



EMORY
LIBRARIES &
INFORMATION
TECHNOLOGY

OpenEmory

Assisted Living Administrators' Approaches to Advance Care Planning

Elise S Abken, *Emory University*

[Molly Perkins](#), *Emory University*

[Alexis Bender](#), *Emory University*

Journal Title: JOURNAL OF APPLIED GERONTOLOGY

Volume: Volume 41, Number 2

Publisher: SAGE PUBLICATIONS INC | 2021-01-27, Pages 391-400

Type of Work: Article | Post-print: After Peer Review

Publisher DOI: 10.1177/0733464820988803

Permanent URL: <https://pid.emory.edu/ark:/25593/vw79m>

Final published version: <http://dx.doi.org/10.1177/0733464820988803>

Accessed August 11, 2024 5:19 AM EDT



Published in final edited form as:

J Appl Gerontol. 2022 February ; 41(2): 391–400. doi:10.1177/0733464820988803.

Assisted Living Administrators' Approaches to Advance Care Planning

Elise S. Abken, BA¹, Molly M. Perkins, PhD^{1,2}, Alexis A. Bender, PhD¹

¹Emory University

²Birmingham/Atlanta VA Geriatric Research, Education, and Clinical Center

Abstract

Objectives: This project examined administrator processes, barriers, and facilitators for conducting advance care planning in assisted living.

Methods: Data from qualitative interviews with 27 administrators from seven diverse assisted living communities in the metropolitan Atlanta area were linked with descriptive and administrative data collected from each site and analyzed using thematic analysis.

Results: Although administrators generally contended with a lack of staff training and stakeholders' reluctance to discuss advance care planning and end-of-life care, important facilitators of advance care planning in some assisted living communities included periodic follow-up discussions of residents' wishes and successfully educating consumers about the importance of planning. Three study communities whose administrators discussed planning with residents and informal caregivers during regular care plan meetings had more advance care planning documents on file.

Discussion: These findings demonstrate the potential for non-medical organizations, such as assisted living, to successfully promote advance care planning among their members.

INTRODUCTION

Most Americans indicate they would prefer to die at home; for residents of assisted living (AL), that means dying in AL. As the population of the United States ages, nearly a million people currently live in 30,000 AL communities, which increasingly provide end-of-life (EOL) care (Ball, Kemp, Hollingsworth, & Perkins, 2014; Harris-Kojetin et al., 2019; Vandenberg et al., 2018). AL communities are state regulated non-medical care settings that provide room and board, and assistance with activities of daily living and instrumental

¹Nasreddine ZS, Phillips NA, Bedirian V, Charbonneau S, Whitehead V, Collin I, et al. The Montreal Cognitive Assessment, MoCA: A brief screening tool for mild cognitive impairment. *J Am Geriatr Soc.* 2005;53(4):695–9.

Corresponding Author: Molly M. Perkins, PhD, Associate Professor (School of Medicine) and Graduate Faculty of Emory Sociology, Division of Geriatrics and Gerontology, Department of Medicine, Emory University School of Medicine, 1841 Clifton Road NE, Atlanta, GA 30322, 404-728-6570, molly.m.perkins@emory.edu.

Conflicts of Interest

The authors declare no conflict of interest.

IRB

Emory University's Institutional Review Board approved the study (#00075456).

activities of daily living, such as assistance with medications. AL communities seek to help residents maintain independence and age-in-place, working to enable their residents to consider AL home (Vandenberg et al., 2018). Although AL communities are considered social-care institutions (in contrast to nursing homes, which provide skilled care), residents' aging-in-place necessitates their receipt of healthcare from external sources within and outside of the community. As AL communities are responsible for their residents' welfare, their staff increasingly coordinate resident healthcare, a role which is substantially supported by informal support from family or friends (Kemp, Ball, & Perkins, 2019). When residents approach EOL, AL communities play a key role in facilitating their EOL care (Arneson, Bender, Robert, & Perkins, 2020; Harris-Wallace et al., 2011).

Because AL communities manage care of dying residents, knowledge of their preferences for EOL is essential for quality EOL care. Approaching EOL, individuals may lose capacity for medical decision-making while still requiring medical care (Silveira, Kim, & Langa, 2010). The medical system's bias toward intervening to prolong life makes knowledge of individual's preferences for EOL care especially important (Brinkman-Stoppelenburg, Rietjens, & Van Der Heide, 2014). Advance care planning (ACP) is a series of conversations over time in which a person's preferences, values, and goals for EOL care are discussed with formal and informal caregivers, providing opportunities to share information about the individual's state of health and to explore and accept values and goals for healthcare at EOL (Levi & Green, 2010). In the United States, advance directives (AD) are the legally recognized vehicle by which individuals record and share their preferences for medical care, values during EOL, and choice of proxy decision-maker(s). They are used when someone has lost the capacity to make medical decisions and are only legally valid if completed in accordance with the states' legal codes (Silveira & Rodgers, 2017). In Georgia, rule 111-8-63-.24 requires communities to make copies of ACP documents, defined in Table 1, available to residents upon admission and throughout their residency upon request. Additionally, the communities must keep any completed documents in residents' files.

ADs are the legal record of ACP and the focus of state regulations in AL; however, ACP interventions facilitating multiple discussions over time focusing on ADs are more effective in aligning care with patients' preferences than simpler programs emphasizing form completion (Brinkman-Stoppelenburg et al., 2014). The Institute of Medicine (2015) supports this broader definition, emphasizing that successful ACP efforts treat it as an "ongoing process... facilitating discussion of values and preferences. It shifts the locus of planning from hospitals and physicians to the community and family."

