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Parents' Experiences and Perceptions when Classifying their Children with Cerebral Palsy: Recommendations for Service Providers.

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Abstract

Aims: This study investigated the experiences and perceptions of parents of children with cerebral palsy (CP) when classifying their children using the Gross Motor Function Classification System (GMFCS), Manual Ability Classification System (MACS), and Communication Function Classification System (CFCS). A second aim was to collate parents' recommendations for service providers on how to interact and communicate with families. *Methods:* A purposive sample of seven parents participating in the On Track study was recruited. Semi-structured interviews were conducted orally and were audiotaped, transcribed, and openly coded. A descriptive interpretive approach within a pragmatic perspective was used during analysis. *Results:* Seven themes encompassing parents' experiences and perspectives reflect a process of increased understanding when classifying their children, with perceptions of utility evident throughout this process. Six recommendations for service providers emerged, including making the child a priority and being a dependable resource. *Conclusions:* Knowledge of parents' experiences when using the GMFCS, MACS, and CFCS can provide useful insight for service providers collaborating with parents to classify function in children with CP. Using the recommendations from these parents can facilitate family-provider collaboration for goal setting and intervention planning.

Keywords

Cerebral palsy, parents, classification systems, experiences, recommendations

The Gross Motor Function Classification System (GMFCS), developed by Palisano and colleagues, was first established in 1997 (Palisano et al., 1997) and subsequently expanded and revised in 2008 (Palisano et al., 2008) as a valid and reliable means to classify gross motor function in children with cerebral palsy (CP). Subsequently, two complementary systems were developed: the Manual Ability Classification System (MACS) to classify hand use and object manipulation (Eliasson et al., 2006) and the Communication Function Classification System (CFCS) to classify receiving and sending of information (Hidecker et al., 2011). Table 1 contains a brief description of the levels in each of the three systems. The prognostic value of these systems is demonstrated through stability of the GMFCS (Palisano et al., 2006) and MACS (Ohrvall et al., 2014) classifications through childhood. Stability has not yet been determined for the CFCS.

[Insert Table 1 about here].

Taken together, the GMFCS, MACS, and CFCS can provide a functional profile of children with CP (Hidecker et al., 2011). With this in mind, the aim of the On Track study (Understanding developmental trajectories of impairments, health conditions, and participation of young children with cerebral palsy) is to create developmental trajectories as a means of determining whether children with CP in functionally distinct groups are developing ‘as expected’, ‘better than expected’, or ‘more poorly than expected’ (http://canchild.ca/en/ourresearch/on_track_study.asp). One of the methods for the On Track study includes consensus classifications of children using the GMFCS, MACS, and CFCS between parents and therapists (Bartlett et al., in press). **Full details of each classification system were provided to parents either in hard copy or online before their children’s scheduled assessments. Parents were encouraged to complete the classifications and other parent-completed measures prior to discussion with the assessing therapist.** This method is useful because parents are most familiar with their children’s usual performance, as opposed to their optimal capability (Jewell et al., 2011), and their motor function in different environmental settings (Morris et al., 2006). From a parent's perspective, reaching consensus with a service provider is also beneficial as it allows information to be more accessible and can help address the dissatisfaction parents have experienced about the level of information they are typically provided (Liptak et al., 2006). 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. There is also a lack of knowledge about parents' perspectives on learning about the prognosis for their children with CP.

Therefore, the primary purpose of this **sub-study** was to understand parents' experiences of classifying their children using the GMFCS, MACS, and CFCS, both independently and collaboratively with therapists from the On Track study. A secondary purpose was to understand parents' perceptions of the utility of these systems relating to current and future function. A final purpose was to collate parents' advice and recommendations for service providers on how to employ a family-centered approach when communicating information.

Methods

Participants

Participants were selected from parents: a) who are participants in the On Track study, b) whose children received services at a children's rehabilitation centre in [redacted], and c) who agreed to be contacted for future research. Purposive sampling based on children's ages (18 months to 11 years) and functional abilities (GMFCS, MACS, and CFCS levels I-V) as well as the parents' level of consensus with therapists when classifying their children during the On Track assessment was used to gather the sample. Ethical approval was obtained from the both the Ethics Review Board at [redacted] and the Research Advisory Committee at the [redacted] children's treatment centre. Eight to 10 parents were targeted for recruitment, **anticipating saturation of themes with this number based on our previous**

experiences (Brunton & Bartlett, 2013; Reid et al., 2011) and recommendations in the literature (Morse, 1994). Seven parents (all mothers) consented to participate after contacting 13 parents for recruitment by mail and telephone. Descriptive information for each participant is presented in Table 2.

