RESEARCH REPORT

Quality of life and childhood disability

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1. BACKGROUND

1.1 Health-related quality of life (HRQoL) instruments are becoming a key tool in service evaluation and policy making. Fuelled by the rise of evidence-based practice and pressure to incorporate lay perspectives in decision-making, these instruments shape and continually reinforce what outcomes are considered to be worth measuring and how they are measured, and have considerable potential to influence services. The use of HRQoL instruments, particularly with disabled people, therefore raises important moral and ethical questions and a need for careful scrutiny.

1.2 One of the specific functions of HRQoL assessment is to ensure that policies and services are sensitive to the priorities of service users. However, there has been a tendency to omit children’s voices in the development of HRQoL instruments so little is known about their priorities and those of their families and how well these are represented in HRQoL instruments. Drawing on Thomas’s social relational model of disability, writings in the field of childhood studies and childhood disability, this study has examined how disabled children and their families conceptualise HRQoL and how well their priorities are reflected in KIDSCREEN, a recently developed HRQoL instrument. The study has also provided an opportunity to investigate the pathways to quality of life for disabled children, including the influence of wider social structures and processes in shaping their lives and how they exercise agency in negotiating these.

2. OBJECTIVES

The study aimed to address the following questions:

A. How do disabled children and their parents conceptualise HRQoL and how do their conceptualisations compare with those represented in KIDSCREEN, a recently developed generic quality of life instrument? This objective has been addressed successfully. We describe how we did the analysis for this in paragraph 4.2 and provide an overview of the outcomes in paragraphs 4.3-4.11.
B. How might children’s and parents’ accounts and the social model of disability inform the refinement of HRQoL instruments for use with disabled children? This objective has been addressed successfully. We also describe how we did this in paragraph 4.2 and provide an overview of the outcomes in paragraphs 4.3-4.11.

C. What is the extent of agreement between qualitative and quantitative assessments of HRQoL with disabled children? This objective has been addressed successfully. We describe how we did the analysis for this in paragraph 4.12 and provide an overview of the outcomes in paragraphs 4.13-4.17.

D. What are the possible environmental, social and psycho-emotional pathways and barriers to quality of life for disabled children, and in what ways do children and families exercise agency in negotiating these? This objective has been addressed successfully. We describe how we did the analysis for this in paragraph 4.18 and provide an overview of the outcomes in paragraphs 4.19-4.23.

3. METHODS

Sampling and recruitment

3.1 Our qualitative study recruited participants through a larger quantitative study, SPARCLE, \(^{19}\) which is examining the influence of environmental factors on quality of life and participation in children with cerebral palsy (CP). SPARCLE itself recruits from an existing CP register, the North of England Collaborative Cerebral Palsy Survey (NECCPS). We purposively sampled families who had participated in SPARCLE using children’s scores on KIDSCREEN, and child and family demographic characteristics.

3.2 Sampling was done in 4 waves by KP who examined KIDSCREEN total scores \(^{4}\) and score profiles to select children with high, medium and low scores, and to achieve a balanced sample in terms of the scores on the 10 KIDSCREEN domains. All other members of the team remained blind to the KIDSCREEN scores. Within each sampling wave, scores falling approximately one standard deviation above

\(^{4}\) It should be noted that the designers of KIDSCREEN do not advocate the totalling of scores as this can hide important differences between children on the different ‘domains’ of the questionnaire. For this reason the children’s domain scores were also considered when conducting the sampling and analysis.
or below the mean were defined as high or low, with medium scores falling within these extremes. In practice the following total score cut-offs were used: low \( \leq 65 \); medium 66-81; high \( \geq 82 \). Families were also selected to achieve a balanced sample in terms of the ages and gender of the children and family socio-economic status (SES) (defined broadly as whether at least one parent was in full-time paid employment). We aimed to include a minimum of 5 single parent families, 5 families from ethnic minority backgrounds, 8 rural dwelling families and 5 children with special communication needs. The sampling strategy was reviewed at each sampling wave to monitor progress towards targets, and to develop and test our emerging findings in the light of the ongoing data analysis.

3.3 Of the 116 children who participated in English arm of SPARCLE, 81 (70%) had self-report HRQoL scores and so were eligible for the current study. Of these, 3 families could not be approached due to the timing of the MREC approval. The 78 remaining families were approached and 67 (86%) agreed to further contact. An application to the Northwest MREC for the current study was submitted in early June 2004 and approval was granted in early September 2004.