AL communities are increasingly relevant community-based facilitators for residents' ACP; however large gaps remain in understanding ACP processes in AL. This paper addresses these knowledge gaps by investigating administrators' knowledge and attitudes toward ACP, the processes implemented to facilitate ACP in AL, and identifying barriers and facilitators to this process.

METHODS

Approach and Background

This project is part of a 5-year prospective, qualitatively driven study that employs grounded theory methods to investigate EOL care in seven diverse AL communities in the metropolitan Atlanta area from the perspective of residents, administrators, external healthcare workers, direct-care workers, and informal caregivers (i.e., family and friends). It aims to gain an understanding of all stakeholders' experiences related to residents' EOL, characterize the relationships between formal and informal caregivers, and describe the structures and processes which constrain and shape EOL care in AL communities. Quantitative data includes descriptive information collected on communities, residents, and other stakeholders as well as information abstracted from residents' files and health assessments conducted with residents over time. These data are used to describe the sample and characterize residents' EOL trajectories as well as provide context for the qualitative data. This analysis contributes to the aims of the larger study by examining the role of ACP in AL communities from the perspectives of administrators.

Data Collection

Data for this analysis come from three sources: administrator interviews (n=28), residents' file abstractions (n=100), and community profiles (n=7). Each community's executive director (ED) was interviewed as well as additional administrators with varying leadership roles (e.g., resident care managers and activity directors). One ED left during the study period and was replaced by a second ED who also completed an interview. Additionally, an admissions coordinator transitioned to ED during the study period and was subsequently re-interviewed. Interviews lasted 86 minutes on average and ranged from 30 – 172 minutes. Sampling a range of administrative roles resulted in variation in the time spent discussing ACP during each interview. Administrators who were more involved in admissions or direct care (e.g., EDs or resident care managers) generally discussed ACP in more detail than administrators who were further removed from care decisions (e.g., activity or floor manager). Similarly, our initial interviews in each community tended to be longer and cover more topics in depth than later interviews as we reached saturation on some topics and added new probes based on earlier interviews.

Domains addressed in the semi-structured interviews were informed by the study aims and included: information about each administrator's role, community policies and procedures (criteria for admission, discharge, and levels of care), information about staff and staffing, formal and informal care of residents, resident's EOL decision-making and ACP, general EOL care and EOL experiences, hospice use, and policies and procedures related to EOL care and resident deaths. Each administrator also completed a sociodemographic survey that included employment characteristics and specialized training in long-term care (LTC). In addition, each community's ED completed a community profile, detailing the history of the community, licensure, and staffing and resident characteristics. Researchers periodically reviewed resident participants' files and abstracted medical information pertinent to ACP, including independence in ADLs, medical diagnoses, medications, outpatient appointments, and hospitalizations.

Emory University's Institutional Review Board approved the study (#00075456). AL communities and all interview participants or their legally authorized representative provided written informed consent following a discussion about risks and benefits of participation. All key stakeholders in these settings were informed about the study through ongoing communication and could decline participation at any time during the study. We used pseudonyms to protect AL community and participants' anonymity. All study data were stored in a locked cabinet in a locked room or on secure servers.

Data Analysis

We utilized a thematic analysis approach (Braun & Clarke, 2006) to analyze these data. The primary author conducted the initial analysis by inductively approaching the study's set of administrative interviews, becoming familiarized with all the interviews by reading them twice through and proceeding to analyze the interviews. Based on notes taken during the initial reading, codes related to administrator process and attitudes toward ACP were created after this initial familiarization and assembled into a preliminary codebook. The codebook was refined during the initial coding of the interviews with NVivo 12 (QSR International) and in consultation with two senior qualitative researchers. Interviews were coded multiple times by the primary author; this analysis was reviewed by the full author team and any coding differences were reconciled to ensure rigorous coding. Themes (i.e., patterns salient to our research questions) were identified through comparison within and between codes which were developed, refined, and revised based on ongoing analysis and input from the full author team. Reading and rereading the interviews multiple times grounded the analysis of coded text in familiarity with the whole qualitative dataset until no new themes emerged and saturation was reached. Creation of thematic analysis tables, identification of sub-codes within a single code, matrix queries with NVivo 12, and word searches within the interviews aided the iterative process of identifying patterns and themes among the codes.

To inform the qualitative analyses and provide context for these findings, we used descriptive statistics to summarize the characteristics of administrators, communities, and resident participants as well as characterize ACP documentation across communities (Tables 2–5).

RESULTS

Descriptive Characteristics

While administrators had a wide range of educational attainment, all communities had administrators with at least a bachelor's degree (see Table 2). Six administrators had health professions degrees. Eighty-one percent of administrators were female, and the mean age was 44.

Table 3 shows the characteristics of the participating communities, including ACP documentation found in resident participants' community files. *Echelon* and *Solis* had the highest percentage of ACP documentation (i.e., indication of resident completion of any of the four document types). Six communities experienced multiple deaths in the year prior to

completion of their community profiles. Table 4 presents sociodemographic and functional characteristics of the 100 resident participants included in this analysis.

Results of Thematic Analysis

Similar values, knowledge, and practices regarding advance care planning.—

Administrators at all communities endorsed ACP as a safeguard for resident and family welfare during resident EOL, though no study communities included ACP in staff training. Administrators identified the do-not-resuscitate order (DNR) and healthcare power of attorney (HPOA) as the ADs most pertinent to community operations and overall had vague knowledge of AD completion among their residents.