[Insert Table 2 about here]

Data Collection Procedure

Participants were scheduled for an interview that was either face-to-face (n=4) or over the telephone (n=3) based on parent preference. A semi-structured interview was completed with each participant. Each individual interview lasted 30 to 60 minutes in length and followed an interview guide of 8 to 12 questions focusing on parents' experiences and perceptions of the classification systems, followed by their advice for service providers. The interview guide was developed iteratively through a collaborative process among study authors and was then sent to parent collaborators of the On Track study team who have children with CP. These parent team members provided feedback on clarity, meaningfulness, and appropriateness of the questions to maximize acceptability for study participants [Key elements of the interview are described in Table 3; the complete interview guide is attached as an electronic Appendix]. The primary author of this study ([redacted]) was responsible for conducting each interview with training from co-author ([redacted]) experienced in qualitative interviewing, **thus minimizing any influence on the results based on variation in probing questions.** The interviews were audiotaped, transcribed, and returned to participants for review and approval before beginning analysis.

[Insert Table 3 about here]

Data Analysis

Our motivation for pursuing this research study was pragmatic. Therefore, a descriptive interpretive approach with a pragmatic perspective was used. Pragmatism is gaining recognition as a research paradigm that permits blending of different methods with the goal of achieving meaningful and useful results (Creswell and Plano Clark, 2007). A pragmatic paradigm is an appropriate fit for physiotherapy research that is outcome and context-oriented and addresses implications for practice (Shaw et al., 2010).

A descriptive interpretive approach was used during analysis that allowed the primary author ([redacted]) to immerse herself in the data, particularly through transcription verification and repeated readings, followed by manually generating initial codes and organizing these codes into themes (Braun and Clarke, 2006); this process occurred concurrently with data collection. Initial review of the transcripts revealed that the interview responses could be segmented into two distinct portions to be analyzed separately. The first portion pertained to parents' experiences and perceptions of the classification systems and the second portion pertained to parents' recommendations for service providers. The themes and corresponding codes that emerged from each portion were then discussed among the study authors ([redacted]) **who approved the codes as well as reviewed and refined each theme** to produce the final analytic results. No specific framework was used when coding, allowing for flexibility when identifying the overarching themes in the data, as well as a reduction of preconception bias.

Rigour was achieved through peer debriefing among the study authors. **Although the lead author is a novice researcher, all other authors have research experience and expertise in quantitative and qualitative research.** Initial analysis included the first four interviews and it was during this preliminary analysis that all of the themes in our results emerged. Subsequent analysis of the final three interviews provided evidence of saturation (i.e. no new themes emerged). A member check with parent participants was conducted for the recommendations.

Results

Experiences

Seven themes emerged about parents' experiences and perceptions when using the classification systems. Four of the themes focused on experiences and three focused on perceptions of utility. Figure 1 represents the first four themes and the chronological relationship among them: *status quo, personal reaction, benefits of explicit conversation,* and *processed reaction*. *Status quo* represents whether or not parents had been exposed to any of these systems prior to participation in the On Track study. The first point of exposure to these systems either happened during the *status quo* phase or upon enrollment in the On Track study. From the point of exposure forward, a process occurred that reflected parents' experiences with these systems through participation in the On Track study.

[Insert Figure 1 about here]

Status Quo: When asked about their prior exposure to these classification systems before enrolling in On Track, participants fit well into one of two subcategories. Some participants distinctly remembered their therapist explaining why and how these systems were used and could remember the point in time when they were first introduced.

> *"We have participated in the GMF classification system. I think that started…around 2010. ...It was a physiotherapist through the [children's rehabilitation centre]…who introduced it to us and…explained to us basically what the purpose of the classification system was, and how it can kind of benefit us just in terms of knowledge"* – Norma

Other participants were uncertain about whether they had been previously exposed to these systems during their child's regular therapeutic services.

> *"I don't think so. …They could have... we've had so many appointments, so..."* – Brooklyn

This uncertainty suggests that either service providers may not use these systems, or that that there is an absence of explicit discussion between the service providers and parents that introduces and effectively explains these systems.

