Published in final edited form as:

Arch Gerontol Geriatr. 2016 ; 64: 90–95. doi:10.1016/j.archger.2016.01.004.

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

Lee A. Lindquist^{a,*}, Vanessa Ramirez-Zohfeld^a, Priya Sunkara^a, Chris Forcucci^b, Dianne Campbell^c, Phyllis Mitzen^d, and Kenzie A. Cameron^a

^aDivision of General Internal Medicine and Geriatrics, Northwestern University Feinberg School of Medicine, Chicago, IL, USA

^bAging and In-Home Services of Northeast Indiana, Fort Wayne, IN, USA

^cLincoln Park Village, Chicago, IL, USA

^dSkyline Village, Chicago, IL, USA

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 health 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 in uncles, 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)

Keywords

Aging in place; Home care; Older adults; Qualitative

*Corresponding author at: Division of General Internal Medicine and Geriatrics, Northwestern University, Feinberg School of Medicine, 750 N. Lake Shore Drive, 10th floor, Chicago, IL 60611, United States. Fax: +1 312 503 2777. LAL425@northwestern.edu (L.A. Lindquist).

Conflict of interest
None.

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 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, stake-holders, 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 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.

3. Results

Sixty eight adults with ages ranging from 65 to 87 (with a mean age of 73.8 years, $sd \pm 6.5$) participated in one of the eight focus groups (Table 1). A majority (72.1%) of participants were female. Regarding education, 8.8% had some high school education, 14.7% were high school graduates, 26.5% reported some college education, 19.1% were college graduates, and 25.0% had obtained some postgraduate education. A majority of focus group participants reported residing in the community (70.6%) as well as living in an urban setting.

3.1. Advanced life events themes that have an impact on independence

When asked, “Why do people move out of their homes as they get older?”, older adult subjects perceived that five specific ALEs would impact a senior’s ability to remain independent at home: (1) Hospitalizations, (2) Falls/Functional Loss, (3) Dementia/Cognitive Loss, (4) Spousal Illness or Loss, (5) Home Upkeep Issues (Table 2).

3.1.1. ALE #1: Hospitalization—Many subjects had personal experiences with or had acquaintances/family who had been affected by a hospitalization. In describing personal experiences, participants described being unprepared for their needs at home following a hospitalization, rehabilitation stays at care facilities (e.g., “nursing homes”), and dependence on multiple people (e.g., friends, families, therapists, caregivers).

3.1.2. ALE #2: Falls/Functional Loss—A fall was seen as an event that had a strong possibility of ending participants’ ability to remain in their own home. A few subjects felt that a fall would mean sudden death. Others had actively moved to a home that would be easier to navigate, for instance on one level, in an attempt to avoid a potential fall.

3.1.3. ALE #3: Dementia/Cognitive Loss—Subjects were deeply aware of the effects of Alzheimer’s disease and the impact that memory loss had on maintaining independence. Many had personal experiences caring for a parent, spouse, or friend. The trend was for subjects to have seen someone worsen from dementia and have to be placed in a nursing home, which was viewed negatively.

3.1.4. ALE #4: Spousal Illness or Loss—A theme emerged among subjects who had partners or spouses that loss of a spouse would make living independently difficult or impossible. Pairs living together had created a symbiotic relationship—one had may have impairments (e.g., physical), which were reciprocal to the other’s impairment (e.g., cognitive). Disparities in age also aligned with this theme; with some couples noting that a younger spouse was able to help an older spouse. It was stated that if the younger spouse developed illness or was deceased, the older spouse would be unable to remain at home.

3.1.5. ALE #5: Home Upkeep Issues—In the absence of additional help, subjects foresaw that inability to perform home care (e.g., lawn-mowing, shoveling snow, household maintenance) would necessitate leaving the home. Specifically in rural areas, the additional inability to use or maintain their car was perceived as a likely reason for them to be unable to remain in their home.

3.2. Lack of planning and rationale for not planning for ALEs

After readily identifying these ALEs, participants predominantly described a lack of planning for them. However, many participants voiced their belief that they had “sufficiently” completed end-of-life documentation, including wills, trusts, power of attorney, and funeral arrangements. Several participants stated that their families and loved ones would take care of any issues with ALEs for them, but, when asked, noted that they had seldom, if ever discussed these issues with their loved ones.

Subjects were subsequently probed for their rationale for the lack of planning for ALEs. The emergent themes included: uncertainty over future, being too healthy or too sick, offspring influences, denial and procrastination, overwhelmed and perceiving a lack of options, financial concerns, and pride.

