

Measuring Care and Comfort in Children With Cerebral Palsy: The Care and Comfort Caregiver Questionnaire

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Objective: To evaluate the psychometric properties of the Care and Comfort Caregiver Questionnaire (CareQ), which was developed to measure the perceived effort of caregivers in providing care for children with moderate to severe cerebral palsy (CP).

Design: Cross-sectional data collection from a representative sample of a large racially/ethnically diverse geographic region.

Setting: Outpatient CP clinics at a metropolitan rehabilitation institution.

Participants: A total of 100 primary caregivers of children with CP whose Gross Motor Function Classification System (GMFCS) levels were III-V.

Methods: The CareQ was administered to primary caregivers of children with CP. Internal consistency of the CareQ and its 3 domains (Personal Care, Positioning/Transfers, and Comfort) were evaluated with the Cronbach α . Construct validity of the CareQ was evaluated by its correlation with the Pediatric Functional Independence Measure (WeeFIM). Associations between CareQ scores and child and caregiver characteristics were assessed.

Results: Mean CareQ scores for children with GMFCS levels III, IV, and V were 30.6, 42.8, and 45.1, respectively ($P < .01$). The Cronbach α was 0.90 for total CareQ and 0.93, 0.80, and 0.82 for its Personal Care, Positioning/Transfers, and Comfort domains, respectively. Total CareQ and WeeFIM scores were negatively correlated ($r = -.22$; $P = .03$). Total CareQ scores were positively correlated with the child's age ($r = .38$; $P < .01$) and with body weight ($r = .37$; $P < .01$); however, no caregiver characteristics were associated with CareQ scores.

Conclusions: The CareQ is a concise and internally consistent measure of difficulty of care as perceived by caregivers of children whose GMFCS levels were III-V. Further investigation should include assessment of responsiveness of the CareQ to changes in the child's functional status over time and/or with rehabilitation interventions.

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INTRODUCTION

Cerebral palsy (CP) is the most common of the childhood motor disabilities [1]. It is a heterogeneous central nervous system disorder that is frequently accompanied by disturbances of sensation, cognition, communication, perception, and behavior, along with epilepsy and secondary musculoskeletal disorders [2]. Children with Gross Motor Function Classification System (GMFCS) levels IV and V are more dependent on caregivers for assistance in performing activities of daily living (ADL) and transfers than are children at other levels, and they often must use wheelchairs for mobility [3]. Caregivers of children with CP may be under more physical, psychological, and financial burdens compared with those who provide care for children who develop in a typical manner because their responsibilities are greater [4-7]. In addition to providing direct daily care and support, caregivers of children with CP invest time and effort in assisting with interventions such as physical, occupational, and speech therapy. Thus caregivers' perceptions of their child's needs and of efforts related to the daily care of their child are likely to have substantial impact on the selection and success of the child's rehabilitative management.

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The Caregiver Questionnaire (CQ) was developed in 1990 to measure the perceived level of caregiver difficulty in performing ADL for children with quadriplegic CP undergoing selective rhizotomy [8]. Health care professionals experienced in the care of children with CP, family members, and caregivers contributed items for the CQ that covered major aspects of personal care, positioning/transferring, comfort, and interaction/communication. The CQ also included items to assess caregiver satisfaction with the child's progress in such activities but did not emphasize the caregiver's own psychological or physical burden. The CQ has been modified for use in the general pediatric CP population to obtain qualitative information on effectiveness of treatment. McCoy et al [9] developed the Care and Comfort Hypertonicity Questionnaire from the CQ to evaluate the efficacy of different methods of treating severe hypertonicity. Clinical and research protocols have shown that Care and Comfort Hypertonicity Questionnaire scores are useful in comparing efficacy among different spasticity management interventions. Items in the CQ also have been adapted into the Caregiver Priorities and Child Health Index of Life with Disabilities, a disease-specific measure of caregiver perspectives of activity limitations, health status, well-being, and ease of care for children with severe CP [10].

The CQ recently has been modified to the Care and Comfort Caregiver Questionnaire (CareQ), which measures perceived caregiver effort in caring for a child with CP whose GMFCS level is IV or V. The primary purpose of the CareQ is to facilitate discussion between the caregiver and the clinician in setting therapeutic goals for the child. The CareQ consists of 19 questions that pertain to ADL and comfort, and it can be completed readily by the caregiver in the clinic before the child's appointment.

