A qualitative analysis into children's experience of living with cerebral palsy

And

Clinical Research Portfolio

Volume I
(Volume II bound separately)

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Submitted in partial fulfilment of the requirements for the degree of Doctorate in Clinical Psychology (DClinPsy)

University of Glasgow | Faculty of Medicine

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Chapter One

Systematic Review

Do children with cerebral palsy have lower quality of life than that of typically developing children?

Written in accordance to guidelines for submission to
Journal of Child Health Care *(see appendix 1.1)*

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Abstract

Objectives: This article presents a systematic review of studies investigating the self-reported quality of life and health related quality of life of children with cerebral palsy. Studies were critically appraised and findings synthesised with the aim of answering the question: do children with cerebral palsy have a lower quality of life than that of typically developing children?

Methods: A systematic search strategy was employed to identify relevant studies. An electronic database search, combined with a hand search of key journals and of reference sections of key papers, was undertaken. Methodological quality was determined using an idiosyncratic measure.

Results: Eight eligible studies were identified. Five achieved a rating of 'good', the remaining three achieved ratings of 'fair' methodological quality. Results indicate that when physical well-being is not measured, overall health related quality of life appears similar for children with cerebral palsy and their peers. Conversely, when it is taken into consideration, children with cerebral palsy self-report their health related quality of life as lower than that of typically developing children.

Conclusions: Results show that physical well-being impacts on health related quality of life of children with cerebral palsy. Additional influences on health related quality of life are incontinence, gross-motor function, school environment and SES (socio-economic status). Due to measurement of different domains of health related quality of life, and variance in age across samples, only tentative conclusions can be drawn, thus highlighting the need for further research.

Introduction

Cerebral palsy (CP) is the leading cause of disability in children with prevalence rates being in the region of 2 to 2.5 per 1000 live births (Winter et al., 2002). Cerebral palsy is a non-progressive medical condition resulting from damage to the developing brain, which depending on the location, can result in difficulties with movement, spasticity, cognition, communication and behaviour (Carlon et al., 2010).

Cerebral palsy is divided into subtypes (spastic, dyskinetic and ataxic), based upon the predominant motor impairment. The category spastic cerebral palsy is also subdivided, based upon the number of limbs affected, for example hemiplegia affects one side of the body, diplegia affects the legs only, while quadriplegia impacts on all four limbs. Dyskinetic cerebral palsy (athetoid and dystonic) is associated with fluctuating or rigid muscle tone, while ataxic conditions are associated with problems with co-ordination, muscle tone and balance.

In addition to motor impairment, children with cerebral palsy may also experience learning difficulties, have difficulty feeding and have seizure conditions. Moreover, many children may experience sensory impairments and have difficulties communicating (Pellegrino, 1997; Shapiro & Capute, 1999).

Research suggests that people with cerebral palsy have greater rates of mortality than the general population (Strauss, 2010). A literature review, proposes that a number of disabilities are associated with increased mortality in children with developmental disabilities, these include an inability to speak or to recognise voices and an inability to interact with peers. The presence and severity of seizures, cortical blindness,

incontinence and severity of physical disability are also associated with increased mortality (Katz, 2009). As aforementioned, many of these disabilities are experienced by individuals with cerebral palsy. More recent research supports these findings, proposing that preserved motor function is associated with survival (Strauss, 2010) and that presence of gastrostomy dependence is associated with increased rates of mortality (Brooks et al., 2012).

As there is no cure for CP, traditionally interventions have focused on the improvement of physical functioning (Bjornson & McLaughlin, 2001; Parkes & McCusker, 2008). Recent advances in medical care, however, have resulted in individuals with CP living longer. Consequently, the need to support individuals' emotional, social and psychological well-being, as well as their physical health needs has been recognised (Evans et al., 1990).

For the child with CP, difficulties in physical functioning and movement may lead to challenges to independence and autonomy, and subsequently impact on quality-of-life (Bjornson et al., 2008; Sparkes & Hall, 2007; Viehweger et al., 2008). At a time when socialising with peers is crucial for developing one's identity and independence from the family (Erikson, 1968), children with physical disabilities tend to spend more time in isolation and away from their peers (Cole & Cole, 1993). Research has also shown that children with disabilities are at an increased risk of developing mental health difficulties, including emotional or conduct disorders (Goodman, 2002; Goodman & Graham, 1996; Rutter et al., 1970). Thus the investigation into quality-of-life is deemed important when considering a holistic approach to care and well-being.

While definitions of quality-of-life vary across the literature, it is often described as ‘an overall assessment of well-being across various broad domains’ (Bjornson & McLaughlin, 2001). This may encompass physical, psychological, social, economic and spiritual dimensions. Heath-related-quality-of-life is somewhat different, being defined as “the functional effect of an illness and its consequent therapy on a patient, as perceived by that patient” (Vargus-Adams, (2005) p.940). Bjornson et al., (2008) suggest that quality-of-life (QOL) and health-related-quality-of-life (HRQOL) have historically been used interchangeably, therefore for the purpose of the current review, they shall be considered collectively.

While there has been much research into QOL in children with CP, findings are inconsistent. Some studies claim that children have similar levels of QOL to their typically developing (TD) peers (Dickinson et al., 2007) while others report that QOL is lower than would be expected (Livingston et al., 2007; Russo et al., 2008). Difficulties in measuring QOL/HRQOL in cerebral palsied populations, (such as barriers in communication, the wide range of impairments children may experience and a lack of validated measures) may explain some of the discrepancies in research findings (Livingston et al., 2007).

Bjornson and McLaughlin (2001) propose that development of measures has been hampered by indecision regarding whose perspective to assess and which domains of QOL to focus on. Vitale et al., (2005) suggest that when measuring psychosocial or physical functioning in children with cerebral palsy, measures should be reflective of domains such as life duration, functional status, impairments, perceptions and social opportunities. Vitale et al., investigated the efficacy of two commonly used measures

of QOL (Child Health Questionnaire, Pediatrics Outcome Data Collection Instrument) reporting that they were not sensitive enough to capture the heterogeneous nature of difficulties experienced by this population. The authors argued for the development of disease specific measures of QOL, which are more likely to target issues pertinent to the specific disease. In relation to this, in recent years there has been work on the development and validation of condition specific measures. A recent systematic review (Carlon et al., 2010) of the psychometric properties of condition specific instruments reports that five condition specific measures exist (C&CHQ; CPCHILD; CP QOL Child; DISABKIDS, PedsQL 3.0) and that the strongest measures of QOL in children with cerebral palsy are the CP QOL-child (Waters et al., 2007) (retest reliability 0.76-0.89) and the CPCHILD (Narayanan et al., 2006) (retest reliability 0.97).

The benefits of these measures withstanding, generic measures although less sensitive, more easily allow for comparison with norms from the general population (Maher et al., 2008).

Although a review of the literature reveals a plenitude of articles relating to QOL in young people with CP, much of this focuses upon parental or proxy report. This may in part explain some of the inconsistent findings amongst previous studies. While recognising the depth of information that comes via parental and proxy report, there are also important caveats to be considered. It has been argued that the level of correlation between child and parental report is often low to moderate at best (Eiser & Morse, 2001) with parents of children with chronic conditions tending to report that QOL is lower than children themselves do (White-Koning et al., 2007). Discrepancies appear greatest when considering reports of emotional well-being, as opposed to

physical health (Eiser & Morse, 2001; Varni et al., 2005). For instance, Moore et al., (2010) reported that children in their study demonstrated acceptance of their physical difficulties, where as parents tended to focus on how CP restricts their child's life. Further factors to consider in relying on parental report are that of parental stress and anxiety which may impact on the parent's perception and rating of child's well-being (White-Koning et al., 2007).

There is a strong argument for eliciting the perspectives of young people with CP themselves, owing to the highly subjective nature of QOL and HRQOL. Unfortunately, despite the growing body of research examining QOL, first hand accounts from young people with cerebral palsy remain largely absent. In part this stems from concerns over their ability to self-report their QOL, coupled with a shortage of validated and reliable measures in this area (Varni et al., 1999). Conversely, a recent study reported that children as young as five years of age are capable of reporting accurately on their QOL (Varni et al., 2007) and the evidence suggest that children are able to reliably self-report on HRQOL (Ravens-Sieberer et al., 2005; Varni et al., 2005). The recognised importance of allowing children and young people to comment on issues that affect them is also reflected in policy documents such as the Children's Act (DoH, 1999).

Aims

The present review aims to summarise the research evidence on self-reported HRQOL/QOL in children with CP by conducting a methodological critique of the literature. It is hoped that this review will provide an up to date evaluation of the

evidence base and establish whether these children do experience a lower QOL than typically developing children.

Review Question

Do children with cerebral palsy have lower QOL/HRQOL than that of typically developing children?

Methods

Search Strategy

Computerised Search Strategy

In view of identifying relevant studies, the following online databases were searched: Ovid MEDLINE(R) 1948 to June 2011, EMBASE 1980 to 2011, PsychINFO, CINAHL, EBM Reviews including Cochrane database of systematic reviews 2005 to 2011, ERIC 1965 to 2011, Psychology and Behavioural sciences collection, Web of Science. Limits were set to papers published between January 1980 and May 2011.

The following key words were used for the electronic search: [HEALTH RELATED QUALITY OF LIFE], [QUALITY OF LIFE], [HRQOL], [QOL] combined with [CEREBRAL PALSY] or [CHILD*] in title/abstract/or as free text.

Additional search strategies

In view of increasing the sensitivity of the search, key journals (Developmental Medicine and Child Neurology, Quality of Life Research and the Journal of Child

Health Care, from January 2005-May 2011) along with and the reference sections of identified studies were hand searched to identify any relevant articles. These were then systematically reviewed and excluded based upon methodological information.

Inclusion and Exclusion Criteria

Inclusion criteria

- Study measured QOL/HRQOL
- Participants were children (up to 18 years)
- Participants were diagnosed with cerebral palsy
- Participants self-reported on QOL/HRQOL
- Children's QOL/HRQOL scores were compared with normative data/sample
- Study employed quantitative methods
- Samples comprised only of children with CP
- Study appeared in a peer-reviewed journal

Exclusion criteria

- Unpublished dissertations
- Conference presentations
- Case studies
- Articles not published in English

Assessing Methodological Quality

A standardised tool was sought for assessing quality of papers; however published scales are designed to assess outcome studies and are therefore not suitable for use in this review. As such, a checklist was developed by the author in order to rate the

studies (see Appendix 1.2). This checklist was influenced by standardised rating scales produced by Consolidated Standards of Reporting Trials (CONSORT: Schulz et al., 2010) and the Scottish Intercollegiate Guidelines Network (SIGN, 2004). The checklist consisted of 20 items relating to 10 areas: study design (comparison group), participant selection and information provided, measurement of disability, data on non-respondents, measures employed, methods of administration, confounding factors, statistical analysis and discussion. Scores varied across items, with a total score of 36 achievable. Total scores were converted into percentages relating to a quality rating. Studies were awarded quality ratings as follows: poor <50%, fair 50-74%, good >75-79%, excellent >80%.

All studies were examined by the author and 75% were rated independently by another experienced researcher. Levels of agreement reached 86.7% and all discrepancies were discussed and subsequently resolved.

Results

Search Results

Electronic Database Search

The process of identifying studies for the review is summarised in Figure 1. The initial electronic search produced a total of 1292 studies. Of these studies, 1210 were either duplicates or deemed unsuitable for the review based upon information supplied in the title or abstract. On occasion it was unclear from the abstract whether studies had employed self or proxy report and therefore full texts were sought for perusal. Following this stage, the full texts of 82 papers were reviewed. Of these, 74

were excluded, leaving 8 studies which met inclusion criteria for the review. (See appendix 1.4 for a list of excluded studies).

Additional search strategies

No additional articles were identified from the hand search.

Quality Appraisal

Following a systematic review, quality ratings show that five studies (62.5%) were rated as being of 'good' quality (Bjornson et al., 2008; Dickinson et al., 2007; Janssen et al., 2010; Russo et al., 2008; Varni et al., 2005), while the remaining three (37.5%) achieved a rating of 'fair' quality (Maher et al., 2008; Moore et al., 2010; Soyupek et al., 2010). No study achieved an award of excellence (>80%). Study details and scores are provided in Table 1. To aid comprehension of results, a summary of measures employed in studies is provided Table 2, Appendix 1.3.

