


Caregiver knowledge and preferences for gross motor function information in cerebral palsy

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ABBREVIATIONS

GMFCS Gross Motor Function Classification System

AIM To determine caregiver knowledge and preferences for gross motor information and examine differences across Gross Motor Function Classification System (GMFCS) levels.

METHOD A questionnaire was developed. Respondents reported GMFCS knowledge, preference for knowledge, and experience with GMFCS and motor curve information.

RESULTS In total, 303 caregivers of children with cerebral palsy (CP) (GMFCS level I: 22%; GMFCS level II: 16%; GMFCS level III: 15%; GMFCS level IV: 23%; GMFCS level V: 24%) completed the questionnaire. Forty-five per cent of caregivers knew the GMFCS level at survey, and only 31% knew how their child's motor development compared with others of similar age and level. Caregiver education level was associated with knowledge ($p < 0.001$). Most prefer discussing motor development with a therapist. Of caregivers who knew their child's GMFCS level at survey, 83% reported it would be helpful to revisit the topic over time. Compared with GMFCS level IV and V, caregivers of children in GMFCS levels I to III preferred to learn at the same time as CP diagnosis ($p = 0.04$) and were more likely to report having received visual aids ($p = 0.04$). Caregivers of children in GMFCS levels IV and V found it more difficult to learn their child's level ($p < 0.001$) versus those caring for children of GMFCS levels I to III, and reported seeing pictures with descriptions more informative ($p = 0.03$).

INTERPRETATION Caregivers of children with CP may not know GMFCS and motor curve information, and vary in experience and preferences for this information.

Caregivers of children with cerebral palsy (CP) identify motor development as a primary concern when considering treatment options.¹ Physical therapy interventions delivered throughout the lifespan are designed to improve motor capabilities, promote function, and prevent secondary impairments within the context of patient and family preferences and values.² Caregivers of children with CP want as much information as possible about their child's condition, including their prognosis and rehabilitation intervention needs.^{3,4} However, caregivers often feel that health professionals underestimate their desire for information.⁵

The foundation of shared decision-making among providers and families includes both parties participating, sharing information, building consensus, and agreeing upon an intervention plan.⁶ The Gross Motor Function Classification System (GMFCS),^{7,8} which classifies children with CP based on five levels of gross motor function, was designed to be used by clinicians to help families understand a child's current abilities and to discuss what their child's gross motor abilities are likely to be in the future when

used in combination with the motor growth curves.⁹ The GMFCS is valid, reliable, and stable.^{7,8,10,11}

Providing appropriate and relevant information to caregivers, including varying levels of gross motor functioning capacity, and using several mediums such as written, verbal, videos, and the internet can have a positive influence on family's function and adjustment to the diagnosis.¹² However, in a study of home programming for children with CP, caregivers felt therapists were reluctant to give this type of information in order to protect them from painful news.¹³ Clarifying expectations of treatment outcomes is thought to contribute to increased satisfaction for families and professionals.¹⁴ However, authors suggest GMFCS is primarily used in research and not often as part of family-centred care.^{14,15}

In a survey of 283 paediatric physical therapists, fewer than half use the GMFCS consistently.⁹ Most use GMFCS level as a data point rather than a tool to educate families about their child's development or to support shared decision-making about treatments and goals. Limited information exists about caregivers' perceptions of discussions with

providers about their children's GMFCS level. A small qualitative study, (part of a larger study classifying children's gross motor function), suggests perceptions of GMFCS may differ given their child's level of functioning.¹⁶ Caregivers of children in GMFCS level V reported negative feelings and experiences versus caregivers of children in GMFCS levels I to III.

