

## Understanding Knowledge Use in Parents of Young Children with Cerebral Palsy: An Embedded Case Study

### Introduction

In recent years, there has been an emphasis in the health care system for research evidence to inform decision making. This process is known as **knowledge translation**, and involves the synthesis, dissemination, exchange and ethically-sound application of evidence-based knowledge with the end goal of improving the health of Canadians (Canadian Institutes of Health Research, 2015).

A multitude of knowledge translation strategies exist. Examples include summaries from research, such as this *Facts To Go* publication. To know if knowledge translation strategies are having their desired effect (e.g., a change of awareness in a population, or a decision that is based on the information one receives) we must go beyond focusing on the dissemination of knowledge and examine how this knowledge is actually being used (Straus, Tetroe & Graham, 2009).

Young children with cerebral palsy (CP) rely on their caregivers to make decisions regarding their health care management (Newton, 2000). Furthermore, the uniqueness of a condition such as CP may have implications for how parents of children with CP use knowledge across the life course of parenting (Johnston & Marder, 1994). Research to date has focused largely on how to present research-based information for general parent populations (i.e., using input from parents, plain language, real-life examples) (for review, see Lagosky, 2012). How parents actually use health information is unknown. Additionally, there is no research specific to the knowledge use patterns of parents of children with CP.

### Purpose of this Summary

This summary is based on a **qualitative research study** entitled *Understanding Knowledge Use in Parents of Young Children with Cerebral Palsy, An Embedded Case Study* (Lagosky, 2012). The study was designed to understand the knowledge use processes of parents of children with CP and how one might monitor knowledge use in this population.

The **purpose** of this summary is to outline in brief the findings of the above-named study.

### What Was Done

**In-depth interviews** were conducted with three parents (mothers) of young children with CP. All children were under the age of five. The parents ranged in age from 29 to 38, were married or in common law partnerships, worked part time or full time, and held a community college degree or higher. The parents classified their children as levels I to III on the Gross Motor Function Classification System (Palisano et al., 2008).

The format of the parent interview was semi-structured so that it could be guided, but would still allow for elaboration and direction change by the interviewee. The interviews explored parents' **information sources**, **information management** (including gauging relevance and quality of information), and the **outcomes** of their information use.

### Study Findings and Discussion

This study found that knowledge use in parents living with and caring for their young children with CP is **multi-factorial**, **complex**, and **time-dependent**. Seeking information is tied to an event or occurrence in the parent's or child's life. Such an event may be planning for a major transition such as going to kindergarten, needing information to provide to a health care provider or to fill out a form, or wanting information on a general aspect of CP to understand the condition better. To effectively and accurately understand how to monitor knowledge use in parents, it is important to realize that this use will be connected to whatever point families are in the life course.

Parents' **information sources varied** from very few to many. Parents tended to retain these sources; as they reported being satisfied with the information they were receiving. Consistent across all parents was their appreciation of and satisfaction with their health care professionals as their primary source of information. Some parents felt comfortable having therapists find all of their information, while others preferred to have a more active and collaborative role in sourcing information alongside their therapists.

None of the parents particularly sought out information sourced from **research**, citing the reason as a lack of specificity to their child's particular level of CP.

Information from therapists that was **tailored** to their children and that could be **practically applied** was more important to parents than information sourced from research. When parents acquired information from their therapists or doctors, they did not question their sources.

The **process of using information** by parents can be described in a series of steps. The first step is to **acquire** information. Next, parents have to **understand** the information they are receiving or they will not be able to progress further. The third step is to gauge the **relevance** of the information to their child's current condition, their family context, and their child's personal developmental trajectory. The fourth step is to gauge the **quality** of the information, including whether it is in agreement with their personal beliefs and values. The fifth step is to **decide** what to do with this information. Some parents discard information that is not perceived to be useful, others keep information for a later time, and some actively share their information with other parents or use the information to advocate for their child. These initial five steps will either happen independently, with the aid of therapists, or most often will be mediated by the therapists. Lastly, parents will **discuss** their decision or the result of their decision regarding information use with therapists, their family, or other individuals invested in their children's care.

Depending on where one monitors knowledge use throughout these steps, different results will emerge. For example, monitoring knowledge use when parents are gauging the quality of information will look different than monitoring knowledge use when parents are sharing the results of their information use. Not only will **monitoring knowledge use differ** depending on where parents are in their cycle of use, it will differ depending on their context and background. It becomes clear how complicated monitoring knowledge use can be, especially among parents of children with complex health conditions (such as CP), where the children's strengths and needs change over time as they grow and develop.

### Conclusion and Implications

Knowledge use in parents living with and caring for their young children with CP is influenced by multiple contextual factors, including where they are situated in the life course and in the cycle of information use. Parents' health information sources, management, and outcomes can differ widely, depending on the family, parents, and child.

One consistent observation among all parents in this study was that therapists were instrumental in their use of health information. Some parents preferred to use their children's therapists as **knowledge mediators** over an individual who was not involved in the care of their child. Furthermore, some parents adopted the knowledge mediator role themselves. This has implications for how therapists deliver health information to parents who have

different approaches to knowledge use. Moreover, these findings have implications for the type of training and support that therapists should receive in acting as primary knowledge mediators.

In knowledge mediating endeavours, **research-based information** is not necessarily preferred by parents over other sources, primarily due to the perception that studies are not tailored to the needs of individual children and families. When therapists tailor research-based information to a child and parent's particular needs, this could increase the family's use of this form of knowledge.

### Directions for Future Service and Research

This research adds to a little-known area of knowledge translation: the knowledge use patterns of parents of children with CP. Service providers, researchers, and knowledge translation professionals should consider the multiple and time-dependent factors that influence parental decisions in order to optimize their knowledge use. More work is needed to understand how to **monitor knowledge** use in this population, in order to achieve the greatest benefit from knowledge translation activities.

### References

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