Figure 1: Flow diagram of systematic search process and paper selection

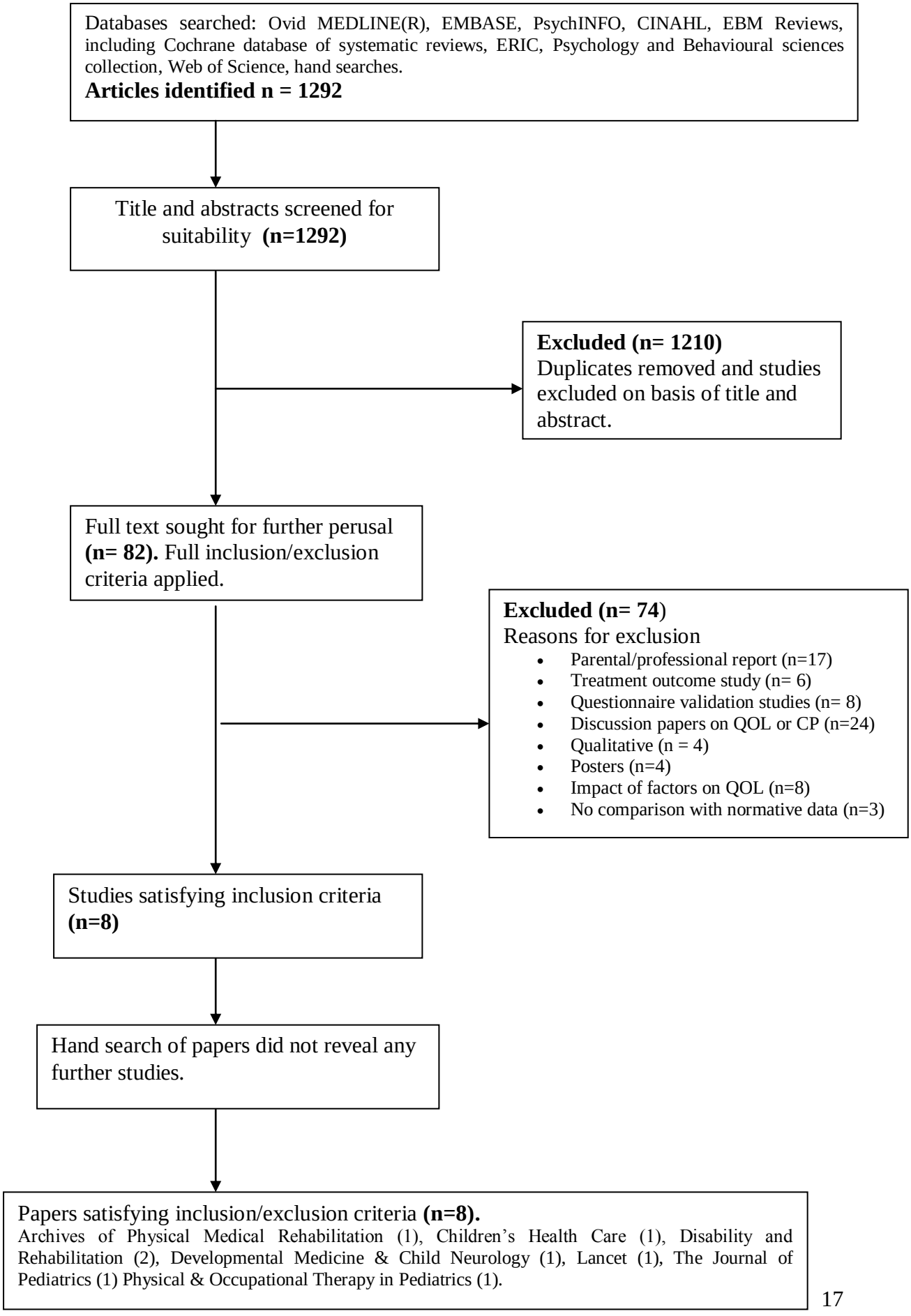

Table 1: Summary of studies reviewed

Author/Score	Country	Design	Sample selection	Sample/Age	Measuring	Diagnostic info	Comparisons	Measures used	Main strength/weakness or point of note.
Bjornson et al., (2008) 28	USA	Cross-sectional	Convenience sample – multiple sites	81 CP 30 TDY 10-13 years	QOL	Defined by motor function. GMFCs levels I to III.	Comparison group	YQOL-R CHQ	Only study to separate measurement of health as distinct from QOL. Matched samples on age/sex.
Dickinson et al., (2007) 28	European	Cross-sectional	Geographic. Recruited from CP registers in France, Germany, Ireland, Sweden, UK.	379 CP 8-12years	HRQOL	Supplied for total sample of 500, not for sub-sample used for comparison (379)	Data from general population, aged 8-12 across same 5 countries.	KIDSCREEN	Physical well-being not compared. Large geographic sample.
Janssen et al., (2010) 27	The Netherlands	Longitudinal	All rehabilitation centres, special schools, outpatient clinics, rehabilitation departments.	91 CP 9 –13 years	HRQOL	Defined by motor function. GMFCs I to V.	Published norms	TNO-AZL (TACQOL-Child)	Only longitudinal study, large number of recruitment sites, compared those who dropped out to those who completed and found no difference between groups.
Maher et al., (2008) 21	South Australia	Cross-sectional	Recruited from the sole provider of community based therapy, family support services.	74 CP 11-17 years	HRQOL	Range of types of CP. Defined on GMFCs levels I to V.	Published norms	PedsQL	Inconsistency in reported data, used visual analysis to compare CP to TDY data.

Key to abbreviations: TDY: Typically developing youth; CHQ - Child health questionnaire, PedsQL – Pediatric Quality of Life Inventory; YQOL-R - Youth Quality of Life Instrument – Research version

Table 1: Summary of studies reviewed continued

Author	Country	Design	Sample selection	Sample/Age	Measuring	Diagnostic information	Comparisons	Measures used	Main strength/weakness or point of note.
Moore et al., (2010) 19	USA	Cross-sectional	Recruited from one private practice	20 CP 5-17 years	HRQOL	Hemiplegia	3 sets of published normative data	PedsQL	No assessment of GMF, sampled from one private practice, reporting of results unclear.
Russo et al., (2008) 27	Australia	Cross-sectional	Recruited from the South Australia CP register	86 CP 86 TD children, matched on sex/age (3-16years)	HRQOL	Hemiplegia	Comparison group	PedsQL	Matched groups on age and sex, wide range of recruit areas.
Soyupek et al., (2010) 25	Turkey	Cross-sectional	Recruited from CP registers at 3 special schools for disabled children.	40 CP 46 Age/ matched peers 9 – 18years	HRQOL	Various types	Comparison group	PedsQL	Provided no information on administration of measures, made few recommendations for future research/practice. Matched samples on age.
Varni et al., (2005) 27	USA	Cross-sectional	Recruited from CP clinics at hospital and at therapy clinics	69 CP 5-18years	HRQOL	Various types	Published data	PedsQL	Provided detailed information on procedure, and much demographic/diagnostic information.

Review of study findings

Having completed quality assessment, identified methodological issues are presented, followed by the salient characteristics of the 'good' then 'fair' studies. The main findings of the review with regard to QOL in children with CP, will be discussed in detail.

Methodological Findings

Number of participants

In total 10356 participants were included across study samples. The total number of participants with cerebral palsy was 840; 490 males: 347 females (male to female ratio is inaccurate due to inconsistencies in reporting by Maher et al., 2008) ranging from 3 to 18 years respectively. Studies employing comparison groups of typically developing children (Bjornson et al., 2008; Russo et al., 2008; Soyupek et al., 2010) culminated in a group of 162; 87 males: 75 females, ranging from 3 to 18 years. Studies comparing with published normative data (Dickinson et al., 2007; Janssen et al., 2010; Maher et al., 2008; Moore et al., 2010; Varni et al., 2005) included scores from 8751 healthy children, aged 6 to 18 years and 612 children with chronic illness, ranging from 5 to 18 years.

Characteristics of the studies

Design and Comparisons

Seven of the studies in the sample employed cross-sectional designs (Bjornson et al., 2008; Dickinson et al., 2007; Maher et al., 2008; Moore et al., 2010; Russo et al., 2008; Soyupek et al., 2010; Varni et al., 2005) to explore QOL/HRQOL in children with CP, and only one study used a longitudinal design (Janssen et al., 2010). Three

studies used comparison groups of TD peers (Bjornson et al., 2008; Russo et al., 2008; Soyupek et al., 2010). Of these, only two of the studies matched participants on age and sex (Bjornson et al., 2008; Russo et al., 2008), and one on age only (Soyupek et al., 2010). The remaining studies compared their data with published normative data (Dickinson et al., 2007; Janssen et al., 2010; Maher et al., 2008; Moore et al., 2010; Varni et al., 2005).

Age and sex of children are important to consider in relation to their impact on QOL/HRQOL because findings vary. For instance, HRQOL is reported to decrease from childhood to adolescence (Maher et al., 2008; Otley et al., 2006). However, Janssen et al., (2010) reported stability over their 3-year longitudinal study, suggesting that the onset of adolescence may increase cognitive and social skills which may act as protective factors against the sequeale of CP.

Relating to gender, females are found to score lower on physical and psychological QOL dimensions than males (Maher et al., 2008). In relation to this, it has been suggested that with an increase in testosterone, males become more aggressive and competitive (Carr, 2006). In view of this, it is argued that matching samples on the basis of both sex and age are important as both may act as confounding variables.

Methodological Issues

Sample characteristics

Only one study (Dickinson et al., 2007) employed a geographic cohort design, and one sampled from CP registers across a whole state (Russo et al., 2008). The remainder of studies used convenience sampling, where participants were recruited

through hospital settings (Bjornson et al., 2008), rehabilitation centres, special schools, outpatient clinics (Janssen et al., 2010), care providers of community based therapy (Maher et al., 2008), private practice (Moore et al., 2010), specialist schools (Soyupek et al., 2010) and therapy clinics (Varni et al., 2005). It is important to acknowledge the sampling procedures used by studies when considering their methodological strengths and limitations. Selection or sampling bias may be introduced when using convenience samples, which impacts on the external validity of the study's findings. Geographical samples are considered superior, as they are more representative of a population, thus allowing results to be extrapolated from the sample and generalised to a population.

In relation to the samples, seven out of eight studies provided inclusion/exclusion criteria (Bjornson et al., 2008; Dickinson et al., 2007; Maher et al., 2008; Moore et al., 2010; Russo et al., 2008; Soyupek et al., 2010; Varni et al., 2005), while Janssen et al., (2010) failed to do so. Of those who provided such detail, it was inconsistently applied across groups (i.e. the CP and TD) or studies (i.e. method of assessing whether the child could self report).

Three studies supplied data on non-respondents (Dickinson et al., 2007; Janssen et al., 2010; Russo et al., 2008). Of the studies that did report on non-respondents, only one proposed any reason for non-response (Janssen et al., 2010).

Of the eight studies, three provided information on participants schooling (Janssen at el., 2010; Maher et al., 2008; Soyupek et al., 2010). Information regarding school is important, as research has suggested that children with mild to moderate impairment

can be expected to perform at mainstream levels and that this may lead to low self-esteem (Russo et al., 2008).

Classification of Cerebral Palsy

Five studies supplied diagnostic data on participants with CP (Maher et al., 2008; Moore et al., 2010; Russo et al., 2008; Soyupek et al., 2010; Varni et al., 2005).

Five studies classified children based upon their motor functioning (Bjornson et al., 2008, Janssen et al., 2010; Maher et al., 2008; Russo et al., 2008; Soyupek et al., 2010) as measured by the Gross Motor Function Classification Scale (GMFCs). Collectively, the samples across studies represented individuals from all levels of the GMFCs I to V. However, more children were reported to be in levels I to III, compared to IV and V.

Consequently, these studies are biased towards children with less severe levels of motor impairment. However, samples may follow this pattern because they focus on children who are able to self-report who consequently may be those less severely affected by CP.

Measures of QOL/HRQOL

All studies employed standardised generic measures of QOL/HRQOL and all were reported to be valid and reliable. Measures used to quantify QOL included the Youth Quality of Life Instrument – Research Version (YQOL-R) (Bjornson et al., 2008), while the Pediatric Quality of Life Inventory 4.0 (PedsQL), (Maher et al., 2008; Moore et al., 2010; Russo et al., 2008; Soyupek et al., 2010; Varni et al., 2005),

KIDSCREEN (Dickinson et al., 2007) or the TNO-AZL (Janssen et al., 2010) was used to measure HRQOL. General characteristics and psychometric properties of measures employed in studies are shown below in Table 2.

Table 2: Questionnaire characteristics and psychometric properties

Instrument	Year	Domains	Number of items	Time to complete (minutes)	Reliability	Validity
KIDSCREEN-52	2005	Physical well-being, psychological well-being, mood and emotions, self-perception, autonomy, parent relations and home life, social support and peers, school environment, social acceptance, financial resources.	52	15-20	Internal consistency Across domains Cronbach alphas ranged from 0.77 (social acceptance and bullying) to 0.89 (financial resources and psychological well-being). Retest reliability 0.56 (autonomy) – 0.77 (school environment).	*Convergent/construct validity KIDSCREEN-52 and PedsQL correlations range from small to medium: r =0.14 (KIDSCREEN-52 social support and peers/ PedsQL school functioning scale) to 0.53 (KIDSCREEN-52 moods and emotions/PedsQL emotional functioning). Strong correlation with KIDSCREEN-27 (r=0.63-0.96), high correlation with domains assessing similar constructs in KINDL (r=0.51-0.68).
PedsQL	1999	Physical functioning, emotional functioning, social functioning, school functioning	23	5-10	Internal consistency Across domains Cronbach alphas ranged from 0.39 to 0.90, for total score 0.66 – 0.92. Test – retest reliability 0.86 (total score)	Content validity Differentiates healthy children from those with chronic health conditions. Construct validity Majority of PedsQL items load most highly on their conceptually derived scale. Change over time following clinical intervention.
*content validity not reported						

Table 2: Questionnaire characteristics and psychometric properties continued

Instrument	Year	Domains	Number of items	Time to complete (minutes)	Reliability	Validity
TACQOL	1998	Physical functioning, motor functioning, autonomous functioning, cognitive functioning, social functioning, positive moods, negative moods	55	10	Internal consistency across domains Cronbach alphas ranged from 0.55 to 0.96. Test – retest reliability 0.30-0.91 (domain).	Content validity differentiates healthy children from those with chronic illness. Construct validity 93% of items loaded higher on their own factors than on others. Correlation between TACQOL and KINDL (r=0.24-0.60).
Youth Quality of Life Instrument – Research version (YQOL-R)	2002	Total QOL, sense of self, social relations, culture/community environment, general QOL.	41	10-15	Internal consistency Across domains Cronbach alphas ranged from 0.77-0.99, for total score 0.94-0.96. Test – retest reliability 0.74-0.85 (domain) 0.78 (total score).	Content validity Differentiates healthy children from those with chronic health conditions. Construct validity All scales show high correlation with scales of KINDL. Low correlations with two instruments measuring different constructs (the Functional Disability Inventory and the Children's Depression Inventory).

While all measures are reliable and valid, the number of QOL or HRQOL domains assessed, as well as the depth in which each domain is assessed, differs. For example, KIDSCREEN is reported to focus heavily on psychological and social functioning with less focus on the physical domain, and while the PedsQL covers each domain, it is poor at assessing social functioning, moreover, the TNO-AZL, fails to assess school functioning (Viehweger et al., 2008). The variance in focus of these measures suggests that they assess different aspects of HRQOL and that this may be one reason for variance in findings across studies.

An additional concern arises in relation to Dickinson at el., (2007) who failed to compare their groups on physical well-being because questions relating to this construct were modified for children with CP. In view of this modification, it is argued that this measure (KIDSCREEN) was not suitable for measuring HRQOL in children with CP.

Administration of measures

Six studies provided detailed information regarding the administration of measures. Soyupek et al., failed to report on procedure. While Maher et al., provided information on instructions given to participants, questionnaires were completed at home; outwith control of the researcher, so one cannot be sure how accurately instructions were followed. Thus potentially threatening internal validity. The administration of measures in remaining studies occurred in the presence of a researcher.

Power Calculations

None of the studies carried out power calculations. One study reported that they did not because they wanted to include all children, proposing that their study was sufficiently powered based upon previous studies (Russo et al., 2008), another study made similar claims (Soyupek et al., 2010). The absence of a power calculation means that results are vulnerable to a type II error.

Statistical Comparisons

All studies employed statistical methods for analysis, however, one study (Maher et al., 2008) failed to carry out statistical analysis when comparing CP group data to that of comparative samples, relying rather on visual analysis. This is not scientific method of comparison and therefore threatens the validity of their conclusions. Only one study reported effect sizes (Varni et al., 2005). As five of the studies in the review employed the PedsQL it was considered that results could be combined and effect sizes calculated. However, this was only possible for two studies (Maher et al., 2008; Soyupek et al., 2010) as the other two studies (Moore et al., 2010; Russo et al., 2008) failed to report sufficient information to allow calculation of effect size. The remaining two studies in the review (Bjornson et al., 2008; Dickson et al., 2007) employed different QOL measures and did not provide sufficient information to allow effect size to be calculated. Details of statistical assessment are provided below in Table 3.