It is unknown if caregivers, outside of participating in a research study, know about the GMFCS and motor curves related to their child or how caregivers prefer to receive this information. It is important to determine if clinicians are conveying this information and to understand parent preferences for receiving it. Patient-centred care includes incorporating evidence into information sharing.¹⁷ Improved caregiver understanding of gross motor function supports shared decision-making. Identifying caregivers' knowledge of GMFCS levels, preferences for learning about gross motor development, and experiences of clinicians sharing this information is critically needed. Results may inform the development of caregiver decision aides and clinician training to improve communication about difficult prognostic information across multiple episodes of care.¹⁸

The purpose of this study was to determine caregivers' knowledge and preferences for gross motor development information in CP by addressing the following questions: (1) What are characteristics of caregivers who know about their child's GMFCS level? (2) Is there an association between knowledge of GMFCS level and caregiver confidence in caring for their child, setting physical therapy goals, and satisfaction with care? (3) What are caregiver preferences and experiences with learning about GMFCS information, and how do they vary by GMFCS level?

METHOD

This was a cross-sectional study carried out via an online (Survey Monkey), anonymous, self-administered structured questionnaire from 29th August 2016 to 29th November 2016.

Survey

The survey (Appendix S1, online supporting information) was designed by a study team consisting of three experienced paediatric physical therapists and two parent collaborators. Survey content was based on research questions and literature review. The survey had 42 questions organized into three sections: demographics (11 questions); respondent characteristics (10 questions); current knowledge, confidence, and perception of therapy (nine questions); and, if applicable, experience and use of GMFCS and motor curves (12 questions). Respondent confidence in caring for their child and setting physical therapy goals, and perception of how therapy is meeting their expectations, were answered on a 5-point Likert scale: really not confident to really confident; and much less than expected to greatly exceeds expectations respectively. Questions about current knowledge included if caregivers knew the

What this paper adds

- Fewer than half of caregivers of children with cerebral palsy (CP) know their child's Gross Motor Function Classification System level.
- Most want to know how their child's function compares to other children with CP.
- The majority of caregivers would like to revisit the topic over time.
- Caregivers want to discuss gross motor information with the therapist and doctor.

child's GMFCS level or not, who they would like to share GMFCS information with them, and when given pictures and descriptors, could they select their child's level and how they felt about it. Only those respondents who knew about GMFCS level at time of survey were asked questions about their experiences and use of GMFCS information.

To evaluate content validity, 10 families reviewed a draft questionnaire. Modifications were made based on their feedback and a final questionnaire was created. This survey took approximately 10 minutes to complete. Pictures were provided alongside the question for clarification of GMFCS level and motor curves. All surveys and methods were approved by institutional review boards.

Sample

The target population was caregivers (aged ≥ 18 years and who could read and understand English) of individuals with CP worldwide. The cover letter and survey link were posted on websites of several national and international CP-related websites. Additionally, the study team recruited participants through word of mouth and provided flyers about the survey during clinic visits at their respective institutions. Families that did not have internet access were provided with paper surveys.

Data analysis

Descriptive statistics summarized demographics, confidence in caring for their child, setting physical therapy goals, satisfaction with therapy, and parental preferences regarding how, when, and by whom information is disclosed and used. χ^2 tests assessed association of caregiver current knowledge (yes/no) regarding gross motor function of their child with CP with respondent and child characteristics, confidence in caring for their child, setting goals, and how therapy meets their expectations. χ^2 tests were used to analyse differences in experiences and preferences across GMFCS levels. SAS 9.4 (SAS Inc., Cary, NC, USA) was used for all statistical analyses with a significance level of 0.05 (two-tailed).

RESULTS

In total, 293 responses were received online and 18 on paper. Eight respondents indicated in question 1 that they were reporting on themselves and therefore were not included, resulting in 303 surveys available for analysis. Most respondents ($n=211$) found out about the survey via social media sites. IP addresses were reviewed; no duplicates were found. We had a 90% completion rate across all questions.

Respondents

Caregiver and child characteristics are reported in Table SI (online supporting information).

The majority of respondents were mothers, had either a bachelor's or graduate degree, and were between 30 and 49 years of age. Most children reported on were males, younger than 5 years old, white, non-Hispanic, and born in the USA. All GMFCS levels were represented (level I: 22%; level II: 16%; level III: 15%; level IV: 23%; level V: 24%). Nearly 50% of individuals reported on were diagnosed with CP before 1 year of age. Eleven additional comorbid conditions were reported; the three most frequent were difficulties with verbal communication (57%), vision impairment (45%), and difficulty eating (42%). The most frequently reported primary doctor managing the person's CP were physiatrists/rehabilitation (28%), followed by neurologists (26%).

