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Advance Directives and End-of-Life Care: Completion, Conversations, and Concerns of Burlington Housing Authority Residents

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Completion, Conversations, and Concerns of Burlington Housing Authority Residents

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Introduction

- An Advance Directive is a document that allows patients to declare their wishes regarding medical care and decision making should they become unable to communicate their preferences due to an accident or illness.
- The Patient Self Determination Act, passed in 1991, requires that health care institutions, such as hospitals and nursing homes, inform patients of their rights to make health care decisions, the hospitals policies regarding recognition of Advance Directives, and educate the staff and community about advance care planning.
- Despite the passage of this legislation, completion of Advance Directives remains low. It is estimated that less than 25% of adults nationwide have completed an Advance Directive (1).

Objectives

- The objectives of this project were to:
- Determine rates of Advance Directive use by residents living in Burlington Housing Authority complexes.
 - Identify barriers to completion of Advance Directives and interventions that might help with end-of-life care planning.
 - Assess attitudes and concerns about end-of-life care.
 - Increase knowledge and awareness of Advance Directives.

Methods

Participants: Study participants were individuals currently residing in three Burlington Housing Authority (BHA) apartment complexes located in downtown Burlington, Vermont.

Survey: An anonymous five item survey about experiences, barriers, and concerns related to end-of-life care and Advance Directives was drafted (2). The survey was distributed door-to-door in each of the BHA Complexes. Additional surveys were distributed at one-hour educational sessions in each of the buildings to participants who had not previously completed the survey. Surveys were collected by the wellness coordinator in each building and at the educational sessions. A total of 43 surveys were collected.

Data: Data were compiled and analyzed based on number or percentage of responses using Microsoft Excel software.

Results

Table 1: Demographic Information of Survey Respondents

Respondent Demographics		n=43	%
Age	18-39	2	5
	40-54	6	14
	55-64	13	30
	65-74	14	32
	75-84	5	12
Gender	85+	3	7
	Male	12	28
	Female	31	72
Education	Less than High School/GED	6	14
	High School/GED	20	46
	Associate's degree	9	21
	Bachelor's degree	6	14
	Post-graduate degree	2	5

