Children's Hospital
London Health Sciences Centre

Shared Decision Making Needs Assessment Report

Pediatric Neurology

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Pediatric Neurology Needs Assessment

Executive Summary

Introduction

A needs assessment was conducted to collect information about opinions, attitudes and preferences of key pediatric neurology stakeholders in the context of decision making. The focus of the assessment was on what the patient population needs to make better decisions and what a population of health practitioners need to improve the support they provide to families during decision making.

Background

Families struggle to make treatment decisions, and many patients and families look to HCPs to make decisions for them. In many cases of medical decision-making, despite best efforts to reduce bias and to account for patient's values, cultural obligations and stress levels, a hierarchical paradigm, generally, continues to prevail. Making decisions in pediatric settings also has added complexities that cause decisions to be challenging including the inherent dynamic of a gradually changing maturity level of the child patient, and the possibility of multiple caregivers factoring into decision making, each of whom carry their own values and treatment goals. A commitment to the structure of a SDM environment assures that factors that support decision making such as reviewing evidence, considering preferences and goals, including important others in the process and recognizing decisional stress- all help to contribute to a better health care decision.

Purpose

A Needs assessment was done to help identify:

- what Pediatric Neurology key stakeholders & families want or need;
- whether existing/current programs or interventions are meeting the needs of those who are supposed to benefit;
- which families need services, and;
- what might be the best alternatives for meeting those needs.

Data Collection

Questions/discussions focused on decisions, decisional conflicts, and factors contributing to decisional conflicts, knowledge, values, support, and resources (appendix A).

Methods

i) Key Stakeholder Interviews – Five pediatric neurologists (one being new to the service area) were interviewed, two clinical fellows.
ii) Questionnaire – one pediatric neurology nurse practitioner, two parent advisors, one transitioned patient advisor.
iii) Focus Group – TVCC of 4 allied health staff participated in a discussion using a written set of questions and topics.
iv) Survey – survey information was collected through personal interviews/discussions with Family Resource Centre, pediatric pharmacist, LHSC clergy, pediatric social worker, and pediatric neurology nurse.
v) Archival Data Review of the Ottawa Framework for Shared Decision Making https://decisionaid.ohri.ca/

Strengths and Limitations

- A large number of archival data sources were available.
- Key stakeholders willingly participated.
- Parent Advisors and transitioned patient were thankful for the opportunity to participate.
- Key stakeholders limited to pediatric neurology.

Summary of Results

The needs assessment was initiated in early September and completed the beginning of November 2018.

A) The current state highlights what parent /patient advisors and health care practitioners (HCP's) want or need related to decision making. Both the parent/patient and HCP groups identified and stated what difficulties they have with decision making.

- HCP's identified a number of medical decisional conflicts, deficits in knowledge and expectations, and resources needed to support their work. Decisional conflicts focused primarily on medical interventions. Decision making with parent/patients varied amongst the five pediatric neurologists.

- Parents/patients focused primarily on the need for social supports, and educational resources needed from HCP's to assist them in their journey.

