End of Life Discussion with Persons with Disabilities
Christine Pham, MD, Kim Le, MD, and Lynne Tomasa, PhD, MSW

Introduction

Research on end of life (EOL) care for persons with intellectual and developmental disabilities (IDD) and debilitating mental illness (DMI) has focused on EOL communication, care preference/interventions, and decision making.[1,2,3] Research in these areas are limited and have not focused on when these discussions should and does occur. The goal of this project is to identify family physicians' perceptions and comfort in addressing EOL issues. Specific objectives are to identify:

1) When EOL discussions should begin with persons with disabilities;
2) Providers' comfort and role in facilitating planning
3) The challenges experienced in communication and planning.

Methods

Setting: The University of Arizona College of Medicine, Family Medicine residency programs (South Campus and University Campus)

Participants: Family medicine residents and physician faculty.

Instrument: Paper and online questionnaire with 25 items, 5-point Likert scale, and open-ended questions. Questionnaire developed by Drs. Pham, Le, and Tomasa.

Data Collection: Paper questionnaire administered during January Teaching Day (University Campus) after brief lecture. Qualtrics link made available to both residency programs during January and February 2015.

Analysis: SPSS version 22 was used for all analyses. Non-physician faculty and medical students not included in data analysis.

Results

There were 15 resident responses out of 47; 4 PGY1s, 8 PGY2s, and 3 PGY3s. Total of 8 faculty responses.

Figure 1: At what age would you consider starting a discussion about EOL wishes as part of an annual physical exam?

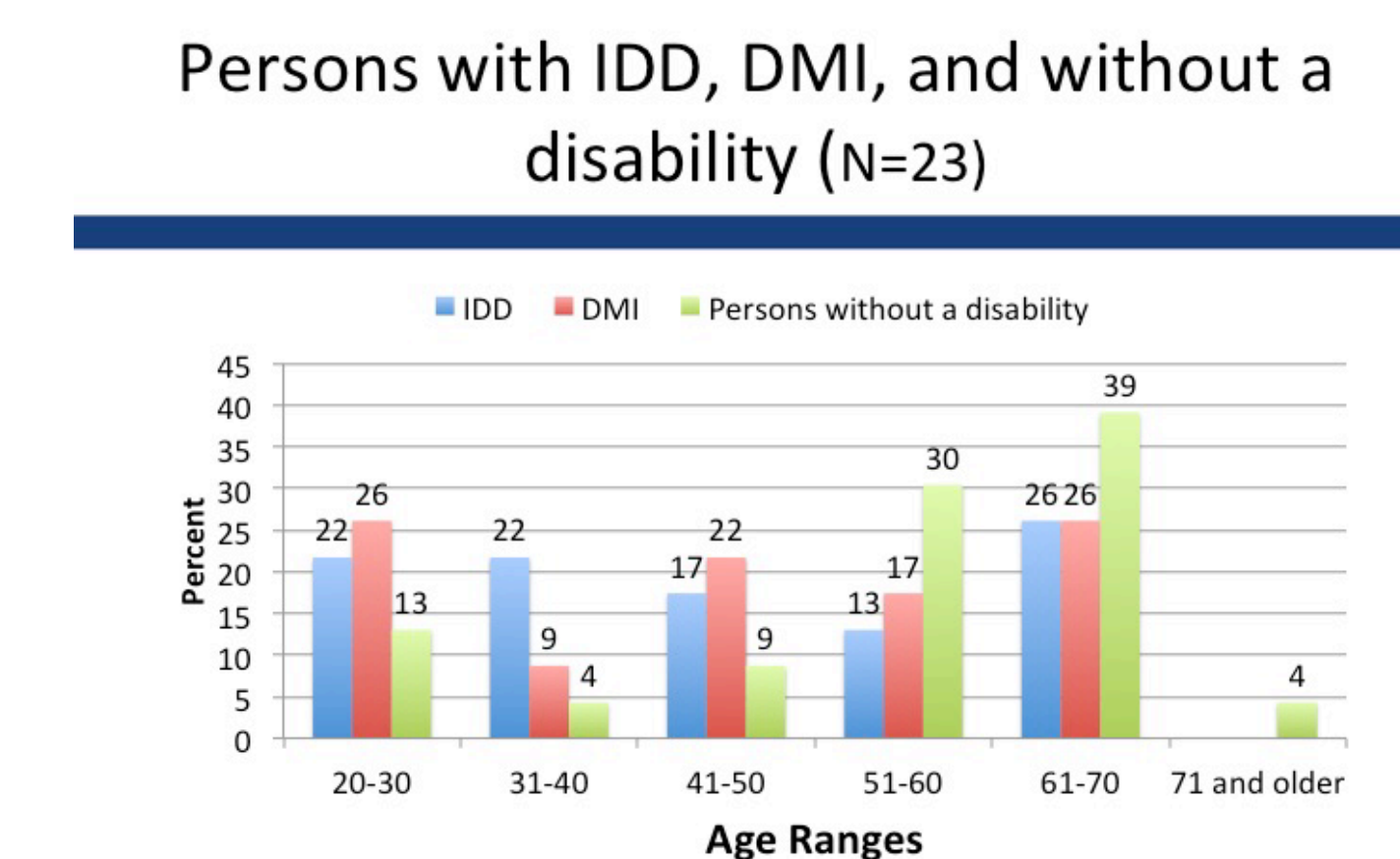Persons with IDD, DMI, and without a disability (N=23)

