Archives of Gerontology and Geriatrics 64 (2016) 90–95

Contents lists available at ScienceDirect

Archives of Gerontology and Geriatrics

journal homepage: www.elsevier.com/locate/archger

Advanced life events (ALEs) that impede aging-in-place among seniors

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ARTICLE INFO

Article history:
Received 13 October 2015
Received in revised form 21 December 2015
Accepted 5 January 2016
Available online 12 January 2016

Keywords:
Aging in place
Home care
Older adults
Qualitative

ABSTRACT

Despite the wishes of many seniors to age-in-place in their own homes, critical events occur that impede their ability to do so. A gap exists as to what these advanced life events (ALEs) entail and the planning that older adults perceive is necessary. The purpose of this study was to identify seniors' perceptions and planning toward ALEs that may impact their ability to remain in their own home. We conducted focus groups with 68 seniors, age ≥65 years (mean age 73.8 years), living in the community (rural, urban, and suburban), using open-ended questions about perceptions of future heath events, needs, and planning. Three investigators coded transcriptions using constant comparative analysis to identify emerging themes, with disagreements resolved via consensus. Subjects identified five ALEs that impacted their ability to remain at home: (1) Hospitalizations, (2) Falls, (3) Dementia, (4) Spousal Loss, and (5) Home Upkeep Issues. While recognizing that ALEs frequently occur, many subjects reported a lack of planning for ALEs and perceived that these ALEs would not happen to them. Themes for the rationale behind the lack of planning emerged as: uncertainty in future, being too healthy/too sick, offspring influences, denial/procrastination, pride, feeling overwhelmed, and financial concerns. Subjects expressed reliance on offspring for navigating future ALEs, although many had not communicated their needs with their offspring. Overcoming the reasons for not planning for ALEs is crucial, as being prepared for future home needs provides seniors a voice in their care while engaging key supporters (e.g., offspring).

1. Introduction

Living in one's own home is paramount to most people, regardless of age. Older adults frequently state that they prefer remaining in their own homes, over other living options (Gillsjo, Schwartz-Barcott, & von Post, 2011; Keenan, 2010). As a whole, seniors play a much needed role in their communities. Seniors retire later today than ever before and approximately 45% of all adults over the age of 65 volunteer annually (Ekerdt, 2010). Seniors who remain in their own homes have greater satisfaction, less depression, and maintain their physical function better than seniors residing in assisted living or nursing homes (Shah, Carey, Harris, DeWilde, & Cook, 2012; Zuidgeest, Delnoij, Luijkx, de Boer, & Westert, 2012).

Over time older adults face increasing frailty and disability, requiring additional support to remain in their homes (Avery, Kleppinger, Feinn, & Kenny, 2010). Nearly eleven million community-dwelling individuals in the United States needed long-term services and support to help address limitations in activities (Jones, Harris-Kojetin, & Valverde, 2012; Kaye, Harrington, & LaPlante, 2010). Research has shown that older adults underestimate the likelihood that they will need assistance in the future (MetLife Mature Market Institute, 2009; Robison, Shugrue, Fortinsky, & Gruman, 2014). Results from the 2012 National Health Interview Survey showed that 60% of older adults believed that they were unlikely to need long-term services and supports in the future, whereas the evidence suggests that nearly 70% of older adults will need them at some point. Only 14% of those surveyed responded that they were very likely to need care in their future (Malone Beach & Langeland, 2011).

In addition, many older adults worry about being removed from their homes and placed in nursing homes (Kaye et al., 2010; MetLife Mature Market Institute, 2009; Robison et al., 2014). Older adults have a 46% lifetime chance of spending time in a nursing

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http://dx.doi.org/10.1016/j.archger.2016.01.004
0167-4943/

home (Kemper, Komisar, & Alexcxih, 2005–2006). Despite many older adults' wishes to remain independent in their own homes, frequent critical health and life events occur that impede their ability to do so. A lack of information exists on what these advanced life events (ALEs) entail and the advanced planning that older adults perceive is necessary.

This patient-centered study sought to explore what older adults perceived would affect their ability to remain in their own home and how they had planned for these potential events. In the case where planning did not occur, we sought to examine the rationale for the lack of planning for these advanced life events.

