

Qualitative Evaluation of a Future Care Planning Program

Abstract

We describe efforts to evaluate the impact of the Future Care Planning (FCP) program. To gain deeper understanding of the context and needs of older adults who attended FCP sessions, we conducted follow-up telephone interviews and a qualitative content analysis of the structured interview calls. We identified areas for which Extension can provide continued support, positive programming impacts, and recommendations for future programming. We discuss how our findings will be used for future efforts addressing the topic for older adults and the implications of our findings and method for others in Extension.

Keywords: [older adults](#), [end of life](#), [future care planning](#), [aging in place](#), [content analysis](#)

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Introduction

The share of the U.S. population aged 65 and older has grown strikingly over the past century, and this trend is projected to continue for several decades (West, Cole, Goodkind, & He, 2014). This demographic trend indicates that Extension professionals will need to generate more aging-related programming. The majority of older adults would prefer to age in place and receive at-home care (Wiles et al., 2011), but most have not made concrete plans regarding their future health care and desire to age in place (Peek & Bishop, 2016). As Extension plays an increasing role in enhancing health care knowledge among older adults and facilitating aging in place, it is imperative that Extension educators include relevant comprehensive, research-based information and planning activities as part of the services they provide to communities.

To assist older adults with future care planning (FCP), we developed a program titled "Future Care Planning" (or "FCP"). FCP is a two-session structured educational Extension program for older adults independently residing in communities. The FCP curriculum focuses on health literacy, self-advocacy, and planning for future health care and at-home care. In particular, the program focuses on using self-advocacy skills in the health care setting, navigating health care decisions, preparing for health events, building social resources by communicating concerns, and attaining overall autonomy while navigating formal and informal resources in

the community (Seymour, Almack, & Kennedy, 2010).

Quantitative survey results from the pilot phase of the program indicated that participants experienced significant improvement in completing FCP activities (Lee, Kim, Peitz, Kahana, & Kahana, 2019). In addition, pilot testing suggested that the program is feasible for and acceptable to most participants and facilitators. However, participants' experiences with and perceptions of the program were not properly captured in the quantitative data collected during the pilot phase. Consequently, we sought to undertake a study of program participants based in participatory action research. We believe that both our findings and our method have important implications for Extension professionals.

Previous research has shown the benefits of participatory action research approaches for overcoming perceived failures of top-down and one-size-fits-all research (Fortune, Brown, Burwell, & Conlon, 2012; Stephenson, 2012). Intended to reduce barriers between researchers and the community, participatory action research, which could include qualitative responses from Extension program audiences, has been valued in Extension (Tritz, 2014). However, few efforts to use qualitative responses from participants after completion of a program have occurred. Instead, previous program impact evaluation efforts have relied heavily on data from surveys administered by facilitators immediately following a program. Although using only quantitative responses from participants and isolating subjective perceptions permits researchers to tabulate program results easily and report satisfaction or dissatisfaction, doing so may not be sufficient for addressing issues participants encounter during a program. Through qualitative analysis of feedback from participants of an Extension program, individual needs of participants can be addressed in further program development.

Purpose and Objective

The overall purpose of our study was to identify benefits, gaps, and needs relative to older adults who participated in FCP. In particular, we sought to explore the range of approaches, methods, options, and content used in the program. Thus, our objective was to learn the perspectives of participants regarding the benefits of the program and suggestions for the program.

Method

Eligible participants had to be 60 years or older, live in the community independently, and read and speak English. In 2018 and 2019, we recruited participants via county partners, public libraries, and senior centers. Participants who met the screening criteria ($n = 161$) were invited to attend the FCP program at a local Extension office or community senior center. Participants from eight counties were offered the educational seminar. After the two sessions of FCP, participants had the opportunity to provide their contact information in order to participate in a follow-up telephone interview.

Trained research assistants, who are members of our author team, conducted the follow-up telephone interviews with the older adults who had participated in the program and consented to the interview. Each interview lasted between 30 min and 1 hr. Detailed notes were taken during each interview. The interview protocol included three open-ended questions intended to elicit participants' evaluation of the program. Specifically, participants were asked to answer questions about continued assistance needs (i.e., how can we help?), program utility (i.e., what was useful?), and potential program improvements (i.e., how can we improve on the current program?). To analyze participants' responses to identify emerging themes, two undergraduate research assistants, blind to the study objective and supervised by a member of our author

team, conducted a conventional content analysis (Hsieh & Shannon, 2005).

