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PATIENT-REPORTED OUTCOMES

Incorporating Children's and Their Parents' Perspectives into Condition-Specific Quality-of-Life Instruments for Children with Cerebral Palsy: A Qualitative Study

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A B S T R A C T

Objectives: This study investigated the extent of agreement between children with cerebral palsy (CP) and their parents concerning their views on what contributed to the children's quality of life. It also investigated how well an Australian condition-specific health-related quality of life self-report measure for children with CP, the Cerebral Palsy Quality of Life Questionnaire for Children (CP QOL-Child), mapped to the views of UK children and parents. **Methods:** UK children with CP aged 8 to 13 years and their parents participated in qualitative interviews about their perspectives on the child's quality of life. **Results:** The interviews with 28 children and 35 parents showed considerable overlap but also some divergence. For example, both parties considered social relationships to be important, but children described how they enjoyed being on their own at times whereas parents tended not to value time spent alone for children. The CP QOL-Child covered most

themes considered to be important to the children's quality of life. Omissions included relationships with extended family members, restful recreational activities and associated possessions, relaxing, tiredness, negative emotions, and safety. **Conclusions:** Both children's and parents' views are required for the development of child health-related quality of life instruments. The CP QOL-Child has good coverage of many aspects discussed in the interviews. Cultural differences may account for its omission of some topics considered important by UK children and parents. Rewording of many of the CP QOL-Child's items and further work on item content would optimize its suitability for UK children and possibly for children elsewhere.

Keywords: cerebral palsy, qualitative, quality of life, child, disability.

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Introduction

Researchers have been criticized for developing health-related quality of life (HRQL) instruments without asking patients what they consider important to their quality of life [1,2]. When qualitative research has been conducted to access patients' perspectives [3–6], the resultant instruments are more relevant to patients, yield higher response rates [7], and potentially provide more meaningful data on the effectiveness of health interventions and other services.

In developing instruments for children, little attention has been paid to the respective contribution of children's and parents' perspectives. Quantitative studies using HRQL measures show that their perspectives are different [8,9]. If one party's perspective predominates in the development stage, the resulting instrument may be incomplete. For example, given their responsibilities to protect children, parents may be more concerned with risk than their children are and may underestimate the role of independence and autonomy in contributing to the child's quality of life.

Qualitative research may also help to refine existing instruments [10]. A recent workshop on patient-reported outcome mea-

asures [11] concluded there should be more emphasis on improving existing measures, rather than creating new ones. Davis et al [12] also recommend this. We have previously reported that what children with cerebral palsy (CP) regarded as important in contributing to their quality of life corresponded well with the items in KIDSCREEN, a generic self-report HRQL measure for children [13]. However KIDSCREEN did not include some themes important to children, including relationships with family members other than parents, inclusion and fairness, home life and neighborhood, pain and discomfort, environmental accommodation of needs, and recreational resources other than finances and free time. Because KIDSCREEN is a generic measure it is perhaps unrealistic to expect the instrument to cover all the themes relevant to children with a specific condition such as CP; condition-specific measures [14–16] might better match children's accounts [17].

We examined how well children's and parents' interview accounts of the important domains of children's lives mapped to those in a CP-specific HRQL instrument: the Cerebral Palsy Quality of Life Questionnaire for Children (CP QOL-Child) designed for self- and parent proxy report. The CP QOL-Child was developed in Aus-

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tralia using recommended psychometric and qualitative methods, and has good reliability and validity [18]. Because it was published after our qualitative interviews were undertaken, we decided to return to the interview accounts to explore how well the CP QOL-Child mapped to the views of UK children and parents. The first aim of this article is to describe the extent to which children's and parents' accounts converged with respect to what they each considered important to the children's quality of life. The second aim is to report how far the themes discussed by the children and parents converged with those in the CP QOL-Child.

Methods

A favorable ethics opinion was granted by the North West Multi-centre Research Ethics Committee (Reference No. MREC 04/8/010) and all participants provided informed consent or assent for the study.

Families were purposively sampled from those already recruited to the north of England arm of a European study of quality of life of children with CP (SPARCLE) [19]. Purposive sampling is widely used in qualitative research where methods such as in-depth interviews preclude large samples and where random samples fail to access participants with potentially important characteristics [20]. We sampled for maximum variation using children's total scores and domain score profiles generated by KIDSCREEN (a generic quality of life instrument), and child and family demographic characteristics to include: 1) children from waged and nonwaged households; 2) those with HRQL reports across the range of total scores observed in the English arm of SPARCLE; and 3) for each domain at least one child with the minimum score and at least one with the maximum score [13].

