AN EXPLORATION OF CARE MAPPING AMONG FAMILIES OF CHILDREN WITH MEDICAL COMPLEXITY (CMC)

Sherri Adams, MSN, NP-Paeds, CPNP 1,2, Sanjay Mahant MD, MSc, FRCP(C) 1,2,3,4, Ronik Kanani, MD, FRCP(C) 1,2, Katherine Boydell MHSc, PhD 1,5, David Nicholas PhD, MSW, RSW 6, Natalie Weiser MA, PhD(c), Eyal Cohen MD, MSc, FRCP(C) 1,2,3,4

1 SickKids, Toronto, Canada; 2University of Toronto, Toronto, Canada; 3Institute for Clinical Evaluative Sciences, Toronto, Canada; 4CanChild Center for Childhood Disability Research, Hamilton, Canada; 5Black Dog Institute, University of New South Wales, Australia; 6Dept of Social Work, University of Calgary, Calgary, Canada

RESULTS

Overview: From the data emerged a deep and nuanced understanding defining what a care map is and how it is useful to parents and HCPs.

A major theme that emerged was USEFULNESS. Insight from parents and health care providers about care maps provided significant understanding into their value. Several subthemes related to usefulness were identified:

Parental Care Priorities
The care map identified what was important to the family and child. It outlined things they felt were helpful that an HCP might not have otherwise identified. It highlighted parental goals of care allowing the HCP to use this to tailor their care so it was meaningful for the family and child.

“I think it gives a nice impression of the family and their perceptions on their goals and things that seem to be must relevant and important to them. I really like that there seem to be very specific goals which are related to the child and what the family wants for him...so we don’t lose sight of their goals and replace them with our medical team goals.” (HCP 8B)

Respect for the child and family
HCPs were struck by the care maps as the maps demonstrated overwhelming life complexity, resulting in a motivation for increased compassion.

“I think I can certainly appreciate that this is a patient with complex needs, but actually looking at the care map and in this specific care map each individual multiple item on it, it is... as a visual point it is more complex than I think I appreciated before.” (HCP 1A)

Coordination
The Care Map was identified as a tool to identify gaps and duplications in care and improve communication related to the child’s care.

“I did actually notice that there was duplication, that’s a good example, on certain things but I did know why there’s duplication so I was okay with that. And we’re actually in the process of trying to eliminate some of that because all of this is very time consuming, not just for him but for me.” (CM 2)

“Well, I think it could be helpful with...getting additional...services or additional needs or seeing new providers, I think it’d be very helpful in communicating what’s currently involved in [the child’s care].” (HCP 1A)

Visual Overview
The Care map was described as being able to show the “big picture” on one page in an engaging manner.

“It’s a lot more appealing for people to see it and it captures the main focus points, right? So the main details are in here and they’re all captured in there.” (CM 2)

“Well, because I can babble on until I’m blue in the face and say, oh, we deal with this...and...This is what I’m saying. But this is the care map and it allows them to see everything...” (HCP 1A)

REFERENCES
- Bolla L. (Jan 10, 2013). Care maps: Special needs must inspire others to illustrate their own support networks. Retrieved May 7th, 2013 from The Huffington Post website: http://www.huffingtonpost.co.uk/2013/01/10/care-maps-special-needs_families_n_2557855.html

BACKGROUND
Care Maps are a pictorial way to assess and describe the individual needs, strengths and assets of a family and child with medical complexity

Health Care Providers (HCPs) may be able to use care maps to help families avoid duplications or gaps in services and prioritize and coordinate care.

There is no research to examine the creation and usefulness of care maps in clinical practice

More information is needed to understand their potential usefulness as a care coordination tool to improve health services for CMC

OBJECTIVES
1. How care maps are constructed by families and the feasibility of construction
2. How they can be applied clinically
3. The potential utility of a care map to drive change for provision of coordinated care

METHODS
Qualitative study informed by Grounded Theory approach

Setting & Sample: Theoretical sampling of:
- Parents of CMCs followed in a complex care clinic
- HCPs recruited from a community hospital and a Pediatric Tertiary Academic Health Sciences Center
- Ethics approval (IRB/REB) obtained

Data collection:
- Care map training sessions targeting parents of CMC (15)
- In-depth, semi-structured interviews targeting: parents of CMC (15), HCPs familiar with particular CMC (15), HCPs familiar with CMC but not particular child (15)

Data analysis:
- Verbatim transcription, and qualitative analysis using NVivo 10
- Data analysis guided by grounded theory methodology of open, axial and selective coding and by visual analysis of care maps

CARE MAP

EXAMPLE #1 (CM 2)

Care Maps were defined as:
- “I think it’s a picture that helps healthcare provider to understand her condition. To understand her condition, what is involved, what is – what she needs at home, what hospitals she goes to” (CM 7)
- “I think it’s a really comprehensive picture of who’s involved and what the issues are that the family’s dealing with. So I feel like it could really guide your questioning” (HCP 10B)

EXAMPLE #2 (CM1)

Parental Care Priorities

RESPECT for the child and family

Coordination

Visual Overview

CONCLUSION

Care maps are a useful communication and coordination tool in a clinical setting. They help identify family and child care priorities in order to promote value based care. Further research is required to understand how to implement care map training for families of CMC. HCPs must also become familiar with medical complexity, resulting in a motivation for increased compassion.

“I think it gives a nice impression of the family and their perceptions on their goals and things that seem to be must relevant and important to them. I really like that there seem to be very specific goals which are related to the child and what the family wants for him...so we don’t lose sight of their goals and replace them with our medical team goals.” (HCP 8B)

Parental Care Priorities

The care map identified what was important to the family and child. It outlined things they felt were helpful that an HCP might not have otherwise identified. It highlighted parental goals of care allowing the HCP to use this to tailor their care so it was meaningful for the family and child.

“I think I can certainly appreciate that this is a patient with complex needs, but actually looking at the care map and in this specific care map each individual multiple item on it, it is... as a visual point it is more complex than I think I appreciated before.” (HCP 1A)

Coordination

The Care Map was identified as a tool to identify gaps and duplications in care and improve communication related to the child’s care.

“I did actually notice that there was duplication, that’s a good example, on certain things but I did know why there’s duplication so I was okay with that. And we’re actually in the process of trying to eliminate some of that because all of this is very time consuming, not just for him but for me.” (CM 2)

“Well, I think it could be helpful with...getting additional...services or additional needs or seeing new providers, I think it’d be very helpful in communicating what’s currently involved in [the child’s care].” (HCP 1A)

Visual Overview

The Care map was described as being able to show the “big picture” on one page in an engaging manner.

“It’s a lot more appealing for people to see it and it captures the main focus points, right? So the main details are in here and they’re all captured in there.” (CM 2)

“Well, because I can babble on until I’m blue in the face and say, oh, we deal with this...and...This is what I’m saying. But this is the care map and it allows them to see everything...” (HCP 1A)