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Research paper

Living wills and end-of-life care of older people suffering from cardiovascular diseases: A ten-year follow-up



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ABSTRACT

Background: Living will (LW) documents have been suggested to act in patients' best interests in end-of-life care. It is unclear, however, whether the LWs influence medical decisions when death is impending. **Aim:** To explore, whether a LW among the community-dwelling older people has an influence on intensity of end-of-life treatment, place of death, or length of the dying process.

Design: A 10-year follow-up; data concerning place and cause of death, event history, intensity of care, decision-making process, and length of the dying process were collected from the death certificates.

Setting/Participants: In a community-based longitudinal cardiovascular prevention trial (DEBATE) in Helsinki, home-dwelling older people with an atherosclerotic disease ($n = 378$, mean age 80.2 years) were questioned about the pre-existence of a written LW at baseline ($n = 44$) in 2000. In 2010, all death certificates ($n = 207$) were analysed, comparing people with a LW ($n = 30$) at baseline with those without ($n = 177$).

Results: Of the deceased, 77% died in hospital. Intensity of end-of-life treatment or cause of death did not differ between the groups. However, dying at home was more common among persons with a LW at baseline (16.7% vs. 5.6%, $P = 0.031$), and length of the dying process was shorter in this group (< 1 week in 50.0% vs. 27.1%, $P = 0.013$).

Conclusions: Length of the dying process was often shorter and home death more common among those with a LW at the beginning of the follow-up. More insight into the dying process is required to ensure that the decision-making process better accommodates the preferences of older people.

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1. Introduction

The importance of a living will (LW) has been emphasized in order to act in a patient's best interest, in terms of respecting their will [1]. However, the growing criticism of its usefulness in common end-of-life circumstances compels us to evaluate its relevancy [1–3]. In Europe, a small proportion of older people have completed LWs. The prevalence of LWs or other advance directives has varied from 10% to 29% in Europe, as opposed to up to 70% of community-dwelling older adults in the USA [2,4–6]. The content of LW or other advance directives vary substantially in different

countries and between individuals. The legal recognition of LWs in Finland compels the professionals to comply with it [7,8].

Increasing the documentation of advance directives has not necessarily resulted in care more congruent with patients' preferences [1,9–11]. An extensive American study aiming to facilitate advance care planning, patient-physician communication, and the dying process (SUPPORT) failed to improve the main outcomes [9,10]. Factors other than documented advance directives may have more impact on end-of-life decisions. Physicians are trained to “do something” and may decide to treat the patient with extreme intensity regardless of the LW [12]. Moreover, a proxy may intervene in decision-making against the patient's preferences [10]. An experienced physician is more likely to forego resuscitation [13]. In addition, cultural, geographical or organizational factors may be stronger determinants for place of death than advance directives [14]. In an inter-European study, end-of-life decisions were more often discussed with patients dying at home

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than in other places of death [15]. The diagnosis may affect daily practice as well; patients with advanced dementia often experience more burdensome interventions than cancer patients [16].

Although evidence regarding the impact of LWs has not been encouraging, some benefits have emerged. Programmes implementing advance care planning have reduced stress, anxiety, and even health care service utilization and costs without increasing mortality or dissatisfaction of proxies in Australia [17], Canada [18], USA [19], and UK [20], especially in nursing home settings. LWs have also resulted in better quality of life, as reported by family members [2].

Death and dying are cultural issues. There is little knowledge about the preferences of the “oldest old” in Europe. To our knowledge, no studies have explored the congruence between wishes expressed in LWs and the comprehensive process of dying and end-of-life decisions according to death certificates.

This study evaluates whether the pre-existence of a LW among community-dwelling older people in Helsinki has an influence later on the intensity of their end-of-life treatment, place of death, or length of the dying process.

2. Methods

The participants in this study ($n = 207$) are the deceased subjects of a cardiovascular prevention trial drugs and evidence-based medicine in the elderly (DEBATE; $n = 400$), the details of which have been described previously [21] (Fig. 1). Briefly, the DEBATE study was a single-centre randomised controlled trial to test the effectiveness of multicomponent intervention on older cardiovascular patients in Helsinki, Finland [21,22]. A random sample of older people (aged 75–95 years and living in Helsinki, $n = 4821$) was retrieved from the Population Information System of Finland in 1998–2000. Of the respondents, 812 had reported an atherosclerotic disease, and 400 of them were eligible and recruited to the DEBATE trial. All participants were home dwelling older people with a verified atherosclerotic diagnosis and willing to participate in thorough examinations, interviews, and follow-up. Of those, 378 responded to an inquiry about the pre-existence of a LW document. In the original cardiovascular prevention study, there were no differences in outcomes of mortality or use of

hospital services between the intervention and control groups so the division into the control or intervention group was not taken into account in the present study. Our analyses are based on a 10-year follow-up of all deceased (207/378) participants of the DEBATE study.