Semistructured interviews were conducted by one researcher (HR) and most took place in the family's home, in privacy from other family members to avoid accounts being influenced by the presence of others. Interviews were conversational and their pace, sequencing, and duration were shaped by the participants. HR undertook extensive preparation to facilitate children's engagement in the interviews and thereby ensure the quality of the children's data. This included: consulting methodological writings on interviewing disabled and non-disabled children; consulting speech therapists to learn about different types of communication devices children used; undertaking specialist training in communication with disabled children; spending time at a school which specialized in teaching children with severe physical and cognitive impairments in order to gain skills in communicating with disabled children; conducting pilot interviews with children of a similar age to those in our study. HR used a range of strategies to establish rapport with children, facilitate their enjoyment and engagement with the interviews, and to assist the participation of children with special communication needs. For example, she usually met with children several days before interviewing them. HR and the children often played with stickers, pens, and pencils that she provided and conducted the interviews alongside these activities. Picture card activities such as "places where I go" and "feelings that I have" were also used. These techniques created a conversational context for the interviews that was more varied and less language dependent than a traditional researcher-led question-and-answer interview.

Separate topic guides were used for children and parents. The children's guide included prompts about interests and activities, relationships, feelings, and school. The parents' guide covered similar topics. The interviews lasted 45 to 90 minutes. All the interviews were audio recorded with the exception of one child's interview which was recorded in detailed hand-written notes by the interviewer. Extensive reflexive notes were recorded to provide the contextual details of all the interviews. HR transcribed the interviews verbatim, usually within a few

days, and was therefore able to synthesize observations of the children and their nonverbal communication into the transcripts ready for analysis.

Analysis of interviews was informed by the constant comparative method [21] and guidelines for qualitative research [20,22,23]. Team members worked in pairs on the child and parent data sets to ensure conceptualizations remained grounded in the respective data sets and particularly to avoid the parent data inappropriately influencing the analysis of the children's. Analysis cycled between the developing analysis and new data to develop open codes, followed by thematic categories. These were organized into separate coding frameworks for the child and parent data, which the team tested and refined by: 1) periodic discussion; 2) coding transcripts that had not previously been open coded; and 3) producing detailed reports of data coding in NVIVO [24]. All the coded data were scrutinized to extract the key components of children's accounts of HRQL, and identify children's HRQL priorities. A similar process was followed for the parent data. Following completion of reports on this phase of analysis, we compared the grouped parent data and the grouped child data regarding their respective views on what contributed to the children's quality of life.

The next stage of analysis identified agreement and disagreement between the children's and parents' accounts. We then examined convergence between the interview accounts and the items in the CP QOL-Child. Figure 1 presents the domains represented in the CP QOL-Child [16,25].

Results

As previously reported, the qualitative analysis generated four overarching themes: social relationships, home and school environments, self and body, and recreational activities and resources. For each of these we provide: 1) a summary of the children's and parents' accounts; 2) a comparison of the children's and parents' accounts; and 3) a comparison of the accounts with the CP QOL-Child items. Our interpretations are informed by the complete data set of 53 transcripts and accompanying field notes. Figure 2 presents illustrative verbatim quotations from the interviews that back up our interpretations. To protect anonymity, all quotations are labelled with the child's age range and a unique participant identity number.

Social relationships

Children valued affection; companionship; and the support of their parents, siblings, and extended family members such as grandparents. They also valued time with friends in and outside of school; interests and activities could be shared and friends were a source of practical help and emotional support. Children wanted to be treated with respect by peers, and they discussed difficulties such as being isolated or bullied by them.

Parents agreed that siblings were important in their disabled child's life. They also discussed the differences between their children in relation to their disabled child's impairments, what he/she could do, and concern about his/her future. Parents did not talk about their disabled child's perception of the parent-child relationship, nor did they attach so much importance to their child's relationship with extended family members; for parents the emphasis was on how they themselves were supported by family members. Parents also discussed the importance of their child having friendships and socializing. A striking feature of their accounts was their efforts to engineer opportunities for their child to be included socially. They were very concerned about their child's experiences of being isolated or bullied by other children, often emphasizing this more than the children themselves.

