A My Gift of Grace White Paper

Accommodation: When communicating about end of life issues, it matters how people speak

Speech that is either patronizing or over the audience's head can carry real costs

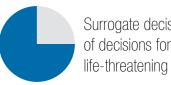
The past decade has seen an emerging consensus on the importance of communication about end of life issues as a way to improve care, reduce suffering, and lower costs in health care. However, few of the interventions that have been introduced have shown measurable results. Recent research by Allison M. Scott of the University of Kentucky points to a possible reason for the mismatch between investment and outcomes: most interventions have focused on increasing the *quantity* of communication about end of life issues but not on improving the *quality* of that communication.

In order to improve communication (and thus care) at the end of life, a deeper understanding of the components and structures of communication and how those components and structures function is necessary. This White Paper examines recent research on a specific component of communication — accommodation — and recent findings about how it can affect people's perceptions and ability to make decisions for others in end of life situations.

BACKGROUND

The problem of how to make decisions near the end of a person's life has attracted much attention in recent years. Interventions have proliferated, new organizations dedicated to addressing the problem have been created, and public service campaigns have been launched, both within the medical field and by members of the press, artists, and legal professionals.

Because of improvements in health care and new methods of extending life, an increasing number of people are unable to make healthcare decisions for themselves at the end of their lives. Studies show that surrogate decision-makers or healthcare proxies make 75% of decisions



Surrogate decision-makers make 75% of decisions for hospitalized patients with life-threatening illness



Over 80% of surrogate decision-makers who made end of life decisions showed symptoms of PTSD

for hospitalized patients with life-threatening illness,¹ and over 40% of decisions for nursing home residents.²

Situations in which a person (most often a family member) makes critical decisions about another person's care

Hiltunen EF, Medich C, Chase S, Peterson L, Forrow L. Family decision making for end-of-life treatment: the SUPPORT nurse narratives. J Clin Ethics. 1999;10(2):126–134.

² Kim SY, Karlawish JH, Caine ED. Current state of research on decision-making competence of cognitively impaired elderly persons. Am J Geriatr Psychiatry. 2002;10(2):151–165.

overaccommodation: dumbed down or patronizing speech **underaccommodation:** talking over a listener's head

can lead to extremely harmful outcomes. In one 2005 study, over 80% of surrogate decision-makers who made end of life decisions showed symptoms of PTSD.³

While new kinds of documentation such as POLSTs (Physician Orders for Life-Sustaining Treatment) have emerged to address the problem of recording decisions for patients, there remain serious obstacles to the use of these documents in real-life medical situations. Documents are often not included in Electronic Health Records (EHRs) or are otherwise not immediately available. And, even when documents are accessible, the complex and rapidly changing nature of emergency medicine and ICUs often results in a mismatch between the decisions that have been recorded and the situation that presents itself to a patient and their family and healthcare providers.

This has led to increasing efforts to improve communication among patients, surrogate decision-makers, and healthcare staff in order to improve in-the-moment decision-making.⁴ Additionally, many Advance Care Planning (ACP) initiatives have shifted focus toward communicating life goals and values over predetermined decisions about specific medical interventions in the hope that this will increase the readiness and ability of surrogates to make good decisions.

The results of these efforts can be measured in concordance: the level of accuracy with which someone can predict another person's end of life choices. In a situation where a patient is unable to communicate for themselves, the concordance that a surrogate decision-maker or health-care provider achieves determines how well a patient's values and wishes are translated into actual care. Unfortunately, surrogate decision-makers have been shown to fail at predicting a patient's treatment wishes about one third of the time, and simply having discussions between patients and surrogates has not been shown to improve accuracy.⁵

In light of all this, what is to be done? A recent study by Allison M. Scott of the University of Kentucky offers some clues as to how we can improve the quality of communication about end of life issues, and in doing so, improve outcomes for patients and surrogate decision-makers.

- 3 Azoulay E, Pochard F, Kentish-Barnes N, et al. Risk of post-traumatic stress symptoms in family members of intensive care unit patients. Am J Respir Crit Care Med. 2005;171(9):987–994.
- Sudore RL, Fried TR. Redefining the "planning" in advance care planning: preparing for end-of-life decision making. *Ann Intern* Med. 2010; 153(4):256-261.
- 5 Shalowitz DI, Garrett-Mayer E, Wendler D. The accuracy of surrogate decision makers: a systematic review. Arch Intern Med. 2006;166(5):493-497.