Alignment of values regarding advance care planning.—

All 18 administrators who discussed ACP at length during their interviews agreed that ACP supported their communities' ability to provide quality care for residents by protecting resident autonomy and the welfare of residents and their families. The ED of *Sunbrite* emphasized that planning is especially important for "people who don't have family involvement." She said: "We need to know what do you want to do?" The admission coordinator at *Echelon* agreed with the role of ACP in protecting resident autonomy: "It's especially important when they have their faculties to make sure that whatever we have reflects what they would or would not want done to them." The EDs of *Parkside* and of *Solis* explained that planning protects resident and family welfare; they perceived decisionmaking "at the time of need" as more emotionally stressful for family members. In their opinion, having ACP in place protected family members from having to make painful decisions.

Administrators' descriptions of how planning protects families' welfare and residents' autonomy at EOL were reflected in their connection of ACP to a "good death." Four administrators explicitly listed ACP as contributing toward good deaths. The ED of *Solis* described how a lack of planning can lead to discord among family members. She said: "It's not everybody around mama's bedside, holding hands...it's everybody bickering out in the hallway about what they wanted, not what mom wanted." The resident care manager of *Summit Place*, the social services coordinator of *Echelon*, and the dementia care unit director of *Solis* all characterized a good death as being surrounded by loved ones and having care aligned with one's own wishes for EOL.

Prioritization of advance directives.—While administrators believed ACP to be generally important and some related planning to elements of a good death, 18 administrators, including seven EDs, stressed the importance of DNR status for their communities' operations, as DNR status directly impacts staff actions during a health emergency. Administrator's explained that if a resident does not have a formal DNR order, "they automatically get full code," obligating staff members to perform cardiac-pulmonary resuscitation (CPR) if a resident has no pulse or is not breathing until medical assistance arrived.

Fifteen administrators also noted the importance of knowing who the designated financial and HPOA is for their operations, and two communities, *Parkside* and *Fairhaven*, required designation for admission. Administrators explained that if a resident loses

capacity, they need to know who assumes financial and medical responsibility, because their communications must then be directed toward that individual. Additionally, they noted the importance of power of attorney designation for reducing family disagreement during medical decision making. However, the current ED at *Parkside* explained that having a single power of attorney makes the community reliant on effective inter-family communication. Poor family communication can result in administrators negotiating family dynamics when uninformed relatives call shocked at news of their relative's change in health status.

Conversely, ten administrators found the living will to be less directly applicable to their communities' operation. Administrators explained that as AL communities are not medical communities, these preferences become relevant only if residents are hospitalized. Since communities (except *Echelon*, a continuing care community) did not have medical personnel on hand, non-hospice residents with acute medical problems that could not wait for a physician's visit were sent to the emergency room for evaluation. DNR orders and other ADs were kept at the front of residents' files, and five administrators noted that ideally if a resident had a DNR order, this was communicated to the EMTs when they arrived. If a resident was admitted to the hospital, communities could provide the hospital with a copy of the AD if family members do not have another copy; however, beyond storing and potentially enabling appropriate outside parties access to a resident's AD, the contents of the living will itself were seen to have little impact on community-specific functions.

Seventeen administrators were asked about their familiarity with the Physician's Orders for Life Sustaining Treatment (POLST) form. Fourteen administrators were familiar with POLST to varying degrees and administrators at four communities knew of residents with POLST. Administrators at *Echelon*, which had instituted the use of POLST during intake a year prior, shared their opinions of its utility. The social services coordinator praised the form for its simplicity, saying that families have "a better understanding of it" compared to the DNR form, while the admissions coordinator worried that residents get mired in the details of the medical interventions it lists. The ED of *Solis* and the resident care manager of *Brookrun* associated its use with nursing homes, though the dementia care unit manager at *Solis* encourages residents to complete POLST on admission stating, "it's easier to get when they first come in."

Discrepancies between administrator report and resident files.—State regulations require AL administrators to ask for residents' ACP and make documents available. Administrators at the study communities perceived varying levels of ACP document completion among their residents, but their perception did not match findings from resident files. Table 5 includes qualitative data illustrating administrators' characterization of community documentation discussed during in-depth interviews and compares data drawn from community profiles completed by administrators to data collected from resident records. With the exceptions of *Solis* (not-reporting) and *Fairhaven*, all community EDs overestimated completion of ADs and/or designation of a HPOA.

Limited training in advance care planning.—Despite the requirement that AL administrators discuss ACP with residents, communities did not provide staff with training

in ACP. Although the former ED at *Parkside* said his staff did receive DNR training, the current ED who is also part of the same corporation did not indicate that staff receive this training. Administrators at *Solis*, *Fairhaven*, *Echelon*, and *Summit Place* indicated their communities offer standardized online continuing education modules which staff elect to take as part of their state-mandated 16 hours of required continuing education. However, none of the communities offered staff training in ACP, electively or otherwise. Four administrators cited previous employment experiences (i.e., hospice, nursing homes) or formal education (i.e., nursing or social work) as helpful to discussing ACP and EOL planning with residents, however those with less healthcare-oriented backgrounds (i.e., culinary school, business administration, human resources) were less fluent when discussing ACP.

Formation of goals and addressing barriers for improving advance care planning.—A key barrier was administrator and informal caregiver reluctance to discuss EOL. Important strategies for accomplishing ACP with residents included educating residents and informal caregivers about the importance of ACP and attending to emotional distress that EOL discussions evoke.