3.2.1. Rationale #1: uncertainty over future—Participants often expressed difficulty understanding how they should plan for their future ALEs. They readily identified specific issues and ALEs, but perceived there was too much uncertainty in knowing if any of the ALEs would occur, which led them to believe themselves to be unable to plan. Although many participants reported having dealt with uncertainty in their lives (e.g., living wills decisions, financial, relationships), they appeared to believe that planning for future home care needs posed too much uncertainty and thus felt unable to adequately plan, or to even begin to plan at all.

“I mean, you know, you just you don’t know until it happens. That’s what’s so terrifying about it. I mean it could be, you know, anything from just come over and talk to me for a while to I can’t do anything by myself anymore.”

“I think the problem is that you never know ... you don’t know what’s coming down the road.”

3.2.2. Rationale #2: being too healthy or too sick—Some subjects reported that they did not feel the need to plan, citing that they were too healthy and did not feel that any of these events were imminent. Alternatively, other subjects who experienced the most disability and comorbidities felt that they were “too sick,” and thus did not feel the need to plan for a future they did not perceive to be long-term.

“Both of us are in fairly good health right now, so we’re not worried, but we also know that tomorrow that could change drastically.”

“So, I’m on borrowed time. So I’m not going to worry about where I’m going to go for my old age because I don’t think I’m going to have one.”

3.2.3. Rationale #3: offspring influences—Participants frequently expressed reliance on offspring for navigating ALEs, although many stated that they had not discussed their current or future needs with their offspring. In addition some of the participants who had tried to discuss their future care needs with offspring reported having experiences where their offspring indicated they did not want to talk about the need for future care.

“I have a daughter who works in the field and she said, ‘Oh no, you’re much too old to start becoming demented now. Don’t worry about it. You’re not going to get Alzheimer’s’ and I have such relief so whether it’s true or not, I’m freed.”

“You know, like I don’t have a way to discuss that too much with my daughter because she doesn’t want to hear it.”

3.2.4. Rationale #4: denial and procrastination—Although readily able to identify ALEs, many subjects did not believe that they themselves would be affected by an ALE in the near future and had plenty of time to consider their future. Several subjects were hoping to die in their own homes suddenly which would preclude the need for support or planning.

“The new 70 is the old 58!”

“I think what I would prefer would be just to drop dead, but who’s that lucky, you know?”

3.2.5. Rationale #5: overwhelmed and perceiving a lack of options—Many participants were overwhelmed with the idea that they may need assistance in the future. Several had amassed a large collections of prized objects and felt overwhelmed at the thought of adapting to their future needs. Some participants seemed to express their beliefs that there were no good choices for their future so why bother planning.

“My time is coming when I’ll have to go someplace else. I will have to give up a lot of things, but I look around my home and think oh my goodness, I have several collections, three collections of clowns and owls and elephants.”

“I checked out every nursing home in [my area]. Some of them I walked right back out—They smelled so bad.”

3.2.6. Rationale #6: financial concerns—Multiple participants noted their concerns that they would not be able to afford their needs in the event that an ALE occurred to either them or their loved one. Acutely aware of the increasing costs of being dependent on help, participants worried about outliving their retirement savings. As a result, some participants reported their choice not to plan. This lack of planning appeared to arise from the perception that if they could not afford help in the future, why should they try to plan for their future.

“I was so young that I didn’t realize you had to start early for long-term care so now it is so expensive that I can’t afford it. So I pray that I will die in my sleep because the other alternative isn’t going to be good.”

“I would like to move to a senior citizen center and I start to look at the prices but it so expensive that I may as well stay in my home.”

3.2.7. Rationale #7: pride—If an ALE occurred, participants stated that they would feel too proud to ask for or accept help. Although participants thought that they would ask for help or “accept charity” when they experienced an ALE, many did not feel that this was a pleasing task and did not want to consider it.

“When you’re a sharecropper you never will get out of debt because people keep putting you more and more in debt. I think people from that background kind of are still skeptical of taking handouts ... But we never was allowed to take anything, that’s pride, you don’t take handouts.”

“But one of the fears I have, I have never accepted any charity from anybody.”

Throughout the focus groups, seniors exhibited unrealistic expectations about their future. While many subjects wished to die in their home, one astute senior asked, “We all want that, but what happens when we do not? There is a chance that we won’t die in our home—what then?” Making their future even more complicated, some seniors stated: “I would not want to go to a nursing home and I would not want to live with anybody. I want to be independent and live on my own.” These expectations make it difficult for realistic planning and for decision-making by offspring and loved ones in the future.