HOW A DEEPER UNDERSTANDING OF COMMUNICATION CAN IMPROVE CARE

Scott's paper, *Message features in family conversations about end-of-life health decisions*, explores the implications of just one aspect of communication about end of life issues between older parents and their adult children, but it is a crucial one: accommodation.⁶ Communication Accommodation Theory, developed by Howard Giles, argues that "when people interact they adjust their speech, their vocal patterns and their gestures, to accommodate to others." Scott's study focuses on two ways that people adjust how they communicate that will likely be familiar.

The first, overaccommodation, involves dumbed-down or patronizing speech, often marked by talking more slowly and using simpler language. We might call this "talking down to a listener." The second, underaccommodation, can be seen when a speaker interrupts, uses overly complicated language, or otherwise shows a lack of concern for the listener's needs. We might call this "talking over a listener's head."

While not universally linked with negative outcomes in discussions about end of life issues, both over- and under-accommodation are problematic. Scott's research points to two serious issues that are linked with speaking at a level that is inappropriate to the listener.

Underaccommodation and uncertainty

In Scott's study, which relied on surveys and an analysis of recorded conversations about end of life topics with 121

In conversations where the level of **underaccommodation** was high, both the parent and the adult child reported higher levels of uncertainty about end of life decisions.

pairs of older parents and their adult children, a clear link was found between underaccommodation and uncertainty. In conversations where the level of underaccommodation

- 6 Scott, AM, Caughlin, JP (in press). Nonaccommodation in family conversations about end-of-life health decisions. *Health* Communication
- 7 Turner LH, West R. (2010). "Communication Accommodation Theory" In: Introducing Communication Theory: Analysis and Application (4th ed). New York, NY: McGraw-Hill; 2010.

was high, both the parent and the adult child reported a higher level of uncertainty about end of life decisions.

Overaccommodation and concordance

When a participant in the study overaccommodated, on the other hand, they reported a greater sense of efficacy about end of life decision making. This seems like a positive outcome: confidence in decision-making is likely to reduce distress. But, when Scott had partners fill out questionnaires about their own preferences in end of life scenarios and then predict their partner's answers to the same questions, people who overaccommodated were actually less accurate in predicting the other person's answers.

The implications here are stark: talking down to someone about their end of life choices is likely to make you both more confident about your understanding of what they want and less accurate at the same time.

IMPLICATIONS

While Scott studied older parents and adult children pairs, her study suggests that it may be valuable to focus on the components of communication (and specifically accommodation) when designing any interventions related to end of life communication.

Simply being aware of the implications of overand underaccommodation is likely to improve how people communicate about end of life issues. Training in identifying instances of unhelpful accommodation and methods for steering conversations and inserting examples of appropriate levels of speech can also help healthcare staff improve their own communication.

In our own work at The Action Mill, we have relied

In conversations where the level of **overaccommodation** was high, decision-makers had both a higher level of confidence and lower accuracy in their ability to predict their partner's answers to questions about end of life treatment.

on observation of conversations and the expertise of hospice nurses, palliative care doctors, and other experts in end of life communication to target specific components of communication. For instance, in the game we developed about end of life communication, My Gift of Grace, there are mechanics built into the instructions that help individuals avoid talking over each other and encourage each person to think and record their thoughts before sharing them, which we have seen leads to clearer, more appropriate communication.

CONCLUSION

The problems that result from a lack of quality communication around end of life issues are well known. Many programs that attempt to deal with these issues focus on ensuring that conversations happen or on documenting the wishes of patients. These programs can be improved by integrating training that helps people identify and correct issues related to accommodation in communication. In addition, processes can be improved by building in measures that remind people about accommodation in speech and providing ways to improve communication between staff, patients, and families.

About the author: Nick Jehlen is a partner at The Action Mill, a company that provides products and services that improve end of life communication and decision-making. Nick is the lead designer of My Gift of Grace.

Improving end of life communication and decision-making in healthcare

My Gift of Grace is an innovative game that helps everyone talk about end of life issues. Developed with hospice nurses, palliative care doctors, and other end of life experts, the game is a non-threatening way to introduce these important conversations. My Gift of Grace is in use in hospitals around the US and is currently the subject of a research study at Penn State.

We also offer trainings that give healthcare staff the knowledge and skills necessary to introduce and facilitate values-based Advance Care Planning (ACP) with patients and families. Over 95% of the healthcare staff who have gone through our end of life communication trainings recommend them to their colleagues. Contact us at jethro@actionmill.com or 267-687-8008 to schedule a training for your staff.

Get more info on our products and services at mygiftofgrace.com



"My Gift of Grace has been wonderfully effective at Mercy – beyond our expectations. We are using the game as a conversation starter in a variety of settings, ranging from physician offices, to inpatient ICU, to area classrooms. The game is a non-threatening, fun way to start a conversation around goals, expectations, and directions of treatment."

Robert Bergamini, M.D. Medical Director, Palliative Care Mercy