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## Take it to the resident: A model for engaging long-term stay residents in advance care planning

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### ABSTRACT

Advance care planning involves a meaningful conversation about residents' end of life goals with the health-care team and documenting these wishes in advance directives; however, these conversations are not taking place early enough or with strategies that allow nursing home residents' preferences to be meaningfully integrated into care plans. This article outlines a new model that nursing home social workers can use to initiate advance care planning discussions called *Take it to the Resident*. This model was tested with 11 long-term stay nursing home residents. Data were collected through structured memos and field notes. Summative content analysis was utilized to analyze the data. *Take it to the Resident* facilitated a discussion about advance care planning and allowed residents to consider their wishes before engaging family members. Although discussions took place, some residents were hesitant to document their wishes formally through advance directives. The results of this study support the utility of continued testing of this model. Having empirically supported tools for nursing home social workers is critical to increasing advance care planning conversations and empowering residents to document their wishes.

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Understanding clients' goals of care is an essential component of advance care planning for nursing home (NH) residents. Advance care planning involves having a meaningful conversation about a resident's goals with the health-care team and documenting these wishes in advance directives (ADs; Momeyer & Mion, 2019). Advance directives include a living will, durable power of attorney for health care, and other documents for advance care planning (NIA, 2018). Unfortunately, conversations with residents about their wishes are not taking place early enough or with strategies that allow residents' preferences to be meaningfully integrated into care plans (Bernacki & Block, 2014). In particular, knowing a person's end of life (EOL) goals improves the quality of life and reduces the stress that families may

experience when making health-care decisions on behalf of loved ones (Levy et al., 2008). Nursing home residents want more collaborative communication with family and staff yet collaborative conversations do not routinely take place (Munn et al., 2008).

Nursing home social workers (SWs) are well positioned to play an active role in advance care planning and engaging residents and families in these discussions early and often (Black, 2005; Morrison et al., 2005; Wang et al., 2017). Although models exist for ways SWs can engage family surrogate decision-makers (see Bern-Klug, 2014), few empirically tested models on engaging residents are available for NH SWs to utilize. This article presents a new model, *Take it to the Resident*, for NH SWs to promote advance care discussions. It can be used alongside and integrated with successful nursing models like crucial conversations (Momeyer & Mion, 2019) and advance care planning models like The Conversation Project (<https://theconversationproject.org/>). In order to explore the clinical usefulness of *Take it to the Resident* and empirically test its use in practice, data were collected and analyzed from a small sample of long-term stay NH residents.

### **Take it to the resident**

*Take it to the Resident* is an approach intended to be utilized by NH SWs with long-term stay residents who are alert and oriented. Long-term stay residents are defined as residents who lived in the nursing home for more than 100 days (Rantz et al., 2017). Ideally, SWs' first engagement with residents is upon admission into the NH. Engagement should be ongoing throughout their care, however, because long-term stay residents' goals may change from initial admission. Engagement at initial admission is ideal in order to establish rapport, get to know the resident, and begin exploring advance care goals. Prior to advance care discussions and building rapport with residents, a first step is to become familiar with the resident's social and medical history. To this end, the SW should review charts including recent notes, patient health questionnaire-9 (PHQ-9), treatment plans, and a brief interview for mental status (BIMS). Before moving into a discussion on advance care goals including EOL goals, it is important to build rapport by talking about the role of social work in NHs, asking questions about family and the role they play in making health-care decisions, and discussing how residents are adjusting to life changes. During these discussions, it is also important to explore how supportive residents perceive families to be and how health-care decision-making has occurred in the past including how conflicting perspectives between the resident and family or between family members were resolved. The use of empathy and support, listening attentively, and allowing time for the resident to express concerns about any aspect of long-term care living helps to build trust and identify the residents' strengths and resources.

Prior to engaging in a discussion about the residents' wishes, information about their medical conditions and options for EOL care is critical to explore. Nurses and SWs should meet with the resident concurrently and discuss medical and mental health conditions, treatment options, and trajectory of disease. The SW assists with discussing options for care, exploring goals quality of life implications, and pain management. As decisions are being made, the SW is available to provide resources and support. Asking questions like "What are your expectations during your stay?" helps to explore resident perceptions about their likely length of stay and prognosis. Using additional tools like the "The Conversation Starter Kit" (Institute for Healthcare Improvement, [n.d.](#)) is helpful to discuss quality vs. quantity of life. Throughout these discussions, it is important to provide assurance that the resident has a say in their care and to encourage self-determination.