The CP QOL-Child has three items on interaction with family members: asking children about being accepted by their family,

Social well-being and acceptance: refers to the ability to interact with family members, peers and people in the environment, and to being socially accepted, being a valued member of the community, and being treated “normally.”

Functioning: refers to having good communication skills with family, peers, and people in the general community; and the ability to carry out normal daily living tasks, including dressing, feeding, and toileting and being independent.

Participation and physical health: refers to participating in school activities, sporting activities, and community activities, and to adequate gross motor skills, and fine motor skills, the ability to use aids (if required), and good overall physical health.

Emotional well-being: refers to being happy, being able to achieve goals, and being satisfied with one’s body and emotions.

Pain and influence of disability: refers to the absence of stiffness and soreness in joints, and pain associated with therapy.

Fig. 1 – Summary of Cerebral Palsy Quality of Life Questionnaire for Children domains (child report version) [16,26].

whether they get along with the person who looks after them, and how they get along with their siblings. There are no items specifically mentioning parents, although they are implicitly incorporated in two of the above items. There is not an item asking the child about extended family members. The CP QOL-Child also represents socializing with friends and other children discussed in the interviews. There are several items about how the child gets on with other children, if they are accepted by them and whether they are able to play with friends, although bullying is not explicitly mentioned.

Home environment

Children valued home as a place for relaxation and restful recreational activities. For example, the interview field notes recorded how children who used mobility aids such as splints often removed these immediately on their return home from school, preferring to crawl around the house or walk on their knees, indicating the importance of home as a relaxed, unconstrained environment. The children’s interview accounts confirmed this; they often talked about how they could “be themselves” at home. Possessions such as televisions, computers, books, and toys played a crucial role in children’s home lives as a focus for relaxing pursuits.

The neighborhood also provided children with opportunities for social interaction and recreation. If children found it difficult to access the streets and spaces near their homes they said it was more difficult to meet friends and this affected their quality of life.

Parents also talked about the home as somewhere the child could rest and relax, often from tiredness related to their child’s impairment but they did not suggest relaxation as an enjoyable pursuit in its own right. Parents regarded home as adapted for their child’s needs compared to other environments such as friends’ houses. They also liked to know that their child was nearby. These views reflected the general emphasis parents placed on protecting their child and the surveillance that they engaged in to ensure their child’s safety.

The CP QOL-Child covers the home environment to some extent. There are items inquiring about the special equipment children might need at home and about family trips. However, there are no items about whether children have opportunities for restful recreation and relaxing or about children’s access to recreational possessions at home.

School environment

School brought enjoyment and stimulation to children and opportunities for social and extra-curricular pursuits. Children worried about inclusion at school and their performance, particularly in physical education and sport. They also had concerns about mobility at school and their own safety. Children discussed safety in terms of special equipment needed as well as how important it was for teachers to take account of their needs and provide help.

Parents’ accounts of their child’s experience corresponded closely to what their children said about school, school relationships, the environment, and safety. Parents emphasized the social aspects of their child’s school life, often implying that this was as, if not more, important than the academic aspects. Parents also often talked about the negative attitudes that others expressed toward their child at school.

School is represented well in the CP QOL-Child. There are items about participating and keeping up academically at school, getting on with teachers and whether special equipment is available for the child’s needs. One item specifically asks if the child is accepted by other children at school. However, the CP QOL-Child does not include items about safety at school.

Self and body

Children talked about positive emotions such as being happy and negative ones such as loneliness, anger, embarrassment, and fear. They talked about what they could “do” and how they accomplished everyday tasks, and the thrills of engaging in risky activities. Children compared their bodies unfavorably with their siblings, friends, and peers. They talked of feeling dependant, needing help with intimate activities such as going to the toilet, and some said they “felt different.” Other children tended not to talk explicitly about their disability. Many reported experiencing tiredness, discomfort, or pain, and others discussed hospital visits and medical procedures and how such events meant they missed out on what they preferred to do.

Parents confirmed children’s reports about what they could do, restriction of their activities, and how their child disliked being unable to do certain things, especially if their siblings or other children could do them. Parents frequently talked about their child’s disability. They also discussed the effects of tiredness, pain, and medical procedures on their child’s life and emphasized the amount of time medical procedures and visits took.