Caregiver knowledge of GMFCS level

Forty-five per cent of caregivers responded 'yes' they were aware of their child's GMFCS level; 31% of respondents knew how the person's motor skill development compared with others of the same age and type of CP as the person they were reporting on; and 74% thought it would be helpful to know this information (Table I).

There was a significant association between caregiver education level and knowledge of GMFCS level ($\chi^2=14.93$, $df=2$, $p=0.001$, $\phi=0.23$); those with higher education were more likely to know their child's GMFCS level. There was no association between ethnic group of the person with CP and caregiver knowledge of GMFCS level ($\chi^2=0.001$, $df=1$, $p=0.98$, $\phi=-0.002$), or between GMFCS level and caregiver knowledge ($\chi^2=2.24$, $df=4$, $p=0.69$, $\phi=0.09$). When asked 'Who would you like to tell you about your child's motor development?', the most frequently selected response was therapist (88%), followed by medical doctor (75%).

Caregiver confidence and expectations for therapy

Most respondents (87%) were confident or really confident in caring for their child, and 61% were confident or really confident in setting physical therapy for the person's motor development. The positive association of knowledge of GMFCS level with confidence in taking care of the person's needs approached significance ($\chi^2=3.771$, $df=1$, $p=0.051$). There was no association of knowledge of GMFCS level with confidence in setting physical therapy goals ($\chi^2=0.008$, $df=1$, $p=0.93$). Sixty-seven per cent of respondents selected therapy intervention matches, exceeds or greatly exceeds expectations, whereas 33% answered less than or much less than expected. There was no association between knowledge of GMFCS level and how the therapy the person receives meets their expectations ($\chi^2=0.007$, $df=1$, $p=0.93$).

Caregiver experiences and preferences for learning about gross motor function

Caregiver experiences and preferences for learning about gross motor function were based on responses of 137

Table I: Respondent answers to general questions about knowledge, confidence, and expectations ($n=303$)

	<i>n</i> (%)
How confident are you taking care of the persons needs related to their CP?	
Really not confident	0 (0)
Not confident	10 (3)
Not sure	29 (10)
Confident	167 (55)
Really confident	97 (32)
How confident are you in setting PT goals for the person's motor skill development?	
Really not confident	6 (2)
Not confident	40 (13)
Not sure	72 (24)
Confident	144 (48)
Really confident	41 (14)
How does the PT intervention the person receives meet your expectations?	
Much less than expected	26 (9)
Less than expected	75 (25)
Matches expectations	124 (41)
Exceeds expectations	55 (18)
Greatly exceeds expectations	23 (8)
Are you aware of what GMFCS level the person with CP is classified in?	
Yes	137 (45)
No	166 (55)
Do you know how the person's motor skill development compares to others with similar age and type of CP to the person you are reporting on?	
Yes	94 (31)
No	209 (69)
Do you think it is/would be helpful to know how the person's motor development compares to others with similar age and type of CP to the person you are reporting on?	
Yes	224 (74)
No	79 (26)
Who would you like to tell you about the person's motor development? ^a	
Therapist	265 (87)
Medical doctor	228 (75)
Parent support group	106 (35)
Internet	59 (19)
Video	44 (15)
Other	16 (5)

Percentages do not always add up to 100 owing to rounding and the possibility of choosing more than one response. Confidence levels were collapsed into two categories for analysis: (1) confident and really confident; and (2) not sure, not confident, and really not confident. Expectations were collapsed into two categories for analysis: (1) matches, exceeds, and greatly exceeds; and (2) less than and much less than expected. ^aCould select more than one. CP, cerebral palsy; GMFCS, Gross Motor Function Classification System; PT, physical therapy.

caregivers who responded 'yes' they know their child's GMFCS level and identified the child's level as I ($n=27$), II ($n=20$), III ($n=23$), IV ($n=34$), V ($n=29$), and missing ($n=4$). See Table II for caregiver experience and preferences for learning about gross motor function.