4. Conclusion

For many older adults, the ability to remain independent in their own homes is jeopardized by ALEs that occur with their health and in their lives. Many health care providers care for older adults, who, depending on their health, may teeter on a cliff between remaining independent in their own home and needing in-home assistance or relocation to a supportive facility. It usually takes one critical event to send older adults over the edge and dependent on others or removed from their home. Through focus groups, we identified five advanced life events (ALEs) that older adults perceived would affect their ability to remain independent at home: (1) Hospitalizations, (2) Falls (3) Dementia, (4) Spousal Loss, and (5) Home Upkeep Issues. Similar to our older adult subjects, most people in the health care community recognize that these ALEs occur frequently to older adults.

Despite awareness of these ALEs, the older adults in our sample overwhelmingly had not planned for the possibility of any occurring to them. Many older adults had completed planning for end-of-life, through living wills, power of attorney, and Physician Orders for Life-Sustaining Treatment (POLST/POST) documentation, showing the strides made through the hospice and palliative care community. While they plan for their end of life, older adults do not consider their “Fourth Quarter”—the time period from 65 to 80 plus years that involves increasing disability, hospitalizations, and/or progressive cognitive impairment.

In our sample, older adults discussed multiple reasons for their lack of planning for ALEs. Some felt that they had no idea on what to plan for as they perceived so much uncertainty regarding their future. Others felt that they were too healthy, although health care professionals may recognize that any of these ALEs could happen at any time to any older adult. Among those who felt that they were too sick or living on “borrowed time,” these older adults could arguably benefit the most from planning as they were closer to requiring assistance. Identified rationales for not planning for future ALEs did not only center on seniors. Several seniors had attempted discussions with family members and loved ones about their future needs. People reported that some offspring had evaded the conversation with close-ended responses (e.g., *You are fine*). This reluctance may stem from offspring and adult children’s unwillingness to acknowledge that their parents are aging. Likewise,

offspring may be apprehensive about the potential burden that they may incur as their parents age. Financially speaking, many older adults in our sample were concerned about planning for their future, particularly if they believed that they had insufficient funds. Finally, pride was identified as a common barrier seniors identified, as they noted they felt too proud to seek help in the future.

As this project was funded by Patient Centered Outcomes Research Institute, a strength of this research was the patient-centeredness and patient engagement. Participants were recruited by community-based patient partners and stakeholders, outside of the research institution. This strategy meant that participants in our sample were truly reflective of people in the community and included many who had never previously participated in research. Older adults spoke out first-hand about their concerns for their ability to age in place and provided numerous reasons to explain why they were not planning for their concerns. A limitation of this study is the predominance of female participants in the focus groups; it is unknown whether or not inclusion of a greater number of male participants would alter final study results. As qualitative methods were used, it was not possible to identify whether or not the frequency or magnitude of the views expressed may differ by sex. However, specific ALEs were identified and discussed by both male and females in our sample. Furthermore, while our participants were diverse in SES, race, urban/rural locales, all of the study sites were in the Midwest. It is unclear if results would differ if a nationally representative sample (e.g., West Coast, East Coast, Southern) was utilized.

Looking toward the future, the “Fourth Quarter” when ALEs occur, requires more planning, research, and interventions so that aging baby boomers and their families are prepared for their growing home needs. The business world has developed long-term insurance and retirement planning so that seniors are financially prepared for their Fourth Quarter needs. The healthcare world lags in handling the lifespan needs of the baby boomer population in their goal to age successfully in place. Our results examine the health events that people must plan for—all of which are readily a part of geriatrics care. Internists and geriatricians can lead Fourth Quarter planning through educating patients about their needs so that they are prepared. It is now increasingly possible for older adults to age in place instead of in institutional settings, provided that they have appropriate support to do so.

The next steps from this research is to provide seniors and their families with education about their health trajectory and assist them with planning and anticipating their future support needs. Our team is currently creating a tool to aid seniors and their families in this planning so that seniors will be able to make informed decisions about their future. It also will provide seniors information (e.g., options for service organizations, physical therapy, meal programs) that they can use to enable them to remain in their own homes in the event that these issues arise.

Ultimately, this is the first study which readily identified ALEs, voiced by seniors themselves, which would impact the ability of older adults to remain in their own homes. Few seniors perceived that these events would occur to them and had not planned for them. The rationale that subjects provided for not planning can help providers tackle assisting their seniors with planning. 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).

Acknowledgements

Research reported in this article was funded through a Patient-Centered Outcomes Research Institute (PCORI) award for Improving Health Care Systems, entitled Advanced Planning for Home Services (PI: Lindquist). All statements in this report, including its findings and conclusions, are solely those of the authors and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute (PCORI), its Board of Governors, or Methodology Committee. Additionally, the authors would like to thank the stakeholder partners and seniors who contributed their time and effort.