Figure 3: Healthcare providers are more likely to stop aggressive treatments and transition to palliative treatments earlier when caring for a person with…
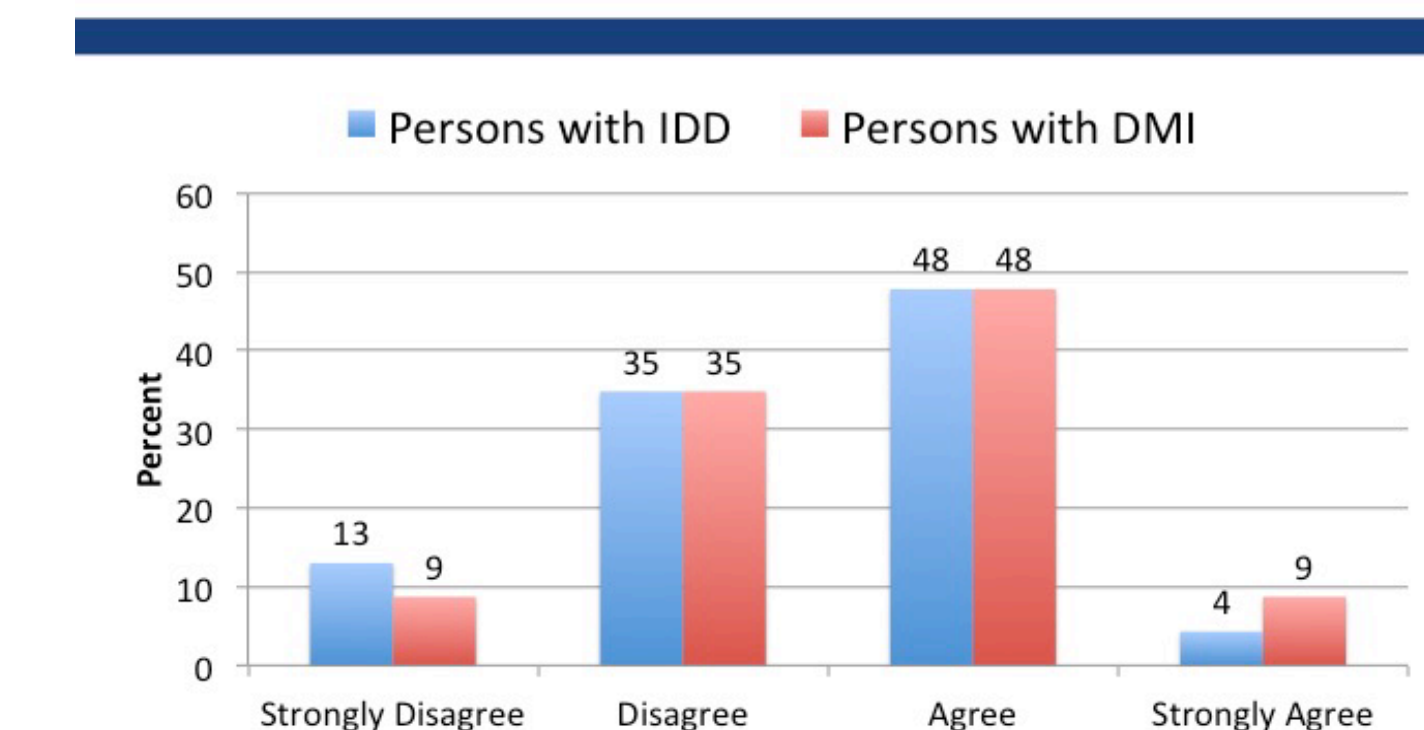