Table 3: Details of statistical assessment

Study	Investigated	Factors analysed	Multivariate method	Results/ES	Comments
Bjornson et al., (2008)	Examined differences between CP and TDY on QOL and health status	General QOL, relationships, environment, self, total QOL.	Yes. (*Kruskal Wallis, Mann-Whitney U test)	Results of Kruskal Wallis analysis revealed that subscales of the YQOL-R did not differ between TDY and those with CP (total QOL, p=0.22; self, p=0.23; environment, p=0.59; relationships, p=0.61; general QOL, p = 0.84). Significant differences were found between self-reported health status of TDY and those with CP. Role/social behaviour (p=0.007), role/social physical (p=0.005), pain (p=0.04), physical function (p=<0.001) and general health perception (p=0.002). No Es reported.	Reported mean ranks, no Sd's, insufficient information to calculate Es.
**Dickinson et al., (2007)	Investigated relationship of socio-demographic variables, pain and impairment to QOL. Subsample comparison of QOL in CP with scores of children in general population.	Socio-demographic characteristics (sex/age of child, family structure, employment/educational qualifications of parents), pain, impairments, KIDSCREEN domains.	Yes. (Linear regression, *Multivariable regression)	Multivariate regression showed that the QOL of children with CP did not differ from that of the general population, with the exception of autonomy which was significantly lower for children with CP (p=0.004). Following adjustment for socio-demographic variables achieved similar results. CI reported, no Es reported.	No comparison of physical well-being domain, due to amendment of a question. Scores of children with CP and those of the general population are illustrated in a boxplot diagram, no presentation of means/Sds, calculation of Es not possible.
Janssen et al., (2010)	Course of HRQOL, differences and associations between parent/child report, investigate relationship between HRQL and gross motor ability and indicators of mental health	TACQOL domains, parent/child report, HRQOL, gross motor ability, indicators of mental health.	Yes. (*Welch t test, paired t tests, Pearson's r, Generalised Estimating Equation Analyses).	At baseline children with CP reported significantly lower HRQOL than the comparison sample, except on physical complaints where the CP group reported feeling better regarding their daily hassles (dizziness, aches, common pains). Course of HRQOL, remained stable in all domains except autonomous functioning which improved over time (regression co-efficient: 0.33, p<0.05). Small positive relationship between GMF and HRQOL domains of motor (regression co-efficient: 0.08 , p<0.01), autonomous (regression co-efficient: 0.11, p<0.001), cognitive and social function (0.06/0.04, p<0.001), indicating that a higher level of GMF was associated with higher HRQOL. Analysis showed a negative relationship between internalising mental health problems and all domains of HRQOL (regression co-efficient range from –0.11 to –0.30, p<0.001). CI reported, no Es reported.	Effect sizes calculated for individual domains range from small to large: physical complaints d=0.34; motor functioning d=0.92; autonomous functioning d=0.65; cognitive functioning d=0.55; social functioning d=0.37; positive moods d=0.35; no negative moods d=0.12.
Maher et al., (2008)	Effect of gender, GMFCS level, SES, number of health issues, assistance in responding on HRQOL scores.	Gender, GMFCS level, SES, number of health issues, sleep quality/quantity, assistance in responding, PedsQL domains.	Yes. (ANCOVA, ANOVA, Spearman's rho, *visual anlaysis).	ANOVA showed that overall PedsQL score differed on GMFC level, number of health issues and SES. Spearman's rho correlations indicate that higher GMF (-0.54), lower number of health issues (-0.51) and higher SES (0.28) were associated with higher PedsQL. Adjusted R-squared (0.68) shows that 68% of the variation in overall PedsQL scores were related to the above 3 variables. Reported CI, no Es reported. Comparison of CP data to published norms suggests that 66.7% of the CP group were at risk of impaired HRQOL.	Effect size calculated for total PedsQL scores (d=1.43) Comparison of CP versus TDY data was through visual analysis only.

Table 3: Details of statistical assessment continued

Study	Investigated	Factors analysed	Multivariate method	Results/ES	Comments
Moore et al., (2010)	Asses QOL and psychosocial needs of children with mild hemiplegia.	Age, gender, PedsQL domains.	Yes. (MANOVA, *Independent samples t-tests).	MANOVA indicated no effect of age, gender, age/gender. Independent samples t-tests showed: children with CP reported significantly lower total scores than TD children (p=0.013), the mean physical score of the CP group was also significantly smaller than the TD group data (p=0.002). Comparing to TD children in Japan, the CP group data was significantly lower on physical well-being (0=0.049) and the CP group data did not differ from that of chronically ill children (no p values reported). No CI or Es reported.	Of note is that this study recruited children with mild hemiplegia from only one private practice and sample size was small (N=20). Study did not report means/Sd's for total score on PedsQL. Calculation of Es not possible for subscales due to presentation of data.
Russo et al., (2008)	Investigated self-esteem, self-concept and QOL	Self-esteem, QOL, age, sex, GMFC level, IQ, PedsQL domains.	Yes. (Pearsons X^2, Independent samples t-test, *Paired samples t-test, Wilcoxon signed rank test, Multiple linear regression).	Paired samples t-tests indicate that the CP group scored lower than TD peers on total and subscales (physical, school, social) of the PedsQL ($p<0.001$) except on emotional functioning where groups did not differ (p=0.829). Analysis revealed a positive correlation between total PedsQL score and global self worth scores for children with CP ($r = 0.625$, $p<0.001$). CI reported, no Es reported.	Failed to report Sd's therefore no calculation of Es was possible.
Soyupek et al., (2010)	Investigated self-concept and QOL in children with CP and investigated predictive variables	GMFC level, self-concept score, incontinence, PedsQL total and subscale scores.	Yes. (Chi-square test, Independent samples t-test, Mann Whitney U-test, Pearson and Spearman's correlations, Multiple linear regression).	The CP group scores were significantly lower than TD peers (p=0.000-0.001). Children in special schools scored lower than those not in special schools on total PedsQL score, physical and psychosocial subscales ($p< 0.05$). Correlations identified between PedsQL score, GMFC level, self-concept score, incontinence, psychosocial and physical subscale scores ($r =-0.370$, $p=0.019$; $r =0.438$, $p=0.005$; $r = -0.387$, $p=0.014$; $r = 0.910$, $p = 0.000$; $r = 0.825$,, $p= 0.000$). Multiple linear regression showed that when PedsQL score was a dependent variable and GMFC level, presence of incontinence and self-concept score were independent variables, 75% ($R2=0.755$) of the change on PedQL scores was explained. Regression showed incontinence was predictive of PedsQL score (beta sign= -0.287, p=0.002). CI reported, Es not reported.	Es calculated for the magnitude of the difference between the total PedsQL score of the CP group in comparison to TDY group: d=1.14 (large).
Varni et al., (2005)	Examined self-reported HRQOL	Parent, child report, sensitivity of PedsQL, domains.	Yes. (ANOVA, *independent samples t-tests, Pearson's product moment correlations).	Healthy children reported a significantly higher HRQOL than children with CP ($p<0.001$, (effect size large) 1.42). Children with CP scores did not differ from children diagnosed with cancer ($p>0.05$, (effect size small) 0.19). Effect size reported, CI not reported.	

*denotes comparisons of interest, relating to comparison of CP data with normative data on QOL/HRQOL.
**only results relating to the sub-sample of children with CP who were compared to normative data are reported as other results relate to the whole sample.
CI – confidence intervals/ Es – effect size
CP – cerebral palsy/ TD – typically developing / TDY – typically developing youth

Synthesis of findings

The majority of studies report that the HRQOL of children with CP is lower than TD youth (Janssen et al., 2010; Maher et al., 2008; Moore et al., 2010; Russo et al., 2008; Soyupek et al., 2010; Varni et al., 2005), and some report that it is similar to that of children with chronic illness (Moore et al., 2010; Varni et al., 2005). This is with the exception of Dickinson et al., (2007) who failed to measure physical well-being, despite the fact that physical disability is central to the diagnosis of CP, and therefore likely to differentiate these children from their typically developing peers. In addition, other studies reviewed here report that groups differ on the physical subscale of the PedsQL (Moore et al., 2010; Russo et al., 2008; Soyupek et al., 2010). Indeed, when QOL is measured independently of physical health, as in the Bjornson et al., (2008) study, there appears to be no difference in self-reported QOL between young people with and without CP. Thus suggesting that it is aspects specific to physical health that impact on HRQOL.

Results also indicate that when domains of HRQOL are considered separately, children with CP differ from TD youth on constructs such as autonomy (Dickinson et al., 2007; Janssen et al., 2010) and those of physical, social and school functioning (Russo et al., 2008). It could therefore be the case that physical health impacts on other domains such as independence and social functioning, thus resulting in further emotional difficulties.

In addition, findings indicate that there are relationships between HRQOL and factors such as GMF, health, (Maher et al., 2008) incontinence and school environment (Soyupek et al., 2010). Moreover, subscales show that in the Moore et al. study,

children with CP reported lower physical well-being, but reported similar scores to healthy samples on psychosocial subscales. This finding is encouraging as it suggests that psychosocial well-being is not being adversely affected, however, these results should be considered with caution. The socio-economic background of participants may have differed as the CP sample was recruited from one private practice. Higher levels of deprivation have been associated with poorer HRQOL (Maher et al., 2008).

Where calculation of effect size was possible, the magnitude of the difference between groups of children with CP and TDY were all found to be large, (ranging from 1.14 to 1.43) indicating that this finding is consistent across different study samples. Calculation of effect size of sub-domains of the TNO-AZL varied from small (positive/negative moods) to large (motor/autonomous functioning), in the direction that may be expected given that children with CP are likely to differ from TD children on domains of motor and autonomous functioning.

Discussion

This systematic review examined the literature on self-reported QOL/HRQOL in children with cerebral palsy. Overall the quality of the research was fair to good, with no studies achieving ratings of poor or excellent.

Due to advances in medical care, children with CP are living longer. Consequently, concern has shifted from focusing solely on physical health, to incorporating that of the child's emotional well-being (Evans et al., 1990), with the aim of improving their health and quality of life (United Cerebral Palsy Association, 1991). Research

demonstrates the divergence between parent and child report (Eiser & Morse, 2001), highlighting the need to elicit children's own perspectives on their lives. Such information is required if services are to become more client centred, enabling people who use services to take control of their lives and to get the services they need.

Studies used different measures to assess HRQOL, and focused on domains differentially. It is therefore difficult to draw any firm conclusions. Another variable that studies have failed to control is that of age. The age range of children in this review spans from 3 to 18 years respectively, with several studies including data from very young children and adolescents in the same comparisons. As children mature and move through childhood and adolescence, they encounter a range of developmental changes. Such changes impact on various domains of functioning, including physical (onset of puberty), social/emotional (individuating from family, increasing emphasis on importance of peer relationships) and cognitive (being able to think in abstract terms, being able to reflect and deal with more complex issues). Consequently, as the child develops this will impact upon the saliency that different aspects of quality of life have for them. The variance in age across studies means that results are potentially confounded by the different developmental stages in which children were involved. Thus, conclusions can only be drawn with caution. With this in mind, the following aspects emerged as variables associated with QOL/HRQOL in children with CP: physical health and well-being, social functioning, internalising behaviour, schooling environment and socio-economic status.

Physical Health

The majority of studies in the review demonstrate that children with CP do report a lower level of HRQOL than their peers. This is with the exception of two studies that found no difference between QOL/HRQOL of children with CP and without (Bjornson et al., 2008; Dickinson et al., 2007). Inconsistencies in study findings seem to stem from whether or not measurement of QOL included physical health/well-being. For instance, Bjornson et al., separated out QOL from health status, and reported no difference between children with CP's QOL and that of their typically developing peers.

Dickinson et al., (2007) who failed to compare the CP group with data from TD children on the domain of physical well-being, found that children with CP enjoy a similar QOL to children in the general population.

Physical impairment is central to diagnosis of CP and consequently is more likely than any other domain assessed in QOL measures to differ. If Dickinson et al., (2007) had examined physical well-being their results may be more consistent with others in the review.

Consistent with this suggestion, all studies measuring physical well-being found that children with CP differed from TD peers. In addition, studies that separated out domains of HRQOL found that groups differed consistently on the physical subscale (Moore et al., 2010; Russo et al., 2008). Other studies reported a relationship between level of GMF (Gross Motor Function, physical mobility) and HRQOL (Janssen et al., 2010; Soyupek et al., 2010; Maher et al., 2008).

Bjornson et al., (2008) suggest that it is the construct of physical health which impacts on overall PedsQL score, thus suggesting that physical health impacts on HRQOL. In support of this, Maher et al., (2008) found that as number of health issues increased, HRQOL decreased. Moreover, Soyupek et al., (2010) found a relationship between incontinence and HRQOL, suggesting that incontinence reduces independence leading to social difficulties, which in turn would obstruct the development of autonomy and independence. Consideration of this, suggests that that 'health issues…negatively affect some life experiences for youth with CP' (Bjornson et al., (2008) p.124), therefore highlighting the importance of how HRQOL is defined and whether that should or should not include physical well-being. Considering that CP is associated with physical disability, it is argued that this impacts on their HRQOL and should therefore be considered.

Given that children with CP differ from TD children on subscales as well as overall score on the PedsQL, it seems that physical well-being also impacts on other domains of HRQOL, such as school and social functioning.

Social domain and mobility

Children with CP differed from peers on the social subscale of the PedsQL (Russo et al., 2008). Research documents that ambulation is related to socialising (Anderson & Klarke, 1982), in that while children are capable of ambulation, they still depend on parents to help them socialise and meet peers. In relation to this, Blum et al., (1991) report that despite the importance of socialising, youths with CP reported limited contact with peers. Reasons for this are complex, but may relate to parental resources or parental attitudes regarding the need to socialise. This finding is however consistent

with suggestions that children with physical disabilities are more isolated from their peers (Blum et al., 1991; Cole & Cole, 1993). Four of the studies in this review did find that level of motor function (ambulation) was related to HRQOL scores, with higher levels of functioning being associated with higher HRQOL. In recognition of the importance of socialising for development of independence and identity, this may be one reason for an increased incidence of mental health problems in children with CP. This is discussed further in the section below.

Internalising

Social isolation may lead to increased internalising behaviour (Janssen et al., 2010). This in turn may present as mental health difficulties, thus accounting for the increased incidence of such difficulties in children with disabilities (Goodman, 2002). Wiley and Renk (2007) employing parental report, found that the presence of internalising behaviour (anxiety, depressed mood, withdrawal) was associated with lower HRQOL scores for children with CP. Investigating from the child's perspective Janssen et al., reported that changes in HRQOL scores were related to changes in motor and social functioning. They propose that this may form a bi-directional relationship where internalising behaviour leads to less activity, leading to further withdrawal. Given such a pattern of interaction, it would seem likely that this would impact on mood, self-perception and the self-rating of HRQOL.