When asked how they first learned about GMFCS level, the top-three responses were 'therapist' (35%), 'doctor' (24%), and 'internet' (14%). Forty-two per cent responded that their child was younger than 2 years old when they learned their GMFCS level, 49% responded that the child was between 2 years and 20 years of age, 2% responded that the child was 21 years or older, and 7% did not know

Table II: Experiences and preferences of caregivers that answered that they knew the child's Gross Motor Function Classification System (GMFCS) level (*n*=137)

	<i>n</i> (%)
How did you first learn about the GMFCS level? (<i>n</i> =133)	
Learned today	4 (3)
Medical literature	9 (7)
Medical doctor	32 (24)
Therapist	47 (35)
Friend	2 (2)
Parent group	11 (8)
Instructional course	1 (1)
Internet	18 (14)
Do not know	2 (2)
Other	7 (5)
How old was the person when you learned about their GMFCS level? (<i>n</i> =130)	
<2y	54 (42)
2–21y	64 (49)
≥21y	3 (2)
Do not know or remember	9 (7)
How emotionally difficult is/was it to learn about the GMFCS level? (<i>n</i> =129)	
Not at all difficult	24 (19)
Slightly difficult	25 (19)
Somewhat difficult	42 (33)
Very difficult	23 (18)
Extremely difficult	15 (12)
How informative is seeing the picture that shows the levels along with the words to describe the GMFCS levels to you? (<i>n</i> =127)	
Not at all informative	2 (2)
Slightly informative	7 (6)
Somewhat informative	27 (21)
Very informative	75 (59)
Extremely informative	16 (13)
Using the faces below, how do you feel when you see a picture of the GMFCS levels with line drawings? (<i>n</i> =127)	
1 (sad)	12 (9)
2	11 (9)
3	20 (16)
4 (neutral)	42 (33)
5	23 (18)
6	11 (9)
7 (happy)	8 (6)
Using the faces below, how would you feel if you saw pictures of actual children (not drawings) at each level? (<i>n</i> =127)	
1 (sad)	17 (13)
2	19 (15)
3	14 (11)
4 (neutral)	24 (19)
5	25 (20)
6	18 (14)
7 (happy)	10 (8)
How do you use the information about the person's GMFCS level? ^a (<i>n</i> =127)	
To discuss with the person with CP	22 (17)
To discuss with health professionals	76 (60)
To discuss with the school team	54 (43)
To communicate with other parents	41 (32)
To discuss with family members, friends, or relatives	53 (42)
To discuss with policymakers, lawmakers, and insurance providers	19 (15)
Do not use	32 (25)
Other	11 (9)
How helpful is it for you to know the person's GMFCS level when setting physical therapy goals for the person with CP? (<i>n</i> =127)	
Not at all helpful	21 (17)
Slightly helpful	16 (13)
Somewhat helpful	39 (31)
Very helpful	40 (31)

Table II: Continued

	<i>n</i> (%)
Extremely helpful	11 (9)
Looking back, when would you have preferred to learn about the person's GMFCS level? (<i>n</i> =127)	
At the same time I learned about the diagnosis	71 (56)
Sometime after I learned about the person's CP, allowing time for me to adjust to the diagnosis	45 (35)
Prefer not to have learned about the GMFCS level	11 (9)
How helpful would it be to revisit the topic of the person's GMFCS level over time? (<i>n</i> =127)	
Not at all helpful	11 (9)
Slightly helpful	11 (9)
Somewhat helpful	43 (34)
Very helpful	48 (38)
Extremely helpful	14 (11)
At the time you discussed the person's GMFCS level with a professional, were you given reading materials, visual aids, or other resources to refer to later or to take home with you? (<i>n</i> =127)	
Yes	32 (25)
No	70 (55)
Do not know	25 (20)
Of those that reported they were given materials ... (<i>n</i> =32)	
Yes, found the materials helpful	23 (72)
No, did not	9 (28)
Has anyone ever shown and explained to you a motor curve like the one pictured above as it relates to the person's motor skill development? (<i>n</i> =125)	
Yes	13 (10)
No	112 (90)