The next step is to explore the resident's familiarity with ADs and provide education even if residents state they are familiar to ensure there is no misinformation and that residents are receiving the most up to date information on ADs. Education provided should include the purpose of ADs, what components are included in the ADs (i.e., a living will – the written wishes a person has for their medical care and their appointed healthcare decision-maker), discussion of code status (i.e., the type of intervention wanted if a person stops breathing or their heart stops) and the types of intervention (e.g., full code, Do Not Resuscitate), an explanation that everyone is "full code" unless documented, and information on CPR risks and benefits. A critical part of this education is discussing ADs as a tool to empower people to talk about and document the kind of care they want, regardless of the level of care, prior to medical emergencies so their wishes can be honored. Following education, some residents may want to complete their ADs while others may not be ready. If residents are hesitant to document their wishes, explore the cause of hesitation and allow time for questions.

Before signing or even discussing ADs, some residents may want to involve family members. Family engagement, when possible, is an important step in establishing advance care plans. However, before engaging family, it is important that the SW meet with the resident and empower the resident to think about their wishes prior to meeting with family. An important message for residents to receive is recognizing how helpful ADs are for families during medical emergencies; it reduces the need for families to guess about what the resident wants and the associated guilt of not knowing their wishes. Prior to meeting with family, the resident needs to provide consent for family involvement. The SW can set up a meeting with family to introduce the SW and their role within the NH. Meeting with families face to face is ideal but not always possible. Using technology like FaceTime or Zoom or a simple phone call to connect with families is helpful when they are unable to be there in person.

The SW typically coordinates the family meetings with other NH staff, residents, and family members. These meetings include the SW and nursing staff but may also include the primary physician, activity staff, nutrition, and physical or occupational therapy depending on the resident needs. The SW provides opening information about the purpose of the meeting and helps facilitate the meeting. During family discussions, the same education provided to the resident is also important for the family. Collaboration with the resident, family, SW, and nursing staff to discuss medical conditions, treatment trajectories, and prognosis is an important component of discussions in order to correct misinformation and provide a foundation for realistic goals of care. Depending on resident and family preferences, education on ADs and medical conditions may take place during one meeting or across two or more meetings.

Family engagement in advance care planning can be complicated. When resident and family can agree, involvement feels supportive, yet when wishes are misaligned, residents may feel disempowered to communicate their wishes (Kim et al., 2020). During family meetings with medical staff, it is important to allow time and patience for the family to ask questions about medical conditions, prognosis, and the impact of ADs on care. Discuss their concerns and identify any disparate goals between the resident and family. SWs can use active listening and empathy, provide support, and explore concerns to learn about the resident's family and build trust and rapport. It is also important to recognize the family and their commitment to supporting their loved one's care. If the family is upset or angered by these discussions, acknowledge their feelings and the NH's commitment to providing the care that their family member wants (Decoster, 2000). Anger may stem from grief or adjustment to their loved one being in an NH (Bernstein, 2018). The SW can provide reassurance to families, probe for reasons for anger, and offer resources for grief support and education, as needed. At the same time, the SW may need to advocate for the resident's right to choose their care plans and use mediation techniques to resolve differences in family and resident preferences (see Sinclair et al., 2016 for details). Transparency and honesty are key ingredients to building trust with families.

It is helpful if there is one point-person for families to contact if they need any information following the initial meeting. The SW is ideal for this primary point of contact but this may vary depending on the NH. Following discussions with residents and families, the SW and nurse should document interactions and update care plans. Residents may not be ready to make changes immediately; *Take it to the Resident* may stretch over several meetings and includes follow-up care with both the resident and the family. Follow-up may be as simple as holding a subsequent meeting or may include a combination of bringing requested information to the resident and family, assisting with setting up meetings with other NH staff, brokering services for grief or other mental health needs for the

resident or family member, or reconvening the family and resident to document EOL wishes. Follow-up should occur within days after the initial meeting. The SW should track needed follow-up but may ask other team members to complete the follow-up tasks, as needed. Changes in code status and completion of ADs should be documented in the chart and copies of any documents should be made for the resident, family, and chart. If electronic medical records are used, adjusting the record electronically is essential to ensuring communication across staff and if transferred to the hospital.

In order to explore the utility of *Take it to the Resident* as a tool to educate and empower residents to establish their advance care wishes, this small pilot study was conducted. The aim of the project was to explore the use of *Take it to the Resident* in long-term care facilities and document the family interactions and outcomes of using this model.