Personal Reaction: This theme represented parents' emotions, concerns, or responses to these classification systems that were reflexive, unfiltered, and truly embodied the parents' initial perceptions. Interestingly, there was a wide range of experiences among participants and it seemed as though the child's functional classification on these systems influenced parent experiences. For example, a participant whose child was GMFCS level V cited the experience as negative, overwhelming, and frustrating.

> *"I remember it was quite extensive,…it was fairly exhausting actually doing it. Particularly because [child] is so impacted by her CP that when you keep going down, like, the lowest level, the lowest level,…and you're like okay…why am I answering these questions, it's a bit frustrating."* – Johanna

In contrast, two participants whose children were GMFCS level I expressed a lack of concern or lack of strong emotional response to these systems and their criteria.

Benefits of Explicit Conversation: This theme highlights the discussion between parents and therapists. Based on parents' responses, it seemed as though the therapists facilitated parents' understanding of these systems.

> *"I know that there was a couple of them that I didn't know how to answer, so she [the therapist] went over them, you know? To ensure that I was getting it."* – Janet

Therapists often clarified and explained distinctions between levels within each system so that parents could better understand why and how they were used. In this particular quote, the participant discusses how her GMFCS classification initially disagreed with that of the therapist and describes how the conversation between them unfolded.

> *"She had just asked me why, and then…I went into well da-d-da and then she said 'well... are you sure? Like think about that.'… She said imagine you're not comparing her to her twin 'cause she knew. …And so then I looked at it…and then I was like 'yeah, I see your point.'*

Like it was more of an...open discussion." – Brooklyn

This participant's discussion illustrates how the therapist encouraged conversation, utilized professional insight in knowing the potential for comparisons to the child's twin, and encouraged thought and an exchange of perspectives.

Processed Reaction: This theme represents a new understanding that was reached when parents processed their personal reaction after having a conversation with the therapists. **In terms of drawbacks, two of the participants mentioned that, of the three classifications systems, the CFCS was the most challenging to understand and apply to their child given the perceived ambiguity of what constitutes communication and lack of clarity regarding how comprehension plays a role in this system.** However, most participants regarded all three systems as equally similar in terms of understandability and ease of use. Some participants also discussed the challenge of assigning a level to their child with all the classification systems because they felt their child's abilities straddled between the criteria of two levels as described in the following quote.

> *"I found that I couldn't for sure pick which [GMFCS] level, 'cause…some of the abilities were on the one level, and then some of his abilities were on the other level, so he was kind of in between both levels. …the classifications the way they were based, I couldn't agree fully with both."* – Ashley

The concept of experiences being influenced by the child's level of function transcended this theme as well. A participant with a child with more significant limitations stated that the systems seemed to have a disability focus or did not capture everything, whereas participants of children with less involvement talked more about how the criteria were appropriate, easy to understand, and perceived the levels as a checklist of abilities. The following quote illustrates how a participant went through this process by having an initial, unfiltered reaction, explicitly discussing the systems and classifications with a therapist assessor, and then describing the experience of using these systems in totality.

> *"Initially I think it was very overwhelming… But it was a very comfortable experience, our therapist explained it very bluntly, she made it easy for us to understand. In terms of following the classification system,…it was pretty straight forward as well. There weren't a lot of concerns with the overall classification at all. …It was very easy to understand and follow."* – Norma

Perceptions of Utility

The subsequent three themes that emerged from analyzing the first portion of the interviews can be superimposed onto the initial process timeline from Figure 1 to reflect the relationship among all seven themes. The Venn diagram highlighted in Figure 2 encompasses the themes of *utility, planning,* and *informing expectations* that occurred from the parents' point of exposure to these systems onward and can be informed or changed over time as parents move through this process. *Utility* represents the broad category of how parents use these systems or perceive their usefulness, with *planning* and *informing expectations* acting as subthemes representing a specific type of utility.

[Insert Figure 2 about here]

Utility: Some participants said that they didn't see the use of these classification systems in day-to-day life, but did see them as useful in terms of things like securing services and resources, advocating for their children, communicating about their children with others, and being aware of potential risks or complications.