Discomfort with end-of-life discussions.—During their interviews, 15 administrators, including six EDs, described their goals and strategies for accomplishing ACP, often connecting ACP to EOL care in their communities. The current ED of *Parkside* said that EOL experiences for her residents could be improved by better timing of EOL conversations with residents and their families. She stated: “That’s a piece that’s challenging because sometimes it gets to be a little too late.” Similarly, the owner-operator of *Sunbrite* stated “I haven’t spoken with residents [about their mortality]... [but] it’s something that I think I need to do.” Administrators at *Summit Place* and *Brookrun* each identified discomfort discussing death with residents as contributing to lack of ACP and EOL-care discussions. The resident care manager at *Summit Place* described society generally as “scared” to have such conversations but disclosed that she would “like to have more of a conversation with the resident in the beginning” about goals for EOL care. *Brookrun*’s ED attributed the lack of ACP at *Brookrun* to her predecessor’s discomfort with the topic: “No one has articulated to the families what [lack of ACP] means for assisted living...that’s a missed opportunity... I don’t think that everyone is comfortable asking for that and explaining why it is important to have in place.” In support of her overall goal to better educate residents about planning, she hoped to improve staff training to develop better understandings of EOL care and ACP. She stated:

I would like for our staff to understand what [EOL] looks like, what residents may be exhibiting, how to engage the resident still, how to talk to families about what you may perceive or...comfort them...we definitely need training on [ACP].

Education and ongoing communication as important components of end-of-life care.—Despite the lack of staff training in ACP, 11 administrators emphasized their efforts to educate residents and informal caregivers about ACP and EOL care. Levels of understanding of the health and legal landscapes around EOL care varied among residents and informal caregivers of study communities. Administrators at *Summit Place*, *Echelon*,

and *Solis* described these consumers as knowledgeable of the importance of advance care planning, many having already completed documentation (*Echelon* and *Solis*) prior to admission. In contrast, the EDs of *Brookrun* and *Sunbrite* found their populations less aware of the importance of ACP.

To increase awareness of the importance of ACP, administrators at five communities identified education as a key component of EOL discussions. The ED at *Brookrun* stated: “The nurse and I are just amazed...people really don’t realize what happens in this community setting when you don’t have [ADs] in place.” To better promote ACP among residents this ED said that she assigned her “education nurse” to educate families about the need for ACP during “assessments and reassessments.”

In discussing EOL and ACP, 16 administrators described both as requiring attention to the emotional distress elicited by these discussions. The social services coordinator at *Echelon* described “[counseling] through” emotional blocks to ACP discussions and how regular care plan meetings help administrators work through emotional walls to create open communication and trust. *Parkside*’s current ED echoed a similar understanding and described the key role care plan meetings played in keeping all caregivers, both formal and informal on the same page regarding a resident’s health. Administrators at *Echelon* and *Parkside* indicated the trust and mutual understanding that grew from regular, open communication acted as a starting board for productive EOL discussions when a resident’s health declined.

Variable processes for advance care planning.—Although administrators in all communities saw value in ACP, their processes for accomplishing this varied. While administrators in all communities discussed advance directives with residents upon admission, these admission processes varied as did their follow-up processes.

Differences in intake.—In line with state regulations regarding ACP, all communities reported they requested any ADs residents had upon move in and stored them in each of the residents’ electronic or paper files. However, *Sunbrite*, the small, privately held personal care home in the study, outsourced intake and care planning processes to its Medicaid providers. All other communities encouraged some form of ACP for their residents. Two communities, *Parkside* and *Fairhaven*, required residents to name a HPOA as a criterion for admission. However, not all resident participants at these communities had a HPOA on file (Table 2). *Echelon* encouraged all incoming residents without extant documentation to fill out the POLST form. None of the communities required residents to have an AD or DNR order.

Differences in follow-up.—Administrators at three communities described centralized tracking of resident ACP documentation. The administration at *Echelon* and *Brookrun* maintained DNR lists, and the administrative assistant at *Fairhaven* oversaw their HPOA list.

Four of the communities had follow-up procedures to increase ACP with residents and families. The current ED of *Parkside* explained that her community has “a 14-day window of requesting [the DNR]...and getting that back” when a resident first moves in. After the

move-in period, *Parkside* did not have any formal follow-up for ACP; however, the same ED noted that *Parkside* “would get that ball rolling” if a resident requested ACP after move-in.

Three communities had formal ACP follow-up during their periodic care plan meetings (instituted in all study communities apart from *Sunbrite*) with residents and their informal caregivers. The ED of *Solis*, a trained social worker who was a previous nursing home administrator, described *Solis*’ care plan meeting ACP follow-up: “[the resident care manager] is very good about asking if they want to make any changes, or if they need to have any updates, and then I step in and do that part with them.” This sentiment was echoed by the activity director at *Solis*. Additionally, the ED met with residents “at least once a year” to have a “serious conversation...about a DNR.” Care plan meetings with residents and their informal caregivers were similar at *Echelon* and *Brookrun*, including review of residents’ ACP. Administrators at *Echelon* described their population as well-versed in ACP. In contrast, the ED of *Brookrun* characterized the families as resistant to ACP conversations and reliant on informal ACP arrangements. While care plan meetings at *Echelon* focused on “[ensuring] that [residents’] wishes are still being met,” *Brookrun*’s care plan meetings prioritized education and encouragement for residents and families to participate in ACP.

In addition to the formal follow-up of care plan meetings, administrators at *Summit Place* and *Brookrun* described an unscheduled follow-up strategy of leveraging minor health incidents to encourage residents who still have capacity to “[get] something in place,” especially the HPOA. As the ED of *Brookrun* explained:

When things happen, we do use that as a discussion point. We can’t share all of this information. You aren’t the power of attorney. We explain what that power of attorney means, what rights they have, and all of this. We tell them, you want to do it now before it becomes a diagnosis of dementia and those things. Then you have to go to court...They’re like ‘Oh, I didn’t know. Oh, no one told us that.’ Yeah. We’re trying to do a lot of family education.

