Kinlessness at the Time of Death: Implications for End-Of-Life Decision-Making

Ornstein, Katherine; Mair, Christine; Kristensen, Marie Skov; Aldridge, Melissa; Thygesen, Lau Caspar

Published in: Innovation in Aging

DOI: 10.1093/geroni/igz038.885

Publication date: 2019

Document version: Final published version

Document license: CC BY

Citation for published version (APA):

Terms of use
This work is brought to you by the University of Southern Denmark through the SDU Research Portal. Unless otherwise specified it has been shared according to the terms for self-archiving. If no other license is stated, these terms apply:

- You may download this work for personal use only.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying this open access version

If you believe that this document breaches copyright please contact us providing details and we will investigate your claim.
Please direct all enquiries to puresupport@bib.sdu.dk

Download date: 23. Apr. 2021
(EOL) planning and decision making. This includes a broad spectrum of choices including advance care planning (ACP) and turning to palliative care or hospice care. Although there has been an increase in palliative and hospice care enrollment and ACP engagement over the past decade, participation remains low for certain subgroups of the population. The purpose of this symposium is to offer insight into reasons for these varying rates of engagement by exploring determinants and barriers to EOL decision making and planning and by examining caregiver knowledge of EOL decision making and planning from the service provider perspective. The first three studies examine various types of influences in EOL decision making and planning. Inoue and colleagues explore factors associated with the length of hospice stay, and Gaines and colleagues examine the impact of environmental characteristics in ACP. Ornstein and colleagues use Denmark registry data to assess the role of kinlessness at the time of death in EOL decision making and healthcare utilization. The final presentation by Noh and colleagues examines how service providers in rural areas perceive community residents’ knowledge of ACP and palliative care. The discussion following these presentations will compare findings across different forms of EOL decision making and planning, consider the impact of the varying methodological approaches used, and highlight implications of these works for potential interventions and policies related to EOL decision making and planning.

THE ROLE OF THE ENVIRONMENTAL CONTEXT IN ADVANCE CARE PLANNING AMONG OLDER ADULTS

Brittany E. Gaines,1 Kathrin Boerner,1 Kyungmin Kim,1 and Sara Moorman2, 1. University of Massachusetts Boston, boston, Massachusetts, United States, 2. Boston College, Chestnut Hill, Massachusetts, United States

Little is known about how environmental context shapes individuals’ advance care planning (ACP). We combined ACP information from the Wisconsin Longitudinal Study with county-level characteristics from the Area Health Resource File, Dartmouth Atlas, and US Census. Multilevel logistic regression models showed that local sociodemographic characteristics (e.g., rurality, racial/ethnic makeup, age composition, and prevalence of one-person households) and healthcare characteristics (e.g., number of hospice agencies, Medicare reimbursement rates) were related to rates of ACP. Additionally, the following environmental factors were moderated by both individual household income and educational attainment, Medicare physician reimbursement rate, racial/ethnic makeup, age composition, median household income, rurality, and the number of hospice agencies. These findings suggest that the environmental context of an individual’s residence can impact their engagement in ACP. Evidence from this study may be used to target areas for, and guide the design of, effective intervention strategies to help increase ACP at an environmental level.

FAMILY CAREGIVERS’ ADVANCE CARE PLANNING FOR COGNITIVELY IMPAIRED OLDER ADULTS: SERVICE PROVIDERS’ PERSPECTIVES

Hyunjin Noh,1 and Temilade A. Aladeokin1, 1. The University of Alabama School of Social Work, Tuscaloosa, Alabama, United States

An increasing number of family caregivers face challenges of advance care planning (ACP) for their cognitively impaired older adults. The purpose of this study was to understand service providers’ views on ACP knowledge and needs among such family caregivers. Purposive sampling was used to recruit 10 service providers who serve older adults and their family caregivers in community settings of West Alabama. Individual, face-to-face interviews were conducted guided by a semi-structured questionnaire, asking about their experiences with and views of family caregivers’ ACP for their older adults. Thematic analysis of the qualitative data revealed several findings: family caregivers’ lack of knowledge about ACP and end-of-life care, discomfort in end-of-life discussions, uncertainty about their older adult’s end-of-life preferences, frustration with the surrogate decision-making role, family conflicts in ACP process, and logistical barriers to access ACP resources. Tailored services should be developed to address these barriers to promote ACP among this population.

KINLESSNESS AT THE TIME OF DEATH: IMPLICATIONS FOR END-OF-LIFE DECISION-MAKING

Katherine Ornstein,1 Christine Mair,2 Marie Skov Kristensen,3 Melissa Aldridge,4 and Lau Caspar Thygesen1, 1. Icahn School of Medicine at Mount Sinai, New York, New York, United States, 2. University of Maryland, Baltimore County (UMBC), Baltimore, Maryland, United States, 3. National Institute of Public Health, University of Southern Denmark, København, Hovedstaden, Denmark, 4. Icahn School of Medicine at Mount Sinai, New York, New York, United States

As our society continues to age and family size decreases, there is increasing concern about lack of caregiver availability. This may be especially important in the context of end-of-life decision-making. The goal of this study was to characterize the size and composition of the family network of adults at the time of death using a population-based register study. All adults in Denmark who died of natural causes 2009-2016 (n= 401,000) were linked to living adult family members (parents, children, spouses, siblings, great-grandchildren). While the majority of decedents were linked to multiple family members (median =5), 21.6% had no identified living family at the time of their death. Kinlessness was especially common among older women and those with dementia. In addition to supporting caregiving families at the end-of-life, we must also recognize that there are many kinless individuals who may benefit from early formal care planning services to facilitate end-of-life decision-making.

FACTORS ASSOCIATED WITH LENGTH OF HOSPICE STAY

Megumi Inoue,1 Matthew G. Kestenbaum,2 and Cameron Muir3, 1. George Mason University, Fairfax, Virginia, United States, 2. Capital Caring, Falls Church, Virginia, United States, 3. Capital Caring, Washington DC, District of Columbia, United States

The benefits of early referral to hospice services have been well documented. However, late admissions and short hospice stays are ongoing issues that are often barriers to improving terminally-ill persons’ and the caregivers’ quality