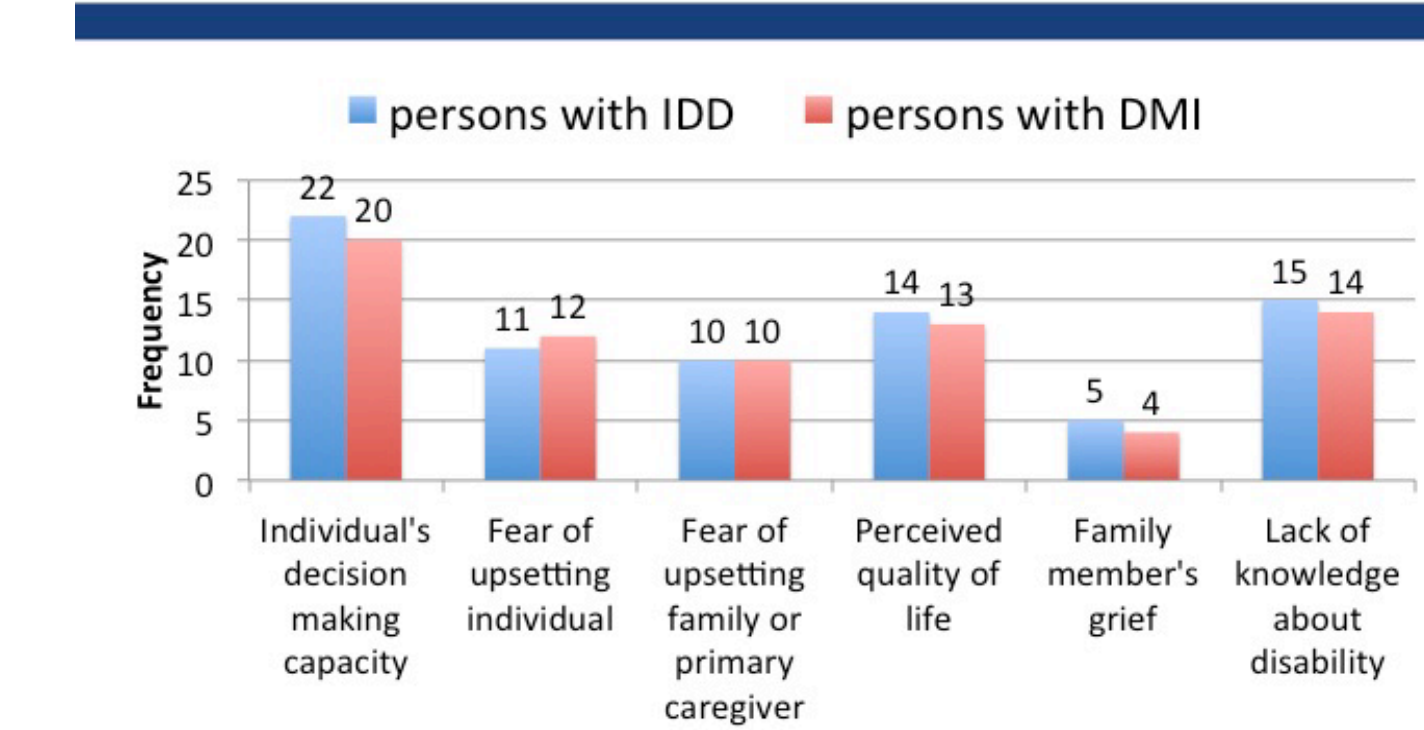Figure 5: Factors that influence ability to initiate EOL discussions with…