School Environment

Children functioning at GMF levels I to III are often in mainstream school (Maher et al., 2008). Research suggests that mainstream school can have a detrimental impact on self-perception as it comes with an expectation to perform at the level of peers, (Russo

et al., 2008) and because children have different relative norms with which to compare themselves (Maher et al., 2008). Conversely, others suggest that mainstream schooling can provide opportunity for socialising and activities (Soyupek et al., 2010). Janssen et al., suggests that when faced with daily limitations, children with CP may adapt their acceptable criteria for HRQOL, in so much as they prioritise what they are good at and focus less on what they find challenging (Franken, 1994). Findings relating to school environment vary, thus making it difficult to draw conclusions relating to this variable.

Socio-Economic Status (SES)

Socio-economic status is documented to impact on QOL (European KIDSCREEN group, 2005). Consistent with this, findings of Maher et al., (2008) show that higher SES was related to higher HRQOL. Moreover, although not measured, this may also have been the case in Moore et al., (2010) study since the sample was selected from a private practice and it was documented that there were no barriers to treatment. A caveat to this however, are the findings of Bjornson et al., (2008) who found no relationship between SES and QOL scores. Again findings are inconsistent, meaning no conclusions can be drawn.

Limitations

While conclusions are restricted due to the aforementioned methodological limitations, there are further constraints to consider. An initial observation is that the review included only studies published in the English language, thus resulting in a publication bias and excluding any potential evidence from authors publishing in other languages.

A further consideration is that the quality rating scale employed in this review was designed for the purpose of the review, thus rendering its reliability and validity unknown. Due to the nature of the studies in the review however, no published rating scale was suitable.

Future Research & Clinical Implications

Future research should measure QOL as distinct from physical health to investigate whether this is a consistent finding. Another recommendation is that research should investigate reasons for lower HRQOL. One method of investigation may be to employ qualitative methods, to allow children to report on their specific difficulties and how these affect their lives, rather than reporting on generic issues predefined by questionnaires. In addition, more creative methods of self-reporting may allow children with more profound disability to have better representation within the research. This is important, as existing studies have focused on those who are mildly affected by cerebral palsy. The current review highlights a need for longitudinal research to allow assessment of QOL over time, moreover separation of age groups may help control for confounding variables such as typical stages of development and the impact they have on QOL.

Findings indicate that children with CP are at increased risk of lower HRQOL. It is therefore proposed that these children be screened at regular intervals so that any difficulties may be identified, and early intervention could begin before difficulties exacerbate. Clinicians could work with the child and system to improve their experience of life, perhaps by encouraging ways that the child can gain more

independence despite the difficulties they experience. Through such early intervention it is hoped that these children may avoid future mental health difficulties.

Conclusions

Results demonstrate that cross-culturally children with CP report a lower HRQOL than their typically developing peers. However, when physical well-being is not measured, their reports are similar. Thus it seems that physical well-being impacts on HRQOL. While studies suggest that multiple factors appear related to HRQOL, it may be that they all impact on the development of independence. Due to measurement of different domains of health related quality of life, and variance in age across samples, only tentative conclusions have been drawn, thus highlighting the need for further research.

The findings of this review demonstrate the need for more research into reasons why children with CP experience poorer HRQOL than their TD peers. It is only in recent years that these children have been given a voice in this research, and while more quantitative investigation is required, it is proposed that adoption of qualitative methods may provide better insight into what life is like for these children. Moreover, it would provide both clinicians and parents with information, from which they could design and implement effective clinical interventions that may improve HRQOL. This information could then be used to ensure services are more client centred and thus these children are provided with the services they need.

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Chapter Two

Major Research Project

A qualitative analysis into children's experience of living with cerebral palsy.

Written in accordance to guidelines for submission to
Journal of Child Health Care *(see appendix 2.1)*

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Submitted in partial fulfilment of the requirements for the degree of Doctorate in Clinical Psychology (DclinPsy)

Lay Summary

Research suggests that approximately 10% of children may experience mental health difficulties. Children with disabilities are at increased risk of developing such problems. Research tends to focus on the views of parents whose children have cerebral palsy and there has been little investigation in to what living with cerebral palsy is like for the children themselves. However, parents and children's views may differ. Therefore the current study investigated the child's experience of living with cerebral palsy, obtaining their own views, in an attempt to find out both what this experience was like, and how it affected their lives. The findings of the study suggest that these children face similar challenges as they grow up as children without cerebral palsy; they are striving to be more independent, cope with the attitudes and behaviour of others and they are trying to fit in with their peers. However, there are additional challenges for children with cerebral palsy such as overprotection, feeling different and feeling excluded which impact on how children view themselves, which in turn may account for an increased level of mental health difficulties. The implications of this are that professionals need to be aware that children with cerebral palsy may require different supports if they are to become content and well adjusted adults.

Abstract

Introduction: Research suggests that children with disabilities are at increased risk of experiencing psychological difficulties. Cerebral palsy is the most common cause of physical disability in childhood and one that has been investigated mostly from the stance of the parent. Given this, the current study aimed to investigate the experience of living with cerebral palsy from the perspective of the child.

Design: Eight children (aged 9-12 years) diagnosed with cerebral palsy and attending mainstream schools were recruited. A qualitative cross-sectional design was adopted and data were collected via a series of semi-structured interviews. Transcripts were coded using Interpretative Phenomenological Analysis.

Results: Four super-ordinate themes were identified: sense of self, participation, autonomy versus dependency, and dealing with others. Themes are discussed in relation to relevant literature.

Discussion: Issues raised by participants suggest that children with cerebral palsy encounter both attitudinal and structural barriers to achieving similar developmental tasks as their peers. The impact of which may result in feelings of being different from peers, of rejection and hopelessness, all of which may impact on their sense of self and lead to psychological difficulties. Children with cerebral palsy should be supported in achieving independence and professionals should be aware that males and females may differ in both the issues they face and the methods through which they cope. Screening for the early identification of psychological difficulties is strongly recommended. Parents and professionals also need to be informed of the impact that the school environment may have on children with cerebral palsy.

Introduction

Cerebral palsy is the most common cause of physical disability in childhood (Parkes & McCusker, 2008; Parkes et al., 2008). Prevalence rates are estimated to be in the region of 2 to 2.5 per 1000 children, with approximately ten thousand new cases diagnosed every year in developed countries (Parkes & McCusker, 2008). Cerebral palsy is a non-progressive developmental disorder present from birth or early childhood. It has no cure, and can affect multiple domains, including language, cognition and praxis. Moreover, it has been associated with behavioural and emotional difficulties, epilepsy and learning disabilities (Aran et al., 2007; Rapin, 2007).

While all people with cerebral palsy will have some level of motor impairment, 60% will also have co-morbid learning disabilities, and may also be affected by co-morbid seizure disorders (50%), difficulties with hearing, speech, language or visual impairment (Pellegrino, 1997; Shapiro & Capute, 1999). Communication difficulties are common in children with cerebral palsy and speech impairments in particular affect approximately 36% of cases (Parkes, Hill et al., 2010). The presence of motor impairment can impact on speech production, facial expression, positioning of the tongue and therefore the interpretability of the speech produced. In addition, cognitive impairment can lead to delayed language development, while sensory (visual and auditory) impairments can also have adverse affects on the ability to interpret communication and conduct successful interactions with others (Pennington, 2008).

Concerning emotional difficulties, it is estimated that as many as 10% of typically developing children of five years and over may experience mental health problems (Parkes et al., 2008). This is higher in children who have a disability (Goodman, 2002; Rutter et al., 1970), including cerebral palsy (Ho et al., 2008). Goodman and Graham, (1996) reported that over 50% of their sample (N= 149; age range 6 to 10 years) of children with hemiplegia experienced psychological problems. Parkes et al., (2008) reported that approximately 25% of their sample (N=818; age range 8-12 years) with cerebral palsy were found to be experiencing psychological difficulties. Moreover, studies show that children with cerebral palsy have fewer friends and experience more rejection and victimisation than peers in mainstream school (Nadeau & Tessier, 2006; Yude et al., 1998)

The cause of this increased incidence of psychological difficulties is complex. One possible explanation is the impingement on development of independence and autonomy that may be experienced by the child with cerebral palsy. This may stem from attitudinal barriers (i.e. parents concerns over protecting their child) or from structural barriers (i.e. being able to travel independently). In a study by Blum et al., (1991), a third of adolescents with cerebral palsy reported feeling infantilised and overprotected by their parents. These young people reported resentment of this position, describing its manifestation as excessive assistance, recommendation to avoid activities and constant vigilance. This group were found to have lower scores on constructs of happiness, self-esteem and popularity, and increased scores on self-consciousness and anxiety in comparison to those who did not report overprotection.

Wood et al., (2003) argued that when children are prevented from engaging in age-appropriate tasks, they may develop a sense of helplessness. In a study by Parkes, McCullough and Madden (2010) children with cerebral palsy experienced a reduced frequency of participation in a variety of activities such as games, sports, visiting the cinema and community activities when compared to typically developing peers. For the developing child, participation is crucial in facilitating the development of identity and in allowing a smooth transition from child to adulthood (Parkes, McCullough & Madden, 2010; Sharp et al., 2007).

Owing to advances in medical technology, increasing numbers of individuals with cerebral palsy are now surviving into adulthood (Evans et al., 1990). However despite recognition of the importance of obtaining the child's perspective (Mitchell & Sloper, 2001) and of their right to express their views (article 7; UN Convention on the Rights of Persons with Disabilities, 2006) combined with acknowledgement that "children's understanding and experience of the world is different from their parents" (Thomas & O'Kane, 1998; P564), much of the evidence base focuses on the parental position (Aran et al., 2007; Brinchmann, 1999; Davis et al., 2009; Parkes & McCusker, 2008). In recognition of this, and of the discrepancy reported between parent and child report (Varni et al., 2005), it is argued that eliciting the views of the children will be more fruitful as it will provide insight into their subjective experience of the disability.

Although limited, some studies have explored the perspective of children and young people with disabilities. Maher et al., (2008) investigated the self-reported quality of life of 11-17 year olds with cerebral palsy. They reported that the majority (67%) of the sample (N=118) had quality of life scores less than would be expected for

typically developing children. Dickinson et al., (2007) however, using different measures reported that their sample (379 children, aged 8-12 years) had similar quality of life to those in the general population. The contradictory findings may be explained by the different measures employed to assess quality of life, the different domains such instruments measure, as well as the different sample populations.

The Dickinson et al., (2007) study is of note as it is part of the ongoing work of the European SPARCLE group (the **S**tudy of **Par**ticipation of **C**hildren with Cerebral palsy **L**iving in **E**urope) who have been investigating both quality of life and participation in children with cerebral palsy across Europe over the past eight years. Aiming to promote quality of life and participation for children with cerebral palsy, their investigations have explored the influence of environment on quality of life and participation. Currently the group are investigating factors that may promote quality of life and participation for children with cerebral palsy. Over the course of the project, this group have published a number of studies relating to various topics such as the psychological problems experienced by children with CP (Parkes et al., 2008), quality of life (Dickinson et al., 2007) and participation (Fauconnier et al., 2009) from a range of perspectives including that of the child (Young et al., 2007) parent and professional (Arnaud et al., 2008; White-Koning et al., 2008). The group hope that their findings will identify best practice and be used to inform policy development so as to ensure children with disabilities are able to participate to the same extent as children with out disabilities.

Much of the research that has attempted to explore quality of life in children with cerebral palsy has been through the use of structured and standardised measures

(Dickinson et al., 2007; Maher et al., 2008). Although these are advantageous in that they allow ease of collection and standardise information, they often fail to capture the subjective experience of living with cerebral palsy. Unfortunately, few authors have employed more in-depth interviews to explore this area. Davis et al., (2008) adopted a qualitative approach to elicit the perspectives of both adolescents and their parents, with the aim of developing a measure to assess the quality of life of adolescents with cerebral palsy. Their results highlighted a variety of themes that appear to effect quality of life, including participation, independence, and acceptance of disability. Such constructs have not been included in existing standardised measures. As the aim of Davis et al., (2008) was to develop quality of life measures, they did not go on to explore the impact that living with cerebral palsy has on psychological functioning.

It is therefore the aim of the current study to adopt a qualitative approach to explore children's experiences of living with cerebral palsy, with a specific focus on psychological well-being. This approach will allow children to guide the conversation with issues that are important to them, as perceived by them, as *they* live with cerebral palsy. It is anticipated that the results of the study will provide rich data that will enable a more holistic view of children with cerebral palsy, which will in turn inform clinical practice. Moreover, it is anticipated that findings will help clarify why children with cerebral palsy are at increased risk of developing psychological difficulties.

Design

Participants

In accordance with IPA methodology (Smith & Osborne, 2007) purposive sampling was used to select a homogeneous sample of participants for whom the research question was relevant. Inclusion criteria dictated that children should be between the ages of 8 and 12 years, have a diagnosis of cerebral palsy and be attending mainstream school. Children unable to communicate in English were excluded from the study. Thus the sample comprised four males and four females aged between 9 and 12 years (Male: M=10.75; SD=0.96) (Female: M=11.0; SD=1.41). All children had a diagnosis of cerebral palsy (confirmed by physiotherapists) and were attending mainstream school. A more homogeneous sample was achieved by recruiting only from Ayrshire. Data relating to participants are shown in Table 1 below. To protect anonymity, participants have been provided with gender congruent pseudonyms throughout.

Table 1: Participant data

Name	Gender	Age	GMFC (Gross Motor Function Classification) Level
David	M	10	II
Christina	F	12	IV
Calvin	M	10	I
Jack	M	11	IV
Laura	F	9	II
Susie	F	11	IV
Jordan	M	12	IV
Sophie	F	12	I

As the study employs qualitative methods and an idiographic mode of investigation, a small sample size is generally deemed acceptable. Smith and Osborn (2003) propose that sample size, while dependent on a number of factors, should be concerned with providing sufficient data to provide a detailed interpretative account of the cases included and explore any differences and similarities between accounts. Published IPA studies have typically involved samples of 6 to 12 participants (Smith & Osborn, 2003) and therefore a sample of eight participants was recruited to the current study.

The study focuses on children aged 8 to 12 years as it has been suggested that difficulties can be exacerbated during this pre-adolescence phase, when typical developmental shifts with regards to decision making tend to happen (Holmbeck et al., 2002). Moreover, this age group has been studied less than pre-school children, with the advantage of not having entered adolescence where other factors start to influence their functioning (Arnaud et al., 2008).