**Participants**

3.4 Thirty-four families were selected and 29 families, comprising 63 family members, participated in our qualitative study. This represents 85% of the selected families and 36% of eligible families. Five families were not contactable or declined participation. Interviews were conducted with 28 children (12 girls and 16 boys) and 35 parents (5 mother-father pairs, 1 mother-grandmother pair, 22 mothers and 1 father). Of the 28 children, 15 were aged 8-10 years and 13 were 11-13 years when interviewed. On the KIDSCREEN questionnaire completed for SPARCLE, 11 children reported high scores, 9 reported medium scores and 8 reported low scores (using the total score cut-offs described above). Nine families were classified as having low SES, as they did not have a parent in full-time employment, though several of the other 20 families are also likely to have been on low incomes.

3.5 Our sample therefore exceeded the targets for the number of parents recruited (30) but fell just short of targets for number of families (30) and children (30). All other sampling quota were satisfied with the exception of ethnic minority families: there were no families from such backgrounds in the English arm of SPARCLE. While disappointing, it is important to note that as the NECCPS
has never recorded ethnicity, and we were therefore unable to anticipate in advance that the SPARCLE population (which is drawn from the NECCPS register) would contain no ethnic minority families from which to sample.

**Interviews**

3.6 All interviews were conducted by HR and took place in participants’ homes, except for a child who was interviewed twice, first at home and then at school several weeks later (this was one of two children who we interviewed twice). The median time lapse between the SPARCLE visit and the interview with the children was 14 weeks (range 3-56 weeks, or 3-27 weeks excluding outliers of 41 and 56 weeks), which is lengthier and more variable than the 3-6 weeks anticipated in the protocol. This was largely due to delays in obtaining an enhanced Criminal Records Bureau disclosure for HR (see Activities and Achievements Questionnaire, part 6 for details), but also reflects the pressures facing the families, which meant that interviews frequently had to be rescheduled. These difficulties account for most intervals beyond our anticipated upper limit.

3.7 We aimed to interview children and parents separately, to avoid the accounts of one party being influenced by the presence of the other. All except 3 children were interviewed in near or total privacy from their parents and all except 6 parents were interviewed in near or total privacy from their children. To facilitate the quality and conduct of the interviews, we worked to ensure that these were conversational and that their pace, sequencing and duration was shaped by the participants. We anticipated that achieving this for children’s interviews would be particularly challenging. Therefore, HR prepared thoroughly by meeting (through personal contacts) children of a similar age to those she would be interviewing and by consulting methodological writings on interviewing disabled and non-disabled children. Other preparation by HR included:

- Attending a two-day training course in communication and consultation with disabled children delivered by Triangle, a specialist training group.

- Consulting speech therapists, attending a demonstration of different types of communication devices and watching videos made by disability groups.

- Spending time at a special school which specialises in teaching children with severe impairments.
This assisted in identifying 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 needs. These techniques helped to create a conversational context that was more varied and less intense and language dependent than a traditional researcher-led ‘question and answer’ interview. We believe these steps helped us to achieve a more child-led and participative model of interviewing than would otherwise have been possible.

3.8 Separate topic guides were used for the child and parent interviews. For children, prompts were included about interests and activities, relationships, feelings and school. For parents, similar prompts about the child’s life were included, as well as questions about the parents’ interests, social support, relationships, worries and concerns and well-being. In interviewing children it was particularly crucial to ask about what they saw as important and avoid making our own assumptions. Therefore while topics such as disability and impairment were raised in the interviews, we did not assume that these would be important to children, and did not pursue them if children seemed uninterested or unwilling to explore these issues. The topic guides were continually reviewed and revised in the light of the ongoing scrutiny of transcripts in order to safeguard data quality. For example, though a ‘places where I go’ card-based activity (devised in line with Thomas’s theory) proved useful in exploring the environmental and other restrictions children faced, it appeared less successful in exploring the psycho-emotional dimensions of their lives. Therefore, a ‘feelings that I have’ card activity was introduced.

3.9 With the exception of one child who did not want to be audio recorded and whose interview was therefore recorded in detailed notes, all interviews were audio recorded and transcribed verbatim by HR who integrated her observations of the children into the transcripts. Extensive reflexive notes were made to record systematically the contextual details of all the interviews and provide an account of the overall interview process.