The aim of this study was to assess the reliability of the CareQ and to examine the extent to which caregiver perceptions of difficulty in caring for a child with CP are associated with functional status. It was hypothesized that CareQ scores increase with the level of GMFCS and the presence of accompanying conditions (eg, sensory and/or cognitive deficits). It also was hypothesized that the age of the primary caregiver, the age and body weight of the child, and the availability of other assistance (eg, respite care, help from family and friends, and in-home nursing) influence perceptions of difficulty of care.

METHODS

Participants

Primary caregivers ($n = 100$) of children with CP (ages 2-18 years) whose GMFCS levels are III-V were enrolled from the pediatric outpatient CP clinics at the Rehabilitation Institute of Chicago (RIC). All were established pa-

tients of the attending physiatrist (D.G.S.) and were recruited consecutively at the time of their scheduled clinic visit if the physiatrist determined their GMFCS level to be III, IV, or V. This study was approved by the Northwestern University Institutional Review Board, and informed written consent was obtained from all participating caregivers. Written or verbal assent was obtained from cognitively capable adolescents who were older than 12 years.

CareQ

The CareQ (Appendix 1) is a 19-item self-report instrument that comprises 3 domains: Personal Care (9 items), Positioning/Transfers (6 items), and Comfort (4 items). All the items in the Personal Care domain and 3 items in the Positioning/Transfers domain are rated on a 5-point scale from 1 (very easy) to 5 (impossible), depending on the caregiver's ease or difficulty in performing the task. All items in the Comfort domain and 3 items in the Positioning/Transfers domain ask the caregiver to estimate the frequency of pain or discomfort experienced by the child in positioning and in various daily situations in the past month. Each of these items is rated on a 6-point scale from 0 (never) to 5 (always). The CareQ typically is completed by caregivers in 5 to 10 minutes.

Data Collection

A single researcher obtained signed consent or assent from all caregivers and adolescents before completion of the CareQ. Demographic data pertaining to the caregiver and clinical information regarding the child were obtained through a caregiver interview, consultation with the attending physiatrist, and review of medical records. The physiatrist rated the child's GMFCS and Manual Ability Classification System (MACS) [11] levels without knowledge of caregiver responses to the CareQ. Similarly, a research nurse certified in administering the Pediatric Functional Independence Measure (WeeFIM) rated the WeeFIM items through direct observation of the child and the caregiver interview.

Statistical Analysis

Continuous variables are presented as mean (standard deviation); discrete variables are presented as n (%). Reliability (internal consistency) of the CareQ was evaluated with the Cronbach α . The Pearson correlation coefficient between CareQ and WeeFIM scores was used to evaluate the construct validity of the CareQ. The mean differences in CareQ scores among the 3 GMFCS levels and among the 5 MACS levels were tested by one-way analysis of variance. The mean differences in CareQ scores by the presence or absence of accompanying conditions in the child were

Table 1. Demographic characteristics of caregivers and their children or adolescents with cerebral palsy

Characteristic	n or Value
Caregivers (n = 100)	
Female gender	91
Age (y), mean \pm SD	39.3 \pm 8.4 (range, 19-58)
Education	
Not a high school graduate	15
High school graduate	18
Some college	28
College graduate	24
Postgraduate level	13
Doctorate	2
Respite services	34
In-home nursing	11
Children (n = 100)	
Female gender	43
Age, mean \pm SD	9 y, 0 mo \pm 4 y, 10 mo (range, 2 to ~18 y)
GMFCS level	
III	19
IV	39
V	42
Race or ethnicity	
White	46
Hispanic	28
African American	16
Middle Eastern	3
Asian	1
Mixed/other	3

GMFCS = Gross Motor Function Classification System [3].

tested with use of the Student *t*-test. Similarly, differences in CareQ scores among caregiver education levels and by availability of respite and in-home nursing services were tested with use of the one-way analysis of variance or the Student *t*-test. The Statistical Package for the Social Sciences (SPSS for Windows, version 15.0, 2006; SPSS Inc, Chicago, IL) was used for all analyses. For inferential tests of association and differences, *P* values $<$.05 were considered statistically significant.