The CP QOL-Child has an item asking the child how happy they are, but there are no items about negative emotions. It has excel-

<i>Social relationships</i>	<p>C: ((my friend)) helps me with everything 'cos like, if I need help with my shoes ((...)) he'll say 'OK, I'll help yer' <i>Female aged 11-13 (ID 233)</i></p> <p>I: If you had to choose one of these ((cards)), just one as your favourite, which one would you pick? C: (5 sec.) ((picks card 'grandma and granddad's house')) I: Grandma and granddad's? C: ((signals 'yes')) <i>Male aged 8-10 (ID 416)</i></p> <p>I: If you could change anything about your body, what do you think you would change? C: Not having a disability, then I wouldn't get bullied I: Is that why you think you get bullied? C: No, that's why I know I get bullied ... I can tell from the names he calls me <i>Female aged 11-13 (ID 44)</i></p> <p>M: Whereas you don't want ((sibling name)) to be her carer, she does things instinctively ((...)) like pick up her fruit shoot bottle and give her a drink <i>Mother of female aged 8-10 (ID 416)</i></p> <p>M: That does concern me, that he could be quite isolated ((...)) I don't worry so much about ((sibling's name)) because he will start to want to be more independent as he gets older ((...)) But ((child's name)) will tend to sort of back off and I do worry that he's sort of going to be left out <i>Mother of male aged 11-13 (ID 35)</i></p> <p>M: When she went to the ((name)) Unit ((...)) and they asked me about respite, and they said to me 'do you know what it is?' and I said 'yeah it's called grandma and granddad' <i>Mother of female aged 8-10 (ID 40)</i></p> <p>M: She likes playing football, she plays on the girl's football team ((...)) so we both help with that F: We coach it ourselves M: Again that was to help her because we thought 'if it's us there doing it nobody's going to pick on her' <i>Mother and father of female aged 11-13 (ID 198)</i></p> <p>M: They'd take his sticks off him and throw them away, places where he couldn't reach, so practically if he wanted them he had to get on his hands and his knees and he crawled in front of them all <i>Mother of male aged 11-13 (ID 74)</i></p>
<i>Home environment</i>	<p>C: Um, well I just like sitting drawing and listening to some music and stuff <i>Female aged 11-13 (ID 198)</i></p> <p>C: I've got three mates who just live in this street who I can play football with, who go to school with us ((local word for 'me')) ((...)) I've got loads of mates in that street <i>Male aged 8-10 (ID 39)</i></p> <p>I: When you go out, who would you have gone out with? C: Well that depends, because, if no one's in who I know, I just come back ((...)) because, with my mobility problems I can't, like, I can't go everywhere <i>Male aged 11-13 (ID 74)</i></p> <p>M: Physically she does get tired, um, so whereas I suppose if you've just got some children who are just sitting on the settee reading a comic or doing quizzes or watching TV you would think 'mm, they should get outside to do some exercises ((...)) with ((child's name)) you can't because she just needs that time where she's actually not, just to stand up is an effort' <i>Mother of female aged 8-10 (ID 258)</i></p> <p>M: As I say ((sibling)) will go to his friend's the other side of the estate and they've got a base and that but I just don't want him ((disabled child)) to go there, I like to be able to see him <i>Mother of male aged 8-10 (ID 519)</i></p>
<i>School environment</i>	<p>C: I don't like doing PE, they ((friends)) sometimes come over as if they know more and that and it makes me upset because like, I feel left out <i>Female aged 11-13 (ID 233)</i></p> <p>M: As I say ((sibling)) will go to his friend's the other side of the estate and they've got a base and that but I just don't want him ((disabled child)) to go there, I like to be able to see him <i>Mother of male aged 8-10 (ID 519)</i></p>

Fig. 2 – Verbatim quotations from children and parents. I, interviewer; C, child; M, mother; F, father; (x sec.), notable pause; (()), author's descriptions rather than actual transcription; ((. . .)), small amount of speech has been removed by author for brevity; . . . , speech trails off.