4. DATA ANALYSIS AND RESULTS

4.1 As set out in the protocol our analysis was informed by writings on quality in qualitative research. We present the analysis and results below as they relate to each of the study objectives. Quotations and other material to support
some of the analysis presented here is reported in output 1, a draft paper, which is to be submitted for publication in a peer-reviewed journal.

Objectives A and B: Conceptualisations of HRQoL, comparisons with KIDSCREEn and recommendations to inform the refinement of HRQoL instruments for disabled children

Analysis

4.2 This aimed to identify children’s HRQoL priorities and compare these with the contents of KIDSCREEn. It built upon earlier work of the whole team in developing separate thematic coding frameworks for the child and parent data, which was guided by the general principles of the constant comparative method.

Specifically, team members worked in pairs on the parent (HR, MDW) and child (BY, KP) datasets to ‘cycle’ between the developing analysis and new data to develop open codes, followed by thematic categories and sub-categories. These were organised into the two coding frameworks that the complete team tested and developed by: i) periodic discussion, which also assisted in linking the analysis of the child and parent datasets; ii) coding transcripts that had not previously been open coded; and iii) producing detailed reports of data coding in NVIVO.

Finally, BY scrutinised all the coded child data to extract the key components and sub-components of children’s accounts of HRQoL, and as the analysis progressed, distil these into HRQoL conceptualisations. These were compared to the HRQoL domains and items in KIDSCREEn. To ensure the conceptualisations remained grounded in the child data, reference to the parent data was avoided until an outline report of the findings of this phase of analysis had been circulated to the project team for testing and development, after which the coded parent data was drawn upon to illuminate the conceptualisation of the children’s HRQoL data.

Results

4.3 Our analysis produced four HRQoL conceptualisations: social relationships; environments; body and self; and recreational activities and resources. These are outlined below and then briefly compared to the domains and concepts in KIDSCREEn.
**Social relationships**

4.4 Relationships with parents, friends and peers were probably the most prominent feature of children’s accounts of their lives, though relationships with siblings and grandparents were very important too. A few children also identified other members of the extended family such as aunts, uncles and cousins as key figures, while teachers and formal helpers were also discussed but not usually in great detail. Most elements of children’s accounts of parent relationships were directly represented in items within the KIDSCREEN domain ‘Parent Relations and Home Life’ including perceptions of parental affection, fairness, understanding, companionship and the role of parents as confidents. However, this particular KIDSCREEN domain was focused on relationships with parents and there were no items on other family members, such as siblings and grandparents. It was also quite common for children to express concern about the loss, absence and well-being of family members, though KIDSCREEN did not contain any items about these concerns. Issues such as the quantity of contact with friends and the companionship and support that friendships provided were well represented in the KIDSCREEN domain ‘Social Support and Peers’, while the domain ‘Social Acceptance and Bullying’ also mapped well to children’s accounts of overtly problematic peer behaviour. However, being included in the activities of friendship groups and being treated with fairness and respect by friends and peers appeared particularly important for the children we interviewed, though these concepts were not explicitly represented in KIDSCREEN.

**Environments: school and home**

4.5 Like social relationships, school life was very prominent in children’s accounts and brought considerable enjoyment and stimulation to the lives of many children. Aspects that detracted from children’s enjoyment of school included worries about their performance, inclusion, safety and mobility, while parents worried a good deal about the appropriateness and amount of work their children were given. Children’s school related priorities were well represented in the KIDSCREEN domain ‘School Environment’, while items in the ‘Moods and Emotions’ domain appeared likely to tap into children’s general concerns about their performance of activities and the pressures they encounter. Specific issues that were prominent in children’s accounts, but were not explicitly covered in KIDSCREEN included concerns about safety and how far children felt their needs were appropriately accommodated at school.
4.6 Home was the other key environment in children’s accounts, and was valued as a place of relaxation, rest and recreation: as a place of recreation, home companions such as neighbourhood friends and entertainment artefacts such as computers, TVs, books and toys served a crucial role in home life. The KIDSCREEN domain ‘Parent Relations and Home Life’ did not tap into children’s priorities for their home environments as it contained only one item ‘have you been happy at home?’ which potentially assessed children’s feelings about their homes or neighbourhood, while the remaining items focussed on parent-child relations.

