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Initiating advance care planning on end-of-life issues in dementia: Ambiguity among UK and Dutch physicians

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ABSTRACT

Background: In dementia, advance care planning (ACP) of end-of-life issues may start as early as possible in view of the patient's decreasing ability to participate in decision making. We aimed to assess whether practicing physicians in the Netherlands and the United Kingdom who provide most of the end-of-life care, differ in finding that ACP in dementia should start at diagnosis.
Methods: In a cross-sectional study, we surveyed 188 Dutch elderly care physicians who are on the staff of nursing homes and 133 general practitioners from Northern Ireland. We compared difference by country in the outcome (perception of ACP timing), rated on a 1–5 agreement scale. Regression analyses examined whether a country difference can be explained by contrasts in demographics, presence, exposure and role perceptions.
Results: There was wide variability in agreement with the initiation of ACP at dementia diagnosis, in particular in the UK but also in the Netherlands (60.8% agreed, 25.3% disagreed and 14.0% neither agreed, nor disagreed). Large differences in physician characteristics (Dutch physicians being more present, exposed and adopting a stronger role perception) hardly explained the modest country difference. The perception that the physician should take the initiative was independently associated with agreeing with ACP at diagnosis.
Conclusions: There is considerable ambiguity about initiating ACP in dementia at diagnosis among physicians practicing in two different European health care systems and caring for different patient populations. ACP strategies should accommodate not only variations in readiness to engage in ACP early among patient and families, but also among physicians.

1. Introduction

Advance care planning (ACP) can improve the quality of end-of-life care (Brinkman-Stoppelenburg, Rietjens, & van der Heide, 2014) and it fits well with the person-centred and anticipatory approach of palliative care (European Association for Palliative Care (EAPC), 2009; World Health Organization (WHO), 2002). Planning can start soon after diagnosis of an incurable or life-threatening progressive disease, or later. However, the optimal timing or how to assess the right moment in individual cases is unclear. In dementia, timing is crucial because the person may be involved in an early phase but not later through progressive cognitive decline. Research has shown that some people in the early stages are able, and may wish to talk about the future, but others resist looking ahead and rather live one day at a time (de Boer, Droës, Jonker, Eefsting, & Hertogh, 2012; Hirschman, Kapo, & Karlawish, 2012). Furthermore, some families even find ACP discussions soon after nursing home admission too early in view of the patient's health (van Soest-Poortvliet et al., 2014). There are many possible barriers to initiating ACP, including among professionals, such as not taking the initiative (van der Steen, van Soest-Poortvliet et al., 2014).

In a Delphi study by the European Association for Palliative Care (EAPC) however, most experts (most of whom were physicians) supported starting ACP early, if possible "as soon as the diagnosis is made" (van der Steen, Radbruch et al., 2014). Compared to expert

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Abbreviations: ACP, advance care planning; GP, general practitioner.

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views, practitioners' perceptions might vary more (Brazil, Carter, Galway, Watson, & van der Steen, 2015) and may also differ between countries because of greater influence of different health care systems and environments in which professionals operate locally. For example, in comparative studies, physicians' presence, certainty of family wishes and perceived responsibility for decision making (or paternalism) were greater in the Netherlands compared with the US and this may translate into different treatment approaches (Helton, van der Steen, Daaleman, Gamble, & Ribbe, 2006; Helton, Cohen, Zimmerman, & van der Steen, 2011).

In this paper, we address the question of whether practicing physicians in the Netherlands and the United Kingdom (UK) who provide most of the care at the end of life, differ in finding that ACP of end-of-life issues for people living with dementia should start at diagnosis. We examine a possible difference by country and whether this is explained by differences in demographics, presence, exposure and role perceptions between physicians in the two countries.

2. Methods

We performed a cross-sectional survey among representative samples of physicians in the Netherlands and the UK. The UK survey has also been reported on elsewhere (Brazil et al., 2015; Carter,. van der Steen, Galway, & Brazil, 2015); in this paper, we focus on cross-national differences in perceptions about advance care planning.