Appendix A. Discussion guide

During this discussion we will frequently ask questions related to your home. By “home” we mean a house, apartment, or condominium where you live by yourself or with other friends or family members. When we discuss “alternative living arrangements” these could include places such as an independent living arrangement that would give you the option of having stepped care if needed as you age.

Planning

1. What types of plans have you made for your future related to your health?
2. As your health changes, have you thought about what changes you may need to make regarding where you live?
3. How many of you have had conversations with others about these living plans?

[Probes]

- a Who have you had those conversations with?
- b What have been the greatest benefits to you from having conversations with others?
- c What has been the hardest part for you of having those conversations, that is, what would you say are the biggest barriers to having these conversations with others? How has that made you feel?
4. Do you share these concerns of your families and friends? What are you concerned about happening to you in your home?
5. People talk about the fear of losing independence. Why do you think people are so fearful?

[Probes]

- a Do any fears come to mind for you when you think about leaving your home?
- b Do any fears come to mind for you when you think about staying in your home?

6. How do you think seniors can overcome this reluctance to accept help or fear of becoming dependent?

[Probes]

a Many of us know seniors who need help but refuse it. What can one do to convince reluctant seniors to accept help in their own homes?

Decision-making

7. Has anyone made a decision either to stay in your own home (long term) or move somewhere else in the future?

8. For those of you who have decided to leave your home, what were the factors that led to that decision?

[Probes]

a What was most helpful to you in making that decision?

b What was the hardest part about making that decision?

9. What types of events do you think would cause you to consider changing your current living environment?

Resources

10. What services do you think people might need to help them live safely in their home?

a Have you ever used these services previously? What was your experience? How did you access these services?

b What information would be helpful to you if you feel you need to access these services?

c Do you think you are prepared?

Closing/thank you

Does anyone have any other thoughts they would like to share regarding our discussion?

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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

Characteristic	Value
Did not respond	5.9
Driving status (%)	
Yes	67.6
No	26.5
Did not respond	5.9

Table 2

Advanced life events and supporting quotes.

Advanced life event	Supporting quotes
Hospitalization	<p>"I was in the hospital for a month ... in a rehabilitation place for two more ... I couldn't walk. I couldn't do anything ... by the time I was conscious enough to be aware of what was going on, I was so horrified ... I thought I'd rather die than live like this"</p> <p>"I was running around, walking, retiring, ready to face the future ... and then I had a stroke. It completely changed my life 180 degrees. I went from someone who had worked all my life, raised two children by myself, worked, took care of mom, and then I went to this person who all of a sudden I'm laying in a hospital in a rehab hospital, and little 18-year-old girls are coming up to me in my face and you didn't do this right or you didn't ... no, you can't"</p>
Falls/Functional Loss	<p>"I have lived in the same walk up ... for 30 years ... I've done various things with falls ... I'm up and down the stairs, but I know it's going to happen quick ... it won't be a slow thing"</p> <p>"If you would fall there's no one here to take care of you, and so I moved into my first apartment. I hadn't been in an apartment [since] the time I was about 20 years old. That was a little scary"</p>
Dementia/Cognitive Loss	<p>"My dad had Alzheimer's ... but my mother never could get herself to really realize that he had Alzheimer's ... she had to put him in a nursing home ... and she just never got to the reality of her husband"</p> <p>"She slipped into the Alzheimer's (so) I had to start having people come in in the afternoon and till I could get home from work. Then she started trying to get out at night, and I was waking up at midnight, and all of a sudden I had to make the decision"</p>
Spousal Illness or Loss	<p>"My wife and I both have long-term healthcare insurance, and we are beginning to think about what happens if one of us becomes disabled or ill ... we have begun to examine or look into retirement homes"</p> <p>"My husband came up the first week (after my stroke) and said I want a divorce. I don't want to be married to a crippled woman ... I said you get out of my room. You will get your divorce, and he run out like a little rat. Well, all he did was just make me mad and I just worked harder... and I thought I am going to walk. I'm going to at least walk. I can't do anything about my hand but I am going to walk. I had them sell my home because they said, oh now, you can't live alone"</p>
Home Upkeep Issues	<p>"I live in a home and I think my biggest problem is planning on caring for the house while I'm in it like when the light in the furnace goes out, it gripes me that I don't have someone there to come in and fix it"</p> <p>"... but being in the rural area, then transportation is a major because there will be a day when my daughter will say I'd like to have your keys, please"</p>