

Abstract

Background and Purpose: The questions of how and when to initiate conversations about goals of care and how best to document personal wishes are not well answered, yet it is clear from the literature that Adolescents and Young Adults (AYAs) living with Neuromuscular Disease want to have these discussions and want them sooner. Conversations about goals of care and advance directives are not common practice in the neuromuscular clinic setting.

Methods: The project used a conversation tool as a one-time intervention to guide conversations about participants' goals and wishes. The number of AYAs with advance directives were compared before and after the use of the intervention and their satisfaction with having a conversation about goals of care using this tool was measured.

Results: A total of 14 AYAs with genetically confirmed neuromuscular disease were enrolled in this project. Statistical significance was unable to be determined, however there was a 92.9% increase in the number of AYAs with an advance directive from the start of the project period (pre-Intervention) to the conclusion of the project period (post-intervention) demonstrating clinical meaningfulness. The majority of project participants were either quite a bit satisfied (21.4%) or very much satisfied (57.1%) with having used the intervention to discuss goals of care.

Conclusion: This quality improvement project demonstrates that although few AYAs with NMD have advance directives, if asked, they willingly agree to discuss their goals of care and find satisfaction in using the intervention to complete an advance directive. Hence, providers should consider systematic processes to include these discussions as a part of routine practice.

Implications: Continued use of the intervention is promising and should be considered as part of routine neuromuscular care, along with ongoing study in this population.

Keywords: adolescents and young adults, neuromuscular disease, advance directives, goals of care, conversations