DISCUSSION

The current study fills important gaps in the literature by contributing to a better understanding of AL administrator attitudes towards ACP and the processes through which they pursue planning with their residents; similar studies have been extremely limited in the United States. In a 2009 retrospective study of ACP prevalence in LTC including AL, Daaleman et al. found that decedents in American AL communities were more likely to have ACP than those in nursing homes. However, this study did not include qualitative examination of staff procedures or attitudes. Arnett et al. (2017) examined clinical routines for ACP by surveying interprofessional healthcare team members, including 23 representatives from LTC; however, they did not specifically report AL staff responses. Their general finding that “most settings lacked systemic clinical routines to support ACP discussions” highlights the utility of our study’s finding that some AL communities are integrating ACP with periodic care plan meetings. Arnett et al.’s (2017) finding that requiring review of ACP on admission facilitated discussion of ACP is confirmed by our

study, as all study communities adhered to state regulatory requirements for ACP with residents.

Some communities in our study exceeded the state requirement to ask for documentation and make forms available on request by continuing to pursue ACP with residents following the initial move-in period. Care plan meetings, held by all study communities (apart from *Sunbrite*), present a regular opportunity for communication between formal and informal caregivers; however, only three communities' administrators describe taking this opportunity to continue ACP with residents. *Echelon* and *Solis*, with their open discussion of resident wishes and scheduled review of these wishes during care plan meetings, approach a broader, less document-centric enactment of ACP. The ED of *Brookrun*, seeking more ACP within her community, is steering *Brookrun* down a similar path as she and her staff educate their residents on the need for ACP, regularly follow-up on their ACP during care plan meetings, and plan better staff training in ACP and EOL care. Resident participant ACP documentation from each community suggests these discussion-rich practices are associated with higher levels of ACP document completion. This finding adheres to established understanding that complex ACP interventions are more likely to impact later interactions with the healthcare system (Brinkman-Stoppelenburg et al, 2014).

The frequency of resident deaths in the study's communities highlights the importance of administrator attention to residents' ACP. Administrators' appropriate attention to ACP is underscored by *Brookrun's* residents, many of whom completed ADs around the time of move in or soon afterwards, indicating administrators can be influential facilitators of ACP for their residents. Change in AL community culture is "inevitable and ongoing" and administrators have the power to effect cultural embrace of ACP among their staff and residents (Perkins, Ball, Whittington, & Hollingsworth, 2012).

As described by Singer et al. (1998), ACP is a "social process" of "open, continuing communication" between patients, their loved ones, and caregivers. This process allows the patient to express her personal values, process her circumstances, and lift pressure from her surrogates. ACP discussions with healthcare providers serve as an educational opportunity for patients, allowing them to "learn more about the process of dying and what treatment options and comfort measures are available...to anticipate and consider aspects of the dying process of which they might not have been aware" (Singer et al., 1998). The openness of many administrators toward bringing more rigorous ACP and training to their communities to facilitate these efforts suggests that AL communities have an interest in moving toward more ACP.

Administrators value ACP for its ability to protect their residents' autonomy, support the welfare of residents while they die, and to protect families from additional emotional conflict as they grieve. The values of welfare and autonomy help form the foundation of medical professionalism (ABIM Foundation et al., 2002). As AL communities embrace the philosophy of aging-in-place and house residents through their deaths, they must decide to what extent they will be involved in the quality of their residents' EOL experiences (Arneson et al., 2020; Bender, Halpin, Kemp, & Perkins, 2019). The current study reveals different degrees of administrator commitment to and institutional support (e.g.,

staff training) for the continuous, open communication required of quality ACP. As AL communities negotiate the changes brought by welcoming residents to age-in-place and die while in residence, there is increasingly less distinction between nursing homes and AL communities, at least among large, newer communities of both types. Smaller, privately-held homes, who often serve low-income populations and accept Medicaid, are left behind by these changes, as they often do not have the staff or resources to offer comprehensive services (Zimmerman et al., 2003).

Whether communities of any size choose to institute robust ACP programs may be viewed as another step toward the ‘medicalization’ of AL communities. The study illustrates this concern about medicalization; all the study communities, apart from *Sunbrite*, now have care plan meetings, a process federally mandated for nursing homes. These care plan meetings are a core process of ACP for *Solis*, *Echelon*, and *Brookrun* and reflect the fusion of care plan meetings and ACP advocated in nursing facility literature (Thompson & Church, 2010). However, ACP does not have to be a medical activity; community based interventions, including the Conversation Project, demonstrate the potential of community-based ACP to help prepare individuals and their families for the EOL (Bisognano & Goodman, 2013; Silveira & Rodgers, 2017; Chiu wu, Perng, Shi, & Lai, 2020). Importantly, open-source ACP tools like the Conversation Project, which conceives of ACP as a series of “kitchen table conversations,” require low material investment (Goodman & Institute for Healthcare Improvement, 2020). Smaller, privately held AL communities would not be disadvantaged in comparison to larger communities with the use of such tools.

Strengths and Limitations

The limitations of this study include its reliance on self-reporting on the community profiles administrators submitted after communities consented to join the study and during the interviews. Additionally, not all ACP and EOL oriented questions from the interview script were answered comprehensively or in the same manner by all administrator, complicating direct comparison across and between homes. We utilized semi-structured interviews, which were modified as the study progressed. This is a strength of longitudinal ethnographic research; however, it results in variation of depth of conversation by topic across interviews and can limit the comparison across individuals. Although our sample is sizeable for a qualitative study about end of life, our findings remain limited to one geographic area, which limits generalizability. Despite these limitations, this project has many strengths including the comparison between administrators’ report with record documentation. The self-reported numbers of AD completion often varied from those found in the community files of the larger study’s non-randomly sampled resident participants, perhaps a reflection of the lack of centralized tracking of ACP in the communities.