Procedure

Ethical approval (REC reference 11/WS/0020) was obtained from the West of Scotland Research Ethics Committee (Appendix 2.2). Children meeting inclusion criteria were identified from the caseloads of Physiotherapists and Occupational therapists. All children identified were approached by their respective caseholder and informed of the study. If they expressed interest, they received an information pack containing: a clinician letter of invitation, a parent and child information form, an opt-in slip (Appendix 2.3) and a stamped addressed envelope. When opt-in slips were returned, the chief investigator (DR) contacted the family to provide more information and to arrange to meet with the child and parent. If after meeting with and discussing

the study, the child still wished to participate, then written consent and assent was achieved and interviews commenced.

Strengths and Difficulties Questionnaire

The Strengths and Difficulties Questionnaire (SDQ, Goodman, 1999), was included as a screening measure solely to give the researcher an overall indication of the child's social functioning. Questionnaires were completed by parents and were not intended for the purpose of analysis. The SDQ is a screening tool, which provides an indication of the child's social functioning, targeting areas such as emotional/peer/conduct and hyperactivity difficulties and pro-social behaviour. Both child and parent versions of the questionnaire have acceptable levels of reliability and validity (internal consistency, mean cronbachs alpha = .73; retest stability, M=0.62; five factor structure confirmed; Goodman, 2001).

Semi-structured Interview

Data were collected via face-to-face semi-structured interviews. All interviews were recorded and later transcribed by the chief investigator. The length of interviews ranged from 16.55 to 123.56 minutes with a mean of 43.15 minutes (SD=34.18). An interview schedule (extract in Table 2 below) was developed by identifying important issues from relevant literature (Blum et al., 1991; Davis et al., 2008; Goodman & Graham, 1996; Parkes, McCullough & Madden, 2010). The measure was also informed by a previous qualitative study with children with epilepsy (Bruce, 2007). This method involved engaging children in drawing a poster relating to topics that were to be covered in the interview; it also served to build rapport. Questions were used to guide the discussion and facilitate a dialogue with participants that allowed

exploration of their experiences. Participants were reminded that there were no right or wrong answers, and that they were the expert on cerebral palsy. The researcher employed a variety of clinical skills, including reflective listening and empathising to enhance and encourage the discourse of participants. Probing questions were used to investigate issues further when necessary.

Table 2: Main Sections of Interview Schedule

What is their understanding of CP and how it effects or will affect them? *"I don't know much about CP, but I would like to find out about it. You know lots about it, so I was wondering if you could tell me what you know about it?"*
How does CP affect a young persons life? *"I would just like to start by asking about your family and friends"*
What have their experiences been like growing up with CP? *"If you think back to when you were (younger age), has CP made things good or bad for you?"*
How do they think it will affect them in the future? *"I am also interested in talking to you about the kind of things you would like to do when you grow up"*

The interview schedule (Appendix 2.4) was discussed with an ex-service user to ensure it covered relevant issues. The final version was piloted with a child of seven years with cerebral palsy and attending mainstream school. The piloting phase indicated that minor changes were required; for instance, ensuring questions were open and developmentally appropriate.

Measures

The Gross Motor Function Classification System (GMFCS, Palisano et al., 1997) was employed as a measure to classify cerebral palsy in terms of ambulation severity. Physiotherapists experienced in the use of the GMFCS provided classifications for each child.

Analysis

Data were analysed using an Interpretative Phenomenological Approach (IPA). This method is particularly suited to health psychology (Smith, 1996) and areas where there has been little investigation (Reid et al., 2005; Smith & Osborn, 2003). IPA is not theory driven, but adopts a 'bottom-up' approach, meaning that the data are analysed without attempts to mould it into pre-existing theoretical paradigms.

The central aim of IPA is to attempt to gain an understanding of the experience of the individual from their point of view. It also recognises that achieving an 'insider perspective' (Smith & Osborn, 2003) is somewhat impossible, as the process of obtaining this is dependent on the researcher's interpretation of the data. Indeed, Smith and Osborn (2003) propose that in using IPA there are essentially two stages of interpretation; the initial stage being where "the participants are trying to make sense of their world" and the second being where the "researcher is trying to make sense of the participants trying to make sense of their world" (pp. 51).

Guidelines on conducting an interpretative phenomenological analysis (Smith & Osborn, 2007) were employed in the current study. Initial stages involved familiarising one self with the data, by listening to and transcribing interviews, and through reading and re-reading of transcripts. During these stages, notes were made on potential points of interest in the left margin of the documents. Following which, the transcripts were returned to and initial notes and ideas were developed into themes, which were noted in the right margin. The next stage in analysis involved a process of data reduction, as preliminary themes were clustered together to form super-ordinate themes, culminating in a final set of themes. Through an iterative

process, a close interaction between the reader and the text took place, whereby the reader checked back and forth between text and interpretation to insure accuracy of interpretation. In keeping with an idiographic approach, the emergent themes from analysis of the first transcript were set aside and the next transcript analysed from scratch. Following analyses of all transcripts, a cross-case analysis was employed to identify commonalities and differences across the data set, culminating in a master list of super-ordinate themes (See Figure 1). An example of a coded transcript can be found in appendix 2.5.

Reflexivity and Reliability

IPA acknowledges that the researcher's own bias can affect interpretation of data, thus necessitating a reflexive approach by the researcher. This reflexivity is viewed as a strength of IPA as it increases the transparency of the analyses (Reid et al., 2005; Storey, 2007). In relation to this, the main researcher kept reflective notes following each interview, in addition to notes on personal thoughts and feelings during transcription and analysis. The main researcher had worked with a child with cerebral palsy and had some insight into the challenges they encountered. Reflecting on this experience, the researcher acknowledges the admiration felt for these children, and of their resilience and positive attitude.

To determine reliability of the analysis, two transcripts were analysed by an independent researcher experienced in the use of IPA to verify whether themes reflected the views of participants. Two additional transcripts were analysed by another clinician to verify identification of themes. Levels of agreement were high and discussion focussed upon the labelling of themes.

Results

The Strengths and Difficulties Questionnaire (SDQ)

SDQ data were collected as a descriptive measure. Scores are shown below in Table 3. Scores were compared with norms and show that all children in the sample function with in 'normal' ranges for strengths (6-10) and the majority do for difficulties (0-13), with the exception that one child scored within the 'abnormal' (17-40) range on difficulties, while another scored in the 'borderline' (14-16) range.

Table 3: SDQ Scores

Child	Total Difficulties Score	Total Strengths Score
David	8	8
Christina	1	9
Calvin	2	10
Jack	20	9
Laura	11	8
Susie	1	9
Jordan	16	10
Sophie	5	10

Interview Data

Participants were asked to talk about what it was like to have cerebral palsy, talking around topics such as friends, family, peers, cerebral palsy and the future. Accounts clustered around four super-ordinate themes: sense of self, autonomy Vs dependency, participation, and dealing with others. These are illustrated in Figure 1 below, along with sub-themes.

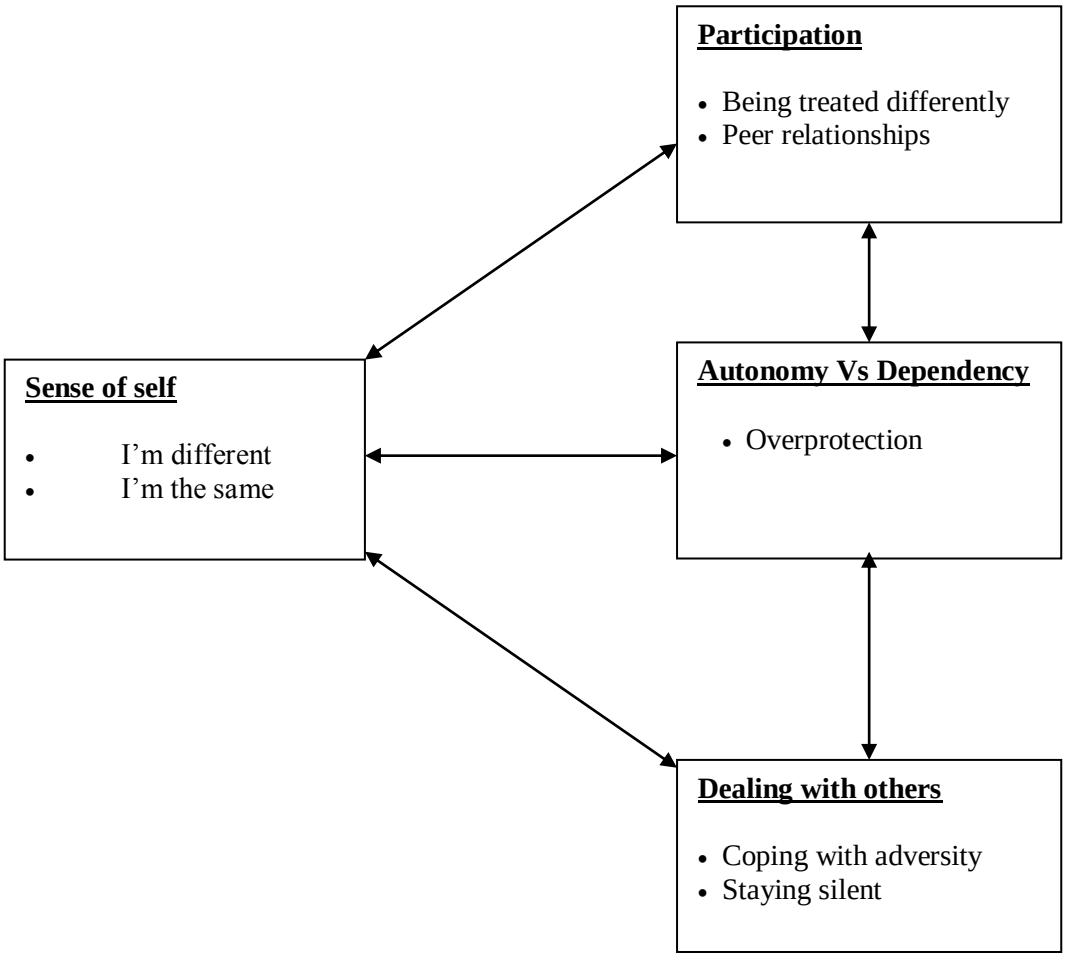

Figure 1: Model of Super-ordinate Themes

As illustrated in Figure 1, a reciprocal relationship between themes is hypothesised. Sense of self is affected by levels of participation in so far as being treated differently and having or not having peer relationships impacts on the sense of self. Moreover participation is linked to autonomy and overprotection in so much as they may reduce levels of participation. These constructs may also impact on sense of self as overprotection may give the individuals the message that they are helpless and incompetent. The ability to deal with others may be dependent on how that individual conceives of themselves, and may be related to overprotection and independence. For

example, an individual with a strong sense of self may be more confident in dealing with others, conversely someone who is overprotected and believes they are helpless may not have the confidence to deal with adversity in an adaptable manner.

Key to quotes
…Short pause
(…) Text omitted to shorten quote
[text] explanatory information included by author
DR – comment by interviewer
C – comment by child

Theme 1: Sense of self

The majority of participants talked openly about cerebral palsy and through their discourse it was apparent that despite recognition of their condition, their sense of self or self-concept was not defined by cerebral palsy:

"*I'm not very disabled, cause all I mean is I've got it in my legs but I'm ok…It's just here, (…) from here to down here is just disabled…its only my leg, its not like its my personality, I'm fine, (…)…I don't really thingwe as being disabled, although I'm in a wheelchair, that's all I class myself as"* (Susie, age 11).

DR: *"Has cerebral palsy made things good or bad for you in any way?"*

C: *"Em, I don't know"*

DR: *"Does it make life different?"*

C: *"Not really, cause I can still do stuff like with my friends and stuff"* (Christina, age 12)

"I just need more help" (Calvin, age 10).

Despite not conceiving of themselves as having cerebral palsy however, children often recognised the limitations they experienced in relation to their condition. In particular they recognised how they were often different from others:

"I can't stand the same (...) I'm very slow, very slow, I take 15-20 mins" [getting changed for gym] (David, age 10).

"I can't physically play tennis and basketball" (Calvin, age 10).

"If I wanted to walk to the park I couldn't, I would need my wheelchair half the way" (Laura, age 9).

"All my friends can walk, I can't" (Jack, age 11).

For the majority of children, there was an acceptance of being different, but for a minority there was evidence of distress in relation to being different from others:

"I would like to do everything the way that other people do them, instead of the way I do them…teachers say, you're going to have to do it your way, (...)…but I would like to try it their way…would just feel like I would be the same… but

what I don't like about it is that I find different from everybody else…because I have to use a walker and everybody else can run" (Laura, age 9).

"They can wear Ugg boots, everything like that, I can't, I can't wear Ugg boots" (Laura, age 9).

For a few children there was some reluctance to talk about what they found difficult, and throughout the interview they attempted to minimise these differences. These children tended to focus the discussion on what they could do, rather than what they could not do.

"I'm very fast last night getting changed…I'll show you" (David, age 10).

This is particularly well illustrated through one participant's use of 'you' when talking about difficulties associated with having cerebral palsy, and the switch to 'I' when discussing strengths:

"It's a eh thing you can't walk…and you can't actually… write…but you can actually do more…than just that, you can type, you can ride a bike…actually em I'm starting to walk…(…) I can actually do quite a lot of stuff" (Jordan, age 12).

Relating to this, even when participants recognised that they differed from others, the majority of children interviewed recognised that they had areas of strength and similarity to their peers:

"I'm good at jumping" (David, age 10).

"Even though I'm disabled, I can still play like everyone…I can still speak like everyone" (Susie, age 11).

"I'm a world record holder…on a three wheeled bike…if I didn't have cerebral palsy, I wouldn't be able to compete in disability running" (Calvin, age 10).

Christina (age 12) stated *"good, so not really that different"* after talking about how she likes to go shopping with her friends.

Most children could recognise both their similarities and differences, but for some it appeared to lead to what may be viewed as a sense of conflict for the self. For instance, Christine acknowledged that she needed assistance getting ready in the morning, however, was also adamant in describing her independence. This conflict perhaps relates to her stage of development, in so much as despite having to be dependent for some things, she desires and strives to achieve the same independence and autonomy as her peers.

"Well eh, I have to get people to dress me in the morning…but like I'm quite independent" (Christine, age 12).

Theme 2: Participation

Throughout the interviews, children discussed their participation in everyday activities, both within and outside the school environment. Some of the children felt they were treated differently from other young people and excluded from activities that their peers engaged in. In addition, the children talked about how this impacted upon their peer relationships. Such themes were apparent across the sample to varying degrees.

Being treated differently

For many children, one of the topics raised was their inability to engage in physical education (P.E) to the same extent as their peers. These lessons did not seem to cater for their needs and as such they felt excluded. Consequently, participants reported a range of feelings in relation to the exclusion surrounding P.E lessons:

> *"I don't mind* [not being able to participate in P.E lessons]*...because I do a lot out of school anyway"* (Sophie, age 12).