Percentages do not always add up to 100 owing to rounding and the possibility of choosing more than one response for some questions. Difficulty levels were collapsed into two categories for analysis: (1) somewhat, very, and extremely difficult; and (2) slightly or not at all difficult. Informative levels were collapsed into two categories for analysis: (1) somewhat, very, and extremely informative; and (2) slightly and not at all informative. Helpful categories were collapsed into two categories for analysis: (1) somewhat, very, and extremely helpful; and (2) slightly and not at all helpful. ^aMore than one response possible. CP, cerebral palsy.

or could not remember. Sixty-two per cent of respondents found it extremely, very, or somewhat emotionally difficult to learn the GMFCS level, and 38% found it slightly or not at all difficult to learn.

Ninety-three per cent of respondents found pictures extremely, very, or somewhat informative to describe GMFCS levels. When asked how helpful it was to know GMFCS level when setting physical therapy goals, 71% responded somewhat, very, or extremely helpful, whereas 29% responded slightly or not at all helpful. Eighty-three per cent reported that it would be somewhat to extremely helpful to revisit the topic of GMFCS level over time.

Caregivers chose a face on a 7-point visual scale to describe feelings of happy to sad when they saw line drawings of children depicting various GMFCS levels. The group was split evenly among happy (33%), neutral (33%), and sad feelings (34%). In contrast, when caregivers were asked how they would feel if GMFCS levels were depicted with pictures of actual children, more reported feeling happy (42%) or sad (39%) than neutral (19%). When asked how they use GMFCS level information, the top-three

Table III: Caregiver preference and experiences based on Gross Motor Function Classification System (GMFCS) level (*n*=137)

	I-III ^a	IV-V ^a	
Looking back, when would you have preferred to learn about the GMFCS level? (<i>n</i> =127)			
At the same time I learned about the diagnosis of CP	45 (65)	26 (45)	
Sometime after I learned about the person's CP allowing time for me to adjust to the diagnosis	21 (30)	24 (40)	
Prefer not to have learned about the GMFCS level	3 (4)	8 (14)	$\chi^2=6.65$, <i>df</i> =2, <i>p</i> =0.04
How helpful is it for you to know GMFCS level when setting PT goals? (<i>n</i> =127)			
Slightly or not at all helpful	15 (22)	22 (38)	
Somewhat, very or extremely helpful	54 (78)	36 (62)	$\chi^2=4.0$, <i>df</i> =1, <i>p</i> =0.05
How helpful would it be to revisit the topic of the GMFCS level over time? (<i>n</i> =127)			
Slightly or not at all helpful	8 (12)	14 (24)	
Somewhat, very or extremely helpful	61 (88)	44 (76)	$\chi^2=3.46$, <i>df</i> =1, <i>p</i> =0.06
How emotionally difficult was it to learn about the GMFCS level? (<i>n</i> =129)			
Slightly or not at all difficult	37 (54)	12 (20)	
Somewhat, very or extremely difficult	32 (46)	48 (80)	$\chi^2=15.40$, <i>df</i> =1, <i>p</i> <0.001
How informative is seeing this picture along with the words to describe the GMFCS levels to you? (<i>n</i> =127)			
Slightly or not at all informative	8 (12)	1 (2)	
Somewhat, very or extremely informative	61 (88)	57 (98)	$\chi^2=4.6$, <i>df</i> =1, <i>p</i> =0.03
Has anyone ever shown and explained to you a motor curve? (<i>n</i> =125)			
Yes	6 (9)	7 (12)	
No	61 (91)	51 (88)	$\chi^2=0.32$, <i>df</i> =1, <i>p</i> =0.57
At the time you discussed your child's GMFCS level, were you given reading materials visual aids or other resources to refer to later or to take home with you? (<i>n</i> =127)			
Yes	23 (33)	9 (16)	
No	36 (52)	34 (59)	
Do not know	10 (14)	15 (26)	$\chi^2=6.28$, <i>df</i> =2, <i>p</i> =0.04
How do you feel when you see the pictures of the GMFCS levels? (<i>n</i> =127)			
Sad (1-3)	18 (26)	25 (43)	
Neutral (4)	23 (33)	19 (33)	
Happy (5-7)	28 (41)	14 (24)	$\chi^2=5.27$, <i>df</i> =2, <i>p</i> =0.07
How would you feel if you saw pictures of actual children (not drawings) at each level? (<i>n</i> =127)			
Sad (1-3)	28 (41)	22 (38)	
Neutral (4)	15 (22)	9 (16)	
Happy (5-7)	26 (38)	27 (47)	$\chi^2=1.30$, <i>df</i> =2, <i>p</i> =0.52

