The Examination of Determinants And Barriers To End-Of-Life Decision Making and Planning

Brittany E. Gaines
*University of Massachusetts*

Debra J. Dobbs
*University of South Florida, ddobbs@usf.edu*

Follow this and additional works at: [https://digitalcommons.usf.edu/gey_facpub](https://digitalcommons.usf.edu/gey_facpub)

**Scholar Commons Citation**
Gaines, Brittany E. and Dobbs, Debra J., "The Examination of Determinants And Barriers To End-Of-Life Decision Making and Planning" (2019). *Aging Studies Faculty Publications*. 57. [https://digitalcommons.usf.edu/gey_facpub/57](https://digitalcommons.usf.edu/gey_facpub/57)

This Article is brought to you for free and open access by the School of Aging Studies at Digital Commons @ University of South Florida. It has been accepted for inclusion in Aging Studies Faculty Publications by an authorized administrator of Digital Commons @ University of South Florida. For more information, please contact scholarcommons@usf.edu.
At least two meals a day to meet the individual needs of residents. Approximately 37% of residents in AL need help with three or more activities of daily living (ADLs), 42% have some cognitive impairment and 39% need skilled nursing services. Approximately 15 to 50% of older adults living in AL communities experience a fall over a 6 to 24 month period. The cause of these falls involves multiple factors at the resident and facility level. In addition to a high rate of falls there is a high rate of polypharmacy, using the polypharmacy definition of taking five or more medications daily. Polypharmacy results in negative outcomes such as falls and hospitalizations among AL residents. Along with high rates of falls and polypharmacy there is also a high incidence of pain among AL residents and concerns that some pain goes unreported and untreated. Pain, polypharmacy and falls can all influence life satisfaction along with other factors such as the environment itself. The purpose of this symposium is to describe the incidence and factors that influence falls, polypharmacy, pain and pain management and the impact of these care concerns, among others, on life satisfaction drawn from 508 residents from 54 nursing homes participating in the first two cohorts of the study testing the implementation of Function Focused Care for Assisted Living (FFC-AL-EIT).

THE INCIDENCE AND IMPACT OF POLYPHARMACY IN AL RESIDENTS
Elizabeth Galik1, 1. University of Maryland School of Nursing, Baltimore, Maryland, United States

The purpose of this study was to describe polypharmacy in AL settings. We hypothesized that: (1) age, gender, race, setting, multimorbidity and cognitive status would influence polypharmacy; and (2) polypharmacy would be associated with falls, emergency room visits and hospitalizations. This was a descriptive study using data from the first cohort of the FFC-AL-EIT Study. A total of 242 participants from 26 AL settings were included. Participants had a mean age of 86.86 (SD=7.00), the majority were women 179 (74%) and white (N=232, 96%) with 5 (SD=2) comorbidities. The mean number of drugs was 7 (SD=3.56) and 51% were exposed to polypharmacy, 24% fell at least once, 9% were sent to the hospital and 13% to the emergency room. Neither hypothesis was supported. Continued research is needed to explore the factors that influence polypharmacy and to identify if there are negative outcomes associated with polypharmacy in this population.

FACTORS THAT CONTRIBUTE TO FALLS AMONG AL RESIDENTS
Marie Boltz1, 1. Pennsylvania State University, University Park, Pennsylvania, United States

Many nurses, patients, and families continue to believe that physical activity increases the risk of falling. The purpose of this study was to test the hypothesis that residents who are exposed to Function Focused Care for Assisted Living (FFC-AL-EIT) and engage in moderate levels of physical activity would not be more likely to fall. This was a secondary data analysis using data from the first two cohorts of the FFC-AL-EIT study. The study included 508 residents the majority of whom were female (70%), white (97%), with a mean age of 87.72 (SD=7.47). Those who engaged in more moderate intensity physical activity were 1% less likely to fall \( b = -.01, \) Wald =6.13, \( p =.01 \). There was no association between exposure to function focused care and falling (\( \text{Beta} =.41, \) Wald =2.35, \( p =.13 \)). Further, engaging in moderate level physical activity was noted to be slightly protective of falling.

PAIN, PAIN MANAGEMENT, AND CONSEQUENCES OF PAIN AMONG AL RESIDENTS
Barbara Resnick1, 1. University of Maryland School of Nursing, Baltimore, Maryland, United States

The purpose of this study was to describe the incidence, management and impact of pain on function, agitation, and resistance to care. This was a descriptive study using baseline data from 260 residents in the second cohort of the FFC-AL-EIT study. The majority of the sample was female (71%) and white (69%) with a mean age of 87 (SD=7). Fifty-two residents (20%) reported pain based on objective (PAINAD) or subjective (verbal descriptive scale, VDS) pain assessments. A total of 75 residents (29%) received pain medication and 22 (42%) individuals reporting pain were not getting pain medication. Controlling for age, gender and cognition, PAINAD was significantly associated with agitation, function, and resistance to care and the VDS was only associated with function. Pain assessments should include objective and subjective measures and management of pain should be considered as it may help to optimize function and decrease behavioral symptoms among AL residents.

FACTORS THAT INFLUENCE LIFE SATISFACTION IN AL RESIDENTS
Sarah Holmes1, 1. University of Maryland, Baltimore, Maryland, United States

Life satisfaction is a multidimensional concept that addresses a personal judgment of quality from the resident's perspective. Components of life satisfaction include satisfaction related to health, the physical environment, relationships and activities. The purpose of this study was to test if there was a relationship between demographic factors, pain, falls, and use of psychotropics with life satisfaction. The sample included the first two cohorts from the FFC-AL-EIT study including 508 residents from 54 settings across Maryland, Pennsylvania, and Massachusetts. The majority of the participants were female (70%), white (97%) and the mean age was 87.72 (SD=7.47). Based on a stepwise linear regression analysis there was a significant association between pain (r=-.20, p=.003) and psychiatric use (r=-.19, p=.003) and the model explained 11% of the variance in life satisfaction. Ongoing research is needed to consider the impact of the environment and staff-resident interactions on life satisfaction.

SESSION 1260 (SYMPOSIUM)

THE EXAMINATION OF DETERMINANTS AND BARRIERS TO END-OF-LIFE DECISION MAKING AND PLANNING
Chair: Brittany E. Gaines, University of Massachusetts Boston, Boston, Massachusetts, United States
Discussant: Debra J. Dobbs, University of South Florida, Tampa, Florida, United States

As individuals are living longer, in many cases with chronic diseases, there is an increased focus on end-of-life
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 of ACP knowledge and needs among such family caregivers. Purposeful 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 Thysesen1. 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, sibling, 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...