Calvin expressed a feeling of sadness in being excluded from P.E lessons, and in relation to this, he hoped for change:

> *"In the inclusion squad we try to make up P.E. lessons for disabled…* [in talking about how it would be to have P.E. lessons in which he could participate, he suggested that it would be] *wonderful"* (Calvin, age 10).

As suggested by these quotes, participation appeared restricted due to the physical disability, which prevented participation in P.E. lessons. However, children's ability to participate was also influenced by having to attend appointments and use communication devices, in addition to structural barriers such as the use of wheelchairs and walkers. In spite of this, however, for some children there was a sense of acceptance in terms of the restriction their disability placed on their participation.

> [Talking about having to be taken out of class to attend appointments with doctors and physiotherapists] *"It just feels like I'm not part of the class, I'm not part of the world, it feels like I'm just alone in my wee world (…) it just feels like I'm a wee kid, I'm alone in this big world…I get treated differently…I have to get taken out of class for appointments…it's the way some people treat me compared to others…and it's not fair"* (Laura, age 9).

> *"Sometimes I can't em like go places…I can't go places where there's like stairs…the wheelchair can't get up the stairs"* [in relation to this, Christina was asked how she felt about not being able to go certain places with her friends] "*…I'm used to it…I know I can go with them next time"* (Christina, age 12).

One child used a communication device, which he acknowledged added to his exclusion and isolation:

"They're missing out on my opinion" [which made him feel] *"sad,"* he elaborated on this later stating that he felt *"left out" "sad and angry"* (Calvin, age 10).

Peer Relationships

While some children talked of their peer relationships, and taking part in extra curricular activities, for others there was a sense of limited social contact with peers. Of those who talked of peers and activities, it seemed that they engaged in a range of pastimes:

"I've got a lot of friends from it [club she attends] *and I keep in contact with them (…) if I don't see her at home, maybe just text her and say, hi, how you doing and stuff"* (Susie, age 11).

"We just sit and chat and stuff (…) we sit at the tables and eat our snacks and then we chat, and sometimes we go outside, or go down the town" (Christina, age 12).

"*I've got Centre Stage* [a club for singing and dancing] *…but that's not until Monday…. and go to after school* [club] *Tuesday, Wednesday and Thursday, and then a Friday, I've got the girls club – so it's quite a busy schedule"* (Susie, age 11).

"Em, we're training twice [a week] *for athletics, twice for swimming, and once for horse riding"* (Sophie, age 12).

It is encouraging that children do feel included and many reported having good social relationships. Nonetheless, this was not universal across the sample, and for several children there was a lack of interaction with peers:

> *DR: "Ok do you ever play with friends at home or just at school?"*
>
> *C: "Well not really…No I play at school with my friends on a few occasions"*
>
> *DR: "Do you play anything with your friends at school?"*
>
> *C*: *"Well yes I remember once, it might have been the day we went into Primary 7"* (Jack, age 11).

Such isolation was also apparent for David, age 10. In talking about whom he played with, David stated that he had no friends at home, and that often he spent time in the company of his parents or a younger relative.

Relating to socialising, and while talking about how he felt about cerebral palsy, Jordan expressed upset, as having a wheelchair impacted on his ability to socialise when the weather was poor. When asked how he felt about cerebral palsy, he stated:

> *"Quite upset about it, because every time I can't get out it's raining, and I can't get in people's houses…because of the chair"* (Jordan, age 12).

Theme 3: Autonomy Versus Dependency

The third theme of autonomy versus dependency includes the two sub-themes of demonstrating independence/self advocacy, and that of parental overprotection. These themes appeared for half of the sample. While some children demonstrated and

embraced their self-advocacy and growing independence, others expressed frustration as they strived to achieve it. The presence of both structural and attitudinal barriers often seemed to hinder the development of autonomy.

Demonstrating independence and self-advocacy:

Some of the children clearly demonstrated their independence when talking about their pastimes or in regards to requiring support:

> *"[I] go out shopping myself and go to the cinema myself and stuff"* (Christina, age 12).

> "*When I say I need help, I need help, but when I say I don't need help, I don't need help basically"* (Susie, age 11).

Other children expressed frustration, as they desired to be more independent and to individuate from their parents. For instance, Laura was aware of the support she needed from her parents in everyday activities, nonetheless, during the interview she expressed the unfairness she felt that she could not engage in age-normative activities that her peers and younger sibling engaged in:

> *"They don't need someone right beside them…they can go off and wander by themselves…but I need to be with somebody…which is not fair…its like I'm, a kid…it feels like I'm not growing up at all (…) I'm not allowed to wander away by myself like* [younger sibling] *can do"* (Laura, age 9).

"It would feel good, it would feel like I would be with my friends…and I could do stuff, I could do stuff myself, which I can, but it feels like em I'm just a kid, I can't do anything, like I'm locked somewhere, I'm not allowed to go out there" (Laura, age 9).

"I wish I was more independent…[I would like to] *play at someone else's house without Mum more often"* (Calvin, age 10).

Parental overprotection

A sense of overprotection was apparent in children's desire to be more independent, especially so when they compared themselves to their same age or younger siblings.

"Feels like I'm a wee kid, I'm getting left in the house with Mum and Dad, when [sibling] *and* [sibling] *is away out…it just feels like I'm a wee kid, (…) I'm not growing up"* In relation to playing outside, she said *"Mum would check on* [sibling] *but not as much as she checks on me"* (Laura, age 9).

Jordan talked of the activities that his twin engaged in, and during this section of the interview, he elaborated on how he felt about his twin going out to places that he was not allowed to go:

"Quite disappointing, that I don't get to go with her…I wanted to go out with her but she goes to [Name of town] *and my Mum won't let me"* (Jordan, age 12).

During some interviews it was apparent that parents wanted to keep the child with cerebral palsy proximally closer to them than their typically developing child. A situation which may reflect some level of overprotection, but arguably also the parents awareness of the child's needs and vulnerability, and the desire to protect them from harm.

Theme 4: Dealing with others

The final theme was dealing with others, and it related to the children's experiences of interactions with other people, mostly peers. This theme included the sub-themes of coping with adversity caused via interaction with others, and that of silence. Coping with adversity was apparent across half of the sample, while a theme of silence was more common.

Coping with adversity

Some children documented negative experiences in having to deal with the attitudes and behaviour of other people, predominantly peers. However, this was not universal, for some children, dealing with the attitudes of others caused no distress.

This theme appears to have a reciprocal relationship with other themes. As it seems that independence, sense of self, and the presence of peer relationships appear to relate to how some children dealt with situations of adversity. For instance, the following account demonstrates that when Christina, experienced bullying, she sought help from teachers, but was also very much supported by her peer relationships. This indicates that she has a sense of self that conceives of herself as important, worthwhile and as an agent of change:

"This one boy…he kept coming up to me and saying 'Steven Hawkin' and he kept kicking my wheelchair…[so] *I went to guidance, and they sorted him out…and ma friends sorted him out"* [talking about another situation involving another boy, she stated] "*he kept saying I got a special chair and stuff…and just being nasty…*[so my] friends *went up to him and we challenged him"* (Christina, age 12).

For others, the support and use of peers was not apparent in how they dealt with situations of adversity. For example, Jordan despite later informing his father, chose to deal with a bully himself. This style of coping may reflect a lack of peer support, but also demonstrates that he has sufficient levels of independence, combined with a sense of self as an agent of change and capability, to deal with this situation on his own.

"I run over them (…) I chased somebody down the street" (Jordan, age 12).

Calvin's experience appeared less confrontational, and again he chose to deal with the situation alone, trying to understand the behaviour of others rather than to take action.

"…some people don't understand the condition I have (…) the little ones keep asking questions about 'why does he need that thing to help him.' In reflecting on how he felt about this, he stated, "*I don't mind, that's what little ones do"* (Calvin, age 10).

It may be argued that Calvin's account reflects a strong sense of self as he accepts that people will ask about why he uses a device to help him talk. He demonstrates a deep level of understanding in that he knows and accepts that young children naturally ask questions. He also externalises the problem, as he views this as a reflection on others rather than himself, which may serve to protect his sense of self.

The above quotes demonstrate the children's resilience in dealing with bullying and social exclusion, and in particular the importance of having good peer relationships and a sense of self as capable and competent. Nonetheless, this was not easy for all children, and for a few, there was a strong sense of frustration in dealing with others and their lack of understanding of their condition:

> *"Cause everybody else like…doesn't understand…If they had it then, then they'd feel different and I could easily go 'ha, ha, ha' instead of them doing it to me (…) this girl…she says …I would like to have a shot of the wheelchair, could you get out and let me in there, and I'm like, I can't get out! I can't do this!…You would not like to have this, you would not lie to have what I've got!"* (Laura, age 9).

> *C: "And what I would like to say is that like I wish I, I wish I was born, but that I wasn't born like this"*
> *DR: "And do you say that to them?"*
> *C: "Well I've not said it, but I think it"* (Laura, age 9).

Silence

A theme relating to dealing with others is that of silence. It was apparent that some children chose not to talk to others about cerebral palsy because it may result in ridicule.

When asked if they talked to others about cerebral palsy, they stated:

> *"Maybe, but not that much, I would rather not just in case they told other people about it…I would ask them to keep it to me, in case they said 'she's got this and she's got that' 'ha ha ha ha', so I'd rather just keep it to myself basically"* (Laura, age 9).

> *"I just want to keep it to myself, don't tell anybody…they would tell their friends and they would come and tell me"* (Jordan, age 12).

Conversely, the children in this study reported that they enjoyed the interview process and the opportunity to share their experiences. This suggested that these children did have issues and concerns they wanted to discuss, however, perhaps did not have anyone they felt comfortable doing so with. This is illustrated by Calvin who expressed a desire to talk about cerebral palsy with *"other people who are keen to help"*, although not with his parents.

Discussion

The overall aim of this study was to explore the experiences of children living with cerebral palsy, while trying to identify reasons for why they may be at increased risk of developing psychological difficulties.

Reflection on SDQ data

Scores on the parent rated SDQ's show that one child scored in the abnormal range for total difficulties, while one scored in the borderline range. Of note is that both of these children found it difficult to talk in the interview about their weaknesses in relation to having cerebral palsy and difficulties with peers. Additionally, the parent's questionnaire of one participant, Laura, age 9, did not reflect the level of frustration apparent in her discourse, for example in relation to feeling different. This may relate to the reluctance that participants had in talking about cerebral palsy with others, including parents (theme of silence). Consequently, Laura may have been experienced in hiding her feelings and worries from others. The inconsistency between parent and child report is often noted in quality of life literature (Varni et al., 2005). Parents tend to focus more on the physical well-being, and support needs of their children, rather than their emotional well-being. A consequence of this is that emotional difficulties can exacerbate in these children to the point of becoming a significant mental health problem.

Reflections on interviews

Some participants were unable to communicate clearly during the interview and found it difficult to reflect and talk about their life and condition, which may have impacted on the quality of data collected. Consequently, some interviews were more didactic

than anticipated. Given the range of potential difficulties associated with cerebral palsy, and the developmental stage of participants, it was expected that some may struggle to both reflect and communicate their feelings. Moreover, some children were not keen to talk about their difficulties and would change subject at such times, perhaps as a way of coping. Of recognition is that this may have been a novel experience for these children, especially given that most of them said that they did not talk to anyone about their condition.

Main Findings

Four super-ordinate themes emerged: sense of self, participation, autonomy versus dependency and dealing with others. These will be discussed separately below, however, the reciprocal relationship between each of these themes is acknowledged.

Sense of self

Societal views of cerebral palsy lead to the assumption that its presence would have a detrimental impact on how children with the condition view themselves (Shields et al., 2007), and some research suggests that children with cerebral palsy schooled in a mainstream environment have poorer self-concept than children in special schooling environments (Russo et al., 2008). However, a systematic review suggests that while children with cerebral palsy may feel less competent in areas such as athletic, scholastic and social achievement, they do not differ from typically developing children on global self-worth (Shields et al., 2006; 2007). It has been suggested that these individuals are aware of their own areas of strengths and difficulties, and it is this awareness that can act as a protective factor for overall self-worth; when individuals know their capabilities, they can maximise what they can achieve (Huitt,

2009; Shikako-Thomas et al., 2009). In relation to focussing on what one can do as opposed to what one cannot do, appears functional, and this was apparent in the findings of a qualitative study with children with cerebral palsy where children talked with a sense of pride about what they could do with their bodies (Young et al., 2007). The children in the current study were well aware of their similarities and differences to their peers, and from an objective point of view, this appeared to feed into a sense of conflict in their self-concept. However, a better term would be a 'sense of balance', where children were aware of limitations caused by their disability, yet were also aware of their individual strengths.

Males in the current study were more reluctant to talk of their weaknesses than females. This could reflect defence mechanisms such as avoidance or denial, where individuals essentially ignore aspects of the self that are incongruent to maintaining their sense of self. For example, a child could deny or avoid recognising that he cannot play football, but still maintain the view that he is strong and capable by focussing on the fact that he rides an adapted bike. Alternatively, Carr (2006) reports that males experience an increase in testosterone during puberty and their reluctance to acknowledge any weakness in ability could be a reflection of their need to compete at this age. As females tend to experience or present more frequently with psychological difficulties, it could be that the coping style of males, acts as a protective factor to self-esteem, whereby they focus on what they can do instead of focussing on what they cannot do.

Participation

Participation refers to the ability to join in life situations, such as socialising with peers (Parkes, McCullough & Madden, 2010). This is an important facilitator for the development of identity in young people (Sharp et al., 2007). Unfortunately, research suggests that children with disabilities participate less in activities and social relationships than typically developing children (Blum et al., 1991; Parkes, McCullough & Madden, 2010). The current study found that while some children enjoyed peer relationships and participating in activities, for others there was a strong sense of isolation and exclusion. These findings are consistent with those of Young et al., (2007) who also reported that children with cerebral palsy expressed feelings of isolation and wished to spend more time with peers.

These children frequently reported feeling different from their peers and reported having little contact with them outside of school. At a time when peer relationships are becoming increasingly important, these children appear to have less opportunity to develop more mature relationships (Blum et al., 1991).

Research suggests that children with cerebral palsy, and particularly females, experience higher levels of rejection than typically developing children (Nadeau & Tessier, 2006). This relates to findings of the current study in that one female reported feeling very different to her peers. Consideration of gender differences suggest that males coping and interpersonal styles may be protective for their sense of self, whereas females style of interacting may lead to an increased risk of rejection. These findings are important as they highlight the differential support needs of males and

females, indicating that professionals should be aware of these differences so they can support children in dealing with peer relationships.

Consideration of different coping styles may relate to reasons for the discrepancy between interview and questionnaire data. If males tended to externalise behaviour, parents would be aware of it, whereas perhaps the female tended to internalise, and so her parent was less aware of her difficulties. In support of this, research supports higher levels of internalising in females and externalising behaviour in males (Leadbeater et al., 1999).