RESULTS

Demographic characteristics of caregivers and their children or adolescents with CP are presented in Table 1. The

vast majority of primary caregivers who completed the CareQ were women. Caregivers other than biological parents were one grandfather, one grandmother, one foster mother, and one nurse. Caregiver education backgrounds varied widely, with 67% having at least some college-level education. Approximately a third had respite services available to them; a few (11%) had in-home nursing services. Availability of respite services did not vary by caregiver age ($P = .580$) or by GMFCS level ($P = .817$). Only 5 caregivers reported that other family members were available to help them provide care for their child.

Among the children with CP, the boy:girl ratio was 1.3:1. Their racial/ethnic distribution was consistent with the diversity of the Chicago metropolitan area; nonetheless, a higher proportion of white participants and a lower proportion of African American participants were present in the sample, which likely reflects the catchment area of RIC (Table 1). The majority of children (81%) were nonambulatory (ie, GMFCS levels IV and V). Study recruitment was based on convenience sampling that did not ensure similar numbers of patients at each level of GMFCS. The relatively low number of children at GMFCS level III may be a function of the types of auxiliary clinics (eg, physical therapy versus surgical) visited by the children during the study interval. MACS levels varied within GMFCS levels III-V, yet were highly associated with GMFCS (χ^2 , $P < .001$) (Table 2).

The Cronbach α was .90 for the total CareQ and .93, .80, and .82 for the Personal Care, Positioning/Transfers, and Comfort domains, respectively. Mean total CareQ scores increased by GMFCS in a doselike manner ($P = .001$). Positioning/Transfers and Comfort domain scores also increased with higher GMFCS, although this finding did not reach statistical significance for the Personal Care domain (Figure 1). Similarly, mean total CareQ scores tended to increase by MACS level ($P = .07$). This dose-like finding was significant for Comfort domain scores but not for Personal Care or Positioning/Transfers domain scores (Figure 2).

Total CareQ and total WeeFIM scores were weakly, negatively correlated ($r = -.22$; $P = .03$). No association

Table 2. Association among MACS and GMFCS levels*

	MACS Levels					Total
	I	II	III	IV	V	
GMFCS levels						
III (% within GMFCS)	5 (26.3)	4 (21.1)	8 (42.1)	2 (10.5)	0 (0.0)	19 (100.0)
IV (% within GMFCS)	0 (0.0)	2 (5.1)	7 (17.9)	18 (46.2)	12 (30.8)	39 (100.0)
V (% within GMFCS)	0 (0.0)	0 (0.0)	0 (0.0)	5 (11.9)	37 (88.1)	42 (100.0)
Total	5 (5.0)	6 (6.0)	15 (15.0)	25 (25.0)	49 (49.0)	100 (100.0)

MACS = Manual Ability Classification System; GMFCS = Gross Motor Function Classification System.

* χ^2 , $P < .001$.

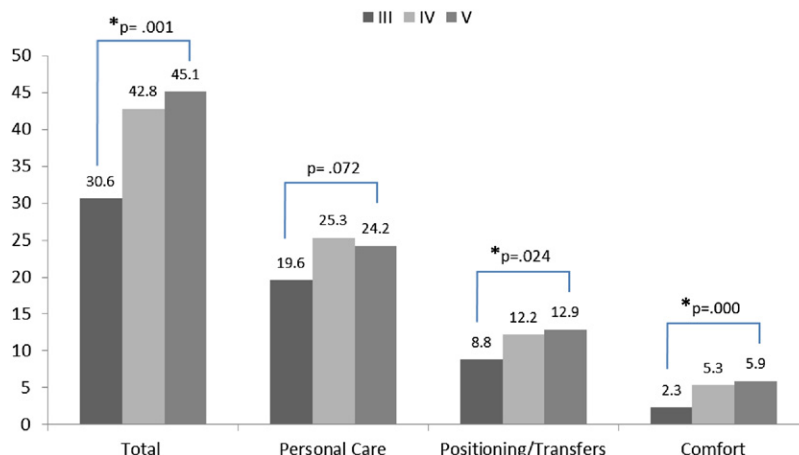


Figure 1. CareQ scores by Gross Motor Function Classification System levels (**P* < .05 for one-way analysis of variance).

was found between the CareQ Personal Care and WeeFIM Self Care domain scores, nor between the CareQ Positioning/Transfers and the WeeFIM Mobility domains. However, the CareQ Comfort domain was weakly correlated with all 4 of the WeeFIM domains (Table 3). The child’s age showed a moderate positive correlation with total CareQ scores ($r = .38; P < .001$) and with scores in the Personal Care ($r = .37, P < .001$) and Positioning/Transfers ($r = -.29, P = .003$) domains. The child’s body weight was positively correlated with total CareQ scores ($r = .37, P < .001$) and with scores in the Personal Care ($r = .39, P < .001$) and Positioning/Transfers ($r = .27, P < .007$) domains. No association was found between total CareQ scores and caregiver age ($r = .11, P = .300$). CareQ scores did not differ by availability of respite services ($P = .295$) or in-home nursing services ($P = .666$).