Results

Profile of Participants

Demographic characteristics of our program participants are shown in Table 1. Mean age of the 161 participants was 78.2 years ($SD = 8.9$), and 122 participants (75.7%) were female. The majority (83.0%) were Caucasian; 12 participants (7.5%) were African American. Most participants (94.4%) had earned at least a high school diploma. Sixty-four participants (40.9%) were widowed, and 53 (32.9%) were married. In general, participants reported having good health ($M = 3.8$; scale ranged from 1, *poor*, to 5, *excellent*).

Table 1.
Demographic Characteristics of Future Care Planning Program Participants

Variable	%	<i>M (SD)</i>
Age		78.2 (8.9)
Gender		
Female	75.6	
Male	24.4	
Race/ethnicity		
Caucasian	83.0	
African American	7.5	
Others	9.5	
Education level		
Less than high school	5.6	
High school graduate	40.0	
1–2 years of college	30.6	
College graduate	11.3	
Postgraduate work	5.6	
Postgraduate degree	6.9	
Marital status		
Married	32.9	
Widowed	40.9	
Divorced	15.7	
Separated	0.6	
Never married	10.1	

Self-reported health^a

3.8 (0.75)

Note. *n* = 161. ^aScale ranged from 1 (*poor*) to 5 (*excellent*).

Continued Assistance Needs

When participants were asked about any continued assistance needed, they generated many ideas. In analyzing their responses, we identified two themes: *providing more information* and *no additional help needed*.

Responses aligning with the first theme, *providing more information*, included those related to the need for more information about FCP. In particular, respondents noted the need for information about creating living wills and making funeral arrangement plans. For example, one participant said, "I need help/more information on the [health-related] forms or living wills." Another said, "A checklist of things to do would be helpful, along with [information on] resources in the area." Respondents also expressed a desire for assistance with navigating conversations with family members and medical providers about their FCP preferences. For instance, one participant said, "I am planning on talking to my adult children regarding my future care. I may need information on what to say to help my children get quality care." Indeed, such information would provide participants with insights on how to approach these sometimes difficult conversations.

The second theme, *no additional help needed*, emerged from responses from participants who did not need more assistance with FCP. These participants said things such as "no need" or "I think I have it pretty well covered." Sometimes participants elaborated further on this response by mentioning that other family members were "taking care of" their FCP needs (i.e., completing the necessary FCP activities on their behalf). Others stated that they were already prepared. These responses indicated that some participants already had taken initiative and completed most of the FCP activities addressed in the program before participating in the program. Finally, others expressed some resistance toward receiving specific help from the program and mentioned their desire to seek out assistance from other sources (e.g., lawyer, medical provider), reflecting that they were still contemplating future care activities recommended by the program.

Program Utility

Next, participants were asked to provide feedback regarding how useful the program was to them. In our analysis of these responses, three themes emerged: *practical tips for navigating future health-related scenarios*, *increased self-awareness*, and *empowering a sense of self-advocacy*.

The first theme, *practical tips for navigating future health-related scenarios*, included responses about how the program had assisted participants with preparing to undertake FCP activities. Useful topics included tips for going to the doctor's office, information on resuscitation orders, suggestions for making lists of medications, answers to health- or FCP-related questions, and assistance with medical resources and information. For instance, one participant said, "Helpful things were the cards with lists to put in emergency bags, prescription forms to post, and conversation starters." Responses such as this acknowledged that the program provided a valuable opportunity for learning how to locate nursing home resources and navigate conversations with doctors.

The second theme, *increased self-awareness*, revolved around the need for FCP. Participants found the FCP program to be a good reminder regarding FCP tasks they already had completed and those they had yet to do. The program made FCP more topically salient and reinforced the urgency of having one's preparations in place. For instance, one participant said, "It refreshed a lot of things that I knew but wasn't doing." Thus, respondents found the program to be helpful because it made them more apprised of financial issues and deficiencies that could hinder their future care and highlighted the importance of having an infrastructure of trusted people in place to ensure that their personal future care wishes would be respected and carried out. Ultimately, the program opened participants' eyes to the significance of prioritizing FCP.