## Methods

In order to examine *Take it to the Resident* in practice, a non-experimental research design was used. Data collected examined the conditions under which this approach was used in NHs and what outcomes occurred the following use. An SW with an unrestricted clinical license delivered *Take it to the Resident*. The SW used field notes and structured memos to document *Take it to the Resident* interactions. Field notes included a description of the model and the specific steps involved in carrying it out with residents. The structured memos included the SW's notes about the residents including a brief section on demographics, notes from the SW and resident discussion about ADs including knowledge about ADs and concerns about completing them, a description of family involvement, and a description of the outcome of *Take it to the Resident* (e.g., resident-documented ADs; follow-up). A structured memo was completed for each participant in this pilot project ( $n = 11$ ).

*Take it to the Resident* was utilized with eleven long-term stay residents living in three NHs in the greater St. Louis area, which is located in the Midwestern region of the United States. This project is part of a larger initiative to reduce avoidable hospitalizations among long-term stay residents across 16 NHs (see Rantz et al., 2018, Rantz et al., 2014 for study details); participants in this pilot were recruited from the pool of participants who took part in the larger study. Nursing staff were informed of *Take it to the Resident* and referred eligible participants to the project SW. Residents were eligible if they were enrolled in the larger study and did not have ADs. If residents were not enrolled in the larger study or they had ADs in place, they were not eligible for this pilot. This research was reviewed and approved by the University Institutional Review Board.

## Analysis

Descriptive statistics were used to describe the demographics of the sample. Summative content analysis was utilized to examine the unique and common instances across the sample. In this study, summative content analysis began with a systematic review of the data outlined in the structured memos (Hsieh & Shannon, 2005). Data in the memos were analyzed line by line across participants to explore and categorize (i.e., code) responses to the *Take it to the Resident* approach. The broad content areas documented in the structured memos (described above) guided the analysis. Responses documented in each content area in the memos were analyzed across participants, summarized into categories, and presented below. One PhD-prepared author conducted the data analysis independently and then discussed initial interpretations with an additional author. Discrepancies in interpretation were discussed until consensus was reached. Data analysis was managed using Microsoft Excel and Nvivo 12 software (QSR International).

## Results

Table 1 outlines the demographics, years in the NH, number of hospital transfers, and what prompted the use of *Take it to the Resident*. Eight women and three men ranging in age from 48 to 87 years old participated. Eight participants identified as White, not Latinx, while two people identified as African American and one person identified as Latina. Participants in the sample lived in the NH between six months and six years. Over the past 24 months, participants had between zero and five hospital transfers. A referral for *Take it to the Resident* occurred as part of the Annual Review process for five out of the 11 residents. Three participants' return from the hospital prompted referral. In one of these cases, the resident's wishes were

**Table 1.** Description of study sample ( $n = 11$ ).

		%*	$n$	$M$	$SD$
Sex	Female	72.7	8		
Race	African American	18.2	2		
	White	72.7	8		
	Latinx	9.09	1		
Precipitating event	Annual review	45.5	5		
	Hospitalization	27.3	3		
	Family discord	9.09	1		
	Goals unclear	18.2	2		
				$M$	$SD$
Age in years (range 48–87)				67.91	12.88
Years in the NH (range 0.5–6)				2.43	1.84
Transfers (past 24 months) (range 0–5)				1.63	1.75

reviewed because of refusal to follow medical orders. Another resident requested hospice services while hospitalized but the family did not support the decision. Two other participants were referred because the nursing staff perceived resident goals of care to be unclear.

Participants had varying levels of knowledge regarding ADs when the SW initially engaged participants. Five of the 11 participants were aware of ADs and had some knowledge while four had little to no knowledge. Two participants had advanced knowledge; one was a retired nurse and the other was her brother's power of attorney. The majority of participants (54.5%) voiced no concerns about talking about their wishes. Three participants were concerned due to family members. For example, two participants reported that they did not think their wishes aligned with their family's wishes. One of these participants reported that she feels guilt bringing up discussions about hospice because her family disapproves and become upset when it is discussed. The other participant was concerned about which family member to appoint as a power of attorney for health care she wanted her daughter to be named but her son lives closer. One resident was concerned because she was unsure about her wishes. Finally, another resident voiced concern because she did not think the NH would honor her wishes.

