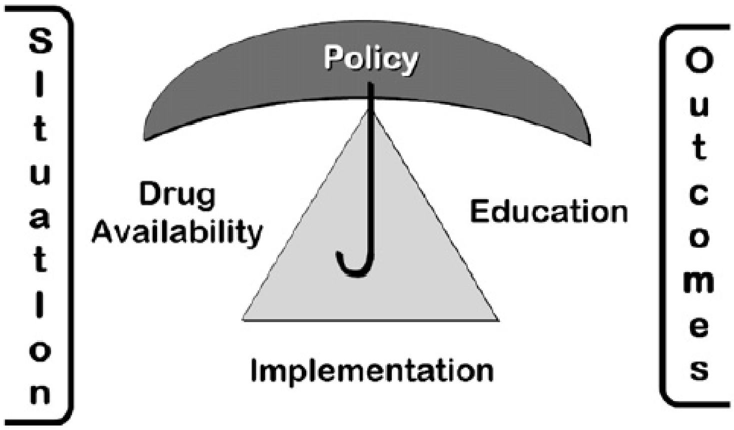
For all these groups, patients may suffer and may experience reduced quality of life from two problem areas: a) symptoms such as pain, dyspnea or confusion are frequent either due to the underlying disease, comorbidities or treatment interventions, and b) functional decline is experienced as a loss of social function and as a loss of control, which again impedes the patients sense of coherence (Antonovsky und Sagy 1986), their feeling of autonomy and (extrinsic) dignity (Chochinov et al. 2002). Palliative care offers symptom control options to alleviate suffering from symptoms. It also includes continuous empathic communication with patients and care givers and shared determination of treatment goals in order to conserve dignity and autonomy to the best possible degree (Parliamentary Assembly of the Council of Europe 2009).

Palliative care uses a two-tier approach,with a general and a specialist level of palliative care (Radbruch et al. 2009). The general level is delivered by primary care givers such as family physicians, nursing home physicians (where available) or nursing services. These primary care givers should have adequate palliative care training. They should be backed up and supported by specialist services such as mobile teams, palliative care units or inpatient hospices. Specialist services provide the training and counsel the primary care givers, and they can provide specialist care for complex cases.

The Parliamentary Assembly of the Council of Europe noted in 2009 that palliative care is a substantial and socially innovative addition to curative, highly scientific medicine, where the subjective well-being of the patient comes after the goal of curing an illness (Parliamentary Assembly of the Council of Europe 2009). The Assembly "regards palliative care as a model for innovative health and social policies, as it takes account of the changes in our perceptions of health and illness and does not assume that curing diseases is the precondition for self-determination and participation in society."

Guidance for palliative care has been prepared by the World Health Organization (World Health Organization 1990), by the Council of Europe (Council of Europe 2003) and by national government agencies (for example (Department of Health 2008).

The World Health Organization has produced a framework on the development of palliative care with: education, access to opioids and implementation forming the three sides of a triangle and policy as an overall umbrella (Stjernsward et al. 2007). More recently, the Latinamerican Association for Palliative Care has produced a set of 10 indicators related to this framework to monitor the development and implementation of palliative care in different countries and regions of the world (De Lima et al. 2013).



Open Questions

However, with the growth of palliative care a number of open questions are emerging. Palliative care is taken up in an increasing number of medical fields and settings, and the broadened scope leads to a diffusion of the terminology and underlying philosophy of palliative care (Radbruch et al. 2009). For example, the England and Wales national strategy refers to end-of-life care, as palliative care may be understood to be for cancer patients only. In other settings palliative care merges with supportive care in an attempt to gain support from oncologists.

The palliative care definition cited above is more than 10 years old and is criticized increasingly, indicating a need for revision.

Whereas the European Association for Palliative Care (EAPC) maintains that euthanasia should not be part of palliative care (Materstvedt et al. 2003) this has been challenged by Belgian palliative care specialists (Bernheim et al. 2008).

In addition to the debates on core values, palliative care guidelines often focus on specific diseases or settings, for example the EAPC guidelines focus on cancer pain and on opioid treatment (Caraceni et al. 2012). The WHO has produced a scoping document for pharmacological treatment of persisting pain in adults with medical illnesses, but only the WHO pain guidelines for children have been released until now..

New palliative care guidelines are often developed at national level only (for example in Germany and UK). This leads to redundancies in effort in European countries. Palliative care guidelines often fail to find broad consensus, as the interests of the stake holders may be too divergent, for example between oncologists and palliative care specialists in the treatment of cancer cachexia.

Need for coordinated action

Coordinated action should be initiated in order to bring together a broad number of different activities in palliative care guidance development, resulting in a larger framework for guidance, which can be used as a toolkit by the different stakeholders.

Such coordinated action will also identify gaps in the ongoing guideline work and stimulate researchers and other stakeholders to fill these gaps. It will also stimulate a new discourse on the core values of palliative care. The collaboration will result in reduced redundancies, thus setting free resources that can be used more effectively elsewhere.

Options for innovative research are needed to produce new knowledge on optimal care during functional decline, which will result in fundamental advances in the field by stimulating collaboration between medical fields such as basic and clinical research, and associated disciplines.

This would then have an additional major impact on the development of clinical care for severely ill and dying patients throughout Europe and beyond, because the framework developed in the project will provide guidance for decision makers on how to improve palliative care in their area of influence.

The impact from such coordinated action would ranges far beyond the meetings and publications produced by the individual action steps. Fostering collaboration between different fields of researchers and clinicians, as well as between primary care givers and specialists will advance the field, produce innovative models of care and support the recently initiated drive for access to adequate palliative care as a human right (Radbruch et al. 2013).

Recommended action steps

Proposed action steps include the revision of the definition of palliative care, which will also provide a platform for discussion of the philosophy and the underlying values.

Ongoing guideline development and guidance work on palliative care should be brought together and coordinated.

Collaboration with experts from related fields such as basic research should be initiated in a structured exchange.

A framework for guidance in palliative care should be constructed, which should be aligned with major stakeholders such as the World Health Organization and the international professional associations.

This would require a series of meetings and consensus procedures on specific items of the agenda (for example on the revision of the definition of palliative care), a series of scientific papers and guidelines, the framework constructed from these publications and an active website presenting a toolkit of guidelines and other instruments related to the framework.

This should include definition of the field as well as expanding existing clinical guidelines on pain and symptom management and essential practices. In addition, a collaboration platform for exchange with other fields of research should be established, offering innovative research opportunities from new collaborations between basic and clinical researchers, legal experts, social scientists and biomedical researchers as well as between geriatric, oncology, nursing care and palliative care specialists. Specific actions steps should also address more specific areas of palliative care, in order to provide a basis for concrete improvement. This should for example based on work done in the ATOME project (Access to Opioid Mediciations in Europe) funded in the 7th Framework programme of the European Commission. Methods for evaluation of national and European legislation and policies on access to controlled medicines as well as access to palliative care will be described and developed where not available.

A description of the role of different professional and volunteer care givers in the provision of care at the end of life should also be part of the programme. Volunteers are a major social force supporting the hospice and palliative care activities and may well be the major drive in the ongoing development. However, there is a broad scope of roles and tasks for volunteers in the different European countries, and research in this area would benefit greatly from exchange and coordination.

The coordinated action should include patients, care givers and volunteer workers in an advisory role, and where possible also as participants in the activities. Ideally this should lead to patient and care giver driven research proposals built on the specific perspectives of these groups. This will be a major innovation in international collaborative palliative care research.

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