Body and self

4.7 Several children spoke with a considerable sense of accomplishment about the things their bodies could ‘do’ including the extra efforts they had to make because of their impairments. Some children, mostly younger boys, said very little about their impairments or the ways in which their lives might be different from non-disabled peers but many others were concerned about how their bodies were ‘different’ to others. About one third of children reported that they experienced some pain or discomfort, and localised tiredness or discomfort in limbs and muscles was mentioned frequently. Children’s priorities for the body mapped most closely to the KIDSCREEN domains ‘Physical Well-being’, ‘Moods and Emotions’ and ‘Self Perception’. The particular importance they gave to their bodies and performance of physical activities was directly represented by 3 KIDSCREEN items, while the relatively low priority given to health in KIDSCREEN was broadly in line with our findings, as only a few children made passing references to ailments. However, many children regularly experienced pain or discomfort and a few had specific worries about hospital visits and procedures that are not represented in KIDSCREEN. Appearance represented another mismatch as KIDSCREEN included 3 items related to appearance and clothing, but the children we interviewed seldom mentioned such concerns.

4.8 Children frequently referred to positive and negative emotional states such as being ‘happy’, ‘sad’ or ‘lonely’ and having a ‘good life’ and ‘fun’, and it was clear that a few children used strategies such as adjusting their goals or making social comparisons to generate a sense of personal satisfaction or achievement. Several of the concepts discussed by children corresponded directly to the words or phrases used in items within the ‘Moods and Emotions’ and ‘Psychological Well Being’ KIDSCREEN domains. However, issues that were quite prominent in
children’s accounts, but not explicitly covered in KIDSCREEN included feelings of boredom, fear, embarrassment, anger and frustration and exclusion.

**Recreational activities and resources**

4.9 Children enjoyed a wide range of non-sedentary activities, clubs and outings, though sedentary activities were given equal priority and were especially important in the lives of some children. Entertainment artefacts such as game consoles and computers were therefore greatly valued by most children. When speaking about recreation, autonomy was a major priority especially for older boys, but was less prominent in the accounts of younger children and girls, a few of whom were greatly concerned with safety. In view of the precedence children gave to physical activities for recreation, the emphasis upon these in KIDSCREEN was broadly convergent with children’s accounts, but there were difficulties with the wording of some items. ‘Autonomy’ and ‘Financial Resources’ were the other KIDSCREEN domains which were most relevant to children’s accounts of recreational activities and 3 items within these mapped very closely to the concept of autonomy that emerged as a priority for some children. However, little precedence was given in KIDSCREEN to sedentary recreational activities and the entertainment artefacts or resources that support these activities, though these were also greatly valued by children. More subtly, the focus within KIDSCREEN on time and finances as barriers to recreation and autonomy did not map well with the accounts of children, as they rarely referred to these in their interviews, though they did discuss a wide range of other barriers.

**Conclusions and recommendations**

4.10 KIDSCREEN is a generic tool for assessing HRQoL in children aged 8-11 years that has recently been developed using a range of state-of-the-art techniques, including item generation focus groups with children and parents. In general, our data suggests it maps well to disabled children’s priorities and there was little evidence that it gave precedence to the medical model of disability at the expense of environmental, social and interpersonal processes that may adversely impact on the lives of children with impairments. With the exception of a few specific items, the instrument was also well accepted by most children and parents. This is an important consideration as several children had little apparent awareness or were reluctant to speak about impairment and disability; a generic
HRQoL instrument such as KIDSCREEN may therefore be more acceptable to disabled children than a condition-specific instrument.

4.11 However, we have identified some specific concepts that were important in the lives of disabled children but which appeared to be inadequately or inappropriately represented in KIDSCREEN. We recommend that particular attention be given to better representation of issues such as home life and neighbourhood; relationships with family members other than parents; inclusion and fairness in relationships, particularly peer relationships; pain and discomfort; accommodation of children’s needs in key environments, including needs for safety and relaxation; and access to recreational resources other than finances and free time. We also recommend that further consideration is given to the wording of several items so that the instrument is suited to the range of different physical pursuits and experiences available to children.

