

# Advance Directives in the Context of Uncertain Prognosis for Residents of Nursing Homes

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## Abstract

This report documents the findings of a mixed-methods study focused on the advanced directives of 182 residents of three LTC facilities in southern Ontario, Canada. Although almost all had a completed advance directive within 3 months of death, most did not have a palliative designation or directive until a few days before they died. Each facility's written Progress Notes revealed staff members usually sought additional confirmation of care preferences from residents' substitute decision-makers within a few days of the death. It was thus common for advance directives to change from a more interventionist approach to the least interventionist approach near death. This change indicates that the meaning and significance of advance care planning and resulting advance directives must be considered in light of the processes and temporal factors involved in their completion and use within this distinct population. The relational nature of advance care planning and concern about ageism as a factor for withholding or withdrawing life support for LTC residents are considered as possible explanatory factors. These findings and their implications are described in relation to end-of-life care policies and practices in LTC facilities.

## Keywords

Advance Care Planning, Advance Directives, Palliative Care, Nursing Homes

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## 1. Introduction

The goal of advance care planning (ACP) is to make one's care preferences known in anticipation of a loss of

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capacity to make healthcare decisions. There is widespread expectation that advance directives (AD) facilitate care that is consistent with the care recipient's wishes, and that they also ease the decision-making process for substitute decision-makers if and when the need arises [1] [2]. Therefore, ACP is promoted as an important aspect of getting one's affairs in order prior to the end of life (EOL). ACP is now being suggested for individuals of all ages and health statuses. In addition to respecting the autonomous wishes of individuals as expressed in their ADs, advance care planning may help in the appropriate use of health care resources [3]. However, studies indicate that while there is considerable agreement that ACP is a good idea, the rate of completion of ADs is modest at best [4]-[6].

In nursing homes and other long-term care (LTC) facilities, ADs can provide crucial information when decisions must be made whether to transfer residents of LTC facilities to hospitals for assessment or interventions that are beyond the scope of the LTC facility. Some studies have identified high rates of transfer to hospital for investigations and interventions with questionable value for nursing home residents; as these persons are typically frail individuals living with multiple co-morbidities in advanced old-age [7]-[10]. Furthermore, some suggest that this interventionist hospital approach may increase suffering, decrease quality of life, and make inappropriate use of acute care resources [11]. In many jurisdictions, health service planners are developing initiatives to reduce inappropriate hospitalizations of older adults, particularly those who are already frail, at the end-stage of an illness or when actively dying [12] [13]. The success of these initiatives may be influenced by the presence and content of ADs.

There is little in the existing literature that elucidates the process of ACP or the use of ADs for residents of long-term care facilities [4] [14]. However, the findings of previous research with 323 substitute decision-makers for residents of LTC facilities in Boston, USA indicated that inadequate support from care providers in nursing homes was the most significant source of dissatisfaction with decision-making [15]. Others have similarly recognized that because ACP often involves significant relationships with loved ones, it can be challenging. Consequently, clinicians may need to assist in supportive family explorations of options and rationales for choices [2]. Furthermore, based on an analysis of AD completion and intent to complete within the general population, it has been suggested that individuals are likely to require more than one supportive discussion in a dynamic process of ACP [6]. Hence, there is a need to develop an understanding of the process of ACP and the utilization of ADs within this vulnerable population.

## 2. Methods

This report uses a sub-set of data collected as a part of a larger study concerning awareness of impending death in LTC facilities [16]. Research ethics approval was granted by the University of Alberta Health Research Ethics Board and the ethics committees of the three LTC facilities in the province of Ontario where the research was completed.

