Supporting Medical Decision Making and End-of-Life Communication Needs

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Disclosures

- Richard Hurtig is Professor Emeritus in the Department of Communication Sciences and Disorders at The University of Iowa and is President and CSO of Voxello which is developing a medical device to support patient-provider communication.
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Learning Objectives

1. Describe the value of being able to participate in medical decision making and the risks associated with the inability to participate in medical decision making.

2. Describe how communication tools enable non-speaking patients to demonstrate competence to participate in medical and end-of-life decision making.

3. Identify key conversational content areas that enable individuals to enhance their quality of life and remain socially engaged.

Presentation Outline

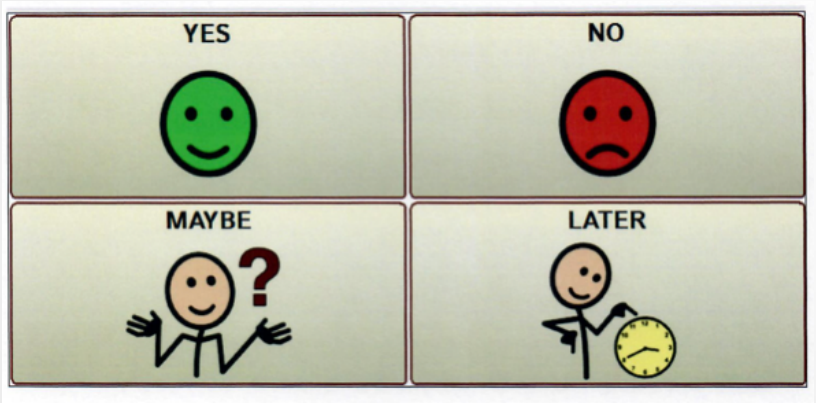
1. Communication Challenges
2. Elements of Medical Decision Making
3. Supporting Psychological and Spiritual Needs
4. Illustrative Cases
5. Demonstration of Communication Templates
6. Summary and Questions

Communication Challenges

- Barriers to effective communication can lead to
  - Adverse medical outcomes
  - Significant isolation and a dramatic shrinkage in the individuals' social world.
  - Loss of autonomy & exclusion from medical decision making
  - The inability to speak makes individuals susceptible to our society's paternalistic approach to dealing with individuals with a disability.
    - "Elder Speak"

Restricted Communication

- Limits of "yes/no" responding
  - Needing options for "maybe" and "later" responses



- Limits of all purpose "on size fits all" communication boards
  - Limited to bodily needs
  - Primarily responsive
  - Preclude in depth exchanges

pALS Communication Preferences

- Use Speech as long as possible
- Write or Type messages
- Speech Generating Device should have natural “individual” voice
  - Voice banking- Recorded Messages
  - Voice Modeling: Synthetic voice based on samples of individual's voice
- Use direct selection rather than scanning
  - Keyboard, Touch Screen, Eye gaze

The problem of thinking "short-term" rather than "long-term"

- Avoiding thinking about "difficult conversations" until it may be too late.
- Failing to appreciate the progression of the disease and unpredictable time course.
  - Decline in ability to speak or write
  - Cognitive decline
- Leaving learning an alternative AAC strategy to a time when the pALS faces greater physical and cognitive challenges may limit the ability to master the strategy.

Medical Decision Making-1
"*Competence*"

- In order for individuals who are unable to speak and write to participate in their care and in decision making, they need to be able to demonstrate that they are **competent**.

Medical Decision Making-2
"not just indicating yes/no"

- Reliance on yes/no responses is a challenge
  - It may introduce a bias based on what questions or options the individual can be presented with.
  - It prevents the individual from easily trying to solicit the critical information necessary to make an informed decision.

Medical Decision Making-3
"*need to be able to communicate*"

- pALS must be able to ***demonstrate that they understand*** their situation and that they can ***articulate their preferences*** when it comes to their care.

Supporting Medical Decision Making

- Have a range of communication templates that would enable non-speaking individuals to
  - indicate their preferences
  - solicit information about the consequences of both making or not making a particular decision.
- Make it easy for individuals to demonstrate an understanding of the consequences of certain decisions about their care.
- Insure that their wishes on medical and spiritual issues are as unambiguous as possible and clearly grounded in their current situation.

Societal Challenges-1

- Patients & Family inclination to avoid talk about death and dying until it is too late.
  - A large part of the task is helping people negotiate the overwhelming anxiety—anxiety about death, anxiety about suffering, anxiety about loved ones, anxiety about finances
  - Arriving at an acceptance of one's mortality and a clear understanding of the limits and the possibilities of medicine is a process, not an epiphany.