<i>School environment</i>	<p>C: I don't like doing PE, they ((friends)) sometimes come over as if they know more and that and it makes me upset because like, I feel left out <i>Female aged 11-13 (ID 233)</i></p> <p>C: They ((teachers)) give me like extra help than other people sometimes, not all the time, (...) and they help me to fasten buttons and to tie my shoelaces, that kind of thing <i>Female aged 11-13 (ID 433)</i></p> <p>C: Sometimes the teachers let us ((local word for 'me')) go a bit early (...) so I don't like get pushed down the stairs <i>Female aged 11-13 (ID 198)</i></p> <p>M: Plus my biggest reason for choosing the school is that all of her friendship group will go there (...) so the friends she knows from Brownies, from dancing, from church, you know she's got a wide circle of friends, they will all go to that one school <i>Mother of female 8-10 (ID 258)</i></p> <p>M: Some kids used to call him like plastic leg and different things <i>Mother of male aged 11-13 (ID 73)</i></p>
<i>Self and body</i>	<p>C: When the ball's coming at me I get scared and I can't put my hand up properly and it makes me angry 'cos um, I just don't wanna do the game, 'cos I feel scared (...) and people were coming up to me and saying 'get on with the game' and things and I was saying 'I don't want to, I feel upset' <i>Female aged 11-13 (ID 233)</i></p> <p>C: Sometimes, you know, like, I just want to do summat ((something)) on me own (...) they just butt in and (2 sec.) it's just, I get sick of it sometimes <i>Female aged 11-13 (ID 198)</i></p> <p>C: If I was running that would be the equivalent of someone else sprinting (...) so often I only run say, ten twenty metres before I get tired out <i>Male aged 11-13 (ID 74)</i></p> <p>C: When I get my injections and when I have to go a long way to the hospital (...) and I have to miss out on school and it's always on a Tuesday and on Tuesday afternoon I usually have art and I like art <i>Female aged 8-10 (ID 43)</i></p> <p>M: The cerebral palsy thing is more, it affects him (...) he finds it difficult, certain buttons he finds it difficult, um doing clothes, (...) obviously his shoes <i>Mother of male aged 8-10 (ID 67)</i></p> <p>M: But it is a bit hard with ((child's name)) because he sees ((sibling)) doing a lot more than he can do and he gets frustrated <i>Mother of male aged 11-13 (ID 73)</i></p> <p>M: It means again pulling him out of school (...) he's always, you know, a bit behind on because he's back in hospital again at the end of next month (...) so we've got to be very careful as to how much we, pull him in and out of school <i>Mother of male aged 8-10 (ID 226)</i></p>
<i>Recreational activities and resources</i>	<p>C: I go on Championship Manager ((Playstation game)) and, up on the Playstation and when the weather's good I go out and play football <i>Male aged 8-10 (ID 499)</i></p> <p>I: Is there anything that you would like to do, that you can't do?</p> <p>C: Walk (...) go to the shops whenever I wanted and go with my friends (...) I'd like to go out on me own with them and all that <i>Male aged 8-10 (ID 226)</i></p> <p>C: There's like a water centre thing, in town (...) it's a bit crowded (...) they have the metal staircases (...) there's loads of people behind yer and if you fall you hit them (...) I always get scared to go <i>Female aged 11-13 (ID 233)</i></p> <p>M: She goes to climbing with her dad (...) but again for that she needs quite a lot of assistance (...) But Kids Club she loves because that is totally independent of me and her dad <i>Mother of female aged 11-13 (ID 433)</i></p> <p>M: He gets frustrated about not being able to (...) when he sees either ((sibling)) or his cousins doing something <i>Mother of male aged 8-10 (ID 527)</i></p> <p>F: ((Child's name)) said 'oh it's not fair, you know, they can just go out by themselves and I can't, I always have to go out with an adult' (...) and I just said 'well, that's the way it is' <i>Father of female aged 11-13 (ID 44)</i></p>

Fig. 2 – Continued.

lent coverage about what the child can do and pain, and there are several items about special equipment and medical matters but there is not an item on tiredness.

Recreational activities and resources

Children enjoyed a wide range of outdoor pursuits and clubs, although restful pastimes were also important for friendships and relaxation. Children enjoyed being able to “do their own thing” and discussed the limitations parents put on their preferred activities. Boys often talked about wanting to visit friends or to go out unaccompanied. Girls often emphasized safety. Children were reluctant to take part in activities that they felt unable to perform well, or because they found the activity uninteresting, disagreeable, or unsafe.

Parents frequently reported that their child enjoyed recreational pursuits and wanted freedom. They also reported that their child noticed the differences in ability between themselves and nondisabled children. Parents were aware that their child wanted to join in with their siblings or peers in everyday pursuits, but were concerned about safety.

The CP QOL-Child includes items that inquire about the child's ability to participate in recreational and sporting activities, and the child's ability to play on their own and with friends. As well as these items concerning children's functional independence there is also one item about whether children had a sense of autonomy in their lives. There is no coverage of resting and relaxing as a form of recreation, and as described previously, the CP QOL-Child does not cover safety, though both children and parents in our study said these were important.

