Increasing Advance Directives for Adolescents and Young Adults Living with Neuromuscular Disease

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Introduction & Problem Significance

- US Adults with advance directives: 36.7%, 38.2% with a chronic illness, and < 50% of severely or terminally; Unknown for adolescents & young adults (AYAs)
- AYAs are not deemed legally competent to make decisions and healthcare providers feel unprepared, uncomfortable, and unskilled in having discussions
- Small number of AYAs in the Neuromuscular Program have advance directives and are at risk for dying without having wishes known → ethical dilemmas and potentially higher end-of-life healthcare costs

Purpose & Aims

To increase the number of advance directives for AYAs being cared for in the Neuromuscular Program and evaluate satisfaction:

- Aim 1: Increase the number of advance directives by 50%, as measured by the change in number of AYAs with advance directives from the beginning of the project period (pre-intervention) to the end of the project period (post-intervention)
- Aim 2: Evaluate participants' satisfaction level of the experience of using the *Voicing My Choices*™ decision-making tool to have a conversation to establish advance directives

Methods

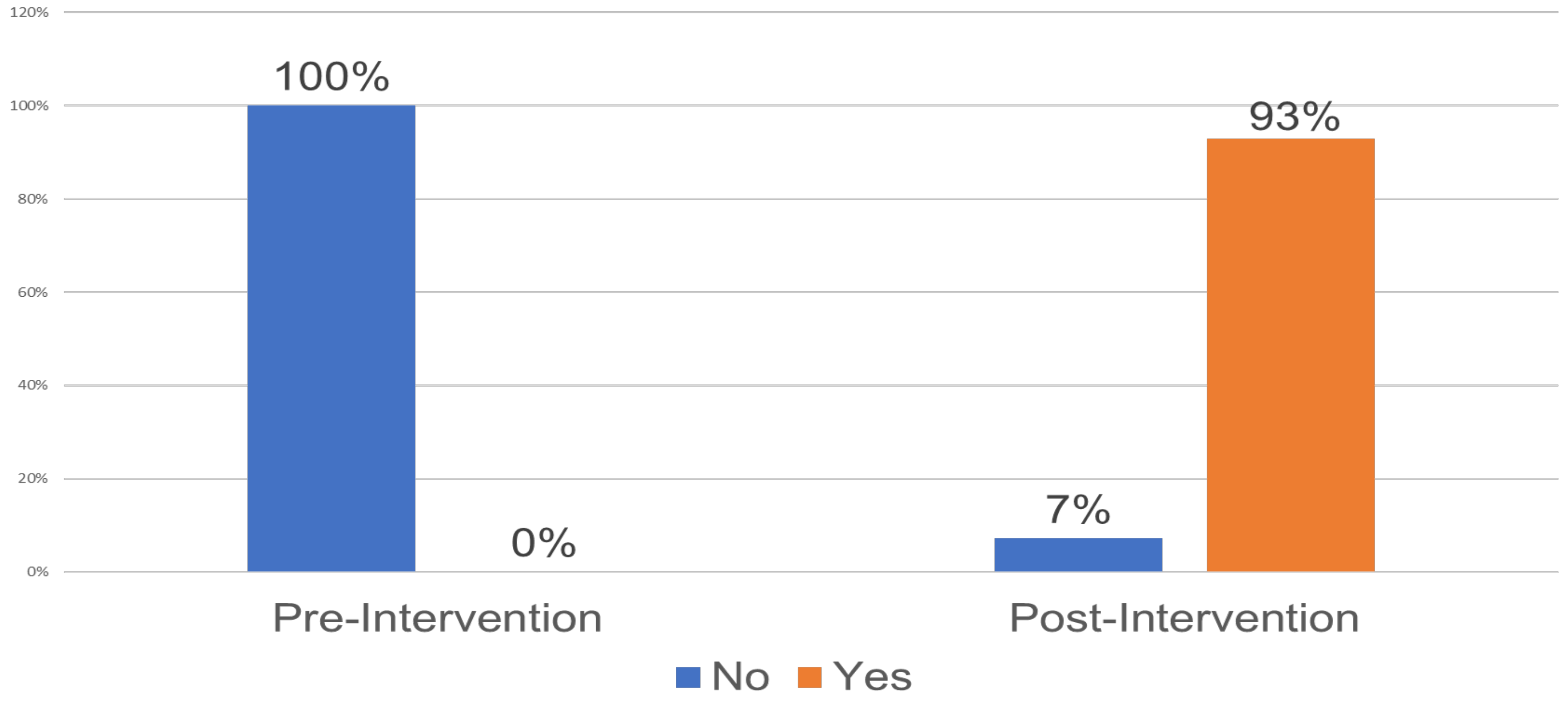
- <u>Design</u>: one sample post-test design; comparing each participant before and after the intervention, with time as the independent variable
- <u>Setting</u>: Young Adult Clinic (YAC) in the Neuromuscular Program at an academic medical center on the East coast
- <u>Sample</u>: convenience sample of 14 AYAs, ages > 18 years, with a confirmed neuromuscular disorder, who had a YAC appointment between July – October 2020, and did not already have an advance directive
- <u>Ethical Considerations</u>: implemented in July 2020 after receiving approval from the hospital's Institutional Review Board (IRB)
- <u>Intervention</u>: conversation tool *Voicing My Choices*™: An Advanced Care Planning Guide for AYAs, 6 sections: 1) My Comfort, 2) My Support, 3) My Medical Care Decisions, 4) My Medical Treatment, 5) My Family/Friends To Know, 6) My Spiritual Thoughts
- <u>Measure</u>: Likert scale survey question to evaluate participants' satisfaction level with using *Voicing My Choices*™
- <u>Analyses</u>: descriptive statistics of central tendency (counts and percentages); statistical analysis was conducted using SPSS software version 27

