

Shared Decision Making Coach For Children and Families: An Analysis of Decision Outcomes

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Introduction

- Relatively few studies have been done about the impact of interventions to support shared decision making (SDM) specifically with pediatric patients. Many patients and families struggle to make a range of medical treatment decisions and often these decisions are made in a more traditional medical model rather than a SDM environment.
- At Children's Hospital LHSC, a clinical program involving a decision coach, outside the circle of care, has been designed and implemented.
- The program assessed a quantitative and qualitative analysis of the SDM Decision Coaching interventions for patients and families.
- The assessment focused on measuring decisional satisfaction, knowledge, and decisional conflict before and after the SDM coaching intervention.

Method

Measures:

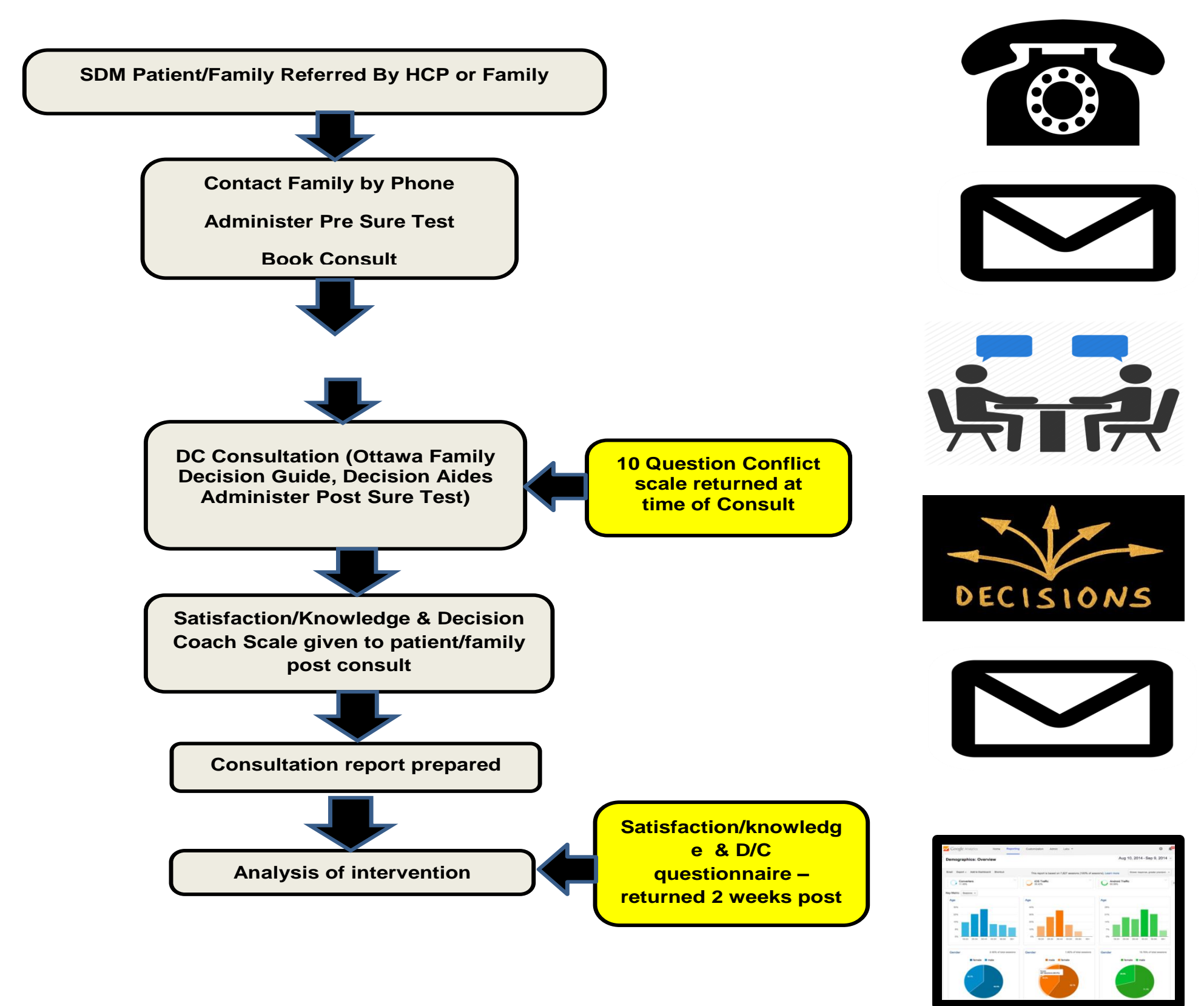
- SURE Test** completed pre and post consult. There are 4 questions. Scores range from 0 (extremely high decisional conflict) to 4 (no decisional conflict).
- Decisional Conflict** using the Decisional 10-point Conflict Scale (pre consult). There are 10 questions and scores range from 0 (no decisional conflict) to 100 (extremely high decisional conflict).
- Preparation for Decision Making Scale.** Assesses how well patients and families feel prepared to make a decision. This is a 10 point scale administered post consult. Scores range from 0 to 100 (higher scores indicate higher perceived level of preparation).
- Satisfaction with Decision Coaching (Parent) tool** – 10 questions administered post consult. No values/scores are assigned.

Coaching Sessions January 2019 – June 2019, 8 parent families participated.
Medical Decisions: Gastrostomy Tube placement, medication changes, hemispherotomy surgery, chemo trial study, determine plan of care, surgery for spinal atrophy, spinal fusion surgery.