> *"…in day-to-day life, it's not really useful. …the only thing is, say if I felt she needed more services and that sort of thing, it's sort of one of those things that I could say well, you know, she is this [level] of CP, most kids with this [level] have this service and she doesn't, that sort*

of thing" – Johanna

Most participants acknowledged the clinical utility of these systems as a baseline or checkpoint assessment, a means for communicating about a child with CP among service providers, and as an efficient assessment tool.

> *"So if they have a general base to start with as somebody coming in and picking up her file and wanting to see her or somebody that is new to her therapy or that, it gives them an idea where they're starting from. So then they don't have to start from scratch and figure it all out."* – Janet

Planning: The concept of planning came up when discussing the prognostic value of these systems with parents. Part of the interview guide involved directly communicating to parents the evidence of prognostic utility for the GMFCS and MACS and ensuring they understood what this evidence meant before proceeding. Upon confirming comprehension, parents were then probed about how useful they found these systems now knowing their predictive value and this is often when parents referred to aspects of planning such as home renovations, assistive devices, and anticipating future needs.

> *"I think it helps us to sort of anticipate…what equipment she's going to need as she gets bigger and she gets heavier what we're going to need in the house to be able to transfer her safely. …So we've already made major changes to her home to accommodate wheelchairs and that sort of thing."* – Johanna

Informing Expectations: All of the participants used the classification systems as a means to collect knowledge about their child and inform their present and future expectations, whether or not they were explicitly aware that they were doing so. This theme represents components such as using the systems and discussions with therapist assessors to reflect on how far the child has developed, set achievement goals, track progress, and develop realistic future expectations.

"It's kind of neat just to look at her, and think what is she capable of? What is she doing. And to kind of check ourselves…into the gamut of where do we want to see her headed. Kind of helps us head in a direction of what did we want her to do next. So it is useful for us to kind of reassess where we are with her. Her progression, her growth." - Brooklyn

In this quote, the participant and her partner used their interaction with these systems as a check-in point to reflect on their child's growth as well as define their vision for her future.

Recommendations for Service Providers

Six key recommendations emerged and were labeled as action statements to reflect how service providers can incorporate parents' advice into practice. Each recommendation was then broken down into more detailed statements that capture each of the unique codes within the recommendation. A number was assigned to each recommendation by study authors to represent the logical sequence among them; satisfying the preceding piece of advice can lay the foundation for seamless implementation of the subsequent piece of advice. Table 4 represents the "Tip Sheet" resulting from our findings.

[Insert Table 4 about here]

1. Acknowledge individual parent reactions: Knowledge of how parents respond to the classification systems from the first part of this study illustrates that not all parents have the same reactions and that a continuum of experiences exist. Service providers must acknowledge these differences and have the flexibility to tailor their communication approach accordingly. Participants also emphasized that service providers' compassion and responsiveness played a pivotal role in creating a supportive atmosphere. The following quote speaks to the emotional stages that can occur when processing information and how service providers should be perceptive to each parent's emotional and information needs.

"I think you have to see where the parents are… Sometimes…just slow and steady coming to

accept what your child's future is like [is] somewhat better, but that's not every parent's wish though either. So you kind of have to feel…how the parent is." – Johanna

2. Make the Child a Priority: This recommendation highlights how strongly a child's perception of their care and relationships with service providers can inform a parent's level of satisfaction. Parents want service providers to understand their child as a person and not just a client of rehabilitative services, as well as take the time to include the child in care and make them feel special and confident.

" And [child] feels very connected and very important to them, and however she feels is how we feel. …As a parent we're happy and she feels very sure of herself, and they help her feel confident. Even if she doesn't like something, they tell her why she has to do it, and what she'll get out of it. And they're very honest with her, which is, I think, good" – Brooklyn

3. Use an Individualized, Holistic Approach: One participant was particularly vocal about how quality of life should play a role in the presentation of these systems and the following quote illustrates her beliefs.

"…just for service providers to kind of stress that [these systems are] only really one small piece of the puzzle… [Children with CP] can still live a happy full life and... It's just a matter of being aware of what…their capabilities are,…but putting that in perspective, with how it will affect their quality of life." - Johanna

Other participants echoed this need for a whole-person approach to care. To parents, a holistic approach entails fostering an understanding of the child's limitations while celebrating their strengths and what they can do. As Johanna eloquently said, service providers should emphasize to parents that the child may still *"grow and flourish within the constraints of their disability"*.