^aGMFCS levels were combined for analysis. Percentages do not always add up to 100 owing to rounding. CP, cerebral palsy; PT, physical therapy.

responses were to discuss with health professionals (60%), discuss with school team (43%), and discuss with family members, friends, or relatives (42%).

Ten per cent of respondents had been shown a picture of a motor curve and were told how it relates to their child. Twenty-five per cent of respondents were given reading materials, visual aids, or other resources to refer to later, and 72% of these respondents found the materials helpful.

Ninety-two per cent of caregivers reported that they preferred to learn about GMFCS level and 56% reported that they preferred to learn at the same time as diagnosis of CP. Thirty-five per cent preferred some time between learning about the diagnosis of CP and being informed of growth motor curves and GMFCS level. There were no differences based on GMFCS levels for caregiver answers to how helpful it is to know GMFCS level when setting physical therapy goals, how helpful it would be to revisit the topic over time, or how they felt about seeing line drawings or pictures of actual children to depict the levels.

Experience and preference differences across GMFCS levels

Caregivers of children in GMFCS levels I to III were more likely to answer they would have 'preferred to learn the GMFCS level at the same time they learned the diagnosis', whereas caregivers of children in GMFCS levels IV and V more often chose 'sometime after they learned the

diagnosis' or 'preferred not to have learned' ($\chi^2=6.65$, *df*=2, *p*=0.04). Caregivers of children in GMFCS levels IV and V were more likely to say it was 'somewhat, very, or extremely difficult' to learn their child's level versus caregivers of children in GMFCS levels I to III were more likely to answer 'slightly or not at all difficult' ($\chi^2=15.40$, *df*=1, *p*<0.001). Caregivers of children in GMFCS levels IV and V were more likely to answer that seeing the picture along with words to describe levels was 'somewhat, very, or extremely informative' than caregivers of children in GMFCS levels I to III, who were more likely to answer 'slightly or not at all informative' ($\chi^2=4.6$, *df*=1, *p*=0.03). Caregivers of children in GMFCS levels I to III were more likely to report having received visual aids than caregivers of children in GMFCS levels IV to V ($\chi^2=6.28$, *df*=2, *p*=0.04; see Table III).

DISCUSSION

In this sample of caregivers of children with CP, most (55%) did not know about their child's GMFCS level before participating in the survey. Most caregivers felt it would be useful to know gross motor information. Of those that did know their child's GMFCS level, only a fraction reported knowing how their child compared with others, or had seen a motor curve. This identifies a knowledge translation gap as GMFCS levels and gross motor curves are powerful tools for family-centred intervention planning.

In this study, level of education was significantly associated with knowledge of GMFCS level; caregivers with higher education were more likely to know their child's GMFCS level. The association of level of education with health outcomes and information needs has been reported in the literature.^{19,20} The sample presented here is not a representative sample and is biased towards educated, white females. The sample does reflect a distribution of GMFCS levels, with slightly higher percentages of more severely involved children than other samples.²¹