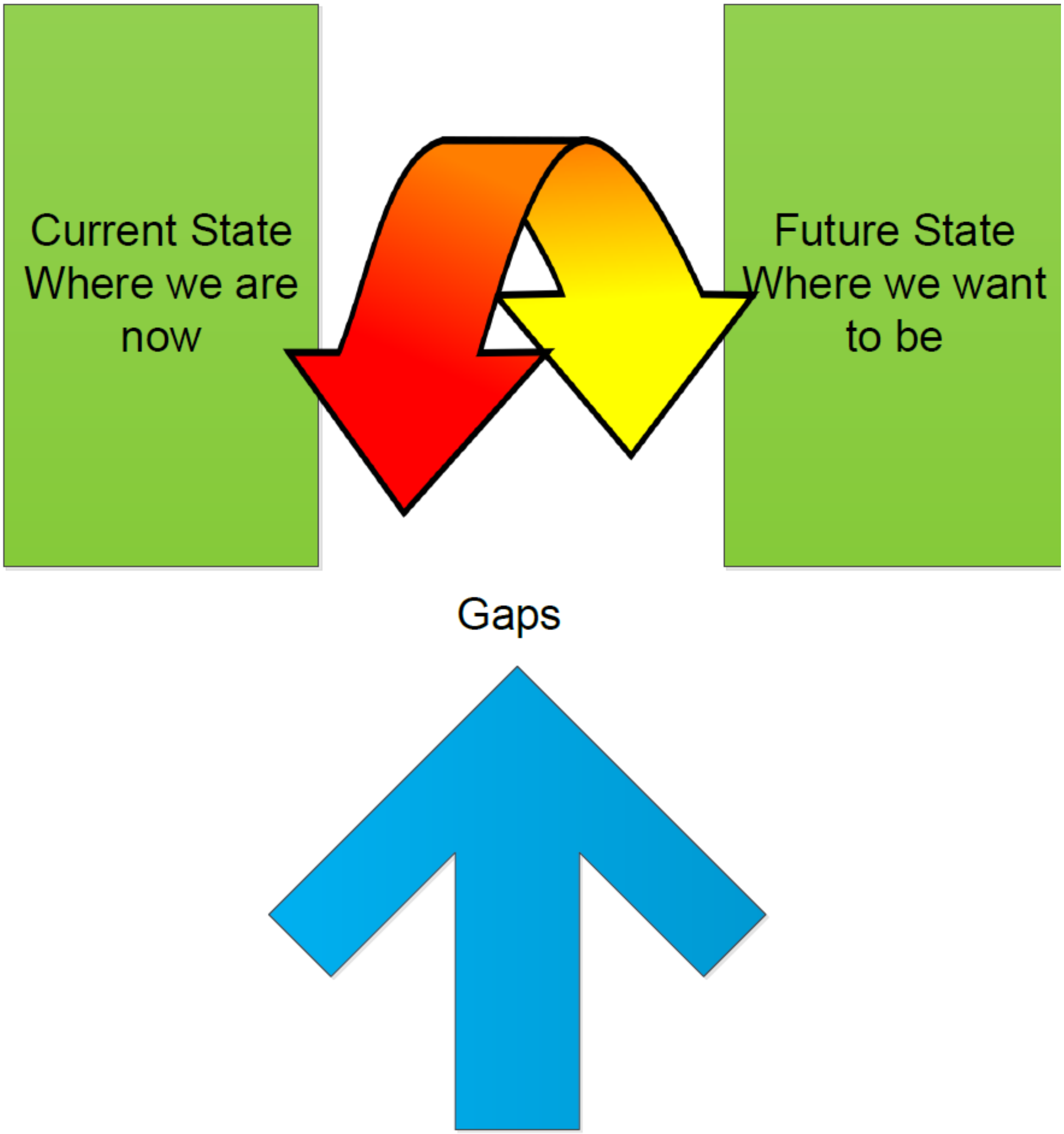
B) Needs or <u>GAP</u>s and are defined as what is and what should be. From this perspective it is important to understand what is already being done and how well it meets the needs of the families and practitioners.

- Health Care professionals identified a lack of dedicated resources (neurology nurse educator, social worker, educational aids, and well defined SDM environment) as barriers to supporting decision making and time needed to support families.
- Parents/patients mirrored these barriers in their request to have more time devoted to them to have a better understanding of their child's social development and future treatment plans.

C) The <u>future state</u> Identified shared decision making strategies by both HCP'S and families that can be developed to help meet their needs both in a general and a specific way.

  - Shared Decision Making methods were identified, such as appropriate resources, continuing education, educational materials, educational programs, and decision aids, all of which can take various formats.
  - Trust was identified by both HCP's and parents/patients as an important need to create a patient centered care environment.
  - The findings from the assessment demonstrate the need for a SDM program and service that can raise awareness of needs and potential interventions, define and resolve problems, reduce decisional conflict in families, increase a parent/patient's knowledge level, impact a level of satisfaction and improve compliance with treatment.

SDM Needs Assessment
November, 2018



Current State
Where we are now

Future State
Where we want to be

Gaps

Current State/Where We Are Now

HCP's Feedback : Current State

Difficulties patients have in making decisions;

- deficits in knowledge base and expectations,
- values clarity,
- low self-confidence,
- lack of skill in decision making,
- methods of clarifying and communicating values,
- lack of appropriate available resources,
- limited evidence (harm/risks/benefits),
- no time to think about,
- pressure from others,
- information overload,
- prognosis,
- feeling unsupported,
- resistant to treatment,
- do not believe in treatment,
- conflicting opinions,
- setting i.e. emergency room environment -more immediate decisions vs clinic ,
- cultural beliefs,
- Status of disease.