4. Facilitate a Positive, Open Dialogue: A very prominent concept that emerged from all interviews was honesty. Participants placed a high value on service providers' honesty in terms of being direct with them, but following up this directness by encouraging discussion, answering questions, being approachable should further questions or concerns arise, and having the patience throughout every interaction to ensure parent comprehension and satisfaction.

> *"…[our therapist] was very personable, she was really easy to talk to. If there was any concerns or anything, there's no hesitation to ask her questions. …and she did have that personable approach to make it easy for us to comprehend the information."* – Norma
>
> *"what I loved as well about both of them is that they weren't afraid to be honest with us, like when we had concerns, especially when we were first learning about all of it"* – Maria

Including elements of positivity or optimism in conversations, particularly those that communicate difficult information for parents to process, was also recommended by participants.

5. Foster Connections: Forming relationships came up directly in all interviews as all participants discussed how profoundly important their connections with service providers are and how the sense of family creates a supportive environment. This recommendation is placed towards the end of this section based on the idea that combining tips 1-4 will allow service providers and families to establish the strong, authentic connection that parents truly need and appreciate.

> *"…These are your support people and...if you're not able to connect with them, or if your child doesn't connect with them, or if there's not that relationship there, it's very hard. Extremely, extremely hard."* – Kari
>
> *"a lot of them have been calling me also and just following up and saying… 'just want to touch base with you, give me a call back'…doing that follow up call is great because then not only [do we] know that they're doing their job, I know that they care."* – Ashley

Developing trust and relationships with families was also important in facilitating productive discussions and allowing parents to feel comfortable voicing their questions and concerns.

> *"I think that we came to the point where we felt we could ask because they were gentle enough and caring enough that we knew we could handle how they were going to answer …eventually after spending time with the PTs and seeing how they were with [child] and listening to their positive comments about how she was progressing, then I felt I could ask those questions."* – Maria

6. Be a Dependable Resource: This piece of advice refers to the important role that service providers occupy in terms of acting as a knowledge resource and gatekeeper to services for parents. Within this recommendation, parents expressed a desire for service providers to be reliable, coordinated with other team members, and willing to provide as much information and access to services as possible to help parents feel informed in making decisions about their children's care.

> *"They've been very good at interacting and giving me information, but I think at the beginning even when you're being diagnosed saying here is different therapies. Like, giving options I guess. …things in the community that will help support and that kind of thing."* – Maria

The quote below reflects the extent to which parents depend on and trust service providers.

> *"…As much information that providers can give, like, they are supposed to be the wealth of information and as a parent sometimes you don't know where to get more information…if you're not getting it from your providers and from your team, you don't know where to get it."* – Kari

DISCUSSION

Although limited by a small sample of seven participants **all recruited from one rehabilitation centre**, saturation of the data was reached during our two-phase analysis. Furthermore, several of the themes that emerged from this qualitative analysis are in accordance with previous literature, supporting the clinical utility of our findings. As this is the first study that examines parents' experiences with the GMFCS, MACS, and CFCS, findings are also interpreted in the context of practice to demonstrate how this knowledge can be translated to parent-therapist interactions.

Participants cited a range of experiences and perceptions when describing their experiences with the classification systems. The functional abilities of the child seem to have influenced parents' experiences in this study, similar to previous research findings (Fernandez-Alcantara et al., 2015). Most participants viewed the discussion of the classification systems positively and used this dialogue as a means to facilitating further understanding of these systems. This suggests that an honest and direct conversation between parents and service providers about the use of these systems is beneficial to parents and can help address their documented desire for information (Darrah et al., 2002; Hayles et al., 2015). With respect to prognostic utility, most parents had a general idea that they could expect their child to maintain a similar level of function over time, and seemed to respond well to having a conversation with the interviewer about prognosis. This positive response indicates that parents seem to be open to discussions about future function and find this type of information useful in terms of planning for the future and developing realistic expectations. Finally, from reading over the transcripts collectively, the study team noticed that the formation of strong partnerships with children and families is critically influential in determining how parents interact with service providers and how supported and satisfied they feel. This concept has been highlighted extensively (Hayles et al., 2015; Kruijsen-Terpstra et al., 2014; Whiting, 2012; Wiart et al., 2010; Ziviani et al., 2014), further emphasizing its foundational importance in influencing parents' experiences with clinical services and staff. Employing the recommendations from parents is expected to facilitate the establishment of these parent-therapist connections.