Qualitative and quantitative data concerning the ACP of residents were collected on 182 residents who had died in the preceding 12 months at the three LTC facilities. Quantitative data concerning selected variables were derived from Quarterly Reviews that had been completed prior to the death of residents. Quarterly Reviews of residents' health status were completed every 3 months at the facilities where these residents lived, in keeping with provincial regulations [17]. Data included whether a substitute decision maker had been identified (yes or no) and the level of advance care directive that had been selected from the four options that were available in the standardized advance directive form that was used at all three facilities (**Figure 1**). Additional data about the number of transfers to hospital in the last month of life, and whether the location of death was consistent with care preferences as stated in the AD at the time of death (yes or no) were tabulated from a review of each resident's Progress Notes. The decedent population was subdivided by age at death (younger than 85 years and 85 years or older), and by sex as illustrated in **Table 1** and **Table 2**. Quantitative data were submitted to basic descriptive analysis using SPSS version 12<sup>®</sup>.

Qualitative data were collected in the ethnographic stage of the study. The data were derived from a review of the Progress Notes contained in each decedent's chart and copied into a Word<sup>®</sup> document. Fifty interviews with staff members (n = 29), family members (n = 12), and residents (n = 9) contributed additional qualitative data. These audio-taped interviews were transcribed verbatim. All the qualitative data were analyzed using Boeije's [18] questions for constant comparative analysis.

**In the event that my health condition is considered to be hopeless, Level \_\_\_\_\_ best represents my wishes.**

**1. Palliative Level 1**  
 Keep me comfortable here at \_\_\_\_\_  
 Give me personal care and pain relief  
 Do not transfer me to hospital  
 Do not give me medication to prolong my life  
 Do not attempt to resuscitate me if my heart stops or I cease to breathe  
**Summary: Let me die comfortably and peacefully**

**2. Supportive Care Level 2**  
 Keep me comfortable here at \_\_\_\_\_  
 Give me personal care and pain relief  
 Do not transfer me to hospital  
 Do not attempt to resuscitate me if my heart stops or I cease to breathe  
 Get me antibiotics and other medications to attempt to cure my illness and prolong my life  
**Summary Try to cure my illness here at \_\_\_\_\_ but do not hospitalize me**

**3. Moderate Care Level 3**  
 Send me to the hospital for further care if necessary  
 Give me intravenous material if recommended by the physician  
 Operate on me if recommended by the physician  
 Do not attempt to resuscitate me if my heart stops or I cease to breathe  
 Do not put me on life-support systems  
**Summary: Try to cure my illness and hospitalize me if necessary but no heroic measures**

**4. Acute care Level 4**  
 Do everything medically and surgically possible to prolong my life  
 Resuscitate me in the event of a witnessed event at \_\_\_\_\_ or I cease to breathe  
 Move me to hospital on life-support systems if necessary, including CPR  
**Summary: Do everything possible to cure my illness and prolong my life including heroic measures**

**Figure 1.** Representative advance directive form used at all three study sites.

**Table 1.** Summary of findings by age group at the last quarterly review prior to death.

Variable	All (n = 182)	Younger than 85 years (n = 58)	85 years or older (n = 124)	Comparative statistics
Mean age at death (years)	86.8	78	90.8	
S.D.	7.6	5.9	4.1	
Range	57 - 101	57 - 84	85 - 101	
Gender (%)				$\chi^2 = 13.8$ df = 1 p = 0.000*
Male	36.8	56.9	27.4	
Female	63.2	43.1	72.6	
Total	100	100	100	
Level of advance directive (%)				$\chi^2 = 146.626$ df = 4 p = 0.000*
None	0.5	0	0.8	
One	13.2	8.6	14.8	
Two	48.9	39.7	54.1	
Three	31.9	41.4	27	
Four	5.5	10.3	3.3	
Total	100	100	100	
Transfers to hospital in month prior to death (%)				$\chi^2 = 220.154$ df = 3 p = 0.000*
None	69.8	53.4	77.4	
One	25.3	34.5	21	
Two	3.8	8.6	1.6	
Three	1.1	3.4	0	
Total	100	100	100	
Location of death (%)				
LTC facility	90.1	87.9	91.9	
Hospital	9.9	12.1	8.1	
Total	100	100	100	

\*Indicates a significant difference.