Cognitive impairment, seizures, visual impairments, and lack of functional speech were prevalent, but rela-

tively few children had hearing impairments or behavioral disorders (Table 4). Total CareQ scores were higher in children with gastrostomy tubes ($P = .009$) and visual impairment ($P = .009$) and appeared to trend toward elevation in children with speech impairment and seizures.

DISCUSSION

This study evaluated the psychometric properties of the CareQ, a questionnaire that focuses on the care and comfort aspects of daily activities and positioning encountered by the primary caregiver. The relatively small number of 19 items in the CareQ was intended for concise but focused communication between the caregiver and the clinician on aspects of care requiring the greatest attention at the time of the clinic visit. Reliability of the CareQ was evaluated with Cronbach α (internal consistency), because

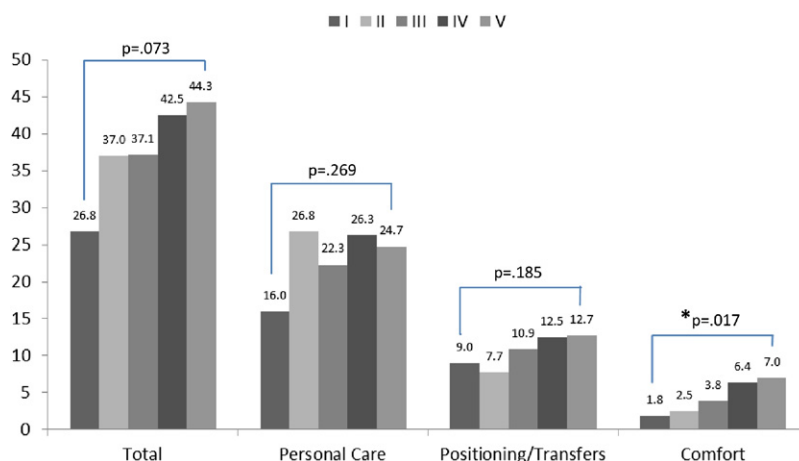


Figure 2. CareQ scores by Manual Ability Classification System levels (**P* < .05 for one-way analysis of variance).

Table 3. Correlation of CareQ domain with WeeFIM domain scores*

	CareQ Domain		
	Personal Care	Positioning/Transfers	Comfort†
WeeFIM domain			
Self Care	-.09	-.17	-.26
Mobility	-.11	-.13	-.23
Communication	.00	-.15	-.25
Social Cognition	-.01	-.17	-.27

CareQ = Care and Comfort Caregiver Questionnaire; WeeFIM = Pediatric Functional Independence Measure.

*Values are Pearson correlation coefficient, r .

† $P < .05$.

this statistic is most appropriately used when items measure different substantive areas within a single construct. The Cronbach α values for total CareQ and for each of the 3 domains indicated good to excellent reliability. The Cronbach α depends not only on the average intercorrelation among test items but on the number of items [12,13]; thus the CareQ achieved high reliability despite the relatively small number of items it contains. Construct validity of the CareQ was evaluated by its correlation with the WeeFIM, a well-established validated measure monitoring disability and change in children with various disabilities, including CP [14,15]. The negative correlation between CareQ and WeeFIM total scores seems to imply greater perceived difficulty of care in caregivers of children who are less functionally independent. However, no significant correlation was observed between the individual domains of the CareQ and the WeeFIM, such as between the CareQ's Personal Care domain and the WeeFIM's Self Care domain ($r = -.09$, $P = .378$), or between the CareQ's Positioning/Transfers domain and the WeeFIM's Mobility domain ($r = -.13$, $P = .207$). Interestingly, weak but significant negative correlations were found between the CareQ Comfort domain and all 4 of the WeeFIM domains, which suggests the possibility that the frequency of pain experienced by the child may affect his or her level of functional independence in many aspects of daily living. This finding is consistent with previous reports of the influence of pain on function and quality of life in children with CP [16,17]. The reason for the relatively weak correlation between CareQ and WeeFIM scores is likely because they measure different constructs: the CareQ measures the caregiver's perceived difficulty in providing assistance for the child and the caregiver's assessment of the child's pain, whereas the WeeFIM measures the child's level of functional independence in relation to his or her level of disability as well as the amount of assistance provided by the caregiver [14,18].

