



Me & My Wishes: An efficacy trial of long-term care residents with Alzheimer's disease using videos to communicate care preferences with caregivers

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This issue brief presents findings from a research project led by the University of Utah College of Nursing, in collaboration with the Center for Long-Term Care Quality & Innovation (Q&I).

People living with dementia, or cognitive impairment, are capable of communicating their preferences for daily care and end-of-life, but these preferences may not be routinely documented or understood by formal and informal caregivers.

This National Institutes on Aging-funded project (PI: Gail Towsley, PhD) involved using a video-based intervention, Me & My Wishes, to elicit long-term care residents' preferences and to improve care plans' alignment with these preferences.

Me & My Wishes

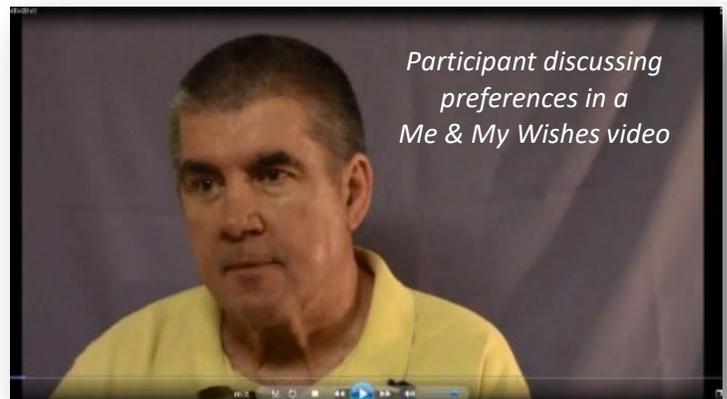
Me & My Wishes consists of four short videos taken of long-term care residents with mild-to-moderate cognitive impairment expressing their day-to-day and end-of-life wishes.

Videos are shown to family and staff to increase documentation, knowledge, and understanding of residents' wishes and to facilitate conversations.

In prior research, Dr. Towsley's team showed that Me & My Wishes was feasible and acceptable ([Journal of Pain and Symptom Management, 2018](#)). In the next phase of research, presented here, the team examined outcomes.

Key Points

- We showed videos of long-term care residents living with dementia discussing their care preferences to family and staff
- We found:
 - > Improved documentation of goals of care conversations
 - > Improved agreement between residents' end-of-life preferences and family and staff knowledge of preferences
- Personalized videos like these may:
 - > Help family and staff to understand resident preferences
 - > Support resident-directed, goal-concordant care



Participant discussing preferences in a Me & My Wishes video



Goal

To elicit preferences from long-term care residents living with dementia and align care plans with these preferences.

Methods

1. We randomly assigned three assisted living communities and five nursing centers in the Pacific Northwest to participate immediately or after a delay.
2. We recruited 36 long-term care residents with mild-to-moderate cognitive impairment to create Me & My Wishes personalized videos with residents.
3. We shared videos with residents' family or friends and care team during their service plan meeting (assisted living residents) or care conference (nursing center residents).
4. We examined outcomes:

Our primary outcome was *communication of preferences*: either documentation of goals of care conversations in resident records or self-report of conversations about preferences.

We also assessed concordance on five end-of-life treatment preferences and four near end-of-life psychosocial preferences, from the videos and through family and staff surveys.

Participants

Residents

- 36 long-term care residents participated
- All had mild-to-moderate cognitive impairment
- On average, they were 78 years old
- More than half (61%) were female

Family

- 50 family members participated
- Nearly three-fourths (72%) were female

Staff

- 38 staff participated
- Staff roles varied: care managers, social services directors, activity directors, dietary managers, etc.

As a "stage II efficacy study," research staff recorded the videos and shared them with staff and families.

Efficacy studies are a first step to demonstrate that an intervention works as intended, before testing implementation by providers.

Improved Documentation of Goals of Care Conversations

Documentation of goals of care conversations was three times more likely after sharing videos vs. prior to sharing them.

We can't say for certain that these results aren't due to chance (they aren't "statistically significant"), because of the small number of study participants – but this finding suggests that sharing videos of resident preferences may be impactful.

When we asked residents, family, and staff whether the videos led to conversations about resident preferences, most family (90%) and staff (92%) agreed they did. A lower percentage (75%) of residents agreed; it's possible some did not recall because of their dementia.

Improved Concordance of Knowledge of Preferences

Concordance, or agreement, between residents' stated end-of-life treatment preferences and family and care team members' knowledge of these preferences improved between baseline (before the videos were viewed or shared) and when the videos were shared.

Concordance was greatest at time of sharing the video, showing a "treatment effect" - in this case, the treatment (sharing the videos) significantly increased concordance between resident preferences and family and care team knowledge of these preferences.

Conclusion

We found that the Me & My Wishes videos of long-term care residents expressing their day-to-day and end-of-life wishes:

- Improved documentation of goals of care conversations
- Improved family and staff agreement with psychosocial and treatment preferences

Our findings suggest that personalized videos, like these, may help family and staff to understand resident preferences and support resident-directed, goal-concordant care.

Issue brief authors Towsley (PI) and Baier participated in the study; Reddy and Wittenberg assisted with the issue brief.

Want to learn more?

The data presented here are published in two papers:

[*Journal of the American Medical Directors Association*](#)
(2021)

[*Journal of Palliative Medicine*](#)
(2022)

About the Brown Center for Long-Term Care Quality & Innovation (Q&I): Q&I partners with researchers and other innovators to test and disseminate interventions that have promise to improve care for older adults, with particular emphasis on those residing in assisted living communities and nursing centers. More: brown.edu/go/innovation