

Editorial

Research on patient needs in palliative care at the end of life

Palliative care for patients who are in the last stage of their life is a relatively new focus of attention in health care. Whereas the traditional medical aims are to prevent or cure disease, it is increasingly recognized by caregivers and policymakers that care for incurably ill patients is another major responsibility of modern health care. During the last decades many efforts have been aimed at improving the care for patients for whom curing disease or postponing death is longer a realistic or desired goal.

In The Netherlands, palliative care started to become the interest of caregivers and policymakers during the early nineties of the previous century. Not in the least due to the first studies into end-of-life decision-making in Dutch medical practice [1,2], many initiatives have been undertaken to improve the quality, organization and accessibility of palliative end-of-life care. Many specialist palliative care services have been established, either within regular health care institutions, such as hospitals or nursing homes, or outside regular health care, such as most hospices and 'nearly-at-home-houses' where people can die in a home-like situation [3,4]. Furthermore, the Dutch Ministry of Health has initiated and funded six university-based Centers for Development of Palliative Care [5]. These Centers are spread over the country and promote the regional organization of and co-operation between existing and new palliative care services. The Centers also stimulate and facilitate scientific research in the field of palliative care. The current funding period of five years will be completed at the end of 2003 and it is currently foreseen that the efforts of the Centers will be continued under the authority of the regional Comprehensive Cancer Centers. Another important government initiative has been the establishment of a Taskforce to study strategies to promote the integration of hospice care into the regular health care system. The Taskforce has completed its advice in October 2001 [6]. The Minister of Health, Else Borst has stated in an official reaction that palliative care will not be a separate part of the health care organization, but there will be a network organization, supported by the regional comprehensive cancer centers, based at a general approach in the palliative care and not a specialization of care. The care will more tuned at the needs of the patients as well as the training of the health care personnel will receive more attention. Also the research in palliative care will be stimulated [7].

Advances in medical technology that increase preventive, diagnostic and therapeutic possibilities, and demographical and epidemiological developments increase the need for rational and evidence-based decision-making in health care. This also holds for care at the end of life. Therefore, much scientific research is needed on epidemiological and clinical aspects of health care at the end of life and on the cost-effectiveness of current and new initiatives. Such research has to deal with several specific problems. First of all, it is rather complex to study patients who are in the last stage of their life. Obviously, it seems most appropriate to refrain from burdening dying patients with researchers asking all kinds of difficult and sensitive questions. Nevertheless, many reports of successful empirical studies have shown that such research is quite well feasible, as long as the researchers ask sensible questions while constantly being aware of the frailty of their population [8]. Whenever terminally ill patients are unable to communicate and provide information about their situation and care needs themselves, relatives and professional caregivers may be able to provide useful information. Another important characteristic that makes research in end-of-life care difficult is its multidimensional and multidisciplinary nature. In the evaluation of interventions or services, many factors have to be taken into account: factors related to patients and their social environment, to caregivers and their education, attitudes and skills, and to the organization of care. Furthermore, guidelines to achieve well-defined aims and instruments to assess the outcome of interventions are lacking in palliative care.

In this issue of *Patient Education and Training*, Osse and colleagues [9] report about problems and care needs of patients who are in the last stage of their life. They interviewed patients with incurable cancer and their closest relatives in a two step qualitative design in order to get a comprehensive overview of the most important problems and care needs of this patient group. The results were listed on a comprehensive checklist that is meant to assist patients and their caregivers in discussing and tuning care efforts. Death and dying are not very common clinical problems for most general practitioners and are as difficult to deal with and talk about for most physicians as for other people. The first experiences with the checklist of Osse and colleagues indicate that it may be an important and promising tool in

end-of-life care. Obviously, the qualitative design of the study precludes conclusions about the incidence and relative importance of the issues encountered and further research has to be done to assess the degree to which using the checklist improves the quality of end-of-life care and, in the end, the quality of the last stage in life including the dying process.

To date, epidemiological research about the quality of life of patients who are in the last or terminal stage of their lives is scarce. Quality-of-life is widely recognized to consist of a physical, a mental, and a social dimension and many instruments are now available to assess quality of life in all its dimensions. But most of these instruments are inappropriate for research in terminal patients, mainly because these questionnaires are aimed at measuring the degree to which the quality of life of ill patients is different from the quality of life of healthy patients. To this end, questions are, for example, included about work, education, and physical activities that are often not suitable or even painful for terminal patients. Furthermore, spiritual or religious tissues and questions about the meaning of envisaging a limited life-span with a possibly deteriorating health status are lacking. Some instruments to assess the quality of the last stage in life have been developed, such as the views of informal carers—evaluation of services (VOICES) and the Toolkit of Instruments to Measure End-of-life care (TIME) [10,11]. However, to date no instrument is available to comprehensively assess patient perspectives on the quality of the last stage of his or her life including the dying process.

The need to make rational choices about how the health care budget is spent extends to palliative care at the end of life as much as to other fields of health care. The study of Osse and colleagues is therefore a timely and worthwhile contribution to the establishment of a tradition of empirically based end-of-life care.

References

- [1] Maas PJ, van der Delden JJM, van Pijnenborg L, Looman CWN. Euthanasia and other medical decisions concerning the end of life. *Lancet* 1991;338:669–74.
- [2] Maas PJ, van der Wal G, van der Haverkate I, Graaff CLM, de Kester JGC, Onwuteaka-Philipsen BD, et al. Euthanasia, physician-assisted suicide, and other medical practices involving the end of life in the Netherlands, 1990–1995. *N Engl J Med* 1996;335:1699–705.
- [3] Gordijn B, Visser A, editors. Issue in Dutch palliative care. *Patient Educ Couns* 2000;41:1–113 [special issue].
- [4] Gordijn B, Visser A. Issue in Dutch palliative care: readjusting a distorted image. *Patient Educ Couns* 2000;41:1–5.
- [5] Gordijn B, Janssens R. The prevention of euthanasia through palliative care: new developments in The Netherlands. *Patient Educ Couns* 2000;41:35–46.
- [6] Projectgroep Hospice Zorg. Verbeteringen voor de zorg voor mensen in de terminale fase en hun naasten (Improvements in the care for people in the terminal stage and their proxies). Rijswijk, 2002.
- [7] Borst-Eilers E. Standpunt op hoofdlijnen palliatieve zorg (Main policy in palliative care). Den Haag, 2002.
- [8] Groenewoud JH. End-of-life decisions in medicine: empirical studies on practices and attitudes in The Netherlands. Erasmus Medical Center, Rotterdam, 2002.
- [9] Osse et al. Problems to discuss with cancer patients in palliative care: a comprehensive approach. *Patient Educ Couns* 2002;47:195–204.
- [10] Teno JM, Clarridge B, Casey Edgman-Levitan S, Fowler J. Validation of Toolkit alter-death bereavement family member interview. *J Pain Symptom Manage* 2001;22:752–8.
- [11] Addington-Hall J, Walker L, Jones C, Karlsen S, McCarthy M. A randomised controlled trial of postal versus interviewer administration of a questionnaire measuring satisfaction with and use of services received in the year before death. *J Epidemiol Community Health* 1998;52:802–7.

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