The level of involvement by families in advance care planning varied across participants. Four participants had family members listed as their power of attorney and four had family members helping make health-care decisions but were not formally designated powers of attorney. The degree of involvement varied, however. On one end, family members attended care plan meetings and visited regularly while others were designated powers of attorney but did not visit, speak with the health-care team, or discuss goals of care with the resident. The other three participants have family but reported to the SW that they were not involved in healthcare planning.

The SW discussed participants' EOL wishes and provided education to all participants. The SW spoke with participants about how to formally document code status and health-care decisions as well as the importance of doing this prior to a medical emergency. Throughout the discussions, participants anticipated how their families would respond to their wishes. Six participants perceived that their family members would honor their wishes once they were told about them. Three participants did not perceive that their family would offer support. Two participants perceived their family would not support their wishes.

Following discussions, the SW contacted family members in all but two cases to summarize the meeting. All of the social work engagement occurred via phone. The SW attempted to contact nine of the 11 participants' families. Two participants had not talked to their family for an extended period of time and did not want to reach out to them. Of the nine families contacted, four returned the SWs' call. In these instances, the SW summarized the meeting,



provided education, and discussed participants' wishes. Several participants reported they planned to speak with family during their next visit about their wishes.

As a result of *Take it to the Resident*, eight of 11 participants reported that they wanted to make a change to their code status from being "full code" to a status of "Do not resuscitate" or "Limited code" (i.e., resident specifies the type of resuscitation wanted in medical emergency). Two participants were undecided and one wanted to defer to her family's wishes. Although eight participants wanted to change their code status, only two were willing at the time of data collection to formally make changes in their charts. Reasons participants did not formally document the change included wanting to speak with family first, needing more time, and only wanting to verbally state their wishes.

Follow-up was not needed for four of 11 participants either because they formally changed their code status or did not want any follow-up. The project SW provided referrals to the NH SWs for follow-up with five participants who were interested in completing their ADs. One participant requested assistance in working with family and assisting with mediation if her family was unable to agree to her wishes. Follow-up was also needed for one participant to further assess health-care goals and another participant to assist with family engagement.

## Discussion

Advance care planning conversations are vital in NHs. *Take it to the Resident* is one model that places residents at the center of these discussions. Advance care planning sets the tone for the resident and family expectations of care and offers opportunity for the family, resident, and health-care staff to take a team approach to the resident's care. Findings from this study indicate the complexities surrounding decision-making about advance care plans and EOL goals. Through a supportive and collaborative approach, SWs can offer residents information about ADs, explore wishes, engage family members in the process, and explore concerns; however, residents cannot be forced to put these wishes in writing. Although *Take it to the Resident* only resulted in two residents documenting their wishes in ADs, it prompted all participants to think about goals of care, learn about ADs, and start conversations with family members.

Family engagement in advance care planning is complex. It is a strength and resource for many residents; however, when resident and family wishes are misaligned, disempowerment, and conflict may result (Decoster, 2000). *Take it to the Resident* provides residents the space to think through their wishes and then pull family members into the conversation. This work highlights the difficulty of engaging families. This project's SW had dedicated time for family engagement, and for some participants, it was still challenging to include family in care planning discussions. This is not a novel finding but a reality that many

NH SWs face. Identification of conflict between resident and family wishes provides the opportunity to resolve conflicts prior to medical emergencies.

Some residents are not aware of the importance of documenting their wishes while others may be hesitant to have advance care planning conversations with loved ones. SWs in NHs play a critical role in creating space and opportunity for these discussions and providing education and advocacy for residents and families alike. *Take it to the Resident* is one model for NH SWs to utilize to increase advance care planning discussions and completion of ADs.

### Limitations

Additional research is needed to examine *Take it to the Resident* with a larger sample of long-term stay residents. This project established that the model can be used as a tool to promote discussions surrounding ADs with residents first. Although these data are primarily descriptive, they do offer insights into the utility of *Take it to the Resident* as an approach to empower residents to consider their wishes first and then engage family members in the discussion.

### Conclusions

The next steps in research on this model include comparing it with other existing models to promote AD discussions, utilizing a comparison group, and exploring resident experiences with *Take it to the Resident*. SWs can play a critical role in NHs in promoting advance care planning discussions with residents, engaging families in these discussions, and increasing the use of strategies to empower residents to voice and document their EOL wishes (Black, 2005; Morrison et al., 2005; Wang et al., 2017). *Take it to the Resident* is one model that can be used early in long-term stay resident care and often throughout their stay to ensure resident wishes are at the center of advance care planning.

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