Results

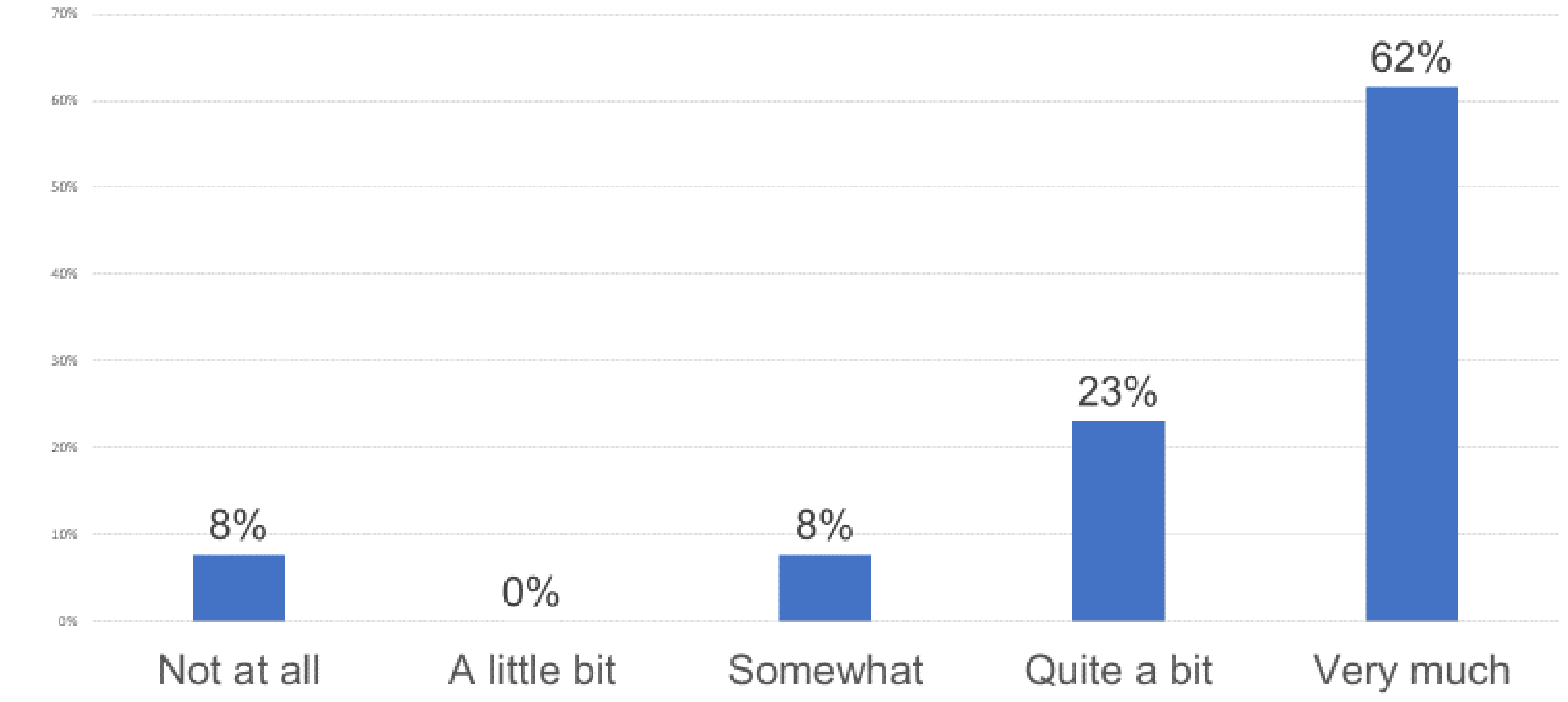
Participant Demographics (n=14)