Understanding the experiences of parents of children with CP is important to inform best practices for using the classification systems in clinical practice. Given the various perceptions of utility cited by parents represented by the themes *utility, planning,* and *informing expectations*, there appears to be a personal and holistic benefit to using these systems. The clinical utility of these systems coupled with the personal utility makes a strong case for integrating the GMFCS, MACS, and CFCS into regular practice. **In considering the responses of two participants regarding some challenges with using the CFCS, more support and explanation may be beneficial when discussing this system in particular with parents**. Overall, service providers are encouraged to recognize their important role in facilitating understanding of these systems.

One limitation of this sub-study is a lack of full demographic descriptions for parent participants which we did not ask for. A second limitation is that parents and their children enrolled in the On Track study at different times (n=3 at baseline assessment and n=4 at 1 year assessment), and these varying lengths of exposure to the classification systems, both within and outside of the study, may have been a potential confounder. A third limitation to these findings, particularly the process timeline in Figure 1, is that the methods from the On Track study may have influenced these results. Parents individually experienced these systems through the On Track booklet, and then subsequently discussed their classifications with the therapist. In routine clinical practice, this opportunity to individually experience these systems may not be present, and thus the process timeline reflected in Figure 1 may not be generalizable to all parents' experiences with these classification systems. However, given our findings, we encourage therapists to collaborate with parents to classify function of children with CP. A collaborative process not only allows parents the time to form these initial perceptions and responses, but also informs therapists about the child's usual performance at home and in the community. This provides a foundation for continued sharing of information for goal setting, intervention planning, and anticipatory guidance.

This qualitative research study provided a direct voice for parents of children with CP to express their advice and recommendations for service providers. Every effort was taken during data collection, analysis, and member checking to preserve the richness and context of these responses, making the “Tip Sheet” an accurate reflection of parents’ needs during clinical interactions. Further research is recommended to explore children and youth’s experiences and perceptions about their own classifications for integration of the child into his or her own care.

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TABLE 1. Brief Description of the Levels in the Three Classification Systems

Classification System	Level	Description*
Gross Motor Function Classification System (GMFCS) (Palisano et al., 2008)	I	Walks without limitations
	II	Walks with limitations
	III	Walks using a hand-held mobility device
	IV	Self-mobility with limitations; may use powered mobility
	V	Transported in a manual wheelchair
Manual Ability Classification System (MACS) (Eliasson et al., 2006)	I	Handles objects easily and successfully
	II	Handles most objects but with somewhat reduced quality and/or speed of achievement
	III	Handles objects with difficulty; needs help to prepare and/or modify activities
	IV	Handles a limited selection of easily managed objects in adapted situations
	V	Does not handle objects and has severely limited ability to perform even simple actions
Communication Function Classification System (CFCS) (Hidecker et al., 2011)	I	Effective sender and receiver with unfamiliar and familiar partners
	II	Effective, but slower-paced sender and/or receiver with unfamiliar and familiar partners
	III	Effective sender and effective receiver with familiar partners
	IV	Inconsistent sender and/or receiver with familiar partners
	V	Seldom effective sender and receiver with familiar partners

*For the full details of each system and their level criteria, refer to the websites below
GMFCS: http://motorgrowth.canchild.ca/en/GMFCS/resources/GMFCS-ER.pdf
MACS: http://www.macs.nu/files/MACS_English_2010.pdf
CFCS: http://www.therapybc.ca/eLibrary/docs/Resources/CFCS_2008_11_03.pdf

TABLE 2. Sample Characteristics

Pseudonym	Child Information					**Visit Number**	Parent Level of Consensus With Assessor *at most recent On Track assessment
	Age	GMFCS	MACS	CFCS	Distribution of CP Involvement		
Maria	2	II	III	II	Diplegia	**1**	A (C); A/R (G, M)
Ashley	4	II	I	II	Diplegia	**3**	A (G, M, C)
Norma	5	II	III	I	Quadriplegia	**3**	A (M, C); A/R (G)
Janet	7	V	IV	IV	Quadriplegia	**3**	A (G); D (C, M)
Brooklyn	8	I	II	I	Hemiplegia	**1**	A (M); A/R (C); D (G)
Johanna	9	V	IV	III	Quadriplegia	**1**	A (G, M, C)
Kari	11	I	II	I	Hemiplegia	**3**	A (G, M, C)

A: agreed with assessor, A/R: agreed with assessor after discussion and revision, D: disagreed with assessor
G: GMFCS, M: MACS, C: CFCS
1: Study entry/baseline assessment, 3: one year assessment
Note: Visit 2 in the On Track study was conducted 6 months after visit 1 and did not include the 3 classifications.