Figure 1: AD Completion Rates **Table 2:** Improving Completion Rates

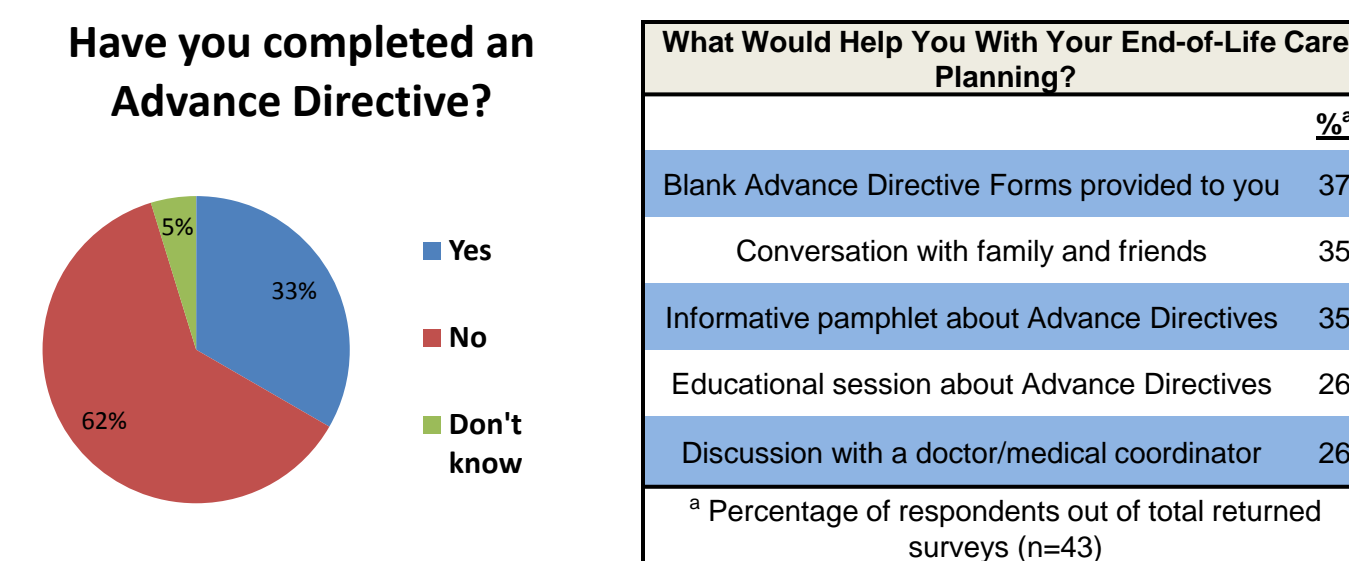


Table 3: Barriers to Completion of Advance Directives

Barriers to Completion of an Advance Directive (AD)		% ^a
I have never heard of this (an AD) before	19	
I haven't gotten around to it / too busy	19	
My doctor never brought it up	14	
I am in the process of completing it now	12	
Some other reason	12	
Someone else will take care of it	5	
Too upsetting to discuss with family / friends	5	
The document is too hard to understand	2	
I am too young to need it now	0	
Too upsetting to discuss with my doctor	0	
I don't understand why I should complete one	0	

^a Percentage of responses out of total returned surveys (n=43)

End-of-Life Discussions

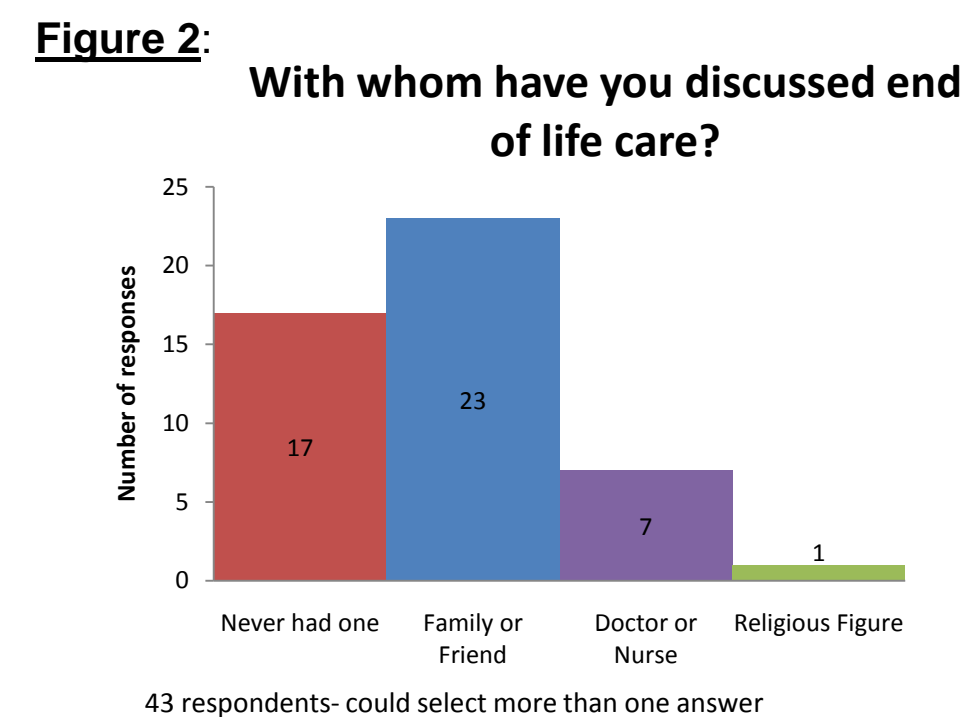


Figure 3: When was your last end-of-life care conversation?