2.1. Setting and sampling

We selected the specialisms that assume primary responsibility for the care for persons with dementia often for years and including at the end of life. In the Netherlands, these are elderly care physicians who are certified after a 3-year specialty training (Koopmans, Lavrijsen, Hoek, Went, & Schols, 2010). They are responsible for care for nursing home residents and part of the care for dementia patients in residential settings. In the Netherlands, 92% of patients with dementia die in nursing or residential homes (Houttekier et al., 2010). In different parts of the UK, this is half or slightly over half of the patients (50–61% across Great Britain; Houttekier et al., 2010), and the GP often remains responsible for the care. We hypothesized that the Dutch physicians would be much more in favour of early ACP because of their specialization, their training in ACP, their greater exposure to patients with dementia, their different role perceptions and the fact that as ACP had not been previously commenced by the GP it is often only initiated by the Dutch physicians upon nursing home admission when the patient generally can no longer communicate effectively (van Soest-Poortvliet et al., 2015).

We aimed at about equal samples and a few hundred responses in total for regression analyses. In the Netherlands, we sampled one in four from an alphabetical list of surnames of the 1248 elderly care physicians who were member of the Dutch Association of Elderly Care Physicians and Social Geriatricians Verenso (almost all) and practicing autumn 2012. Of the 316 self-complete postal surveys we sent out in April 2013, 207 were returned and five were returned as undeliverable, resulting in a response rate of 66.6% (207/311). Nineteen of 207 were excluded from the analyses; 13 had no experience with patients dying with dementia and returned the survey not completed as instructed, and six were not providing any clinical care currently due to illness or for other reasons.

In the UK, the self-complete postal survey was sent to 340 GPs located across Northern Ireland in 2013, the region that has identified the highest dementia diagnoses rates in the UK, (UK Alzheimer's Society, 2014), and represented 174 practices (49% of all practices in Northern Ireland). The response rate was 40.6% (138/340) representing 60.9% of the surveyed practices (106/174) and 133 surveys were complete and available for analyses.

2.2. Procedures

To maximize responses, an incentivizing prize draw was held in each jurisdiction, to win an iPad mini in the UK and 100 euro gift cards in Netherlands. In the Netherlands, we sent another copy of the survey to non-responders in May and in June 2013. In the UK, a system of up to four mail contacts was implemented (Dillman, Smyth, & Christian, 2009). We assured confidential processing of the answers. Survey data was inputted and managed using Blaise which features e.g., range checks (version 4.7.1, 2008, Statistics Netherlands, The Hague) and IBM SPSS Statistics 21, 2012 (UK).

In the Netherlands, the procedure was approved by the Medical Ethics Review Committee of the VU University Medical Center as part of a series of studies on end-of-life care. In the UK, ethical approval was obtained through the Research Ethics Committee, School of Nursing and Midwifery, Queen's University Belfast.

2.3. Items

We assessed physician and practice characteristics in some detail using the same items preparing for the cross-national comparison. The form was translated into Dutch and we discussed and resolved any discrepancies with a back translation by a professional translator.

The outcome was the level of agreement with the statement "Advance care planning on end of life care should be initiated at the time of diagnosis of dementia" (EAPC recommendation 3.2 which is also a statement, but shortened). We developed additional statements for the purpose of the survey. All used the response options: strongly disagree, moderately disagree, neither agree nor disagree, moderately agree, strongly agree, and don't know. The physicians were shown the scale with numbers running from 1 to 5 (and 0 for don't know).

We measured exposure through asking for experience as a physician and the estimated number of dying dementia patients cared for in the past year by the respondent. Presence was measured with a 0–12 scale that added up practice time involving clinical care in the nursing home and frequency of visiting a typical nursing home patient (Helton et al., 2011). Role perception regarding ACP was measured with two agreement items: "The physician should take the initiative to introduce and encourage advance care planning," and "The advance care planning process requires making family members agree with the physician on goals of care."

2.4. Analyses

We compared differences between countries on the outcome of whether ACP should start at diagnosis, and three key variables expected to differ cross-nationally while potentially related to the outcome: exposure, presence and role perception. We used chi-square tests to compare dichotomous variables, and *t*-tests for normally distributed age and experience, and the non-parametric Mann-Whitney *U* test or hierarchical gamma test if distributions deviated from the normal distribution. Next, we used univariable and multivariable linear regression analyses to examine if the outcome was associated with country, demographics, exposure, presence or role perception, and in particular, if any country difference in agreement was affected by differences in the other variables. We examined possible co-linearity of age and experience with Pearson's correlation. The level of significance was 0.05.