2. Methods

2.1. Participants

Participants were recruited through patient partners, stakeholders, flyers, newsletter announcements, email bursts, and word of mouth. Recruitment for the eight focus groups was done across multiple sites: (1) Aging & In-Home Services of Northeast Indiana, Inc. (AIHS), an Area Agency on Aging in Fort Wayne, Indiana; (2) Lincoln Park Village and Skyline Village Chicago, two older adult Village community groups in Chicago, Illinois; (3) Northwestern Medicine Geriatrics Outpatient Offices; and (4) University of Chicago Outpatient Section of Geriatrics Clinics. This range of academic and community-based sites allowed for a wide range of socio-economic status, engaging participants from both urban and rural communities.

Recruitment continued until saturation occurred (i.e., consensus of the research team that no new information was emerging in the focus groups) (Charmaz, 2001; Glaser & Strauss, 1967; Strauss & Corbin, 1990). In order to participate in the focus groups, interested participants had to speak English, be at least 65 years old, and have adequate cognitive abilities. Subjects were screened for cognitive ability over the telephone using the blind-Montreal Cognitive Assessment (MOCA) (Nasreddine et al., 2005). Participants were deemed eligible if they scored $\geq$18 of a possible 22 points, as this cutoff score is considered normal cognition (Nasreddine, Rossetti, & Phillips, 2012).

2.2. Data collection

A semi-structured focus group protocol was designed to elicit participants' views and experiences of their future health care options and support needs, including discussion of plans they have made for their future specifically related to their health. Focus group sessions began with introductions of the moderators (KAC, LAL) and the informed consent process, approved by the Northwestern University Institutional Review Board, which included consent for digital recording of the group discussion to reduce the need for note taking and to facilitate analysis. Participants completed a brief anonymous socio-demographic questionnaire prior to start of the focus groups. The discussion guide (Appendix A) used open-ended questions and probes were used to both clarify responses and engage less vocal participants. Following completion of the group discussion, participants were given a $50 gift card as compensation for their participation in the two hour long focus group. The composition of the focus groups ranged from 4 to 12 participants.

2.3. Data analysis

Digital recordings of the focus groups were transcribed verbatim by an external company and checked by two co-authors (PDS, VRZ) for accuracy. Personal identifiers were removed and the transcripts were then uploaded into NVivo10 for analysis. Transcripts were analyzed by three authors (a communication scholar, a geriatrician, and a public health professional) using content and constant comparative techniques (Nasreddine et al., 2005), through which the coders (KAC, LAL, VRZ) independently assessed participant responses for focal themes before convening to compare and compile their findings to create a preliminary list of categories and major themes. The coders met multiple times to discuss and refine the identified themes and triangulate their perspectives. Identified discrepancies were resolved through discussion; there were no cases in which the coders were unable to reach consensus. The coders then organized the content into an overarching categorical system. It is common to use multiple coders in the development of such categorical systems to control for the subjective bias each coder brings to the analytic process (Cameron et al., 2009; Lincoln & Guba, 1985). From these overarching categories, the coders reached agreement on themes that were particularly relevant to participants' discussions of what was termed "advanced life events" (ALEs). Descriptive statistics were used to analyze the participant surveys.

Table 1
Participant characteristics ($n = 68$).

Characteristic	Value
Mean age, years (sd)	73.8 (6.5)
Female (%)	72.1
Marital status (%)	
Married	30.9
Never married	11.8
Widowed	23.5
Divorced/separated	29.4
Did not respond	4.4
Education level (%)	
Some high school, did not graduate	8.8
High school or GED	14.7
Some college (1–3 years)	26.5
College graduate (4 years)	19.1
Higher degree (5+ years)	25.0
Did not respond	5.9
Employment status (%)	
Retired	83.8
Working	4.4
Unemployed, looking for work	2.9
Other	4.4
Did not respond	4.4
Current residence (%)	
Home in community (apartment, house, condo)	70.6
Retirement community (independent living)	8.8
Other	16.2
Did not respond	4.4
Area of residence (%)	
Urban	70.6
Suburban	17.6
Rural	5.9
Did not respond	5.9
Importance of religion (%)	
Not at all important	8.8
Not very important	7.4
Somewhat important	14.7
Very important	30.9
Extremely important	32.4
Did not respond	5.9
Driving status (%)	
Yes	67.6
No	26.5
Did not respond	5.9