The CareQ was developed to measure difficulty of care experienced by caregivers of children with moderate to severe functional limitations due to CP, that is, GMFCS levels IV and V. In this study, 81% of the recruited participants were children with GMFCS levels IV and V. Children with GMFCS level I and II were not recruited because they are considered to be independent ambulators with sufficient postural stability and motor control to perform age-appropriate ADL activities without caregiver assistance. The remaining 19% were children at GMFCS level III, who have the functional ability to ambulate with assistance but also may need some degree of assistance in daily activities and were thus considered to be an appropriate comparison group [19]. Similar ambulatory and nonambulatory groups of children with CP were compared in a validation study for the Caregiver Priorities and Child Health Index of Life with Disabilities [10]. In this study, the CareQ total score increased with GMFCS level, reflecting greater perceived burden for caregivers of children with more functional disability. This dose-response pattern also was observed for each of the CareQ domains, although it did not reach statistical significance for the Personal Care domain. Compared with the other domains, all task items in the Personal Care domain are ones that the caregiver must directly perform for the child and that may be more difficult to accomplish when children have poor postural stability and motor control. Children in both GMFCS levels IV and V are very limited in their gross motor function, especially when using their lower extremities, and may require similar levels of assistance for per-

Table 4. CareQ scores by presence or absence of accompanying conditions

Accompanying Condition	Present (+)/Absent (-)	Total CareQ Score, Mean (SD)	P Value
Cognitive impairment	+(n = 78)	42.1 ± 15.0	.426
	-(n = 22)	39.1 ± 15.4	
Seizures	+(n = 45)	44.4 ± 16.0	.082
	-(n = 55)	39.1 ± 13.9	
Vision impairment	+(n = 59)	44.6 ± 15.4	.009*
	-(n = 41)	36.9 ± 13.5	
Hearing impairment	+(n = 10)	39.5 ± 12.6	.621
	-(n = 90)	41.7 ± 15.4	
Speech impairment	+(n = 87)	42.3 ± 15.5	.068
	-(n = 13)	35.6 ± 11.0	
Hydrocephalus	+(n = 7)	43.7 ± 13.3	.660
	-(n = 93)	41.3 ± 15.2	
Gastrostomy	+(n = 49)	45.4 ± 14.6	.009*
	-(n = 51)	37.6 ± 14.6	
Tracheostomy	+(n = 6)	53.0 ± 16.4	.128
	-(n = 94)	40.7 ± 14.8	
Behavioral problems	+(n = 11)	40.2 ± 21.3	.778
	-(n = 89)	41.7 ± 14.5	

CareQ = Care and Comfort Caregiver Questionnaire.

* $P < .05$ for Student t -test.

sonal care activities such as dressing lower extremities, toileting, and bathing.

A similar dose-like trend was observed for total CareQ scores by MACS levels, particularly for the Comfort domain. Intuitively, one might assume elevated CareQ scores with increasing MACS level in the Personal Care domain, because most of the items in this domain require the use of hands. However, as noted earlier, this domain's items are performed by the caregiver rather than the child and thus the child's functional use of his or her hands may have little impact on the CareQ, which also may apply to the Positioning/Transfers domain. Elevations in Comfort domain scores among the MACS levels may be seen because the items ask about pain interfering with activities in which the child is actively participating, which may necessitate the use of hands. The higher CareQ scores in children with higher GMFCS and MACS levels reflect that both the estimation of the child's pain and the perceived difficulty of care are greater in caregivers with nonambulatory children. These implications support the importance of pain management in children with CP, especially because pain is associated with many concomitant factors in the child with CP (eg, spasticity, gastrostomy, surgery, and spinal malalignment) and may increase in frequency with age, which leads to a decline in gross motor capacity [17,20].