Objective C: The extent of agreement between qualitative and quantitative assessments of HRQoL

Analysis

4.12 Judgements of child HRQoL based on the data from this study were compared with children’s scores on KIDSCREEN to assess agreement between the two. HR (who was blind to the children’s scores on KIDSCREEN) reviewed the children’s transcripts to assign each to either a high, medium or low HRQoL grouping. She kept a reflexive account of the judgement process and took account of her visit to the family and the parent interview. Similar fieldworker judgements have been useful in dealing with problems of inconsistent responses in fieldwork settings. BY, who was unblinded to KIDSCREEN scores at this stage, reviewed HR’s reflexive accounts of the fieldworker judgement process to identify possible sources of variation between the fieldworker judgements and the KIDSCREEN score categories. A case-by-case analysis of each markedly discrepant case was then conducted to compare the two sets of data at the level of particular domains. This involved a re-examination of all qualitative data for each case with cross-referencing to the KIDSCREEN score profile. In providing a systematic means of identifying cases to examine variation between the qualitative and quantitative data, the primary aim of this analysis was to inform the pathways analysis.
Results

4.13 Concordance between the fieldworker judgements and KIDSCREEN categories was 32% and there were 19 discrepant cases. The time lapse between the SPARCLE visit and the qualitative interview is a likely source of variation, but the reflexive notes made immediately after each interview and during the fieldworker judgement process provided further clues. These indicated that while some girls gave in-depth and quite poignant accounts of their feelings and difficulties, which HR expected would be reflected in KIDSCREEN responses, boys tended not to dwell on their feelings, and some gave very little indication of their emotional lives and difficulties. Reflecting this, 9 of the 12 children assigned to the high HRQoL group by fieldworker judgement were boys, while 4 of the 6 children assigned to the low HRQoL group by fieldworker judgement were girls. The differential focus of the accounts of girls and boys therefore appears to have influenced the fieldworker judgements.

4.14 Of the 19 discrepant cases, 15 involved slight discrepancies that is, medium-low or medium-high combinations of fieldworker judgement and KIDSCREEN categories. Because the fieldworker judgement taxonomies and KIDSCREEN categories are somewhat arbitrary, it was felt that a detailed case-by-case analysis of the slight discrepancies would be relatively uninformative as there is, inevitably, a degree of uncertainty regarding their status as ‘true’ discrepant cases. Therefore the case-by-case analysis focused on markedly discrepant cases, that is, on the high-low fieldworker judgement and KIDSCREEN category combinations as there is more certainty surrounding their status as discrepant cases.

4.15 Four markedly discrepant cases were found: 3 children assigned to the high HRQoL group by fieldworker judgement had low KIDSCREEN scores, and 1 child assigned to the low HRQoL group by fieldworker judgement had a high KIDSCREEN score. Of these, 3 had a time lapse between the SPARCLE visit and the qualitative interview of 4-7 weeks. This compares favourably with the lapse for the whole group and suggests that this may not be a key factor in explaining the low agreement, though notably the lapse for the remaining case was 23 weeks.

4.16 The case-by-case analysis for the 4 markedly discrepant cases showed several apparent consistencies with no discernable inconsistencies between the qualitative data and KIDSCREEN data at the level of specific domains. For example, each child who reported unsatisfactory peer relationships and difficulties
at school on KIDSCREEN also did so in their interviews, and the one child whose interview account indicated that he was being bullied also reported similar experiences in KIDSCREEN.

**Conclusions**

4.17 The analysis of the markedly discrepant cases suggests there is little apparent variation between the qualitative and quantitative data at the level of specific domains. Coupled with chance levels of agreement for the whole group between the fieldworker judgements and KIDSCREEN total score categories, these apparent ‘domain level’ consistencies suggest that using fieldworker judgements to make global HRQoL categorisations of qualitative data may be problematic. However, our rationale for using fieldworker judgements was not to test the method itself, but rather to provide a systematic means of identifying cases to examine the sources of variation between the qualitative and quantitative data as a precursor to the pathways analysis. That little if any apparent variation has been found at the level of specific domains augurs well for the pathways analysis. Additionally, the fieldworker judgement process itself was useful in underlining the importance of gender in shaping children’s accounts and illustrating that the absence of ‘emotion talk’, particularly in boys, is not necessarily indicative of high HRQoL, while its presence, particularly in girls is not necessarily indicative of low HRQoL.

