Nursing and Palliative Care

Editorial

Reflections about palliative care for people with severe dementia

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Approaches to palliative care (PC) that were originally developed for people with cancer are now being adopted for people with dementia, as a response to many reports of poor-quality care for people with dementia at the end of life [1,2]. Currently there are no curative treatments for dementia, so as recommended by the World Health Organization, the PC should be applied from the earliest stages of chronic and fatal disease [3].

Dementia is a syndrome characterized by a progressive decline in memory and cognitive functioning, and it is recognized as a major health problem in the elderly [4]. For these patients, early access to CP improves quality of life and may even prolong life [5].

Whilst PC for cancer has long been established, PC for people with dementia is only just beginning to develop and be accepted across Europe and beyond [6]. Many of the needs in end-stage dementia are similar to those with cancer, including shortness of breath, skin breakdown, infections and constipation [7,8], but in dementia these symptoms can be experienced for a prolonged period of time. Until recent publication of the EAPC White Paper on PC in dementia [9], there was relatively little guidance on the provision of PC for this patient group [10-12].

Several studies have explored the barriers to the delivery of quality PC for people with dementia [13,14]. One barrier is that dementia is often not recognized as a 'terminal' illness requiring palliation. In addition, the course of dementia is unpredictable, making it difficult to reach an accurate prognosis. Communicating with patients and families of people with dementia requires special skills because the cognitive problems associated with dementia complicate decision making around a host of issues.

The different courses of patient deterioration warrant dementia-specific PC strategies. The EAPC White Paper recommends paying special attention to eight areas of care including communication, person-centred care and optimal treatment of symptoms and providing comfort [9].

PC for patients with advanced or terminal dementia should be improved in relation to the PC in cancer processes [15]. Such high-quality evidence is not yet available for PC in dementia, although dementia care at the end of life is increasingly being studied [16,17].

There is a need to improve palliative care provision for elderly with end-stage dementia and, in addition, more research is required on the needs of patients entering the terminal phase of dementia. By the nurses decisions about PC en advance dementia need to be made about how patients live, as well as how they die, thus balancing quality of living/comfort with disease management.

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