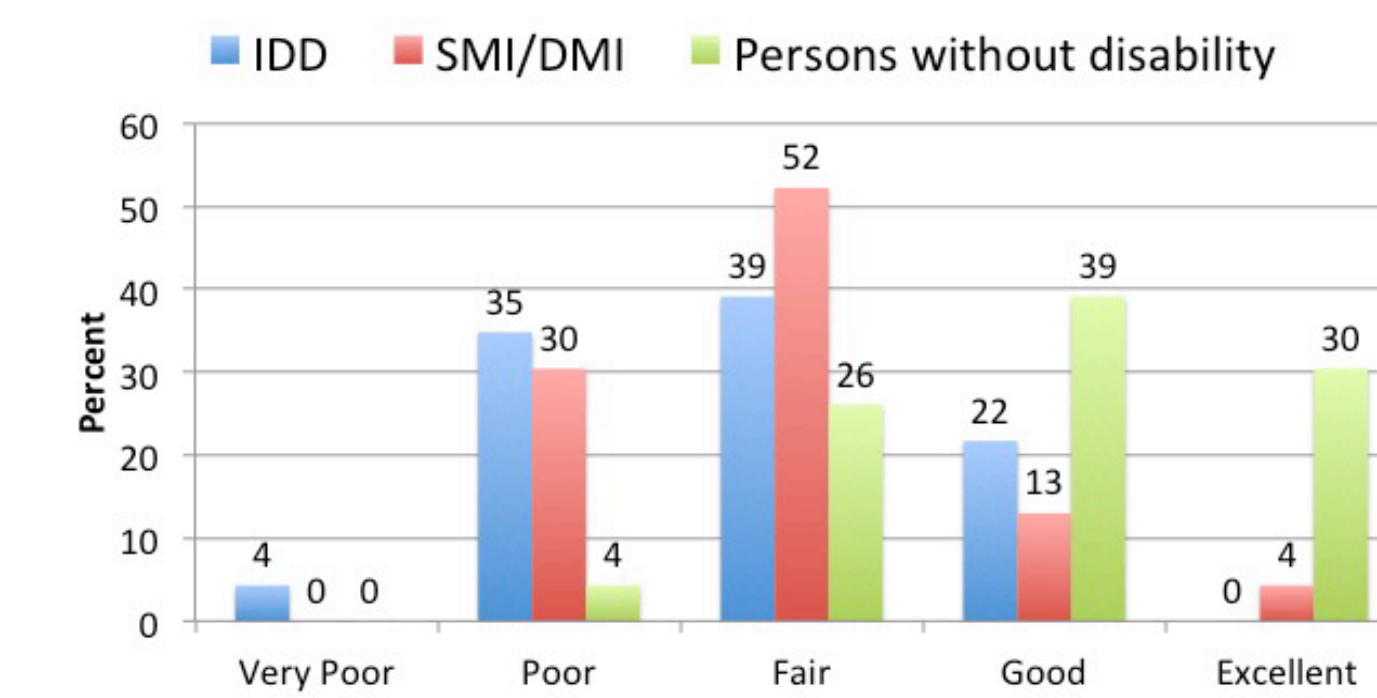Figure 2: How would you rate your level of confidence in talking about Advance Directives?