TABLE 3. Key Elements of the Interview

Key Element	Examples of Questions
Prior Exposure	Had you been exposed to these classification systems prior to participating in the On Track study? Which ones?
Experiences	Describe your experiences when using these three systems to classify your child. At the assessment, did the assessing therapist discuss your child's classification levels with you? How did you and the therapist interact during this discussion?
Perceptions	How useful have these classifications been for your personally and do you see a benefit in using them?
Advice	What advice do you have to service providers when communicating information to children, their parents and their families to make these interactions optimally supportive?

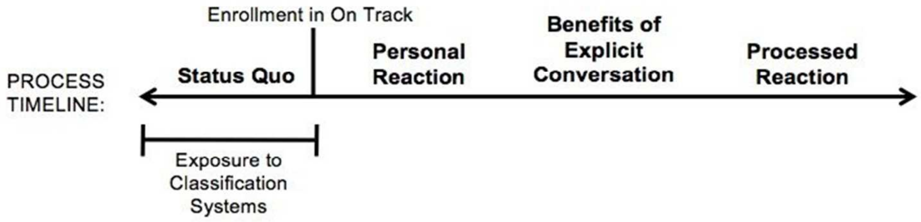

FIGURE 1. Graphical representation of the themes describing parents' experiences and their chronological relationship

FIGURE 1. Graphical representation of the themes describing parents' experiences and their chronological relationship
65x22mm (300 x 300 DPI)

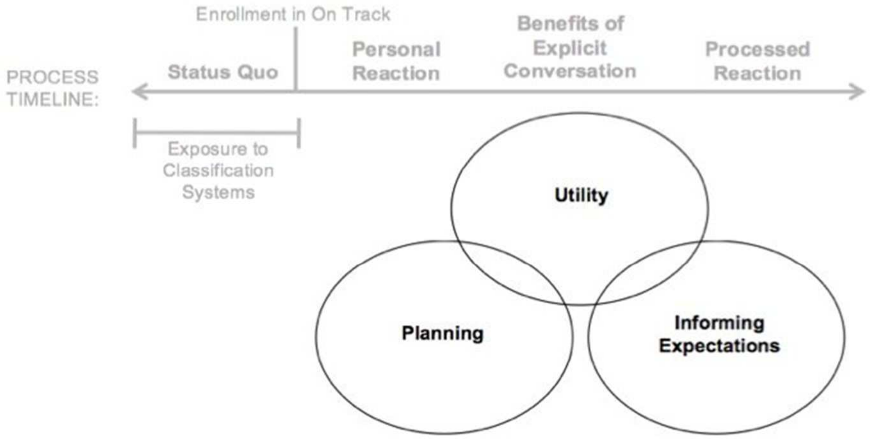

FIGURE 2. Graphical representation of the themes describing parents' perceptions of utility and their relationships both within Figure 1 and among themselves

FIGURE 2. Graphical representation of the themes describing parents' perceptions of utility and their relationships both within Figure 1 and among themselves
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TABLE 4. Tip Sheet: Parents' Recommendations For Service Providers

1. Acknowledge Individual Parent Reactions

- Be professional, but compassionate when communicating information
- Listen, acknowledge, and respect parents' thoughts and perspectives; The parent knows their child best
- Recognize the emotional aspect to discussing a child's abilities and be perceptive and responsive to parents emotional needs
- Present information in a pace that is sensitive to how parents are handling information
- Allow time for parents to process the information you give them
- Understand the important role that hope plays for parents

2. Make The Child A Priority

- Understand the child as a person and not just a client; Get to know them!
- Develop a strong relationship with the child and make them feel special
- Motivate the child during therapeutic services and promote their confidence in themselves
- Involve the child in elements of deciding on and discussing their care when possible

3. Use An Individualized, Holistic Approach

- Recognize the limitations of the classification systems (GMFCS, MACS, and CFCS) and that they are part of a bigger, holistic picture
- Maintain a balance of presenting and generalizing scientific evidence with acknowledging the uniqueness of each child with CP
- Celebrate the child's strengths
- Include discussions about quality of life and engagement in activities