Dealing with others

This theme relates to participants experiences of dealing with other people. For some children there were no difficulties, however, for others there was evidence of bullying. This is consistent with the findings of Young et al., (2007) who also suggest that teasing and name-calling were evident in the peer relationships of children with cerebral palsy. Research suggests that children with cerebral palsy are at increased risk of rejection, isolation and victimisation (Nadeau & Tessier, 2006; Yude et al., 1998). The presence of peer relationships is documented to be a protective factor against victimisation (Nangle et al., 2003) and one child in the study (Christina, age 12) used her peers in this manner. For children without these protective factors, such experiences may lead to low self-esteem, poor self-concept, feelings of helplessness, anxiety, reduced participation, and less independence. Consequently, this may be one cause of the increased frequency of psychological difficulties reported in this population (Goodman, 2002).

Developing and maintaining successful friendships relies on individuals having the necessary social skills and ability to grasp the subtle social rules that govern social behaviour. It has been suggested that due to brain damage, children with cerebral palsy may have difficulty regulating emotion and learning behaviour, thus leading to difficulties in peer relationships (Colver, 2010), which in turn places them at increased risk of psychological difficulties (Carr, 2006).

Silence

Most children reported that they did not talk to others about cerebral palsy. While for some children it could be that they would not know where to obtain support, for others, silence appeared related to a fear of ridicule. It may be that talking about the condition would emphasise how they differ from their peers, thus increasing the likelihood of further rejection and victimisation.

Autonomy versus Dependency

The theme of autonomy versus dependency, while varying in its manifestation, was apparent for half of the sample. For some children there was a sense of growing independence, of being able to go out alone, and being able to self-advocate. This is encouraging as it is through being able to interact with the environment that one can achieve a sense mastery and a sense of being an effective agent (Bandura, 1997). As children mature they engage in new roles, leading to a sense of social worth and competence (Blum et al., 1991). However, for some children there was a strong sense of desiring independence but being unable to achieve it because of perceived parental overprotection. The importance of autonomy was a theme identified also by Young et al., (2007) who report that it appeared important especially for older males in their

study. Research indicates that overprotection can lead to feelings of hopelessness, parental resentment, increased anxiety, self-consciousness and lower self-esteem (Blum et al., 1991; Wood et al., 2003). However, in appreciation of parents' natural desire to protect their child, it is recognised that parents may require support in knowing how to emotionally and practically facilitate their child's growing independence, while continuing to function in a relationship where the child remains dependent for many aspects of living.

Conclusions

Findings of this study indicate that children's experience of life with cerebral palsy needs to be understood within the context of typical development. At stages where typically developing children are striving to be the same as their peers and to develop their levels of independence, it seems that some children with cerebral palsy are struggling. For these individuals, they face additional challenges and barriers to developing their identities and autonomy. The children in this study did not view themselves as disabled, and consequently were striving in a mainstream environment to be the same as theirs peers. It seemed that what prevented them from achieving was the system around them, rather than their disability per se. For example, being excluded from classes, being prevented from engaging in age-appropriate tasks, for many children led to feelings of frustration and could potentially develop into more serious psychological difficulties. These results are important as they highlight the differential support needs of children with cerebral palsy as they function within a mainstream school environment. These results withstanding, the potential of deficits in emotional processing and the impact this may have on peer relationships has not been ruled out.

Future Research & Clinical Implications

Future research should aim to disentangle whether a neurological deficit may underlie the difficulties children have with peer relationships, or whether these are manifestations of the psychological sequeale of having a disability in our society. The results of this study go further than those collected via standardised questionnaires, because they draw attention to issues provided by children themselves. Findings show that children with cerebral palsy are striving to achieve the same developmental tasks as their peers. Therefore it is argued that professionals should provide interventions that will support this. Screening for mental health difficulties at routine appointments will allow early intervention before psychological difficulties become entrenched. In addition, support groups for children with cerebral palsy could address their feelings of being different, while parent groups could focus on supporting the development of independence, and the transition to adulthood. It would also be interesting to investigate whether children with cerebral palsy educated in special schooling would express different concerns.

Strengths and Limitations

Strengths are that this was the first study to directly access the views of children regarding their experience of life with cerebral palsy. However, the sample was limited to eight children from mainstream schools, and consequently, it is likely that the experiences of other children will differ.

Final Conclusions

Children with cerebral palsy who are functioning within a mainstream schooling environment are striving to achieve similar developmental milestones to their

typically developing peers. They however, encounter both attitudinal and structural barriers to achieving this, the impact of which may result in feelings of being different from peers, of rejection and hopelessness all of which may impact of their sense of self and lead to psychological difficulties. In view of this, professionals need to be aware of the different issues with which males and females cope and perhaps offer regular screening for mental health difficulties.

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Chapter Three

Advanced Clinical Practice I

Reflective Critical Account

The analogy of the porpoise: A helpful reframe on the feared experience of getting it wrong.

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Submitted in partial fulfilment of the requirements for the degree of Doctorate in Clinical Psychology (DclinPsy)

Abstract

Introduction

The following reflective account centres around my experience of communicating psychological knowledge to others when I was asked to deliver an information session on personality disorder to a group of assistant clinical psychologists. This experience was chosen because it allowed me to realise something important about myself, in that I think I have a fear of getting things wrong, moreover the experience made me reflect on this fear and reframe it through an analogy. In addition, designing and delivering this information sharing session allowed me to realise the importance of disseminating psychological knowledge, the impact of which is considered in the context of both the National Occupational Standards for Psychology (2002) and Delivering for Mental Health, (2006).

Reflection

Employing Gibbs' (1988) model, I reflect on the experience of being asked to design and deliver psychological knowledge for dissemination. Progressing through the stages of the model, I consider the impact of my thoughts and feelings before considering what I could do differently in the future. I also realise, reflect and reframe my fear of getting it wrong.

Reflective Review

Writing this reflective account has allowed me to realise that I am always learning about myself. Moreover, reflecting on the experience, and on reading about reflection has allowed me to further appreciate the benefits and need for reflection. It is an activity that I have grown to enjoy, and one which I intend to embrace as much as

possible as my career develops. I also consider whether given the level of insight and learning achieved through reflection, it could be proposed that we have an ethical need to engage in self-reflection for the benefit of our practice and our clients.

Chapter Four

Advanced Clinical Practice II

Reflective Critical Account

Reflecting on service delivery via the group experience, as I reconcile my relationship with attachment theory.

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Abstract

Introduction

This reflective account focuses on my experience of delivering psychodynamic individual and group therapy because this facilitated my reflection on the management and delivery of services for people with personality disorder. Involvement in the group experience allowed me to reflect on my relationship with different theories and to learn something about myself and my practice; it also allowed me to see progress as I attempted to change my practice following such realisation.

Reflection

Employing Kolb's (1984) model of experiential learning, I reflect on the experience of not knowing what was expected of me, and my experiences in the group. Moving through the model, I recognise a tendency I have to want to diffuse states of high emotional arousal. Working with the impact of my thoughts, feelings, and new learning, I attempt to deal with my difficult feelings when having to sit with and tolerate high arousal. Moving on from the group experience itself, I reflect on the evidence base, and I consider service management and delivery and the benefits of group therapy for individuals with personality disorder. I frame this in the context of National Occupational Standards for Psychology (2002).

Reflective Review

Through reflection I came to appreciate my tendency to want to diffuse situations and the need to change this for the sake of my practice. In addition, I came to appreciate how much I learned through the group experience and the benefits this would have for individuals with personality disorder. I was also able to reconcile my relationships

with different therapeutic models. I conclude by reflecting on how personal growth can aid practice as it allows a deeper appreciation of the client's experience.

Systematic Review Appendices

Appendix 1.1: Journal Guidelines for Submission

Manuscript Submission Guidelines
Journal of Child Health Care

Journal of Child Health Care is a broad ranging, international, professionally-oriented, interdisciplinary and peer reviewed journal. It focuses on issues related to the health and health care of neonates, children, young people and their families, including areas such as illness, disability, complex needs, well-being, quality of life and mental health care in a diverse range of settings. The *Journal of Child Health Care* publishes original theoretical, empirical and review papers which have application to a wide variety of disciplines.

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Each manuscript is reviewed by at least two referees. All manuscripts are reviewed as rapidly as possible, and an editorial decision is generally reached within 4-6 weeks of submission

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All manuscripts are reviewed initially by the Editors and only those papers that meet the scientific and editorial standards of the journal, and fit within the aims and scope of the journal, will be sent for outside review.

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The Journal of Child Health Care publishes original **theoretical, empirical and review papers** on child health issues.

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In order to protect the identity of children, families and staff, authors should use pseudonyms and remove any information leading to identification of any of the individuals described in the study. The only time that the Editors will consider overriding this convention is if children, families and staff have specifically consented for their identity not to be protected in this way (evidence of this will be required).

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All contributors who do not meet the criteria for authorship should be listed in an `Acknowledgements' section. Examples of those who might be acknowledged include a person who provided purely technical help, writing assistance, or a department chair who provided only general support. Authors should disclose whether they had any writing assistance and identify the entity that paid for this assistance.

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The text should be double-spaced throughout and with a minimum of 3cm for left and right hand margins and 5cm at head and foot. Text should be standard 10 or 12 point. Manuscripts should not exceed 3500 words unless specifically approved by the Editor. Manuscripts which exceed this word limt are likely to be returned.

9.4.1 Keywords and Abstracts: Helping readers find your article online

The title, keywords and abstract are key to ensuring readers find your article online through online search engines such as Google. Please refer to the information and guidance on how best to title your article, write your abstract and select your keywords by visiting SAGE's Journal Author Gateway Guidelines on How to Help Readers Find Your Article Online.

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Provide full contact details for the corresponding author including email, mailing address and telephone numbers. Academic affiliations are required for all co-authors. These details should be presented separately to the main text of the article to facilitate anonymous peer review.

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11. Further information

Any correspondence, queries or additional requests for information on the Manuscript Submission process should be sent to the Editorial Office at bcarter@uclan.ac.uk.

Appendix 1.2:Quality Rating Scale

Author:		
Title:		
Design:		
1. Study	Comparison group	2
	Comparison with published norms	1
	No comparison (not included in review)	0
2. Research Question/Aims	Questions clear, aims stated	2
	Questions or aims unclear	1
	Questions and aims unclear or not stated	0
Section score / 4		
3. Sample selection	*Selection of CP group*	
	Geographical	4
	Random	3
	Convenience	2
	Volunteer	1
	Unclear how sample was achieved	0
	Selection of TD group or norm data	
	Group matched on age, sex, demographics	3
	Group matched on 2 of the above	2
	Group matched on 1 of the above	1
	No matching/discussion of matching	0
	Unclear how sample was achieved	0
Section score / 7		
4. Sample data	*Demographics*	
	Gender, age, SES, diagnosis, schooling stated	5
	Any 4 of the above (state which)	4
	Any 3 of the above (state which)	3
	Any 2 stated (state which)	2
	Any 1 stated (state which)	1
Section score / 5		

5. Measurement of disability	*Level of Motor Function assessed*	
	Yes, reported and discussed	2
	Yes reported	1
	No	0
	Assessed using a standardised measure	1
	Non-standard measure/not measured	0
Section score / 3		
6. Data on non-respondents	*Data supplied regarding non participants*	
	Yes, discussion of demographics	2
	Yes, acknowledged not discussed	1
	No	0
Section score / 2		
7. Inclusion/exclusion	*Inclusion/Exclusion criteria stated*	
	Yes	1
	No	0
Section score / 1		
8.Measures/Administration	*Measures used to quantify QOL/HRQOL*	
	Standardised	1
	Non-standardised (idioscyratic measure)	0
	Measure score	
	Reliable/Valid	2
	Questionable reliability/validity	1
	Poor levels of reliability/validity	0
	Reliability/Validity score	
	Administration of measures	
	Procedure/Conditions stated who, where	2
	Procedure / conditions stated one of the above	1
	Procedure unclear - unreplicable	0
	Administration score	
Section score / 5		

9. Confounding Factors	*Any potentially confounding factors* (for example, study includes proxy report without highlighting that the data is not all self-report)	
10. Statistical Analysis	*Analysis appropriate to design*	
	Yes No	1 0
	Data/Results presented clearly	
	Yes both	2
	One or other presented clearly	1
	No	0
	CI, P values, Es reported appropriately	
	Yes No	1 0
	Power Calculation	
	Yes stated and reported No not stated	1 0
	Management of Missing data	
	Yes discussed and managed	1
	N/A	1
	No/Inconsistencies in data	0
Section score / 6		
11. Discussion	*Conclusions flow from results*	
	Yes No	1 0
	Recommendations are made for clinical practice or future research based upon the findings of the study	
	Yes No	1 0

	Limitations Acknowledged	
	Yes	1
	No	0
Section score / 3		
Total Score / 36		

Appendix 1.3: Measures employed by studies in the review

Table 2: HRQOL Measures

Measure	Construct Measured	Domains Measured
KIDSCREEN	HRQOL	• Physical well-being • Psychological well-being • Moods and emotions • Self-perception • Autonomy • Parent relationship and home life • Financial resources • Peers and social support • School environment • Bullying
Pediatric Quality of Life Inventory (PedsQL)	HRQOL	• Physical functioning • Emotional functioning • Social functioning • School functioning
TNO-AZL (TACQOL- CF)	HRQOL	• Motor functioning • Physical functioning • Autonomous functioning • Cognitive functioning • Social functioning • Positive Moods • Negative Moods
Youth Quality of Life Instrument – Research version (YQOL-R)	QOL	• Total QOL • Sense of self • Social relations • Culture/Community environment • General QOL

