

Shared Decision-Making About Assistive Technology for the Child with Severe Neurologic Impairment



Katherine E. Nelson, MD, FRCPC^{a,b,c,d},
Sanjay Mahant, MD, MSc, FRCPC^{a,b,e,f,*}

KEYWORDS

- Gastrostomy • Tracheostomy • Neurologic impairment
- Children with medical complexity • Technology dependence
- Shared decision-making

KEY POINTS

- Introduction of assistive technology, such as gastrostomy and tracheostomy tubes, for children with severe neurologic impairment is a value-sensitive decision.
- Value-sensitive decisions benefit from a shared decision-making model approach.
- Pediatric hospitalists can use a shared decision-making model to further discussions with families about assistive technology for children with neurologic impairment.

INTRODUCTION

Children with severe neurologic impairment, a growing population with high resource utilization, are frequently admitted to inpatient pediatric medicine wards with acute

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^a Pediatric Outcomes Research Team (PORT), Division of Pediatric Medicine, Department of Pediatrics, University of Toronto, Hospital for Sick Children, 555 University Avenue, Toronto, Ontario M5G 1X8, Canada; ^b Institute for Health Policy, Management and Evaluation, University of Toronto, 155 College Street, Toronto, Ontario M5T 3M6, Canada; ^c Pediatric Advanced Care Team (PACT), Division of Pediatric Medicine, Hospital for Sick Children, 555 University Avenue, Toronto, Ontario M5G 1X8, Canada; ^d Janice Rotaman Fellowship in Home Care Innovation, Division of Pediatric Medicine, Hospital for Sick Children, 555 University Avenue, Toronto, Ontario M5G 1X8, Canada; ^e Child Health Evaluation Sciences, Research Institute, Hospital for Sick Children, 555 University Avenue, Toronto, Ontario M5G 1X8, Canada; ^f CanChild Centre for Disability Research, 1280 Main Street West, Hamilton, Ontario L8S 4L8, Canada
* Corresponding author. Division of Paediatric Medicine, Hospital for Sick Children, 555 University Avenue, Toronto, Ontario M5G 1X8, Canada.
E-mail address: sanjay.mahant@sickkids.ca

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issues. Conversations about the introduction of life-sustaining technology often arise during admissions, and pediatric hospitalists are asked to help families navigate these complicated issues. This article discusses shared decision-making (SDM) as a strategy that can be used to help families make decisions and applies concepts from SDM to clinical cases about the introduction of technology for children with severe neurologic impairment.

SHARED DECISION-MAKING

Definition and Potential Resources

In the past 2 decades, SDM has become an accepted model for collaborative communication between providers and patients or families to determine a treatment plan when multiple options exist, each with its own slate of risks and benefits.¹ In SDM, family members express their goals and values related to the decision, the provider discusses the risks and benefits of each option, and the plan is negotiated jointly as the best of the available options within the context of those values (Fig. 1).^{2,3} SDM differs from “paternalistic” (provider-based) and “informed” (patient or family-based) decision-making because neither the provider nor the family bears independent responsibility for the decision; instead, all sides listen to input from each other and decide together which options to pursue.^{4,5} Box 1 lists some practical tips for engaging with families in SDM conversations. Box 2 provides some example questions for eliciting family values. Pediatric palliative care teams often have experience with elicitation of family values and can be a resource for shared decision-making. Similarly, decision aids, which present neutral evidence about various treatment options in paper or electronic form, may help facilitate the SDM process.

Importance of SDM in Decisions About Introduction of Technology

Introduction of technology has a substantial impact on families, often influencing their daily routines, as well as the frequency and intensity of their interactions with the health care system.^{6,7} Technology also may have implications that are harder to measure, as they potentially affect a child’s social interactions and influence parents’ perceptions of their efficacy as parents.⁸ The evidence about the utility of these interventions is limited; there are no randomized controlled trials demonstrating clear efficacy in this population to guide decision-making. Therefore, for decisions about technology in this population, utilization of SDM, which formally incorporates inclusion of family values in the decisional process, helps enrich the conversation and ensure that the family and provider have confidence in the resulting decision. This article

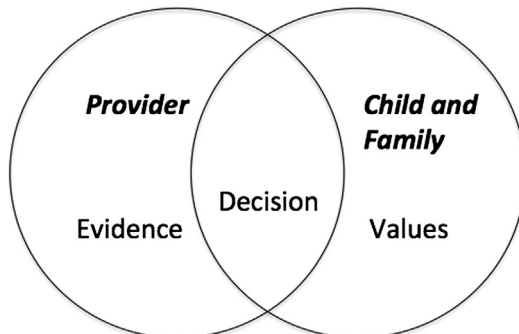


Fig. 1. SDM model.

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