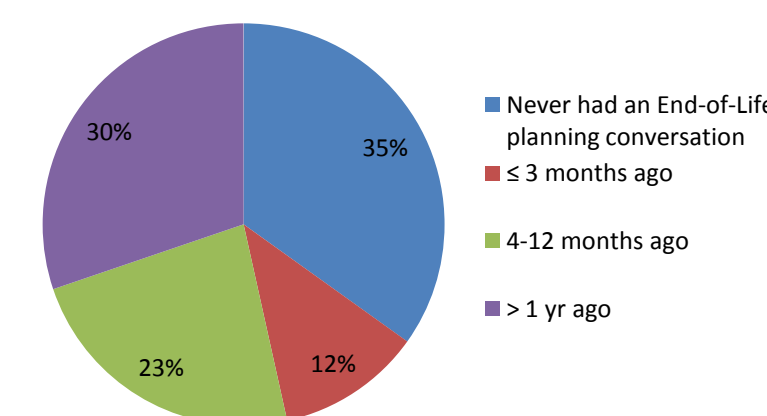
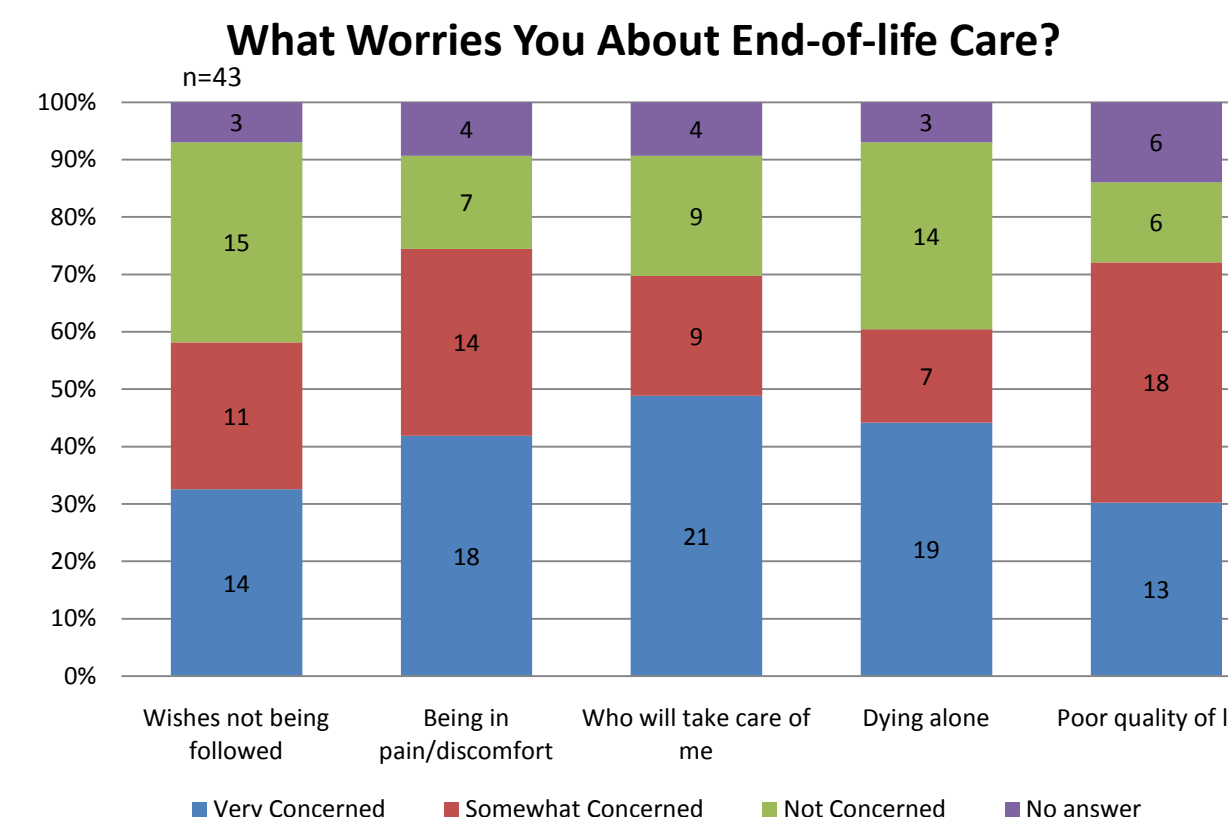


Figure 4: Concerns About End-of-Life Care



Discussion and Conclusions

- About 1/3 of participants had already completed an Advance Directive; the majority had not.
- The most common barriers to Advance Directive completion were lack of knowledge about Advance Directives, being too busy to fill one out, and that health care providers had not broached the subject. Only 16% of respondents had ever discussed end-of-life care with their health care provider, and 26% reported that a conversation with their doctor would be helpful for their advance care planning.
- 35% of participants had never had an end-of-life care conversation while an additional 30% had not discussed it in the past year.
- 35% of respondents indicated that more information about Advanced Directives would help them and 26% requested educational sessions..
- The vast majority of participants have significant worries about end-of-life care regardless of whether they are having end-of-life conversations.
- The results of our survey may not be representative of the surveyed population due to a low response rate, n= 43, and possible selection bias such that people with some previous knowledge of Advance Directives may have been more likely to fill out the survey distributed on this topic.

Lessons Learned

- Barriers to completing Advance Directives in this population are largely due to a lack of knowledge about what Advance Directives are.
- Providing information about Advance Directives should be the responsibility of health care professionals.
- Conversations about end-of-life care initiated by health care providers have the potential to help improve Advance Directive completion rates.

References

- 1) Salmond, S.W. and E. David. 2005. Attitudes toward advance directives and advance directive completion rates. *Orthop. Nurs.* 24:117-27.
- 2) La France SV, Solloway M, *et.al.* End-of-Life Care planning in New Hampshire: A statewide survey (2000).