Implications for Practice

Findings from this study suggest that open and early communication about ACP with resident and family members in AL communities can result in positive experiences around ACP and improve EOL care. This suggestion is in line with the Institute of Medicine’s (2015) call for community settings to assume leadership for ACP and anticipates the positive experience care homes (institutions analogous to AL in the United States) in England report

following institution of robust ACP policies (Stobbart-Rowlands & Thorn, 2018). The social processes (e.g., open and continuing communication) of ACP support the administrators' goals for improved EOL care and ACP. While administrators of AL communities may not always have the knowledge to provide specific medical education to their residents, they do have the opportunity and ability to motivate residents to start important conversations with their doctors and loved ones. We recommend that administrators use available, community-oriented ACP tools to discuss ACP with their residents. In this way, regardless of the scale of the community, holding ACP conversations potentially provides all communities with a means to build relationships with their residents which safeguard their quality-of-life at EOL.

Further, the SARS-COV-2 pandemic highlights the importance of AL administrator facilitation of early and on-going communication of EOL goals and values between residents and caregivers. Older adults with multiple co-morbidities, such as the majority of AL residents, face worse prognoses with COVID-19 and are less likely to recover from intensive care without consequent decline in quality of life; having a baseline of open communication about ACP between formal and informal caregivers will help define appropriate care for an individual, appropriately allocate health system resources, and protect caregivers from psychological distress (Kemp et al., 2019; Curtis, Kross, & Stapleton, 2020).

Acknowledgements

The authors wish to thank the administrators who generously gave of their time and attention to completing interviews and providing data. Thanks to Laura Arneson, MD, Allison Bay, MPH, Nikki Georges, MD, and Mary Coyle, NP, MPH, who performed the medical record abstractions of resident participants' community files. They also wish to thank Kayla Burrell, M.S., for her help with REDCap and data organization. The authors would also like to thank Drs. Kemp & Vandenberg, who provided valuable suggestions during the development of the study concept and in the analysis phase.

Funding

This study was supported by funding from The National Institute on Aging (NIH/NIA) (R01AG047408) for the larger study, "End-of-Life in Assisted Living: Links between Structure, Process, and Outcomes."

References

- ABIM Foundation, ACP-ASIM Foundation, & European Federation of Internal Medicine. (2002). Medical professionalism in the new millennium: A physician charter. *Annals of Internal Medicine*, 136(3), 243–246. [PubMed: 11827500]
- Arneson L, Bender AA, Robert MN, & Perkins MM (2020). Optimizing quality of life with cognitive impairment: A study of end-of-life care in assisted living. *Journal of the American Medical Directors Association*, 21(5), 692–696. 10.1016/j.jamda.2019.10.012 [PubMed: 31784190]
- Arnett K, Sudore RL, Nowels D, Feng CX, Levy CR, & Lum HD (2017). Advance care planning: Understanding clinical routines and experiences of interprofessional team members in diverse health care settings. *American Journal of Hospice and Palliative Medicine*, 34(10), 946–953. 10.1177/1049909116666358 [PubMed: 27599724]
- Ball MM, Kemp CL, Hollingsworth C, & Perkins MM (2014). "This is our last stop": Negotiating end-of-life transitions in assisted living. *Journal of Aging Studies*, 30(1), 1–13. 10.1016/j.jaging.2014.02.002 [PubMed: 24984903]
- Bender AA, Halpin SN, Kemp CL, & Perkins MM (2019). Barriers and facilitators to exercise participation among frail older African American assisted living residents. *Journal of Applied Gerontology*. 10.1177/0733464819893923