The positive correlation between the total CareQ score and the child's age and body weight is consistent with the hypothesis that the caregiver's perceived difficulty of care increases with the child's physical growth. Similar associations were observed between the child's age and body weight with Personal Care and Positioning/Transfers domain scores but not with Comfort domain scores. Because items in both the Personal Care and Positioning/Transfers domains require physical exertion of the caregiver, the amount of physical stress may increase with an older and heavier child, whereas items in the Comfort domain measure the frequency of the child's pain and are not directly associated to the caregiver's physical activity, which is in agreement with previous reports that physical and psychological well-being for the caregiver increases with decreased caregiving demands [2]. CareQ scores did not increase with caregiver age. Older caregivers may become more innovative in caring for their child over the years and/or may foster their child's ability to assist with his or her own care with age. Factors such as the personality of the child and the caregiver, the relationship between the child and the caregiver, the age difference between the child and the caregiver, and the socioeconomic characteristics of the caregiver [21,22] should be further investigated. Because CareQ scores were higher for children with gastrostomy tubes, vision impairment, speech impairment, and seizures, accompanying conditions also should be considered in future studies.

CONCLUSION

The CareQ is a concise and reliable measure of the perceived difficulty of care experienced by caregivers of children with GMFCS levels III-V. Further investigation of the CareQ's responsiveness to changes in the child's functional status over time and/or with rehabilitation interventions is needed. By monitoring changes in the CareQ, clinicians may be better able to provide personalized treatment modalities that are optimal for the aspects of care that are identified as most pertinent for both the child and caregiver.

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CME Question

Correlations between the total Care Questionnaire (CareQ) scores and characteristics of the child and caregiver showed a:

- a. positive correlation with the total WeeFIM scores
- b. a negative correlation with the child's body weight
- c. positive correlation with the child's age
- d. strong association with caregiver age

Answer online at me.aapmr.org

APPENDIX 1.

Care and Comfort Caregiver Questionnaire (CareQ)

Patient's name: _____ Date of birth: ___/___/___ Date of visit: ___/___/___

Name of person completing form: _____

Relationship to patient: Mom Dad Other relative Other nonrelative

For the sections on personal care and positioning, please rate how easy or difficult it is *for you* (the caregiver) to perform the following tasks. In the right-hand column, please indicate how much of the task you would say your child is able to do himself or herself, for example, 20%, 50%, 80%, or some other percent that you believe is appropriate.

Thank you very much for taking the time to complete this questionnaire.

Personal Care		Very Easy					Impossible	Child Is Able To Do:
		1	2	3	4	5	_____ %	
1.	Performing oral-facial hygiene (eg, brushing teeth, washing face, combing hair)	1	2	3	4	5	_____ %	
2.	Putting on shirts	1	2	3	4	5	_____ %	
3.	Taking off shirts	1	2	3	4	5	_____ %	
4.	Putting on pants	1	2	3	4	5	_____ %	
5.	Taking off pants	1	2	3	4	5	_____ %	
6.	Changing incontinence pads or briefs (underwear)	1	2	3	4	5	_____ %	
7.	Cleaning buttocks or perineum with toileting	1	2	3	4	5	_____ %	
8.	Washing upper body	1	2	3	4	5	_____ %	
9.	Washing lower body	1	2	3	4	5	_____ %	

Positioning/Transfers		Does Not Use	Very Easy		Impossible			Child Is Able To Do:
10.	How easy do you think it is for your child to remain sitting in a wheelchair for about 3 hours?	<input type="checkbox"/>	1	2	3	4	5	_____ %
11.	Ease of transferring your child into/out of wheelchair or other surfaces		1	2	3	4	5	_____ %
12.	Ease of applying orthotics (braces)	<input type="checkbox"/>	1	2	3	4	5	_____ %
<i>In the past month,</i>			Never					Always
13.	How often do you think your child has had pain or discomfort during diaper or clothing changes?		0	1	2	3	4	5
14.	How often do you think your child has had pain or discomfort during position changes?		0	1	2	3	4	5
15.	How often do you think your child has had pain or discomfort while sitting in a wheelchair?	<input type="checkbox"/>	0	1	2	3	4	5
<i>Comfort In the past month,</i>			Never					Always
16.	How often do you think pain or discomfort has prevented your child from participating in family activities?		0	1	2	3	4	5
17.	How often do you think pain or discomfort has prevented your child from participating in school programs or community activities?		0	1	2	3	4	5
18.	How often has your child had difficulty sleeping through the night?		0	1	2	3	4	5
19.	How often has your child used pain medicine?		0	1	2	3	4	5