4. Facilitate a Positive, Open Dialogue

- Maintain an open, two-way, and consistent line of communication with families; Gestures such as therapy notes or follow-up phone call are greatly appreciated by parents
- Be direct, honest, and clear when providing information or answering questions
- Consider the message you convey with all communication channels (i.e. tone of voice, body language)
- Be accessible and patient for parents should they have questions, require further explanation, or need clarification
- Encourage a level of optimism and positivity during conversations with parents; Be sure to emphasize the child's improvements, progress, and potential

5. Foster Connections

- Form authentic relationships with the child, their parents, and their family members
- Understand the fundamental importance of trust between parents and service providers in developing a collaborative partnership
- Facilitate a sense of community among the child and their family, clinical team, and rehabilitation centre; Engage the child outside of clinical services where possible (e.g. to community partnered special events such as fundraisers, BBQs, family events)
- Remind the child and their family of your role in supporting them wherever you can

6. Be a Dependable Resource

- Recognize that you are a gatekeeper to other resources and sources of knowledge for parents
- Understand parents' desire for information and provide them with the many opportunities, programs, and services available to them and their child for care and support
- Be reliable and timely when following up with parents' questions or concerns
- Fulfill your role in coordinating care with other team members or clinical services
- Always remember this integral role that you play within your service provider-parent relationship and in all of your interactions; Parents rely heavily on service providers for support, knowledge, resources, and assistance in understanding elements of their child's care;

Appendix

Semi-Structured Interview Guide

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

Thank you for agreeing to participate in this study. Today we'll be discussing your experiences with and perceptions of using the standardized classification systems from the On Track study to classify your child with cerebral palsy. I will be recording this interview so I can focus on the conversation and type it out later. I just want to remind you that you can choose not to respond to any question without any problem. After this interview you will be given the written transcript of what we discuss today and you will have the option to include it in the study or remove any parts you wish. Are you ready to begin?

As you may remember from the On Track study, 3 classification systems were used to describe the functional status of children with CP. These include the Gross Motor Function, the Manual Ability, and the Communication Function Classification Systems.

First, I'd like to explore your experiences and impressions surrounding the GMFCS, MACS and CFCS. Had you been exposed to these classification systems prior to participating in the On Track study through your child's treatment centre?

If no: *Next question*
If yes: Which ones?
    How were they introduced or discussed with you?

Think back to your initial experience going through the On Track booklet and reading the insert about the various classification systems and levels. Can you describe your experience when using these three systems to classify your child? *[Looking for: comfortability, ease of use, challenges with use, understandability, emotions; Probe positive or negative responses to gain a deeper understanding.]*

Did your experience in classifying your child vary among the three systems? *[Ex. One was easier to use, one was clearer]*

At the assessment, did the assessing therapist discuss your child's classification levels with you?

If no: *Next question*
If yes: How did you and the therapist interact during that discussion?
    How useful was this discussion for you?
    Was there an agreement regarding which level your child is classified under for each of the three systems?
        If no: How did that disagreement unfold?
            How did it make you feel?
        If yes: *Next question*

Now, I'm interested in learning about your perceptions regarding the utility of these systems.
How useful have these classification systems been for you personally and do you see a benefit in using them?

Two of these measures, particularly the GMFCS and MACS, have bodies of work supporting the stability of these systems in older children with CP. Worded another way, this means that there is evidence to show that children will remain in the same level throughout childhood and adolescence and that these two systems are able to predict future function.

How useful do you find these classification systems now knowing their ability to predict future function? [*Probe positive or negative responses to gain a deeper understanding.]*

Finally, what advice do you have to service providers when communicating information that describes current and future function to children, their parents and their families to make these interactions optimally positive and supportive? *[Probe as appropriate.]*

As indicated at the beginning, I will be transcribing this interview and referring to you by a pseudonym that is a name other than your own to identify you by. Is there a particular name you would like me to use?

Do you have anything to add before we end the interview?

Thank you for your responses. Next time you hear from me, I will be sending you the transcript of this interview for your review and approval. After the analysis takes place, I will be contacting you again with a summary of the advice for service providers that have been gathered from this study for you to review for comprehensiveness and accuracy. Once the final report has been completed, I will be sending you a brief summary of the results of this study. Thank you again for your participation in this study.