- Bisognano M, & Goodman E (2013). Entry point: Engaging patients and their loved ones in the ultimate conversation. *Health Affairs*, 32(2), 203–206. 10.1377/hlthaff.2012.1174 [PubMed: 23381510]
- Braun V, & Clarke V (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101.
- Brinkman-Stoppelenburg A, Rietjens JAC, & Van Der Heide A (2014). The effects of advance care planning on end-of-life care: A systematic review. *Palliative Medicine*, 28(8), 1000–1025. 10.1177/0269216314526272 [PubMed: 24651708]
- Chiu wu C-H, Perng S-J, Shi C-K, & Lai H-L (2020). Advance Care Planning and Advance Directives: A Multimedia Education Program in Community-Dwelling Older Adults. *Journal of Applied Gerontology*, 39(8), 811–819. 10.1177/0733464819831596 [PubMed: 30795711]
- Curtis JR, Kross EK, & Stapleton RD (2020). The importance of addressing advance care planning and decisions about do-not-resuscitate orders during novel coronavirus 2019 (COVID-19). *JAMA*, 323(18), 1771–1772. 10.1001/jama.2020.4894 [PubMed: 32219360]
- Daaleman TP, Williams CS, Preisser JS, Sloane PD, Biola H, & Zimmerman S (2009). Advance Care Planning in Nursing Homes and Assisted Living Communities. *Journal of the American Medical Directors Association*, 10(4), 243–251. 10.1016/j.jamda.2008.10.015 [PubMed: 19426940]
- Goodman E & Institute for Healthcare Improvement. (2020). The Conversation Project is dedicated to helping people talk about their wishes for end-of-life care.
- Harris-Kojetin L, Sengupta M, Lendon JP, Rome V, Valverde R, & Caffrey C (2019). Long-term care providers and services users in the United States, 2015–2016. In *Vital and Health Statistics (Vol. 3)*.
- Harris-Wallace B, Schumacher JG, Perez R, Eckert JK, Doyle PJ, Beeber AS, & Zimmerman S (2011). The emerging role of health care supervisors in assisted living. *Senior Housing and Care Journal*, 19(1), 97–108. 10.1038/jid.2014.371
- Institute of Medicine, Committee on Approaching Death: Addressing Key End of Life Issues. (2015). *Dying in America: Improving quality and honoring individual preferences near the end of life*. Washington, DC: National Academies Press (US). <https://www.ncbi.nlm.nih.gov/books/NBK285681/> doi: 10.17226/18748
- Kemp CL, Ball MM, & Perkins MM (2019). Individualization and the health care mosaic in assisted living. *The Gerontologist*, 59(4), 644–654. 10.1093/geront/gny065 [PubMed: 29917071]
- Levi BH, & Green MJ (2010). Too soon to give up: Re-examining the value of advance directives. *American Journal of Bioethics*, 10(4), 3–22. 10.1080/15265161003599691
- Perkins MM, Ball MM, Whittington FJ, & Hollingsworth C (2012). Relational autonomy in assisted living: A focus on diverse care settings for older adults. *Journal of Aging Studies*, 26(2), 214–225. 10.1016/j.jaging.2012.01.001 [PubMed: 22707852]
- Silveira MJ, Kim SYH, & Langa KM (2010). Advance directives and surrogate decision making before death. *New England Journal of Medicine*, 363(3), 295–296. 10.1056/NEJMc1005312
- Silveira MJ, & Rodgers P (2017). Advance directives and advance care planning: The US experience. In Thomas K, Lobo B, & Detering K (Eds.), *Advance Care Planning in End of Life Care* (pp. 218–255). 10.1093/oso/9780198802136.001.0001
- Singer PA, Martin DK, Lavery JV, Thiel EC, Kelner M, & Mendelsohn DC (1998). Reconceptualizing advance care planning from the patient’s perspective. *Archives of Internal Medicine*, 158(8), 879–884. 10.1001/archinte.158.8.879 [PubMed: 9570174]
- Stobbart-Rowlands M, & Thorn M (2018). Experience of use of advance care planning in care homes. In Thomas K, Lobo B, & Detering K (Eds.), *Advance Care Planning in End of Life Care* (pp. 129–137). 10.1093/oso/9780198802136.001.0001
- Thompson S, & Church L (2010). The Structure and Process of Advanced Chronic Illness and Palliative Care in Nursing Homes. In Bern-Klug M (Ed.), *Transforming Palliative Care in Nursing Homes: The Social Work Role* (pp. 31–58). New York: Columbia University Press.
- Vandenberg AE, Ball MM, Kemp CL, Doyle PJ, Fritz M, Halpin S, ...Perkins MM (2018). Contours of “here”: Phenomenology of space for assisted living residents approaching end of life. *Journal of aging studies*, 47, 72–83. <https://doi-org.proxy.library.emory.edu/10.1016/j.jaging.2018.03.001> [PubMed: 30447872]

Zimmerman S, Gruber-Baldini AL, Sloane PD, Kevin Eckert J, Richard Hebel J, Morgan LA, ...
Konrad TR (2003). Assisted living and nursing homes: Apples and oranges? *The Gerontologist*,
43(suppl_2), 107–117. 10.1093/geront/43.suppl_2.107 [PubMed: 12711731]

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Table 1.Advance Directive Document Definitions^a

Type of Advance Care Directive	Definition
Do-Not-Resuscitate (DNR) Order	A physician's order reflecting a patient's expressed preference not to be treated with cardio-pulmonary resuscitation, if found without a pulse and not breathing.
Physician's Order for Life Sustaining Treatment (POLST)	A single-sheet physician's order which combines a DNR order with a patient's wishes for medical care.
Living Will	Written documentation of a patient's wishes and goals for medical care, to be used in the event that the patient has lost the capacity to communicate directly with caregivers.
Healthcare Power of Attorney (HPOA)	Legal designation of surrogate to make medical decisions should a patient lose the capacity to communicate or decide for herself.
Combined Advance Directive	Since 2007, the state of Georgia has used the "Georgia Advance Directive for Healthcare" which combines the living will and designation of a HPOA in one form.

^aSilveira MJ, Rodgers P. Advance Directives and Advance Care Planning: the US Experience. In: Thomas K, Lobo B, Detering K, editors. *Advance Care Planning in End of Life Care*. Oxford University Press; 2017. p. 218–55.

Table 2.

Administrator Characteristics (n = 27)

Variable	Number (%) or Mean (Range)
Gender (Female)	22 (81%)
Race (Percent White)	8 (30%)
Age ^a	44 (20 - 70)
Education ^b (Mean)	6 (2 - 9)
Training	
Dementia	5 (19%)
Other, non-medical (health administration, social work, gerontology)	9 (35%)
Other, medical (medication tech, LPN, CNA, RN)	7 (27%)
Titles	
Executive Director	8 (29%)
Activities Director	7 (25%)
Other Category ^c	6 (22%)
Resident Care Manager	5 (18%)
Dementia Care Unit Director	2 (7%)

^aOne participant declined to share her age.

^bEducation indicates years of formal education, quantified on a 0-9 scale. 0 = less than high school diploma, 1 = GED, 2 = high school diploma (not GED), 3 = post-high school technical training, 4 = some college or 2-year associate degree, 5 = three or more years of college but no bachelor's degree, 6 = bachelor's degree, 7 = one or more years of graduate training but not graduate degree, 8 = master's degree, 9 = degree beyond master's.