**Table 2.** Summary of findings by gender at the last quarterly review prior to death.

Variable	Male (n = 67)	Female (n = 115)	Comparative statistics
Age at death (years)			t = -3.593
Mean	84.2	88.3	df = 180
Standard deviation	6.7	7.7	p = 0.000*
Age group (%)			
Younger than 85 years	49.3	21.7	$\chi^2 = 14.761$ df = 1
85 years or older	50.7	78.3	p = 0.000*
Total	100	100	
Level of advance directive %			
None	0	0.9	
One	6.0	17.4	$\chi^2 = 146.626$ df = 4
Two	47.8	49.6	p = 0.000*
Three	41.8	26.1	
Four	4.5	6.1	
Total	100	100	
Transfers to hospital in month prior to death (%)			
None	59.7	75.7	$\chi^2 = 220.154$ df = 3
One	31.3	21.7	p = 0.000*
Two	6.0	2.6	
Three	3.0	1.6	
Total	100	100	
Location of death (%)			
LTC facility	86.6	92.2	$\chi^2 = 266.121$ df = 1
Hospital/other	13.4	7.9	p = 0.000*
Total	100	100	

\*Indicates a significant difference.

### 3. Findings

As described below, the quantitative findings revealed that advance directives were commonly documented for all LTC residents at the last Quarterly Review (these were completed from 1 week to 3 months prior to the death of each of these 182 decedents). However, it was common for this care directive to be changed as a result of a conversation between a staff nurse and the substitute decision-maker one or two days in advance of death. This change was documented in the Progress Notes along with clinical changes in the resident that led to the conversation.

#### 3.1. Quantitative Data Findings

At the last Quarterly Review prior to death, the rates of identification of a substitute decision-maker or power of attorney for health care decisions were high (almost 97%) for both age groups and for both males and females. Similarly, the AD form had been completed for over 96% of residents in each age and sex subdivision.

A preference for EOL care to take place within the facility rather than after transfer to hospital was documented more commonly for older residents (68.9%) than for younger residents (48.3%). Overall, the least interventionist approach in care (level 1) was documented for less than 15% of residents. The palliative directive (level 1) was chosen more often by or for older residents and women (14.8% and 17.4% respectively), than for younger residents and men (8.6% and 6.0%). Most ADs (86.3%) identified a preference for some attempt to modify the progression of a life-threatening illness, as indicated by the choice of levels 2, 3 or 4. However, few residents indicated a preference for resuscitation to be attempted (level 4). Level 4 was more likely to be chosen by or for younger residents than older residents (10.3% vs 3.3%).

By cross-checking transfer-to-hospital experiences and location of death as documented in the Progress Notes and ADs, it was determined that when transfers occurred, all were in keeping with the wishes that had been expressed by the resident or substitute decision maker at the time of transfer, either in the AD or in a conversation that was recorded in the Progress Notes. Similarly, all deaths occurred in the location that had been chosen closest to the time of death, whether this choice appeared in the Quarterly Review or the Progress Notes.

### 3.2. Qualitative Data Findings

The qualitative data provided insights into the dynamics of completion and interpretation of advance care planning and care directives. Staff perspectives were particularly apparent and influential. Overall, staff members understood ACP as the process of getting an AD signed. The AD was seen as the document that justified crucial decisions regarding the balance of potentially life-prolonging and comfort care, and whether care should be provided at the LTC facility or in hospital. It was expected that the AD would be signed as soon as possible after admission and reviewed annually or when a change in a resident's condition raised questions about the goals of care. As one RN explained, "Well, we have to have the directive—right from the first—because the staff has to know what they're supposed to do, you know. You can't be trying to figure whether they're a transfer or a DNR when they are crashing in front of you. It has to be on the chart. Because who knows if you're going to be able to find anyone to ask if it isn't there."