References:

Satisfaction with decision coaching (Parent) ©Bryan Feenstra, Ottawa, Canada, 2012 .
 O'Connor, Stacey, Jacobsen. (2015) Ottawa Personal Decision Guide. Retrieved from <https://decisionaid.ohri.ca/decguide.html>
 Decisional Conflict scale © AM O'Connor 1993, revised 2005.
 The SURE test © O'Connor and Légaré, 2008.
 ID Graham & AM O'Connor, User Manual Preparation for Decision Making © 1995 [updates 2010].

SDM Assessment Intervention Flow Chart



Delivery Process

- Pre-Decision**
SURE TEST: Administered at the time of introduction of process and referral
- 10 Point Conflict Scale**
Conflict Scale sent to family prior to consult and returned by the family at time of Consult
- Satisfaction/knowledge**
Given to family at end of consult and returned 10 days post consult
- Decision Coach Satisfaction**
Given to family at end of consult and returned 10 days post consult
- Post Consult**
SURE TEST: Post Consult : Administered with Ottawa Family Decision Guide at end of consult

SDM Analysis

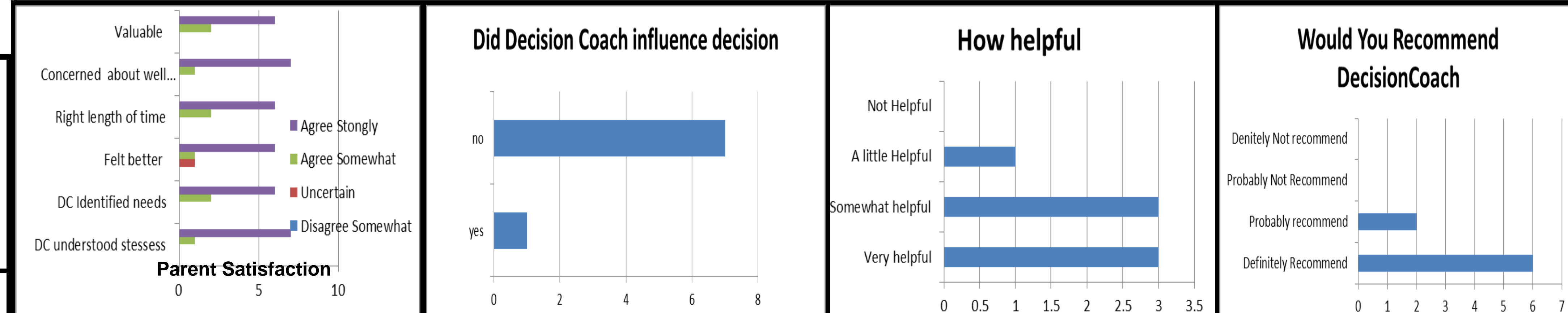
Description of Measures

Pre SURE parent: median (IQR) = 2.50 (2.00,4.00).
Post SURE parent: median (IQR) = 4.00 (3:00,4:00).
 SURE scores increased pre to post but the increase was not significant $p=0.083$. Out of the 8 families the primary issue was mainly focused on needing more knowledge about the risks and benefits.

Conflict 10 point scale: median (IQR)=25, (0,45).
 87.5% or 7/8 families were clear about their personal values and felt supported to make a choice. 100% or 8/8 of the families were either unsure or unclear about risks benefits and unsure about best choice for them.

Satisfaction/Knowledge scale: Median (IQR) = 4.560, (4.375 – 5.000).
 Knowledge and satisfaction levels indicated a high level of preparation in 87.5% or 7/8 of the families. One family had received conflicting information from 2 surgeons and unable to make a final decision.

Decision Coaching Satisfaction: Results based on 10 questions – qualitative.



Testimonials

"The decision coach was so helpful in clarifying our options and in creating a plan for our appointment with the neurologist. I also appreciated the fact that she was completely unbiased, to both my opinions/options and the doctors. She was completely neutral and so didn't pressure us one way or the other."

"We found it helpful to have some devoted time away from home to have a formalized discussion about our goals, concerns etc. with someone who could understand the weight of our decision and why we were struggling so much with it. There was a quick turn around time to have a meeting with the Decision Coach so we were happy to know that our needs could be accommodated quickly."

"This discussion was so good, I really like it. When the doctor recommended surgery for our son, we really did not know much about what it meant. After having received this information (decision aids) with the pictures describing the surgery its benefits, and risks we have a much better understanding of what this type of surgery means for our son, thank you."

"Was helpful to speak to someone else and not just your partner. One feels pressure when speaking to the physician."

"While we haven't made any final decision, we felt as though the decision coach sessions were helpful in helping us look at the bigger picture and have some objective input from someone else looking in. We also appreciated the decision coach's role in being the mediator and helping us organize conference calls with our specialists.."

Summary

Healthcare delivery and patient-centered care will serve as an indicator of organizational readiness for a SDM environment. This study is ongoing, but in this small sample, decision coach services in a pediatric setting provided in a consultative fashion, outside the circle of care, results in known SDM benefits of reduced decisional conflict and increased decision satisfaction and knowledge.

Acknowledgement

I would like to offer special recognition to the Children's Health Foundation for funding support, SDM Advisory Committee for their guidance and advice in the report presentation.

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