Parents' experiences and perceptions when classifying their children with cerebral palsy: Advice for service providers

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BACKGROUND

- Taken together, the Gross Motor Function Classification System (GMFCS),[1] Manual Ability Classification System (MACS),[2] and Communication Function Classification System (CFCS)[3] can provide a functional profile of children with CP.
- With this in mind, the On Track study was created to track the progress of children with CP in order to establish developmental trajectories that can be used as a means of determining whether children, grouped by classification system levels, are developing 'as expected', 'better than expected', or 'more poorly than expected' across a range of developmental domains.
- One of the methods for the On Track study includes a consensus classification of children using the GMFCS, MACS, and CFCS between parents and study assessors.
- A gap in knowledge exists with respect to how parents respond to classifying their children's levels of function and how they interpret and integrate this information into goals for their children. In addition, there is a lack of knowledge about parents' perspectives and experiences with a prognosis for their children with CP.

OBJECTIVES

1. To understand parents' experiences of classifying their children using the GMFCS, the MACS, and the CFCS, both independently and collaboratively, with therapist assessors from the On Track study
2. To understand parents' perceptions of the utility of these systems relating to current function and predicting future function
3. To collate parents' recommendations and advice for service providers on how to employ a family-centered and holistic approach when communicating information

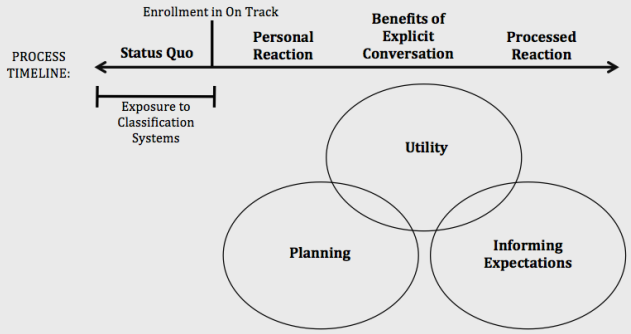
STUDY DESIGN

- A purposive sample of seven parents participating in the On Track study was recruited by mail; factors considered during the purposive sampling process included:
  - a range of ages (18 months to 11 years)
  - a range of functional abilities (GMFCS, MACS, and CFCS levels)
  - level of consensus between parent and assessor on classification levels
- Semi-structured interviews were conducted either face-to-face or by telephone
- Interviews were audiotaped, transcribed, and openly coded
- A descriptive interpretive approach within a pragmatic perspective was used during analysis

RESULTS

- In analyzing the first portion of the interviews pertaining to parents' experiences and perceptions when using the classification systems, seven themes emerged (Figure 1)
- Four of these themes focused on experiences and three focused on perceptions of utility

FIGURE 1. Graphical representation of the themes describing both parents' experiences and perceptions of utility and the relationship among themes



- In analyzing the second portion of the interview, six key themes emerged and were labeled as action statements to reflect how service providers can incorporate these pieces of advice into practice (Table 1)
- A number was assigned to each theme by study investigators to represent the logical sequence among these themes; satisfying the preceding advice piece can lay the foundation for seamless implementation of the subsequent advice piece

TABLE 1. Parents' Advice For Service Providers

1. Acknowledge Individual Parent Reactions
2. Make the Child a Priority
3. Use an Individualized, Holistic Approach
4. Facilitate a Positive, Open Dialogue
5. Foster Connections
6. Be a Dependable Resource

CONCLUSIONS

- Participants cited a range of experiences and perceptions when interacting with the GMFCS, MACS, and CFCS and the severity of CP in their child seems to have some influence over their experiences
- Discussions with On Track assessors about the classification systems were viewed positively by parents and used as a means to facilitating further understanding of these systems
- Most parents responded well to having a direct conversation with the interviewer about prognosis and the stability of these systems, suggesting that parents seem to be open to discussions about future function and perceive this type of information to be useful
- Formation of strong, authentic connections is extremely influential in determining how parents interact with service providers and how supported and satisfied they feel

CLINICAL RELEVANCE

- Knowledge of parents' experiences and perceptions of using the GMFCS, MACS, and CFCS can provide useful insight for service providers collaborating with parents to classify function in children with CP
- Given the various perceptions of utility cited by parents from this study as explored by the themes *utility, planning,* and *informing expectations*, it can be concluded that there is a personal and holistic benefit to using these systems
- The clinical utility of these systems coupled with the personal utility established through this study makes a strong case for integrating the GMFCS, MACS, and CFCS into regular practice
- Service providers should recognize their important role in facilitating understanding of these systems and addressing parents' concerns or confusion through an open discussion

- The"Tip Sheet" produced from this study contains the collated advice for service providers expressed by parent participants
- Utilizing the advice from these parents can help facilitate the establishment of important family-provider connections and provide an evidence base to inform service providers on how to directly address parents' needs

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ACKNOWLEDGEMENTS

We would like to acknowledge:

Canadian Institute of Health Research (CIHR) as the funding source for this study