When a resident's condition changed suddenly, or when the accumulation of incremental changes over time was recognized as predictive of imminent death, there was some urgency to ensure that a palliative directive, level 1, was in place. One Registered Nurse observed that "the staff on the floor has to recognize when the time is right. We wait until they're true end-of-life, within hours, and if we're lucky we get days." One administrator described the resulting problem: "The staff is just going around doing their jobs and then it's like—oh whoa—and then it's a scramble ... to get the family on board."

It was also acknowledged that ACP could be an emotional and complex process for all concerned. Staff members commented that families often found it difficult to make transitions toward a less interventionist plan of care. However, discussions about changes in ADs often occurred in telephone conversations or during family visits when residents had been *deemed palliative* by their physicians within a day or two of death. Staff members reported that family members usually do not want to talk about their family members' decline or think about palliative care. However, one family member, commenting on her father's declining condition and impending death said: I ask a lot of questions. If you don't ask questions they will think you are not ready to hear it."

Staff perceptions about the sensitivity of ACP may also have influenced their interactions with family members in other ways. For example, in one of the LTC facilities, members of both the Residents Council<sup>1</sup> and the Family Council had agreed that there should be sections about preparing advanced directives, funeral planning, and EOL care in a new handbook for residents and families. However, staff members on the Handbook Committee had rejected the idea, claiming that the topics were too sensitive to include in a handbook.

In another example, a nurse-manager noted that the RNs in that facility were reluctant to discuss changes in ADs to level 1. She had concluded this was because "they feel that the minute they do that, everyone—you know, will stop caring for them. So they hesitate. But even so, actually a palliative patient gets a tremendous amount of care—probably more than a patient who is up. I think their hesitance is in the change, and realizing that—it's going to be like this. It's never going to be the way it used to be for this person" (Director of Care).

In all instances, late changes in AD were made by the family member who was the substitute decision-maker, rather than by the resident—as they were no longer able to be involved in care decision-making or planning. Despite the apparent ambivalence in staff members' readiness to embrace a palliative perspective, they tended to be critical of family members who were reluctant to consider the level 1 directive despite obvious decline. As exemplified in the following quotation, staff members commonly attributed family members' decisions to persist with life-prolonging interventions to their denial of impending death: "Often times I see someone whose quality of life is poor, and whose family—for what we perceive to be their own personal reasons or personal agenda—refusing, or insisting that they be sent to hospital. We just had one woman who I would say is 100% palliative ... and we had the conversation, but her family only changed the advance directive from four to three—it's just because the family is in denial" (RPN).

Some staff members understood the challenge of changing ADs differently: "Well, I don't mean to be crude or anything, but yes, it's I guess kinda like what you go through with a pet—you know, having to decide if your cat, who's been just like one of the family, gets another chance—or is this it—kaput, you die—only I think it's even harder if it's your mother you're talking about—it's *her life* you're looking at—like wow, that's a big one to say, guess what, it's no more antibiotics for you (Personal Support Worker [PSW]). Often, a family member's account of this decision point was accompanied by comments such as, "We didn't want him to have to suffer

<sup>1</sup>Resident Councils and Family Councils within LTC facilities have been organized to provide a forum for residents and families to discuss their concerns and participate in advocacy to improve the quality of life in LTC facilities.

any longer.”

It was clear that staff members believed that the AD should enable residents to die at the LTC facility, as this had become their home. By cross-checking the specified level of care in the ADs and notations in the Progress Notes with location of death data, it became evident that the level 1 AD was usually chosen very late in the trajectory of decline, but normally in time to avoid dying in hospital. Staff members were concerned that residents who were transferred to a hospital might be left waiting for attention in the hallway of an overcrowded emergency department and die there without care and also without anyone who really knew them. They believed that residents were likely to be “shipped” back to the LTC facility having received minimal assessment and treatment, or would die alone in a busy hospital. They considered hospitalization as an abandonment of their LTC residents as compared to their remaining to be cared for in the LTC facility. As one PSW said, “It would be my worst nightmare to think they ended up dying all alone up at the hospital when we could have been with them right here.” A family member echoed a similar sentiment: “I guess the hospital is supposed to be where the best care is, but I kind of think I would rather have Mom here where all the girls are almost like family to her.”