The research protocol of the DEBATE study was approved by the Ethics Committee of the Department of Medicine, University of Helsinki, Finland. Each participant signed an informed consent at baseline.

The baseline data were retrieved from medical records, clinical examination, postal questionnaire, interviews, and assessments by the study nurse. The presence of a LW document (yes/no) was inquired about after the study nurse had explained the LW as “a signed consent, in which a person, who becomes unable to communicate as a consequence of a serious and incurable disease, gives permission in advance to forgo artificial life-sustaining treatments” [4]. The completion of a LW was confirmed during the follow-up. By signing the most common LW form in Finland [8], a person limits all life-sustaining treatments in approaching death when he/she loses the capacity to express own wishes, and treatment would not improve the prognosis.

Cognition was assessed with Mini-Mental State Examination (MMSE) [23], and comorbidity with the Charlson comorbidity index [24], a weighed measure taking into account the number and severity of comorbid diagnoses. Subjective health was categorized as “good” with the responses of “healthy” or “quite healthy”, and “poor” with the responses of “poor” or “very poor”.

After a 10-year follow-up, census data were retrieved from the Population Information System through in January 2010. All death certificates ($n = 207$) were available and analysed for this study. In addition to place of death and ICD-10 [25] diagnosis for cause of death, the event history was extracted from the certificates. The last events leading to death are described in a few sentences on each death certificate in Finland.

The death certificates were independently evaluated by two authors (HK, MLL). Any incongruence was discussed. In case of different conclusions, a consensus was reached with the third author’s (KP) contribution. Place of death was classified in four categories: “home”, “acute hospital”, “nursing home or other long-term care ward”, or “hospice”. Terminal care was considered “intensive” if the patient was admitted to an intensive care unit. “Active acute” care included symptomatic or invasive treatments, e.g. treatment of congestive heart failure or severe dyspnea in hospital, administration of parenteral antibiotics, or surgery. “Palliative” care was chosen to relieve symptoms and avoid admission to hospital. In a case of “sudden death”, the participant was either found dead or had the most severe symptoms leading to imminent death. “Length of the dying process” was the time elapsed between the final transfer to the place of death and dying. In case of dying either in a nursing home (where treated > 1 year) or at home, length of the dying process was extracted from the event history. Furthermore, these event details on the certificates were evaluated to determine whether involvement of the patient or a family member was mentioned in end-of-life decisions.

We compared differences in demographics at baseline and outcomes at end of life in two groups: those with a completed LW in 2000 and those without one. We analysed the associations between the groups in relation to intensity of end-of-life care, site of death, and length of the dying process. All analyses were performed with NCSS software. The Chi-square test was used for comparing the two groups for categorical data and the Mann-Whitney U-test for continuous variables. A two-sided P -value of < 0.05 was considered to indicate statistical significance.

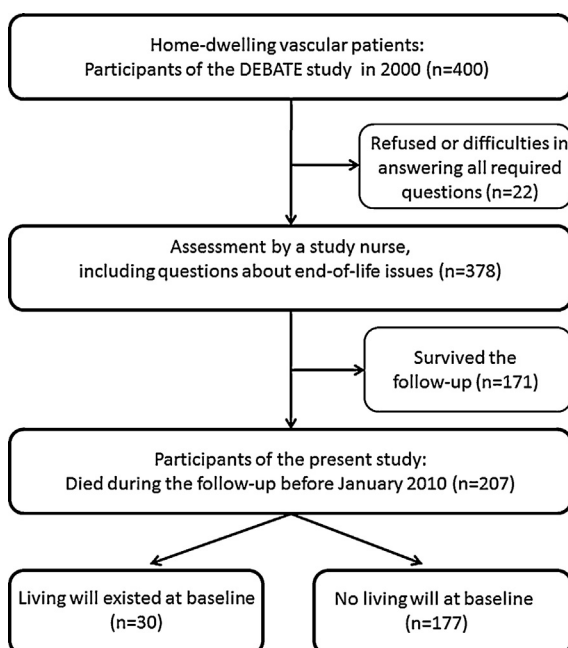


Fig. 1. Flow chart of recruitment of research participants ($n = 207$).

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