- Mean age: 24.36 years
- Gender: Male: 64.3%, Female 35.7%
- Race: White: 50%, Other: 50%
- Ethnicity: Hispanic: 50%, Other: 50%
- Primary Language: English 85.7%; 14.3% Spanish
- Education level: high school 14.3%, high school grads 35.7%, some college 28.6%, bachelor degree 21.4%
- Diagnoses: Congenital Myopathy 7.1%, Duchenne Muscular Dystrophy 57.1%, Spinal Muscular Atrophy, Type II 28.6%, Congenital Myasthenic Syndrome 7.1%

Percentages of Participants with and without Advance Directives Pre-Intervention and Post-Intervention (n = 14)



How satisfied are you with the conversation you had about advanced directives with the nurse practitioner using the "*Voicing My Choices*"™ conversation tool? (n = 13)



Discussion

- Clinically meaningful change shown by 93% increase in advance directives
- High satisfaction rate with using *Voicing My Choices*™ as a conversation tool
- AYAs are eager to discuss goals of care & are satisfied with the conversation
- Innovative given limited evidence about advance directives for AYAs with NMD
- Goals of care discussions should be a part of routine care for this population

Limitations

- Sampling technique (convenience; may not be represent the whole population)
- Small sample size
- Intervention not validated with disease-specific population
- Time and setting
- Not all providers are comfortable having these conversations
- Some AYAs may not be comfortable having these conversations
- Satisfaction assessed by person delivering intervention

Sustainability

- **Short-term:**
  - Continue using the intervention to discuss advance directives with AYAs
- **Long-term:**
  - Training other interdisciplinary team members to use the intervention
  - Expand the intervention to other patient populations in the department

Dissemination

- Findings communicated to organizational stakeholders to guide the implementation of goals of care/advance care planning into routine care for AYAs
- Presentation at community meetings, national conferences, publication

Conclusion

- Unclear how and when to initiate conversations about goals of care and how best to document personal wishes, yet AYAs with NMD want these discussions, want them sooner, and rely on providers to initiate them
- Using conversation tools designed for AYAs and including them as routine care is beneficial in allowing AYAs with NMD to express their desires for future care
- *Voicing My Choices*™ is an effective tool in increasing the number of advance directives among AYAs receiving care in the Neuromuscular Program

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