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Short Version

Palliative care in Germany

Perspectives for practice and research

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When compared with other countries, Germany's provision of palliative care still leaves much to be desired; sustained commitment towards research in palliative care would be an important step towards addressing such shortcomings.

The aim of palliative care is to achieve or maintain the best possible quality of life for patients, their families and relatives in the face of life-threatening, incurable conditions. 'Palliative care' is used here as a generic term for any activities involving such individuals. The prevention and relief of suffering are key priorities. A prerequisite of this is the early recognition and accurate recording of all impairments, symptoms and areas of conflict at all physical, mental, social and spiritual levels.

In recent years, public discussion about the topic of life and death has gained in importance. In surveys, 54 percent of respondents reported having contemplated their own mortality. Thirty-nine percent claimed that the topic of life and death was an important or very important concern for members of their immediate circle.

The most common causes of death in Germany are cardiovascular disease and cancer, which account for more than 500,000 fatalities every year. Most of these afflicted people spend their final days suffering from physical symptoms such as pain or dyspnoea, and both they and their families can also be burdened with psychosocial or spiritual problems.

Patients with other severe diseases, such as neurological disorders (Parkinson's disease, dementia, multiple sclerosis, etc.) and lung diseases, as well as frail, older patients with a range of medical conditions, also require palliative care. Children and adolescents need special care depending on their developmental stage, on the prevailing spectrum of diseases and on their family circumstances.

There is also conjecture about the efficiency of palliative care, since health care research in this area is still in its early days, and there is a substantial need for studies focused on the field of palliative medicine. This statement will make recommendations about what has to be done in the light of both the need to catch up and the perceptible additional demands the future will bring.

These recommendations take into account the irrefutable entitlement we have to the best possible quality of life, and the specific care required by critically and terminally ill patients.

The statement makes three basic recommendations for the provision of:

1. a homogeneous, comprehensive level of high-quality care throughout Germany, which – in contrast to the present situation – is accessible to all those in need;
2. a commitment by every region in Germany to meet in full the actual costs of science-based palliative care in hospitals, care facilities and the home environment;
3. a package of care, scientifically proven and available to all those in need of it in Germany. This will necessitate the ongoing development of a body of evidence supporting the provision of palliative care in Germany.

Palliative care in Germany should attain at least the same level of excellence as is achieved by global leaders in the field (such as the USA, Great Britain and Sweden). This will require a paradigm shift so that palliative care becomes a science-based discipline, and a concomitant guarantee that appropriate support will be provided for research in palliative medicine.

Ensuring care provision and healthcare research should extend beyond palliative care for cancer patients. Explicit efforts should also be made to improve palliative care in the long term for patients with other medical conditions: those with multimorbidity, dementia and disabilities, patients from all age groups and social situations, care home residents, prison inmates, or the homeless.

Thus, in addition to the recommendation that a basic knowledge of palliative care should become an integral part of initial and advanced training courses for all professional groups involved in the area of palliative care, and that a reliable regulatory framework should be established for the voluntary sector, the following individual recommendations are formulated:

Recommendations

Recommendation 1: The development of an independent national palliative strategy

The strategy should incorporate:

- the nationwide standardisation of regulatory requirements for evidence-based palliative care, in order to ensure the provision of comprehensive, high-quality care throughout Germany;
- the establishment of a research agenda for palliative care;
- the development of nationally consistent quality assurance standards in palliative care based on research results (e.g. as a national palliative register);
- the integration of palliative care into the development of the National Cancer Plan, the National Dementia Strategy, the National Health Care Guidelines, the Disease Management Programme (DMP), and care strategies for other medical conditions.

Recommendation 2: Promoting specific methods and key issues in the area of interdisciplinary palliative care research

The integration into palliative care of different disciplinary perspectives and research approaches from the life sciences, the humanities and the social sciences. The basically interdisciplinary research approach should take into account the specific conditions arising from simultaneous physical and psychosocial changes, as well as changes in spiritual attitudes at the end of life.

Intervention studies with endpoints on issues relating to palliative medicine, with the aim of ensuring that a sufficient body of evidence exists on which to base guidelines concerning patient care.

Studies on the current and future role of medical technology in maintaining the autonomy and independence of palliative patients, and on how to counterbalance to some extent the anticipated, demographically caused care deficit.

Improving palliative medicine by carrying out basic research on systemic biological changes at the end of life and where chronic medical conditions have progressed to the terminal stage.

Recommendation 3: Promoting the structures for interdisciplinary palliative health care research

Grants aimed specifically at young researchers to provide the necessary incentives to attract them to inter- or transdisciplinary projects.

The development of time-limited interdisciplinary research structures involving clinical scientists and basic researchers, as well as researchers in the fields of palliative nursing care and spiritual and psychosocial studies.

Recommendation 4: Involving patients and their families in decision-making on the drawing-up of a research agenda

The involvement of patients and their families in the development of the research agenda for palliative care is essential if their palliative care needs are to be met. Their input, where appropriate, should serve to make palliative care more responsive to the needs of the recipient.

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