Important decisions for patients to make were those related to:

(*Responses identified were usually specific to the type of decision and characteristics of the patients and practitioners*)

- medications
- treatment choices,
- clinical trials,
- medical interventions,
- change in life style,
- GT insertion/placement,
- ortho surgeries,
- shunts,
- equipment,
- home renovations,

- school placements,
- financial,
- acceptance of diagnosis,
- steroids for duchenne MD,
- bi pap,
- resources,
- withdrawal of care,
- referral to other HCP,
- Investigations ie MRI.

Usual role of HCP in decision making:

(responses differed amongts HCP's)

A) shares information/knowledge with patient so they can make their own informed decision,

B) makes a recommendation based on knowledge pros and cons - give choices,

C) makes decisions and present information that is easy to understand the implications and treatment,

D) Imparts knowledge, discusses consequences, provides perspective of what the the future holds, lead through existing options, risks.

What hinders the decision making:

- families who are not realistic/listening/hearing the information due to their own learning disabilities or mental health/emotional issues,
- poor knowledge about the disease,
- conflicting opinions,
- pressure from others,
- website/internet,
- loss of Pt/Physician contract - seeking second opinion,
- perceived loss of function,
- inabliltiy to accept diagnosis,
- refusal of family to consider the options presented ,
- profound cultural differences and beliefs.

What would help overcome barriers to decision making:

- piloting Decision Coach role and gathering data on outcome,
- giving the family options,
- education and communication with tools to make a decision that is best,.
- family needs to come with an open mind and trust the physician to make the best decision for the child - more is not necessarily better,
- make decisions and collaborate,
- guide families,
- provide fact based education and dispell myths,
- too many cooks - remove barriers for families to enter the system,
- ability to listen to parent being mindful of the interaction,
- physician good to make the decision or who ever is delivering the message,
- providing family with written information.

Family Advisors/Patient Feedback : Current State

Note: Patient Version Questions Differ from HCP's

Most important decisions families/patients with a neurology health problem face?

- the use of medications and monitoring medications. Side effects of medications, when to stop and try something different,
- how can I best support myself and my child when at times the diagnosis is too much,
- decisions that affect autonomy for the person afflicted with the disease
- trying to understand how the diagnoses or assumed diagnoses implicates the patient and family immediately, as well as, throughout the duration of their life and how to cater the everyday decisions to long term implications.

If you were to focus on one particular important decision that families/patients have to make with a neurology problem, what do the families need a lot of help with? Or where do practitioners spend a lot of time?

- overall support throughout the journey,
- knowledge of various therapies, peer groups or support and ongoing research,
- easier to make decisions in a supportive dynamic environment,
- increase support at times of transition or typical milestones that are not being reached example: school, driving, dating etc.
- medication management.

How do you feel when making a decision? Focus on the difficulty with making decisions

- decisions are challenging when you are in an environment that you feel you may be judged.,
- choice can be difficult: safe or unsafe, good or bad,
- what if I choose to do nothing,
- my decisions affect my child and my child is my world,
- does delaying choice mean failure?
- questioning what is important,
- it is so hard to make a decision as a patient – especially a young patient because you do not fully understand the ramifications of the illness, nor do you feel well enough to want to participate in the decision making process. You are merely trying to remain a normal kid.

What things make the decision difficult for you?

- self doubt - decisions are difficult if I feel I do not have all the information I could have,
- have I talked to the right people,
- are the people I am talking to the right people,
- is there someone or something I do not know about that I have missed that could support my decision,
- is the information I have received correct and up to date,
- decisions are difficult if there is a lack of supports at home or in the family,
- info about options/risks/benefits,
- often, doctors will speak to the parents when it comes to the decision making – thus, it almost feels as though you are not making the decisions at all for yourself,
- as a sick child, if the scientific tests cannot prove immediately why you might be sick – the doctor will sometimes jump to the conclusion that perhaps the child is making the illness up. Thus, how is one supposed to make an informed decision about anything when they are being falsely accused of faking an illness.