Finally, some participants worried that choices to provide comfort care consistent with a level 1 AD might be considered disrespectful or neglectful. The following quotations illustrate the desire of staff members to avoid any appearance of ageism in ACP for very elderly residents of LTC facilities: “I think [families] struggle with saying ‘no, we don’t want them to go to hospital.’ They have a sense that they are abandoning their mother or father, and that they really should be doing everything they can, even though it’s futile” (Administrator); “Families just aren’t prepared to do less than—they feel obligated—they don’t want to be seen as abandoning—its their way of showing that they are still caring and interested” (RN); “When the decision is made to stop [antibiotics or fluids] it’s not because we’re giving up, it’s because it’s the best thing to do” (RN); “Why does age have to affect whether somebody’s going to—like, you know—having a do-not-resuscitate order—like just because he’s in his 90s—what’s the difference? We still should be treating him as a person” (PSW); and “I’d be offended if they thought our residents were dying. They may be old, but that shouldn’t make a difference” (RPN). Concerns of this sort were summed up by one RN who said “You never want to be the one who gives up on somebody!”

#### 4. Discussion

This study in three Canadian nursing homes is revealing of advanced care planning and changes in advance directives as death neared, with these changes demonstrating the significance of the perspectives of staff members. The findings are of interest in part because of the high rate of AD completion as compared to recent reports of AD completion in the general population and also among LTC facility residents [4] [5] [6] [19]. Although not required by legislation, ADs were present for weeks or months prior to the deaths for almost all of the 182 individuals, with this a practice apparently to meet the needs of staff members should a care crisis arise. The least interventionist approach was more likely to have been selected by or for residents 85 years of age or older than for younger residents. This pattern may suggest that the age of the care recipient influences perceptions about timeliness or readiness for dying, with allowing death seen as more acceptable in advanced old age in LTC facilities. As many members of the older age group were also women and widowed [16], it would be of interest to explore the significance of age, sex, and marital status on the process and meaning of ACP within this population. It could also be that persons aged 85 and older are more frail and nearer death, and so chronological age was not a decision factor but functional health in old age was.

Regardless of the age or sex of the resident, the transition to the palliative directive occurred eventually but was usually delayed until it was clear that death was inevitable within a very short time (as reported elsewhere [20]). Hence, the impact of the AD on the provision of timely and appropriate EOL care for these residents can be questioned, since the AD appeared to have little effect as death become imminent. In addition, there remained an undercurrent of dissatisfaction with the AD among staff members in the face of impending death. The mere presence of an AD was not sufficient to meet the perceived needs of staff members as residents neared death. They were concerned that unless they could get permission to adopt the palliative directive (level 1), they might be compelled to provide interventions that would not be in the best interests of the resident then or in their last days of life. At the same time, they were concerned that the palliative directive should not be adopted too soon lest it be perceived as their giving up on the resident. It appears that the perceptions and beliefs of staff members as they communicated with family members became significant mediators of transitions in care planning.

Staff members tended to hold family members responsible for their conflicted position. Similar to participants in a study of good nursing care in Norwegian nursing homes [21], staff members in these three facilities worried that the needs of family members became obstacles to acting in the best interests of residents. However, the interview data from family members in this research study suggested that they took their responsibility as advocates very seriously. End-of-life advocacy by family members has been found to benefit through time to build trust and prepare for death [22]. Furthermore, family decision-makers have been found to be motivated by the desire to do what was best despite the uncertainty of the situation, and conflict between the values of protecting life and avoiding suffering [23]. Similarly, family members in this study were concerned about doing what was best, but uncertain about when pursuing further assessment and interventions would no longer be the most caring thing to do. Hence, maintaining the advance directive at a level 2 or level 3 until death is inevitable within a few days or hours may reflect the need to be more certain of the possibilities, rather than denial of an obvious reality. From this perspective, it may be easier to understand and accept that family advocates similarly will delay the transition to a level 1 AD until it is unquestionably clear that prolonging life is no longer the loving, caring thing to do.