(Gawnade, 2014, p. 182)

Societal Challenges-2

- Healthcare Professionals' reluctance to be bearer of "bad news". Not knowing how to talk about death and fear of negative reactions.
  - "a family meeting is a procedure, and it requires no less skill than an operation" (Susan Block, quoted in Gawande 2014, p.181)

Societal Solutions

- Community Awareness
  - Gunderson Lutheran Hospital, LaCrosse Wisconsin, Advanced Directives Plan
- Early post-diagnosis engagement of patient & family
  - Training healthcare professionals
  - Seeing it as a process not a “one off”

What is "Giving Hope"

"The word ***hope*** first appeared in English about a thousand years ago, denoting a combination of **confidence** and **desire**. But what I desired—life—was not what I was confident about—death." (Kalanithi, 2016 , p133)

Supporting Psychological Needs

- Providing the means to initiate "difficult conversations"
  - Confronting likelihood of death
- Providing the means to express a wide range of emotions
  - Anger and humor are what make us human
- Providing the ability to control interactions
  - start, continue, postpone, end & cutoff

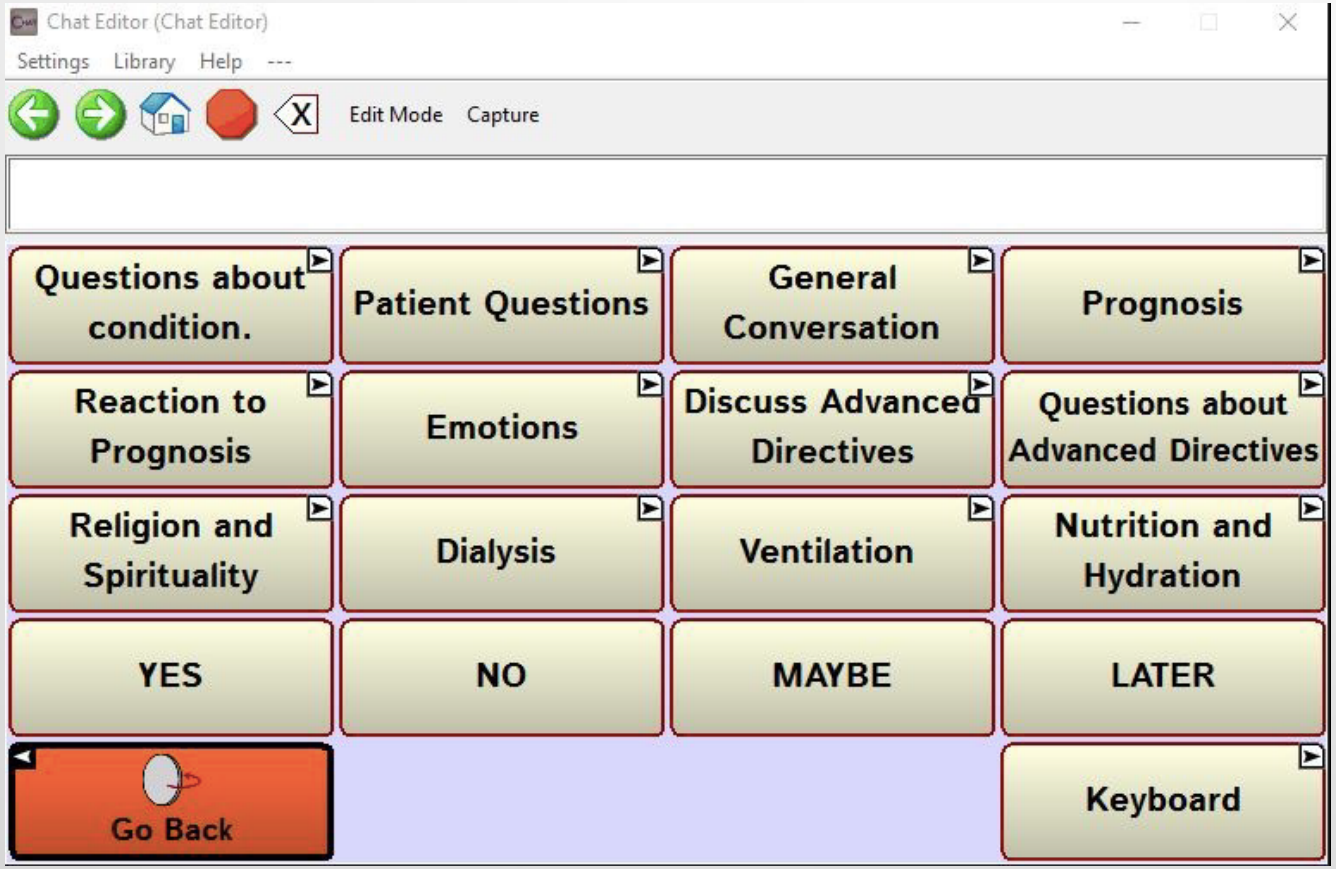
Supporting Spiritual Needs

- Provide the means of discussing beliefs related to
  - Mortality & Afterlife
  - Prayer and intercession of a higher power
  - Wishes related to funeral/ memorial service rituals
    - Burial, Cremation, Organ donation…

Illustrative Cases

- Absent Advanced Medical Directive – Losing Control
  - "chocolate ice cream and football" The value of the "difficult conversations"
  - "dueling siblings" – Emergent Trauma
- Early Advanced Medical Directive – Changing Wishes
  - "living with the disease" perspective changes

Demonstration of Communication Templates



Summary-1

- The decision to accept or terminate life-sustaining treatment is always a painful one for patients, caregivers and their family members.
- Allowing the patients to have a significant role in those decisions
  - preserves their autonomy
  - can also reduce the stress of the caregivers and family members.

Summary-2

- The approach to empowerment of individuals who may be unable to speak and who may only be able to generate a single intentional gesture has enabled individuals
  - To remain engaged with their caregivers.
  - To actively participate in medical decision making even in terminal end-of-life scenarios.

Questions

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