Discussion

Children's and parents' accounts of what contributed to the child's quality of life were generally similar but with some important exceptions. Whereas it was clear that children highly valued their relationship with parents, parents themselves did not mention the child's perception of the parent-child relationship. Both children and parents emphasized the importance of siblings and friends as companions, but parents also tended to focus on how their child got frustrated at being unable to physically participate in the ways that nondisabled children could. Children enjoyed opportunities to spend some time on their own. Parents recognized the need for social inclusion and tried hard to facilitate their child's social life, often expending much effort in the process. Indeed, sometimes parents discouraged their child from spending time on their own, even when they were aware that this was what the child preferred. Children talked about home as a place for leisure and where they could do activities they enjoyed, particularly restful ones, whereas parents discussed the home as somewhere the child could recover from tiredness resulting from his/her impairment. Children often wanted autonomy, to be allowed to come and go as they pleased, whereas parents highlighted the need for surveillance to keep their child safe. Children emphasized the discomfort and distress that medical and therapeutic procedures caused, whereas parents also considered the amount of time spent attending hospital visits. Finally, some children were reluctant to speak about impairment and disability but parents readily mentioned them.

While there is a quantitative body of literature reporting the concordance of child and parent reports of children's quality of life [8,9] using questionnaires, there is little using qualitative interviews. Two studies have used their qualitative data to generate domains and items for self- and proxy report questionnaires for children's HQOL [14,16]. However, neither of these studies described how the child and parent accounts converge and diverge.

One study has compared the accounts of children with CP and their parents regarding quality of life, although it focused on adolescents [26]. This study did find differences between the adolescents' and parents' accounts. By describing how child and parent accounts converge and diverge in the present study, we have identified factors that are important in how younger children with CP perceive their lives, and helped to delineate key differences between the two parties' accounts which need to be considered in instrument development.

There is a small amount of qualitative research on the quality of life of young disabled people with which to compare our findings. One study interviewed 13 to 18-year-old adolescents with CP and reported that health issues, participation, education, CP-specific issues, family issues, independence, and transition to adulthood were important [26]. Other studies reported: that 18- to 20-year-old adolescents with CP perceived that “happiness in life” was related to how they thought other people perceived them [27]; that 12- to 16-year-olds perceived that their quality of life [28] was influenced by the congruence between their interests and opportunities to participate in appropriate activities and leisure pursuits; and that 11- to 16-year-olds with a range of disabilities thought that adult surveillance and negative peer experiences, such as being bullied by peers, adversely affected their lives [29]. The age ranges in the above-cited studies are older than in our study. Nevertheless their findings resonate with ours in highlighting the importance of social relationships and autonomy in disabled adolescents' quality of life.

The CP QOL-Child questionnaire generally mapped well to the children's and parents' accounts of the children's lives, although there were some omissions. The CP QOL-Child does not ask specifically about parents and extended family members, restful recreational activities and possessions, relaxing (in the sense of doing very little and enjoying it), tiredness, negative emotions, or safety. There are however references to the family and “the person who looks after you.” Further consideration is needed to represent the above issues in the instrument for UK children and possibly for children elsewhere. As previously reported [13], KIDSCREEN also does not include items about relaxation, safety, or relationships with family members other than parents.

The words used in questionnaires for children should be familiar to children [30]. However, terms and phrases used in the CP QOL-Child such as *academically*, *communicate*, *independently*, *recreational activities*, *social events*, *participate in your community*, and *being accepted* were not used by children in our study. For example, rather than talking about “being accepted” the children we interviewed talked about “fairness” and not being “left out” and about being “picked on” or “bullied” by their peers. Only five children were involved in the development of the CP QOL-Child and this may have been insufficient to ensure that the instrument reflected the language used by the intended audience of children aged 9 to 12 years. Cognitive debriefing is recommended to assess if items in the CP QOL-Child are understood by self-reporting children in the United Kingdom and elsewhere.

This study demonstrates the importance of using the accounts of both children and parents to inform the development of children's HRQL instruments. Where there is divergence in their views these should be described. Further consideration is needed of how each party's perspective should be integrated and balanced in such instruments to ensure the two parties' accounts contribute appropriately. We also showed that the CP QOL-Child covers many of the aspects of children's lives that children and parents thought important, although some aspects are not represented. These omissions might be explained by cultural differences. The CP QOL-Child also needs some refinement of its vocabulary for UK children, and perhaps for children living outside the UK.

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