Clearly, care planning and clinical decision making can become complicated matters of avoiding futile interventions without denying opportunities for the fullness of life or appropriate palliative care. These decisions may be hampered by dichotomous thinking that presents a choice between whether one is considered to be living or dying, the strong and pervasive allegiance to life, and the valuing of life equally for everyone, without regard for age [24]-[29]. Hence, ACP can involve a potentially difficult challenge for the timing of transitions in ADs, particularly in light of the uncertainty that characterizes the long and uncertain end of life decline noted for many, if not most, residents of LTC facilities [30] [31]. The findings of this research study suggest that the decision may be easier to make or more possible and probable when a dire clinical status is obvious. Then, it is not necessary to imagine a hypothetical situation in the future [32], but instead, to act with certainty.

In EOL decision-making with elderly residents of LTC facilities, substitute decision-makers may be uncertain whether their decision to adopt a palliative AD will contribute to a good or preferred death, or be confused with ageist neglect or disinterest in the well-being of their family member. For many family and staff members who participated in this research study, this uncertainty may have been resolved by considering that no one was in need of a palliative care directive until death was unquestionably unavoidable within a very short time. Then, in a context of certainty, the transition to a level 1 AD was more clearly acceptable and unquestionable to all.

## Limitations

The findings from this research conducted at three Canadian nursing homes cannot be generalized to other aged care facilities or jurisdictions. Furthermore, consistent with qualitative research ontology, findings derived from qualitative data are not intended to represent all of the perspectives that may be held by staff or family members who did not participate. Participants who chose to be interviewed may have been systematically different in characteristics and experiences than those who did not. Nevertheless, the qualitative findings offer insights that contribute to an understanding of the complex and situated phenomenon of ACP. It would have been informative to engage in discussion with residents or their substitute decision-makers about their reasons for selecting the various levels of AD. This discussion would have provided additional insight on their reasons for their choices and the timing of transitions, and contributed to insight regarding their needs for decision-making support. However, those questions were not within the scope of the original research.

## 5. Summary and Implications

This report documents the findings of a mixed-methods study related to the AD of 182 residents of three LTC facilities in southern Ontario, Canada. Although almost all had completed an AD within 3 months of death, most did not have a palliative directive or designation until a few days before they died. As death became clearly and obviously imminent, staff members were concerned about the potential for interventions that they considered were not in the best interest of the resident. Staff members attributed this delay in transitioning to a palliative directive to family member attitudes and wishes. However, staff members also exhibited reluctance to change ADs to a less interventionist approach until imminent death was certain.

For both staff and family members, the uncertain prognosis of LTC residents was likely a significant confounding factor in this dynamic process of advance care planning. In the face of uncertainty, opting for some

form of intervention may have offered a means of affirming the value of the person. Concerns about direct or indirect ageism, the caring nature of nursing home staff which lead to strong caring relationships with LTC residents, and the needs of family members for clarity in the face of uncertain prognoses must be considered in the dynamic process of ACP with and for residents of LTC facilities.

These considerations about a process of ACP and late-stage changes should be included in educational programs for all health care disciplines and in supportive programs for residents of LTC facilities and family members. Furthermore, if a directive is to be referred to as a palliative directive, its meaning should be clarified in relation to the extent of intervention, rather than as a predictor of imminent death. Its contribution to a caring approach, rather than ceasing to care, must be made clear. Family members could benefit from ongoing conversations with staff members who are comfortable with ambiguity in the complex mix of chronic and palliative care that is common with residents of LTC facilities. Staff members would benefit from opportunities to become comfortable in these sensitive conversations. The utilization of a variety of simulation modalities could support this educational development. Finally, when policies and standards are developed in relation to palliative/end-of-life care in LTC facilities it is important to acknowledge uncertainty, complexity and time involved in appropriate planning for care near the end of life.

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