The final theme, *empowering a sense of self-advocacy*, revolved around the confidence and drive to take control of one's own FCP activities and articulate personal wishes to family and friends. We found this theme to be distinct from self-awareness because it emphasized the need to "be one's own advocate" and assert the personal control that ensures that one's FCP needs are respected. One participant said, "I really needed prodding and information to do this. It was helpful." Specific helpful topics mentioned by participants included planning, remaining prepared and organized, and developing emergency packing lists. Participants also described the need to engage in conversations with various individuals (e.g., attorneys, family caregivers, doctors). Thus, these topical areas of the program helped older individuals feel a greater sense of confidence and empowerment about FCP.

Potential Program Improvements

Finally, participants were asked to respond to the question "How can we improve upon the current program?" Two themes emerged: *more practical resources and inclusion of a guide for end-of-life planning and information or program is not currently relevant*.

The first theme, *more practical resources and inclusion of a guide for end-of-life planning*, stemmed from responses expressing a desire for more user-friendly materials. Specifically, individuals mentioned the need for information about making funeral arrangements and establishing living wills as practical steps they needed to take to enact their own FCP. One participant said, "Talk more about the power of attorney and living will." Participants also expressed a desire for future training to include real-world examples about how to apply the information they received in the program. One participant said, "Possibly have real-life examples that are good and bad." Essentially, respondents indicated that inclusion of specific action items and assignments for individuals to abide by when conversing with family members or medical providers would have been perceived as more helpful than some of the information that was presented. Finally, participants expressed wanting the program to continue and offered suggestions for future iterations, such as "more meetings," "maybe a refresher course," and "more information given over a longer period of time."

The second theme, *information or program currently not relevant*, centered on the idea that the program did not contribute to participants' knowledge of their own FCP. These participants mentioned that they already had a plan in place or that the presentation did not provide them with any "additional" information. One participant said, "We have done most of these things already." Some participants also expressed that FCP was not relevant to their current life stage and that, therefore, the program was not helpful. Finally, other participants did not provide additional commentary supporting their responses surrounding the program's efficacy, simply stating that "the program was not helpful."

Discussion and Implications

Our study served as a method for identifying benefits of, gaps in, and future directions for the FCP program. The themes we identified are similar to findings previously identified by researchers on the need for more education for older adults about FCP and the need to apply behavioral steps to make concrete behavioral changes (Fried, Bullock, Iannone, & O'Leary, 2009; Kahana et al., 2019).

A major strength of our study was that we obtained data directly from older adults who had participated in an Extension program offered in a variety of senior living communities. These individuals had an opportunity to describe their program experiences in their own words at least 1 week after attending the program. Our qualitative interviews provided an in-depth understanding of participants' experiences with the program and their preferred learning outcomes.

Our findings exemplify the need for researchers and practitioners to fully understand different stages of FCP among older adults. As noted in the findings related to potential program improvements, some participants did not consider the information or program materials to be relevant to their needs. When probed by the interviewers, some participants noted that they had already completed most of the relevant legal and financial arrangements before attending the program. On the other hand, some participants expressed a desire for more sessions to learn about FCP activities. This information confirms that older adults are in different stages of FCP (Sörensen, Mak, & Pinqart, 2011). One way of addressing this circumstance would be to assess older adults' existing levels of planning and provide individualized programs depending on one's level of preparedness (Sörensen et al., 2011).

Our findings suggest that considering future care needs of older adults may provide the opportunity for Extension professionals to offer more aging-related programming (Peek & Bishop, 2016).

A final implication of our work is that the qualitative interviews we have described could be used to evaluate Extension programs in areas beyond FCP. Extension professionals who are using quantitative surveys to evaluate their programs may also wish to include a qualitative aspect to their evaluation plan that captures the richness of participants' experiences and perspectives on program improvement.

Conclusion

The stories and statements previously described provide evidence that participants completing FCP sessions develop a new perspective and understanding of FCP. Participants described an increased awareness of FCP and personal realization of the need for change to prepare for any future health events, such as hospitalization. Our findings will be used as background support to improve future programming efforts, such as by providing more resources to older adults (e.g., information on community resource exploration, informal care arrangement), reaching a broader audience that includes individual who are not as far along with FCP, and personalizing FCP programming for older adults according to their existing planning stages.

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