**Objective D: Pathways and barriers to quality of life for disabled children**

**Analysis**

4.18 Qualitative data from children with high total scores on KIDSCREEN was compared with that from children with low total scores to inform the identification of environmental, socio-structural and psycho-emotional pathways to good HRQoL. This was led by HR and built upon the work to develop the coding framework outlined above, but mainly took a narrative-style approach\(^\text{27}\) whereby HR ‘iterated’ between a) the original transcripts of child and parent interviews and reflexive notes and b) the KIDSCREEN score profiles and information on family SES and material resources. Specifically, using KIDSCREEN total scores the children were ranked from highest to lowest scorers. The datasets of 4 children from each end of the range were examined in detail to produce two explanatory
frameworks, one for high and one for low scorers, whilst also scrutinising each for variation between the qualitative and quantitative data at the level of specific domains. Progressing through the ranked datasets these frameworks were applied to the transcripts of a further 12 high and low scorers (which was well beyond the point at which saturation had been achieved), whilst attending to any newly emerging issues. The narrative-style analysis focussed on understanding children’s responses to KIDSCREEN in the context of the full interview accounts and helped to avoid ‘atomising’ participants’ accounts.

**Results**

*Pathways to good quality of life*

4.19 Children with the highest quality of life scores gave very positive accounts of school and scored highly in this KIDSCREEN domain. They typically mentioned having a close-knit group of friends at school and some were doing very well academically. Children also described adaptations made by their school to accommodate their needs and most of the higher scorers went to after-school clubs or participated in extra curricular activities. This group also tended to come from families where at least one parent was in full-time paid employment (though this is not entirely surprising as 70% our sample came from such families), score very highly in the ‘Parents and Home Life’ KIDSCREEN domain, and many spoke at length about the closeness of their relationships with members of their family. With one exception, this group also had high scores in the ‘Social Support and Peers’ KIDSCREEN domain. A striking finding was that most had maximum score in the ‘Social Acceptance and Bullying’ KIDSCREEN domain. Where bullying or taunting was mentioned, most children reported that they had been able to combat this in an effective way either by themselves or by enlisting the help of others, underlining the importance of children’s agency.

*Barriers to good quality of life*

4.20 Most children with lower scores had difficulties in their relationships with their peers. Pointing to the role of discriminatory processes in this, children who were being bullied or taunted often described how their impairments were a focus of such behaviour. Having friends but not being able to see them was another barrier to good quality of life. A few of the children with lower scores also spoke
about not getting on well with their parents although this was less common than accounts referring to problems in relationships with siblings, or feeling lonely at home because they had no siblings or friends to play with. Just under half of these children came from families without a parent in paid employment.

4.21 Several of the children were very unhappy at school and in some cases this was closely connected to the problems with their peer relationships, but in other cases was associated with difficulties in their relationships with teachers or other aspects of school. Some of the children scoring lowest on the ‘School Environment’ domain were those with relatively mild impairments and it seemed that their needs were inadequately recognised or accommodated by the school. Children also pointed to their lack of autonomy, which became particularly acute in relation to socialising with peers. Parental accounts revealed that they often perceived their child as being younger or more vulnerable than their peers and therefore believed them to be in need of more protection and surveillance.

4.22 Generally, the accounts of children with low scores pointed to the adverse impact of impairment and disability processes on their lives. Prominent among these were: the embarrassment felt when comparing their bodies with others’ bodies; fear of getting hurt, which was a major concern for a few children; pain and discomfort; and difficulties with mobility devices which interacted with the environment to restrict peer interaction. The relationship between impairment and quality of life was far from straightforward: some of the children scoring lowest in the ‘physical’ domain and who spoke about their unhappiness with their bodies were children with impairments that were ‘invisible’ or appeared very mild. Accounts clearly highlighted disabling structures, practices and processes, particularly the lack of understanding and accommodation to children’s needs. For example, children described not feeling listened to and their opinions and wishes being repeatedly ignored or discounted, which greatly constrained their exercise of agency. In other cases social or environmental adaptations that would help the child had not been provided or were inadequate.

Conclusions

4.23 The pathways and barriers analysis highlighted the ways in which environmental, social and psycho-emotional factors interact and thereby mediate the quality of disabled children’s lives. There was no straightforward association between the apparent severity of a child’s impairment and their KIDSCREEN
HRQoL score, even within the most ‘physical’ domain of KIDSCREEN. In line with Thomas’s model, this suggests that physical and social environments play a key role in influencing the quality of children’s lives, whatever the nature of their impairments. Similarly, there were no straightforward relationships between child gender and HRQoL. We are planning to further interrogate our data in relation to HRQoL and SES as our marker for SES (whether or not at least one parent was in full-time paid employment) may be insufficiently discriminating. Examining the contrasts in children’s accounts of similar events highlighted children’s use of agency, particularly in their interpretations of their experiences. However, there were significant constraints on children’s enactment of agency, prominent among which were family processes and disabling institutional practices within schools and recreational arenas. Confirming the results of the analysis for objective C above, there were few inconsistencies between the qualitative and quantitative data at the level of specific domains.