Our results highlight that clinicians are not using GMFCS and gross motor curves to share current and prognostic information with families about gross motor development of their child with CP. This finding is consistent with prior research suggesting that some paediatric physical therapists found it difficult to share data from standardized measures with caregivers after a knowledge translation initiative to improve their skill in administering them.²² Individual clinicians make decisions about using evidence-based tools according to multiple contextual factors, including risks and benefits of practice change, caregiver preferences and readiness for information, opinions of peers, and level of administrative support.²³ However, failure of healthcare providers to use current available knowledge when caring for patients can lead to overuse of unhelpful care or underuse of effective care.²⁴ The reasons clinicians do not share this information may include time, comfort in sharing difficult information, inadequate clinical processes, and communication skills. More research is needed to identify the contextual factors influencing clinicians' use of the GMFCS and motor curves, and their reluctance to share this information with families. Future work should also target improving healthcare processes that support shared decision-making, as well as training clinicians in effectively sharing information about gross motor development for children with CP. One way to improve practice in the healthcare setting would be to build alerts or phrases into the electronic record that remind the clinician to share information with families. Clinicians across all settings could provide families with newer web-based tools to supplement face-to-face conversations.^{25,26}

Increased emotional difficulty with learning about GMFCS level reported by caregivers of children with more severe gross motor disability aligns with the preference not to learn GMFCS level the same day as receiving the diagnosis. Similarly, Scime et al.¹⁶ found caregivers of children with more severe CP reported negative experiences when discussing GMFCS levels. Given our finding that caregivers of children at levels IV and V found GMFCS pictures informative, future work to create decision aides and education materials using several forms of media, as recommended by Higginson and Matthewson,¹² may help clinicians provide information to caregivers on their child's GMFCS level with compassion and sensitivity.

It was not surprising that knowledge about GMFCS level was not associated with confidence in caregiving or making goals. For half of caregivers, this was their first experience with the tools. It is likely that caregivers might

not understand how evidence specific to their child's level of functioning may inform decision-making. For example, are caregivers aware of specific guidelines for hip surveillance depending on their child's GMFCS level,²⁷ or implications of their child's GMFCS level for adaptive equipment to optimize movement in the community?^{28,29}

Clinical implications

Caregivers want therapists and doctors to provide information about gross motor functioning. Deville et al.⁹ suggest that physical therapists are unsure of their role in providing prognostic information. Clinicians may be hesitant to share bad news or feel that it is not their responsibility. However, shared decision-making is the crux of patient-centred care,³⁰ and honest, accurate prognostic information is the basis for shared strategy and decision-making.³¹ Information that is provided with compassion, sensitivity, and hope has been found to help families gain a sense of control over the future.³² Multiple instalments of bad news are likely for families of children with CP, and clinicians must be equipped with tools and skills needed to share information with empathy and psychological support each time. Most caregivers would like to revisit the topic of gross motor development over time and feel that pictures are helpful when describing GMFCS levels. Simultaneously, clinicians should be sensitive to timing of when information is shared, as some caregivers may want time between diagnosis and prognosis, or not want to know at all. Asking caregivers if they would like this information is a first step. Using a stepwise protocol may also assist clinicians with presenting distressing information in an organized and compassionate way to families.³¹

Limitations

Our sample is one of convenience and is biased toward those individuals willing to participate and who knew about the survey. Our results are only generalizable to people with similar characteristics. We have no information on non-responders or those who did not complete the survey. Given the high level of education of respondents, results may be an overestimate of all caregivers' knowledge of gross motor development. The findings are limited by caregiver recall. It is possible that professionals have shared information but caregivers did not recall or did not understand the information shared was referred to as GMFCS levels.

CONCLUSION

Most caregivers of individuals with CP may not be aware of their child's GMFCS level or where they function on motor curves. Caregivers vary in their emotional response to knowing about their child's classification level, and if or when they want to be told about it. Clinicians who care for children with CP can improve information-sharing techniques and skills to meet needs and preferences of caregivers. Further study of clinician practices and caregiver information needs is warranted. In addition, clinicians and caregivers should collaborate in the development and

evaluation of knowledge translation tools to improve caregiver understanding of their child's motor development.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.

Appendix S1: Parent and caregiver knowledge and preferences about gross motor function for individuals with cerebral palsy.

Table S1: Caregiver and child characteristics