

Advance care planning and the relevance of a palliative care approach in dementia

With the greying of our population, the number of people with dementia is rapidly increasing and will continue to rise for the next decades to come. Although health care systems vary from one nation to another and degrees of institutionalisation differ, in most western countries a very substantial number of people with dementia (up until 70% in the Netherlands and 90% in the United States) will be admitted to a nursing home before death. Hence, the typification of this institution as ‘the waiting room for death’ [1, 2]. Unfortunately, this waiting room often lacks an appropriate ambiance as is demonstrated by many recent studies that highlight the poor level of care in nursing home settings [3–5]. In addition, in the case of acute illness, demented nursing home residents are often transferred again to acute care hospitals where they undergo burdensome and often aggressive interventions while receiving totally inadequate care for their cognitive and functional problems, with subsequent consequences such as delirium, anxiety, constipation and pressure ulcers [6, 7].

Although there is growing recognition across the globe that people with dementia are entitled to appropriate palliative care, the weighty question is why so many of them are still exposed to disproportional hospital interventions in the face of death. The reasons behind this seeming paradox are multiple, such as the lack of funding, understaffing and sociocultural (i.e. legal) factors influencing medical decision-making. Here, however, we call specific attention to the following three mutually related problems.

Firstly, dementia is often not recognised by physicians as a terminal condition. For example, in the United Kingdom as well as in the United States, patients with dementia, including nursing home residents, are much less likely to receive hospice care by comparison with patients suffering from cancer [8, 9]. Conversely, the number of nursing home residents with terminal cancer, who have advance directives limiting aggressive care (including do-not-resuscitate orders and do-not-hospitalise orders), is substantially higher than the number of residents with end-stage dementia having similar advance care arrangements [6]. This discrepancy can be explained—in part—by the fact that, in many countries, physicians have limited experience with advanced dementia and do not receive any specific training with regard to medical treatment policies in this population of vulnerable patients. Most of them only visit their nursing home patients in the case of acute medical problems. In addition, prevailing criteria for dementia severity predominantly focus on the degree of cognitive and functional disability and not on life expectancy. So ‘severe’ or ‘advanced’ dementia does not necessarily indicate that death is near, whereas,

only one of seven (14.2%) nursing home patients survives to late dementia (FAST stage 7d) [10]. Such findings, besides raising the question as to which clinical features can be held responsible for this low conversion to late dementia, demonstrate that dementia-staging criteria alone do not yield sufficient information to guide end-of-life decision-making.

Secondly, to date, scientific research into the appropriateness and possible effect of several therapeutic interventions for people with advanced dementia is still rather scarce, and findings are inconclusive. In a sense, this scarcity reflects the low priority given to clinical research into the last phase of dementia, in contrast to the large investments to improve treatments in the earlier stages of the disease. Nonetheless, there is an urgent need to identify whether interventions, such as tube feedings, antibiotics, artificial rehydration and a whole lot of psychoactive drugs, can truly contribute to the quality of life of people with advanced dementia. Evidence-based answers to these questions would help to reduce the ‘grey area of uncertainty’ between clinically appropriate and evidently futile interventions, thus allowing clinicians and health care proxies to make thoughtful decisions on quality care near the end of life and to forgo unnecessary hospital admissions [11].

To that end, however—and this is the third reason behind the above-mentioned paradox—healthcare proxies are in need of support by professional care providers and physicians. For family members, the decision to institutionalise a loved one brings with it several adaptive challenges and is often accompanied by feelings of guilt. They not only have to cope with the loss of proximity of their loved one but also have to accommodate themselves to a new role in passing over their former caregivers’ responsibility to the nursing home staff, while at the same time, the progression of the dementia process confronts them with difficult moral decisions with regard to end-of-life care. Research shows that family members often experience a lack of information not only with regard to the specific decisions to be made but also with regard to the natural course of the disease, which makes it difficult for them to anticipate the future [12]. With limited knowledge regarding the disease trajectory and often no more than occasional contact with physicians who do not know their patients very well, one should not be surprised that healthcare proxies often insist on hospital admission in case of acute illness in their demented relative.

In this issue of *Age and Ageing*, Meller *et al.* demonstrate that in order to improve palliative care for people

with dementia, there is already a world to win by just communicating with family and proxies, giving them clear and transparent information with regard to the disease trajectory, the ultimate complications of dementia and the limited treatment options available [13]. They set up an educational programme for families, nursing home staff and general practitioners, encouraging advance care planning and treatment for acute illnesses—when appropriate—in the nursing home. This intervention resulted in a significant fall of hospital transfers of demented nursing home residents and even in a slight reduction of mortality compared with the control region. Most importantly, however, the programme resulted in a relevant change of culture: family members felt relieved by the information because this helped them to prepare for the future, whereas the staff felt encouraged to address the subject of advance care planning as part of their regular talks with proxies.