5. FUTURE RESEARCH PRIORITIES

Comparative work on the lives of disabled and non-disabled children

5.1 Our project has identified disabled children’s HRQoL priorities and informed an understanding of the pathways to good quality of life. However, disability was only one aspect of the lives of the children in our study, and the accounts of some children decentred its importance in their lives. Therefore we might anticipate that many of the priorities and pathways we have identified would also be important in the lives of non-disabled children. Further comparative work with disabled and non-disabled children is needed to examine this further and to delineate how disabled children’s priorities should be interpreted. For example, we were struck by the number of children who identified being helped as a valuable feature of their friendships. This could be seen as an undesirable form of dependency, to which HRQoL instruments and researchers should be sensitive, however it could simply be feature of friendships that children value at this stage of their lives. Comparative work could also address how key concepts should be represented in HRQoL instruments for children, as the emphasis on finance and time as barriers to autonomy and recreation in KIDSCREEN did not map well to the accounts of children. If the same is true for non-disabled children this could point to influence of adult rather than child perspectives in the development of
KIDSCREEN. Further comparative work would elucidate such complexities and inform the refinement of HRQoL instruments for all children.

**Conceptualisation of condition-specific health-related quality of life with disabled children.**

5.2 Arguably some of the omissions from KIDSCREEN that our work has identified such as pain, discomfort, inclusion, fairness and environmental accommodation to children’s needs could be more appropriately addressed by specialised or condition specific instruments, which are often used alongside generic instruments like KIDSCREEN. Using the data we have collected, we plan to examine how well children’s priorities are represented in one or more ‘condition-specific’ HRQoL instruments. This will enable us to further explore whether HRQoL instruments give precedence to the medical model of disability at the expense of assessing the role of environmental, social and interpersonal factors.

**Families and the development of a positive identity as a disabled child**

5.3 Our study has identified the crucial role played by family, peers and school in the lives of disabled children. Of these different spheres of children’s lives, least is possibly known about the role of family life, particularly in the psycho-emotional development of disabled children. Our emergent findings suggest that families’ discourses about impairment and disability, and how they balance concerns about the different elements of children’s present lives and future lives, would benefit from further detailed investigation to understand how children develop a positive identity as a disabled child. We plan to further explore this using the data we have collected, but ultimately this is a question about social developmental processes and a longitudinal data would be helpful to fully illuminate these complex processes.

6. **ACTIVITIES**

We have had numerous informal contacts and enquiries about our study with various local and national agencies and organisations in order to disseminate
information about our study to parents and other interested parties. More formal activities included:

- Young, B. Scope/Hemi-help Conference for Parents, Liverpool, Saturday 26th November 2005. (Attended to discuss study informally with delegates and distributed leaflet but did not present).

Helen Rice also participated in several training events including:

- Demonstration of using NVIVO and NUDIST 6 Provided by QSR International at Edinburgh University, 21st August 2004;
- Introduction to communication aids (AACs) provided by ‘Communicate’ (Northgate and Pruhoe NHS Trust), September 2004;

7. OUTPUTS

- Young, B et al What’s important in life? Disabled children have their say. Article for Hemi-help Newsletter. In press.

In addition, we have drawn-up plans for a number of academic outputs, including two priority papers which relate closely to the study objectives. One of these is
currently in draft form and is intended for submission to Developmental Medicine and Child Neurology. This is enclosed as one of our nominated outputs. The other is currently in outline form and is to be submitted to Social Science and Medicine (see Activities and Achievements Questionnaire, section 2 for further details). Further papers are planned and we are also in the final stages of preparing booklets on the study findings to send to children and parents who participated or were approached about the study.

8. IMPACTS

The SPARCLE and the qualitative study teams have benefited from the links they between the two studies. For example, the qualitative data were helpful in providing a possible explanation of early results from the SPARCLE study (see EOA questionnaire, section 7 for details). Discussions between the two teams were also helpful in understanding difficulties for parents and children in relation to particular items in KIDSCREEN. We have also had correspondence with a group at Deakin University in Australia (including Elise Davis and Elizabeth Waters) who are developing a ‘condition-specific’ HRQoL measure for children with cerebral palsy and are interested in the implications of our findings for such a measure.

REFERENCES


