

Palliative Care and Dementia



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with dementia should be improved, for example, through education of professionals so that the care addresses the specific needs of the patients and the families (4,5,6).

What is Palliative Care in Dementia? A Framework.

Until recently, it was unclear what palliative care in dementia exactly entails, and general guidance for practice and research around the globe were lacking. Therefore, the European Association for Palliative Care (EAPC) developed a framework, i.e., a definition of palliative care in dementia in terms of eleven domains which are listed and briefly explained in Box 1 (7). For each domain, specific recommendations are provided for optimal care, totalling 57 recommendations. Official EAPC translations include a translation in Arabic of the domains and recommendations (Annex 1).

Box 1. Framework defining palliative care in dementia resumed in eleven domains in sum:

Domain 1. Applicability of palliative care

Palliative care in dementia is based on recognizing dementia as a terminal condition. It aims at improving quality of life, with maintaining function and maximizing of comfort being main treatment goals. Specialist palliative care is not always needed. A baseline palliative approach, however, is inclusive: it may start at diagnosis, and refer to treatment of symptoms and other health problems.

Domain 2. Person-centred care, communication, and shared decision making

Patient and family needs and preferences are central to palliative care, and the providing of information and shared decision making process should reflect this.

Domain 3. Setting care goals and advance planning

Advance care planning pro-actively sets care goals to guide treatment that meets the patient's and family's preferences. The process ideally starts soon after diagnosis, when the patient, with help, may still be

involved, and it needs revisiting over time.

Domain 4. Continuity of care

Continuous care by all disciplines and through transfer is facilitated by appointing a central coordinator.

Domain 5. Prognostication and timely recognition of dying

Discussing the terminal nature of the disease may help prepare for the future. Mortality prediction is difficult but the best predictions combine clinical judgement and prognostic tools.

Domain 6. Avoiding overly aggressive, burdensome, or futile treatment

Hospital transfer, medication for chronic conditions, and antibiotics should be considered prudently in relation to care goals. Permanent enteral tube nutrition and restraints should be avoided as a rule, and in the dying phase, this also refers to artificial hydration.

Domain 7. Optimal treatment of symptoms and providing comfort

Symptoms may be interrelated, and its assessment and treatment helped by a holistic approach, integrating views of more caregivers, the use of assessment tools, and the combining of non-pharmacological and pharmacological treatment. Nursing care is very important in the dying phase, and specialist palliative care and dementia care may be needed for specific symptoms.

Domain 8. Psychosocial and spiritual support

Needs for specific psychosocial and spiritual support may vary throughout the disease course, for example with patient's awareness of the condition and when the patient is dying. Spiritual care should not be neglected and even in severe dementia religious activities may be recognized and helpful.

Domain 9. Family care and involvement

Families need education for their changing roles and support, especially so at moments when they likely experience feelings of loss (for example, at diagnosis, with patient's decline and problems, with institutionalization, and near and after death).

Domain 10. Education of the health care team

The full health care team needs to have adequate skills in applying a palliative care approach, and core competencies should include the domains above.

Domain 11. Societal and ethical issues

Patients with dementia should have access to

palliative care, families need support in the caring for the patient, professional caregivers should be educated and motivated to care for patients with dementia, and the public's awareness should be increased. Incentives should encourage excellent end-of-life care, and collaboration between palliative and dementia care should be encouraged, also through linking of national strategies. (7)

The domains and recommendations were developed as part of a Delphi study with 64 experts from 23 countries, including 9 experts from the Middle and Far East. The basis is expert consensus and evidence, as where available, evidence from the literature was used to back up the recommendations. The evidence is provided in explanatory text with each recommendation (available in English). The experts found the most important domains to be: "Optimal treatment of symptoms and providing comfort" (domain 7), and "Person-centered care, communication and shared decision-making" (domain 2). The domain of "Societal and ethical issues" focusses on policy and recommends integration of palliative care and dementia care services (recommendations 11.3 and 11.8).



Introduction

Palliative care may have benefits not only for patients with cancer, but also for older people with chronic-progressive diseases, such as dementia or organ failure (1). Dementia is a disease that causes severe impairment in memory, cognition, and behaviour, which subsequently leads to disability and increased dependency. Globally, over 35.6 million people live with dementia with the majority being older adults. The numbers will increase rapidly. The prevalence of dementia is projected to almost double in Europe between 2010-2050, but it will more than triple in Asia and Africa (2,3). Dementia not only affects the patients, but also has negative repercussions for patients' families and healthcare providers who may struggle with providing appropriate care (2). Multiple barriers to end-of-life care delivery in older adults with dementia have been reported, including inappropriate care related to dementia not being viewed as a terminal illness, difficulties in the communication with the patient and family about care preferences, and inappropriate assessment and management of symptoms including pain (4,5). The delivery of palliative care for people

Palliative Care & Elderly People in Lebanon

In Lebanon, as elsewhere, older adults are the fastest growing segment of the population. Today, just under 10% of the population is above the age of 65 years; by 2030, this number is expected to increase to 12%, and will approach 18% by 2050 (8). With longevity comes chronic disease, prolonged dying trajectories, and increased resource utilization, and Lebanon is currently ill-prepared to handle either. In Lebanon, the increase in the number of older adults is unmatched by any increase in the services provided to them; this raises serious public health concerns. Major strides have been made in the last few years to develop the field of palliative care and make it an integral part of the health care delivery system in Lebanon. The national committee on pain relief and PC has made a number of recommendations in the domains of education, practice, research, and public policy (Box 2) (9)

Box 2: Summary of Recommendations on PC in Lebanon

- Training of all health care professionals in palliative care (PC) at the undergraduate and graduate levels.
- Palliative care content should be included in nursing and medical curricula.
- Creation of continuing education programs in PC.
- Provision of specialist training in PC for physicians and nurses.
- Standards and multidisciplinary clinical practice guidelines should be developed to guide PC practice.
- Coordination of care and rapid-access to PC services.
- Integration of PC services in the health care delivery systems.
- PC research priorities need to be developed and funding mechanisms for research established.
- Revision of legislation governing the delivery of opioid analgesics.
- Development of a model to fund PC services.
- Launching of public awareness campaigns to raise the profile of palliative and end-of-life care in the country. (9)

All the recommendations in Box 2 will have significant implications for the provision of palliative care services for older adults. Additionally, high quality research is still needed in palliative care for older adults in Lebanon

including research on palliative care in dementia. It is hoped that the Arabic translation of the important domains and specific recommendations of the EAPC white paper on palliative care in dementia (7) will provide a helpful framework for research and practice of palliative care in dementia in Lebanon.

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