With this rather simple intervention, Meller *et al.* have set an example that is worth following, although one must realise that advance care planning alone will not suffice to guarantee the quality of end-of-life care in dementia. The problem of ‘physicians missing in action’ and the subsequent consequence of erroneous diagnosis and failing symptom management must also be addressed here [3–7, 14]. In this respect, one might worry about the passive role of the physicians in this study, because such an attitude contrasts with the responsibility they bear for initiating and coordinating hospital transfers as well for guaranteeing acceptable quality of care in case a decision is made to forego hospitalisation. Although they mention the possible benefits of an outreach hospital team to offer treatments that would otherwise require hospital admission, Meller *et al.* are rather silent on the provision and actual content of palliative care measures once a decision to forego hospitalisation is made. In this respect, the Dutch model is one step ahead of the Australian experiment [15]. A characteristic feature of the organisation of long-term care in the Netherlands is that nursing homes are staffed by specially trained nursing home physicians who are experienced in the field of chronic diseases, including (advanced) dementia, and who have their principal site of practice in the nursing home, which allows them to develop intimate knowledge of their patients [16]. On their initiative, a palliative care approach was introduced to the nursing home setting in the 1990s [11]. Besides adequate symptom management, this approach implies a proactive attitude of nursing home physicians in developing care plans and in facilitating discussions with patients and families on advance care planning and treatment of complications and exacerbations of the dementia process [17]. This model has proven to be successful, both in improving communication and shared decision-making and in reducing hospitalisation rates and the use of burdensome interventions such as tube feeding and parenteral rehydration in late dementia [18]. In fact, hospital admissions of demented residents are rare in the Netherlands because most acute illnesses can be treated adequately in the nursing home, and nursing home physicians are experienced in discerning the sequelae of dementia that warrant a palliative rather than a curative approach [7, 11, 15]. In this respect, a novel reading of the expression

‘Dutch comfort’ might inspire a relevant follow-up to this Australian initiative.

CEES M. P. M. HERTOIGH
Institute for Research in Extramural Medicine,
VU University Medical Centre Amsterdam,
Van der Boechorststraat 7,
1081 BT Amsterdam, The Netherlands
Tel: (+31) 20 4448329;
Fax: (+31) 20 4448231;
Email: cmpm.hertogh@vumc.nl

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Published electronically 18 September 2006

Pharmacist-led medication reviews can reduce patient morbidity?

Preventable drug-related morbidity is responsible for a median of 3.7% [1] to 4.3% [2] of hospital admissions. In patients aged ≥ 70 years, the percentage of admissions is doubled (mean 7.6%) [2]. Regular medication reviews are believed to help avoid drug-related morbidity. Guidelines in England recommend that patients aged ≥ 65 years should receive a medication review annually or 6-monthly if they take four or more medications regularly [3]. There is, however, minimal evidence to date to support a reduction in morbidity or mortality with medication reviews [4]. Indeed, evidence for pharmacist-led medication reviews is conflicting [5]. Holland *et al.* described eight large studies of face-to-face, pharmacist-led medication review in older populations conducted in the western developed world. Although those studies that focus on medication-related outcomes (such as changes to medication or medication appropriateness) show some benefit, there is no evidence for improvements in mortality or quality of life [5]. Even data on health service utilisation are conflicting. One study showed a small decrease in hospital admissions [6], whereas another study showed a significant increase [7]. The remainder of studies showed no effect on hospital admissions [5]. Despite the paucity of evidence for patient benefit, spending on pharmacist-led medication reviews continues to increase. It is, therefore, important to continue to assess the impact of pharmacist-led medication reviews in different populations.

In this issue, Zermansky *et al.* [8] reported further research into pharmacist-led medication reviews in older people. In an earlier study, they showed that pharmacist-led medication reviews with patients on repeat medication reduced numbers of medications and costs of medications compared with usual care. In addition, they found a non-significant reduction in mortality (2.5 versus 4.5%, $P = 0.56$) [9].

The study published in this issue [8] compares pharmacist-led clinical medication reviews with usual care in a high-risk population of care-home residents aged ≥ 65 years (mean age 85 years), taking one or more repeat medications. Zermansky *et al.* had an ambitious recruitment target of 1,600 patients to detect a difference in measures of cognitive and physical functioning in this population. This level of recruitment was unachievable in the given timescale. They

did, however, attempt to randomise 661 patients from the 1,163 recruited from 65 care homes in Leeds, UK.

In common with previous studies, Zermansky *et al.* found that compared with usual care, a dedicated pharmacist increased the number of patients who received medication reviews and the number of changes that were made to medication. The study did not show a reduction in health service utilisation, but unlike the HOMER (HOMe-based MEDication Review) study [7], there was no evidence of a significant increase in general practitioner consultations or hospitalisations. In addition, the fact that a pharmacist performs an annual or biannual medication review reduces the number of routine general practitioner consultations, which would otherwise be required to achieve the National Service Framework recommendation [3].

The potentially most important outcome from this study, however, is the statistically (and clinically) significant reduction in falls. Although noting that this was a secondary outcome measure, patients in the intervention group experienced a mean of 0.8 falls per patient compared with 1.3 in the control group. Notably, the number of falls per patient remained unchanged in the control group compared to baseline. There are, however, many reasons for caution with the outcomes of this study, including a greater number of patients falling at baseline in the intervention arm and the non-random recruitment of patients.

Previous studies including medication reviews in interventions to reduce falls in primary care have been unsuccessful [4]. Royal *et al.*'s systematic review of interventions to reduce medication-related adverse events and hospital admissions identified 13 studies that included medication reviews as part of complex interventions to reduce falls. Meta-analysis of nine randomised controlled studies did not find a significant reduction in falls [odds ratio (OR) 0.91; 95% confidence interval (CI) 0.68, 1.21].

Zermansky *et al.* suggested that the reduction in falls seen in their study is largely attributable to stopping CNS drugs that are known to increase the risk of falls by causing sedation, confusion and hypotension. In addition, they noted that recommending calcium and vitamin D supplementation in $\sim 15\%$ of patients may have