What factors make it easier for you to make a decision?

- it is easier to make a decision when I have the right resources, right people involved,
- when I have the ability to focus on the decision without distractions,
- information, communication,
- it really came down to what my parents thought was best.

What hinders you (gets in the way of making decisions)?

- knowing if you have made the right decision,
- too many opinions,
- when various specialties having differing opinions about the decisions I have made or are making,
- agreement from all parties especially the child with the disease,.
- being too young and often not included in the process.

GAPS

HCP's Identified Gaps

- a social worker dedicated to pediatric neurology would be beneficial,
- decision making is a broader issue (culture of blame, broader than culture),
- lack of decision aids,
- evaluation/ outcome of decision coach role
- mutual lack of trust is core for decision making, and communication - continually challenging cases - patients need education on their rights and collaborative process,
- need educator with neurology knowledge to spend time with patients.
- engagement of key stakeholder groups for successful outcomes with buy-in (patients, staff, physicians),
- more educational videos, that are easily accessed.

Family Advisors/Patient Identified Gaps

- need psychosocial supports,
- need opportunity to connect with others going through the same circumstance,
- need peer support group to discuss living with the disease,
- need more time for an appointment if declared by family or child,
- understand that people are trying to balance living fully and managing their disease. Children respond differently at different states of emotional and social development and there needs to be room for that to happen
- families unware they could bring a friend or relative as a second set of eyes and ears,
- lack of understanding that children respond differently at different stages of emotional and social development.

Future State (Where We Want To Be)

HCP’S Future State

- well established and functioning SDM pediatric culture and environment,
- informed value based decisions,
- accessible on line tool box for HCP’s and families,
- engaged and knowledgable HCP’s on SDM,
- inventory of pediatric evidence based decision aids,
- a recognized Children’s Hospital patient endorsed service,
- smoother transition to timely & challenging decision making for families of pediatric patients,
- trusting enviroment / less barriers/reduced decisional regret,
- needed resources to support families,
- dedicated multidisciplinary clinics

Family Advisors/Patient Future State

- reliable (vetted) and accessible books, journal articles, websites,
- pharmacist on site to counsel and discuss side effects of medications,
- strong linkage with family doctors on how the neurology meds interact with other medication that family doctor may prescribe,
- Information on how neuro meds may interact with antibiotics or birth control (normal things that become complicated),
- a template for families to guide them through the decision making process that would include: topic of decision, what they now about topic, possible outcomes, what they do not know, who they need to talk to to find out more, what are your questions, follow up discussion, reliable info to share with family and friends supporting decisions,
- no judgement,
- patient centered care environment.

Appendix - A

Decisional Needs Assessment

Worksheet of Information, Source, and Method

Ref: Jaconsen MJ, O'connor AM, Stacey D. Decisional Needs Assessment in Populations. © 1999 [updated 2013]. Availablefrom

Information Collected	Source (physicians HCP's, Patient Advisory)	Method (Key informant interviews, Focus Groups, Surveys via face to face interview, telephone interview, mailed questionnaire, records
Decisions made by Patients	Pediatric Neurologists	1:1 interviews
Focus on one decision	NP	Focus Group
Decisional Difficulty	TVCC Allied Health	Questionnaire
Factors contributing to difficulty	Clinical Fellows	Face to face discussions
Practitioner's usual role in decision making	Social Worker	Phone discussion
Practitioners barriers supporting patients decision making	Pharmacist	
Practitioners supporting patients decision making	Clergy	
Other participants in decision making	Child Life Specialist	
Other participants roles	Outpatient RN	
Usual patient strategies in decision making (strategies to address knowledge deficits, unrealistic expectations, support]	Children's Family Resource Center	
Facilitators; that help patients' decision making	Patient Support Services	
Barriers: that hinder patients' decision making	Parents/transitioned Patient	
Anything else to overcome barriers		
Possible strategies for decision support [counseling, groups, information]		
Anything else that would help support patients in decision making		

www.ohri.ca/decisionaid.from www.ohri.ca/decisionaid.

Acknowledgement

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