Figure 4: To what degree does a person's disability impact your decision making about termination of life support?
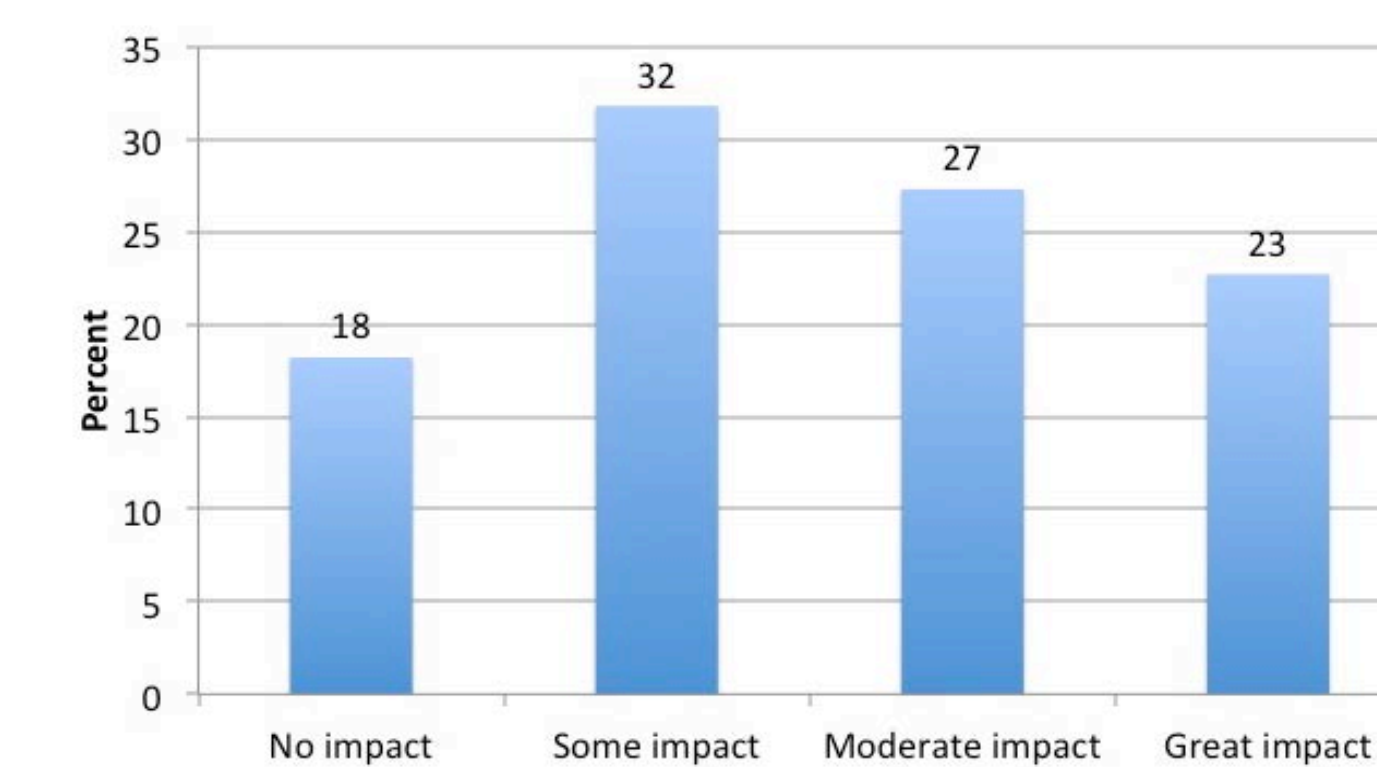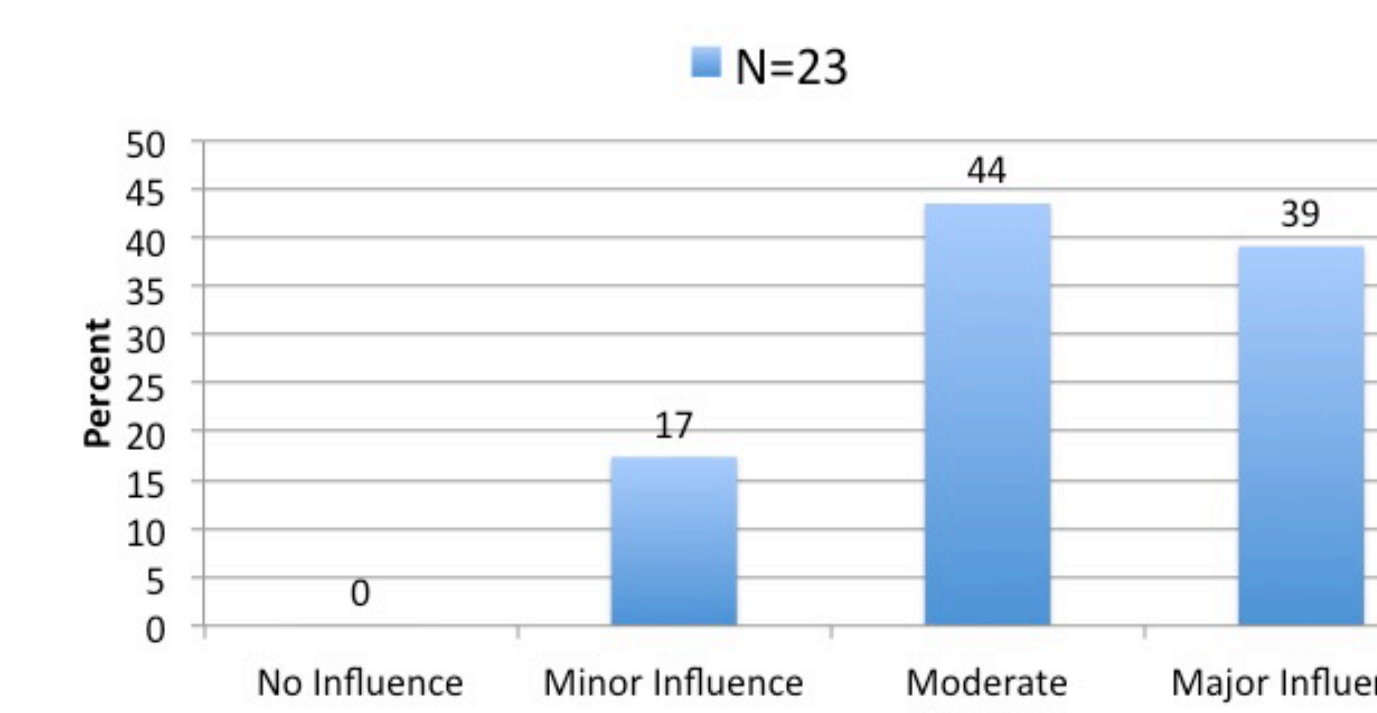

Figure 6: To what degree does your personal experience with death influence how you approach EOL discussion?

Results continued

Challenges in addressing EOL for persons with IDD:
- Assessment of the understanding of their condition
- Determining capacity, assessing level of understanding
- What they are ethically capable of deciding
- How safe and protective is living situation

For persons with DMI:
- Assessment of how DMI affects their plan at given time
- Patient's interpretation of the goals of our discussion
- Variability from day to day in function, mood, determining if a decision is appropriate

Conclusions

End of life discussions should start at a much younger age for persons with a disability. Many factors can influence a health care providers' comfort and ability to address EOL planning.

References

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2. Foti, ME, Bartels ST, Merriman MP, Fletcher KE, Van Citters AD. Medical advance care planning for persons with serious mental illness. *Psychiatry Serv.* 2005; 56(5): 576-84.
3. Bikkema N, de Veer A JE, Wagemans A MA, Hertogh D, Francke AL. Decision making about medical interventions in the end of life care of people with intellectual disabilities: a national survey of the considerations and beliefs of GPs, ID physicians and care staff. *Patient Education and Counseling.* 2014; 94: 204-209.

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