^cThis category includes an admission coordinator who was later re-interviewed in her new role as executive director, as well titles such as social services coordinator, floor manager, and administrative assistant.

Table 3.

Community Characteristics

Characteristic	Fairhaven	Brookrun	Summit Place	Solis	Parkside	Sunbrite	Echelon ^e
Ownership	Family owned	Religious non-profit	Non-profit	Corporate	Corporate	Private/Medicaid Waiver	CCRC ^f
Current population ^a	80	30	24	73	106	5	16
Community fee range (monthly)	\$2,500 - \$4,500	\$3,440 - \$5,840	\$3,634 - \$3,904	\$3,450 - \$6,049	\$2,700 - \$6,000	\$1,300 - \$2,200	\$6,107 - \$7,335
Community location	Urban	Suburban	Suburban	Suburban	Urban	Suburban	Urban
Number of in-house resident deaths ^b	4	10	8	7	39	0	1
Admission associated documentation ^c	n/a	6	n/a	2	n/a	n/a	0 ^g
Number of resident participants	25	11	16	13	25	5	5
Living Will (N (%))	6 (24%)	5 (45%)	4 (25%)	11 (85%)	9 (36%)	0 (0%)	3 (60%)
DNR (N (%))	2 (8%)	2 (18%)	1 (6%)	3 (23%)	6 (24%)	1 (20%)	0 (0%)
POLST (N (%))	0 (0%)	0 (0%)	0 (0%)	0 (0%)	2 (8%)	0 (0%)	0 (0%)
HPOA (N (%))	15 (60%)	5 (45%)	5 (31%)	11 (85%)	9 (36%)	0 (0%)	4 (80%)
None	10 (40%)	5 (45%)	9 (56%)	1 (8%)	11 (44%)	4 (80%)	1 (20%)
DNR, Living Will, POLST, or HPOA (N (%)) ^d	15 (60%)	6 (55%)	7 (44%)	12 (92%)	14 (56%)	1 (20%)	4 (80%)

^aIncluding DCU (dementia care unit) population, if applicable.

^bIn the twelve months prior to completion of the community profile.

^cAdmission associated documentation indicates the number of residents who completed documentation within a month of move-in or after. Dates of ACP documentation were only collected during the second wave of the study. This data was not collected for the *Parkside*, *Fairhaven*, *Sunbrite* or *Summit Place* homes.

^dDNR = do-not-resuscitate order; POLST = physician order for live sustaining treatment; HPOA = healthcare power of attorney

^eDue to administrator turnover, *Echelon's* community profile was completed in the second half of the study's presence in the community. All other profiles were completed upon entering the study.

^fContinuing Care Retirement Community

^gAll ACP documents for resident participants at Echelon were dates prior to a month before their move-in date.

Table 4.

Descriptive Statistics for Resident Participants

Characteristics	% or Mean	Range
Sociodemographic (n = 100)		
Age	86	58 - 103
Percent Female	64	
Percent White	63	
Mean Level of Education ^a	5	1 - 9
Functional (n = 85) ^b		
Score of MoCA ^c	16	2 - 30
ADLs ^d	3	0 - 7

^aEducation indicates years of formal education, quantified on a 0-9 scale. 0 = less than high school diploma, 1 = GED, 2 = high school diploma (not GED), 3 = post-high school technical training, 4 = some college or 2-year associate degree, 5 = three or more years of college but no bachelor's degree, 6 = bachelor's degree, 7 = one or more years of graduate training but not graduate degree, 8 = master's degree, 9 = degree beyond master's. Two participants have missing values.

^bEighty-five resident participants completed interview III, during which these data were collected.

^cCognitive impairment was assessed with the Montreal Cognitive Assessment (MoCA)1. MoCA scores of 18–26 are defined as mild CI; 10–17 are moderate CI; <10 are severe CI. Three participants have missing values.

^dThe number of activities of daily living (ADL) a resident required assistance with is noted as a proxy for functional limitation. ADLs include bathing, toileting, dressing, eating, transferring, and continence.

Table 5.

Advance Care Planning in Study Communities: Administrator Report vs. Documentation in Participant Resident Community Files (n = 100)

Home (N)	Administrator perception ^a	Administrator report ^d	% Resident completion ^{e,f}
<i>Fairhaven</i> (25)	"It just depends. Sometimes not very, sometimes, usually they've already had them"	13%	60%
<i>Brookrun</i> (11)	HPOA ^b : "less than 50%"	87%	55%
<i>Summit Place</i> (16)	"60% of our people have something"	100%	38%
<i>Solis</i> (13)	"Most of them"	Not given in community profile	92%
<i>Parkside</i> (25)	"a lot of them have already made those decisions"	100%	52%
<i>Sunbrite</i> (5)	One person "does have something actual in written hard copy" [DNR ^c]	20%	0%
<i>Echelon</i> (5)	"most residents do...very organized"	100%	80%

^aAdministrator perception indicates qualitative statements made during interview regarding completion of ACP among community residents.

^bHPOA = healthcare power of attorney

^cDNR = do-not-resuscitate order

^dAdministrator report indicates total community living will and/or healthcare power of attorney completion (as percent of current population). This data is based on self-report from community directors in the community profile each completes for the larger study.

^ePercent resident completion indicates the percent of resident participant community files found to include living will and/or healthcare power of attorney documentation. For purposes of 1:1 comparison between administrator report and resident participant files, data presented here is restricted to healthcare power of attorney and living will, which were combined in one question for the community profile.

^fCalculated based on residents selected for participation in the larger study.