Original Article

Advance Care Planning and Physician Orders in Nursing Home Residents With Dementia: A Nationwide Retrospective Study Among Professional Caregivers and Relatives

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Abstract

Context. Advance care planning (ACP) is key to good palliative care for nursing home (NH) residents with dementia.

Objectives. We examined the extent to which the family physicians (FPs), nurses, and the relative most involved in the resident's care are informed about ACP, written advance directives, and FP treatment orders (FP-orders) for NH residents dying with dementia. We also examined the congruence among FP, nurse, and relative regarding the content of ACP.

Methods. This was a representative nationwide post-mortem study (2010) in Flanders, Belgium, using random cluster sampling. In selected NHs, all deaths of residents with dementia in a three month period were reported. A structured questionnaire was completed by the FP, the nurse, and the patient's relative.

Results. We identified 205 deceased residents with dementia in 69 NHs. Residents expressed their wishes regarding end-of-life care in 11.8% of cases according to the FP. The FP and nurse spoke with the resident in 22.0% and 9.7% of cases, respectively, and with the relative in 70.6% and 59.5%, respectively. An advance directive was present in 9.0%, 13.6%, and 18.4% of the cases according to the FP, nurse, and the relative, respectively. The FP-orders were present in 77.3% according to the FP, and discussed with the resident in 13.0% and with the relative in 79.3%. Congruence was fair (FP-nurse) on the documentation of FP-orders ($k = 0.26$), and poor to slight on the presence of an advance directive (FP-relative, $k = 0.03$; nurse-relative, $k = -0.05$; FP-nurse $k = 0.12$).

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Conclusion. Communication regarding care is rarely patient driven and more often professional caregiver or family driven. The level of congruence between professional caregivers and relatives is low. J Pain Symptom Manage 2014;47:245–256.

Key Words
Advance care planning, advance directive, family physician treatment orders, end-of-life care, nursing home, dementia

Introduction

Patient-centered advance care planning (ACP) is a communication process between a patient and his/her care providers, which may involve family or friends, about the goals and desired direction of care at the end of life in an event when the patient loses the capacity to make decisions.[1,2] ACP is one of the key components of the quality of palliative care for nursing home (NH) residents, in particular for those with dementia who are often not able to express their preferences at the end of their life.[3]

Research to date has tended to focus on the written outcomes of ACP, such as written advance directives, living wills, and the appointment of a durable power of attorney.[4–8] However, communication about future care does not always result in a written record but just may involve conversations with residents, or residents expressing their wishes to professional caregivers. Verbal communication has received little attention so far, although it may be more common than written ACP communication.

Because of the progressive nature of the disease, NH residents with dementia face a threshold in their ability to engage meaningfully in the advance planning of their own care.[9] Ideally, the resident, their family, and professional caregivers will have discussed the desired direction of care and/or have made written plans about future care in the last phase of life, but this is not always the case. On the contrary, family physician treatment orders (FP-orders) are very common in such cases.[10] The FP-orders are usually documented in the resident's medical file and may be discussed with other professional caregivers, relatives, or with the resident, but only when they have been discussed with the residents themselves can they be considered as patient-centered ACP. Their prevalence and content have not been studied extensively.

Decision making about the care of people with dementia residing in NHs is complex and involves the residents, who may have expressed or documented their wishes, their FPs, the NH nurses, and their relatives/friends. Ideally, there would be consensus about what has been discussed with the resident and about the future direction of care. Therefore, it is relevant to examine the level of congruence among those involved in care regarding the existence of verbal ACP communication and the decisions documented in advance directives and FP-orders. So far, however, research has focused on the level of congruence between patients and health care proxies.[11,12] To describe the final phase of life in a representative sample of deaths, it has been recommended to use a retrospective study design.[13,14]

The purpose of this study was to examine, using data from a representative nationwide survey: 1) the extent to which FPs, nurses, and relatives are involved in ACP communication, and informed about the existence and content of written advance directives and FP-orders for care, 2) the level of congruence between FPs and nurses about the content of FP-orders for the end-of-life care placed in the resident's medical record, and 3) the level of congruence among the FPs, nurses, and the relatives about the content of the resident's written advance directives.

Methods

Study Design

Data were obtained from the Dying Well with Dementia Study (2010), a post-mortem study of NH residents dying with dementia in Flemish NHs. Different questionnaires were