Appendix 1.4: Studies excluded from systematic review

Author/Date	Reason for exclusion
1. Alsem et al., (2010)	Parent report
2. Aran et al., (2007)	Parent report
3. Bjornson & Mclaughlin (2001)	Article discussing HRQOL measures
4. Bjornson et al., (2008)	Investigated the impact of physical mobility on HRQOL
5. Carlon et al., (2010)	Systematic review of HRQOL/QOL measures for children with CP
6. Ceiciniece et al., (2009)	Poster presentation
7. Colver et al., (2006)	SPARCLE: study protocol
8. Cuomo et al., (2007)	Outcome study
9. Davis et al., (2008)	Commentary
9. Davis et al., (2009)	Outcome study
10. Davis et al., (2009)	Qualitative research
11. Davis et al., (2010)	Questionnaire validation study (CP-QOL teen)
12. Davis et al., (2010)	Questionnaire comparison study
13. Demuth et al., (2006)	Poster presentation, parent versus child perspective
14. Dickinson et al., (2006)	Assessment of data quality of SPARCLE study
15. Dieruf et al., (2009)	Outcome study
16. Du et al., (2010)	Parent report
17. Erhart et al., (2009)	Questionnaire validation study
18. Gates et al., (2010)	Parent versus adolescent report
19. Houlihan et al., (2004)	Parent report
20. Jones et al., (2009)	Systematic review
21. Karaduman et al., (2010)	Parent report
22. Ketelaar et al., (2006)	Questionnaire development study
23. Kolaski et al., (2010)	Investigated the impact of participation and BMI on QOL
24. Liu & Lin (2010)	Poster presentation
25. Lim & Wong (2009)	Parent report
26. Liu et al., (2007)	Outcome study
27. Liu et al., (2009)	Investigated relationship between functioning and HRQOL
28. Livingston et al., (2007)	Review of QOL in adolescents with CP
29. Livingston et al., (2008)	Assessment of stability of HRQOL, no comparison with norms
30. Madden & Parkes (2010)	Discussion paper
31. Majnemar et al., (2007)	Compared child to parent report
32. Majnemar et al., (2008)	Compare parent to child report
33. Michelson et al., (2009)	Article on participation of children with CP
34. Morris et al., (2005)	Review relating to participation of children with CP
35. Morrow et al., (2008)	Parent versus professional report

36. McManus et al., (2008)	Investigated the impact of participation on QOL
37. Narayanan et al., (2010)	Questionnaire validity study
38. Penning et al., (2010)	Questionnaire development study
39. Petersen-Ewert et al., (2011)	Discussion paper on HRQOL assessment tools
40. Poleshuck (1999)	Review
41. Rapin et al., (2007)	Discussion paper, children's assessment of their parents influence on their QOL
42. Reading (2007)	Commentary on Dickinson et al., (2008)
43. Redman et al., (2008)	Outcome study
44. Reid et al., (2011)	Parental views on raising a child with CP
45. Rennan et al., (2010)	Parental report
46. Rosenbaum et al., (2007)	No comparison with norms
47. Rosenbaum et al., (2008)	Discussion article
48. Russo et al., (2008)	Impact of pain on QOL and self-concept
49. Shelly et al., (2008)	Investigated the relationship between functioning and QOL
50. Shikako et al., (2009)	Qualitative research
51. Simsek et al., (2011)	Not all CP, investigated relationship between functional independence and HRQOL
52. Sparkes & Hall (2007)	Discussion article
53. Taisa et al., (2008)	Outcome study
54.Tuzun et al., (2004)	Parent report
55. Tuzun et al., (2010)	Impact of pain on QOL
56. Upton et al., (2008)	Review of parent/child agreement across HRQOL instruments
57. Vargus-Adams et al., (2005)	Parent report
58. Vargus-Adams et al., (2009)	Review article
59. Varni et al., (2006)	Questionnaire validation study
60. Varni et al., (2007)	Investigation into validity of self-report in young children
61. Verrips et al., (2010)	Not CP
62. Viehweger et al., (2008)	Review of QOL markers
63. Vinson et al., (2010)	Qualitative research
64. Vitale et al., (2005)	Parent report
65. Volman et al., (2006)	Poster
66. Wang et al., (2010)	Questionnaire validation study
67. Waters et al., (2005)	Questionnaire development study
68. White-Koning et al., (2008)	Parent/professional report
69. White-Koning et al., (2011)	Comparison of parent versus child report
70. Wiley & Renk (2007)	Parent report
71. Wormwood et al., (2011)	Parent report
72. Yeh et al., (2005)	Not CP
73. Young et al., (2007)	Qualitative research
74. Young et al., (2010)	No comparison with norms, compare youth to adults with CP

MRP Appendices

Appendix 2.1: Journal Guidelines for Submission

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Appendix 2.2: WoS Research Ethics Approval

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West of Scotland Research Ethics Service

NHS
Greater Glasgow and Clyde

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Ground Floor · The Tennent Institute
Western Infirmary
38 Church Street
Glasgow G11 6NT
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Date 5th September 2011
Your Ref
Our Ref
Direct line 0141 211 2123
Fax 0141 211 1847
E-mail Liz.Jamieson@ggc.scot.nhs.uk

Dear Miss Redford

Study title: **A qualitative analysis into children's experience of living with cerebral palsy.**
REC reference: **11/WS/0020**

Thank you for your email of 23rd August 2011 responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a sub-committee of the REC. A list of the sub-committee members is attached.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised subject to the conditions specified below.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Appendix 2.2: Research & Development Approval

Healthcare Quality, Governance and Standards Unit
Research, Development & Evaluation Office
58 Lister Street
Crosshouse Hospital
Kilmarnock
KA2 0BB

NHS
Ayrshire
& Arran

Miss Donna Redford
Rainbow House
Ayrshire Central Hospital
Irvine
KA12 8SS

Tel: (01563) 825856
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Date: 15 September 2011
Your Ref:
Our Ref: CAW/KLB/NM R&D 2011AA049

Enquiries to: Karen Bell
Extension: 25850
Direct Line: 01563 825850
Email: [redacted]

Dear Miss Redford

A qualitative analysis into children's experience of living with cerebral palsy

I confirm that NHS Ayrshire and Arran have reviewed the undernoted documents and grant R&D Management approval for the above study.

Approved documents:

Document	Version	Date
SSI form	Version 3.1	19/07/11 signed
R&D Form	Version 3.1	08/07/11 signed
Interview Schedule	Version 1.0	27/05/11
Assent Form 8-10 years	Version 1.0	15/08/11
Assent Form 11-12 years	Version 1.0	15/08/11
Child information form - long	Version 2.0	15/08/11
Child Information Form - Short	Version 1.0	15/08/11
Clinician Invite Letter	Version 1.0	04/07/11
Opt-in Slip	Version 1.0	17/08/11
Parent Guardian Info Sheet	Version 2.0	15/08/11
Parental Consent Form	Version 2.0	15/08/11
Questionnaire - Strengths and Difficulties	No version	No date

The terms of approval state that the investigator authorised to undertake this study within NHS Ayrshire & Arran is: -

- Miss Donna Redford, Trainee Clinical Psychologist, NHS Ayrshire and Arran

With additional investigator(s): -

- Dr Gail Milroy, Clinical Psychologist/Supervisor, NHS Ayrshire and Arran

The sponsors for this study are NHS Ayrshire & Arran.

Appendix 2.3: Clinician Invite Letter

Dear Parent and Child,

As you know, I am part of a team of people who are involved in your/your child's ongoing care. As your healthcare professional I would like to inform you of some new research that is being carried out, as I thought that you may be interested in taking part.

The research is investigating what it is like to be a child who has cerebral palsy. It is hoped that the results of the study will provide us with further insight into the experience of living with cerebral palsy from the child's point of view.

Taking part would essentially involve your child meeting with the researcher for approximately an hour, during which the researcher will talk to your child about cerebral palsy and the things they do in their life, for example, hobbies, school, friends etc.

If you think that you would like to take part then please read the enclosed information forms for further details. If you wish to take part, then you can contact Donna Redford (Trainee Clinical Psychologist) directly on 07981475203 / 01294 323072. I will not pass your details on to the researcher without your consent.

Kind regards,

Local Clinician

Appendix 2.3: Child Information Form Short

Researcher
Donna Redford, Trainee Clinical Psychologist
Department of Psychological Medicine
Academic Centre
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow
G12 0XH

Telephone: 01294 323072 / 07981475203

I am doing a project on cerebral palsy, and I thought that you might like to take part.

I am asking the question, 'what is it like to be a child who has cerebral palsy?' Since you have cerebral palsy, I thought you might be a bit an expert, and that you could tell me what it is like for you.

If you would like to take part, then you and I would meet together for about an hour, at a clinic near to where you live. Your Mum, Dad or Guardian can come with you. When we meet, we will make a poster together and I will ask you about yourself and cerebral palsy.

When we are talking I might record what we are saying, just so that I don't forget what we have said. Everything you say will be kept secret and no-one will know what you have said because I will take your name and date of birth away from what you say in the meeting.

The only reason I would have to tell someone what we have said is if you tell me something that makes me think that you or someone else might be in danger. If this happens then I would have to tell someone just to make sure that you are safe.

If you decide that you don't want to take part even after we have started then that is ok. We can stop at any time for a break and you can leave with your parent when you decide you want to leave.

If you would like to take part then you can phone me on **01294 323072 / 07981475203** or you can return the enclosed slip in the free post envelope or tell the person who gave you this information sheet.

Appendix 2.3: Child Information Form Long

Researcher
Donna Redford, Trainee Clinical Psychologist
Department of Psychological Medicine
Academic Centre
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow
G12 0XH

Telephone: 01294 323072 / 07981475203

Part 1

Study title: **An investigation into what it is like to be a child who has cerebral palsy.**

We are asking if you would join in a research project to find the answer to the question 'what is it like to be a child that has cerebral palsy?'

Before you decide if you want to join in, it is important to understand why the research is being done and what you will have to do. So please think about this and talk about it with your family, friends, teacher or doctor if you want to.

Why are we doing the research?
We are doing this research so we can find out more about what it is like to be a child who has cerebral palsy. I don't know much about cerebral palsy, but since you have it, I think you must be a bit of an expert. Really I want to know what it is like for someone to have cerebral palsy. I would like you to tell me about how you feel about having it, and how it affects your life. Maybe even what is good and bad about having it.

Why am I invited to take part?
You have been invited to take part because you have cerebral palsy and know what it is like to be a child with cerebral palsy. We are hoping that eight people with cerebral palsy will be involved in our research.

Do I have to take part?
No. It is up to you. We will ask for your assent and then ask you if you would sign a form. We will give you a copy of this information sheet and your signed form to keep. You are free to stop taking part at any time without giving a reason. If you decide to stop, this will not affect the care you receive.

What will happen to me if I decide to take part?
Taking part will involve meeting with me for up to an hour. I will ask your parent to complete a questionnaire that asks about different things like your mood and what you

are good at. After this, we will make a poster and we will talk about cerebral palsy, I might ask you some questions about how you feel and what you find difficult about having cerebral palsy.

When we are doing the interview, if you agree, then I will record it so that I don't forget what we have been talking about. Anything you tell me will be kept private and no one else will know about what you have said, apart from my supervisors, who are also involved in doing the research. Anything you say can be used in my research but no-one will be able to tell that it was you that said it because everything will be anonymised, which means that your name or personal details will all be removed.

The only thing that would mean I have to speak to someone else is if you tell me something that makes me think that you or someone else is in danger. If this happened then I would have to tell the appropriate people, but I would tell you about that first, this would be done to make sure that you are safe.

If you want to stop for a break during our meeting then you can tell me. Also, if you decide at any time that you don't want to carry on with the interview, then that is ok and we will stop. You can decide not to take part at any point and this is ok too.

What else will happen?
Nothing else will happen to you. All we will do is make a poster and talk about how you feel about having cerebral palsy. It's ok if you don't really know how you feel about it.

Is there anything else to worry about if I take part?
No. All we will do is have a talk about you, your hobbies, family, school and cerebral palsy; you can leave at any time you choose.

Thank you for reading so far – if you are still interested then please go to Part 2.

*Part 2 More **details – information you need to know if you want to take part.***

Will anyone else know I am doing this?

No. We will keep your information in private. We will only use information that has been anonymised, which means that no one can recognise you from your information as your name, address or date of birth have been removed.

What will happen to the information you collect in the interview?

The things we talk about may be recorded, if they are, then they will be anonymised when they are typed into a secure computer. This information will be analysed by the researcher and her supervisors who are also involved in the research. The supervisors will not know your name, as the researcher will have removed this from your interview information. The results of the study will be printed as part of a project, while we may print something you have said, no one will know that you said it because it will be anonymised and unidentifiable.

<u>If you have any questions then please ask.</u>

If you wish to ask any questions or you want to take part then please contact Donna Redford on **07981475203 / 01294 323072** or you can tell the person who gave you this information form or return the enclosed opt in slip in the envelope provided.

Appendix 2.3: Parent/Guardian information sheet

Researcher
Donna Redford, Trainee Clinical Psychologist
Department of Psychological Medicine
Academic Centre
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow
G12 0XH

Telephone: 01294 323072 / 07981475203

Please take the time to read this information sheet, you will be able to review the information with the researcher if you decide to meet with them. At this meeting you will have the chance to discuss and ask any questions you have concerning the research project.

Study Title: An analysis into children's experience of living with cerebral palsy

We would like to invite you to take part in our research study. Before you decide, we would like you to understand why the research is being done and what it would involve for you and your child. The researcher will go through the information sheet with you when you meet and at this point they will be able to answer any questions you may have. We suggest that this may take approximately 5 to 10 minutes. Please talk to others about the study if you wish.

Part 1 of this information sheet provides you with information about the purpose of the study and what will happen if you and your child decide that your child would like to take part.

Part 2 of the information sheet provides you with more detailed information about the conduct of the study.

If anything is unclear, then please do not hesitate to ask for further information.

Part 1

I am studying for a doctorate course in clinical psychology at the University of Glasgow. As part of my course I am carrying out research into children's experience of living with cerebral palsy. Really I am interested in what it is like for children to live and cope with cerebral palsy, as such I am inviting your child to take part. It is hoped that the research will highlight issues that children think are important. These issues can then be used to inform clinical practice which may lead to a more holistic and rich understanding of children with cerebral palsy, thus perhaps leading to better care for them.

What is the purpose of the study?
While there has been much research in to cerebral palsy, most of this research has focussed upon the view of the parents. This research has provided us with a degree of understanding as to what it may be like to have a child with cerebral palsy and some of the challenges that parents face. However, while informative, existing research does not provide us with insight into what it is like for the child who has cerebral palsy. The current research focuses on the views of children to allow us to develop a more detailed view of what it is like for children to live with cerebral palsy. It is hoped that a better insight will result in clinicians being more aware of issues affecting these children and that this in turn will lead to better care for them.

Why is my child being invited to participate?
As I am interested in the views of children who are living with cerebral palsy I thought that your child may like to participate in my study. There has been a lot of research about cerebral palsy but most of it focuses on the views of parents, this research is informative but I would like to focus on the child's views as I think this will lead to a different understanding of the child's experience of living with cerebral palsy.

Does my child have to take part?
It is up to you and your child to decide to join the study. The study will be described in detail as you go through the information sheet. If you agree to take part, we will ask you to sign a consent form and your child to sign an assent form. You are free to withdraw at any time, without giving a reason. This will not affect the standard of care you receive.

What will my child and I have to do if they are taking part?
If you consent to your child taking part then they would be required to meet with me for approximately one hour. During this time, we will discuss the study and you can ask me questions about it. Then you will be asked to complete a questionnaire. The questionnaire asks about the child's strengths and difficulties and will be used as an indication of areas that they are satisfied and dissatisfied with.

The child will then help me to design a poster as we talk about cerebral palsy. The child will be asked questions about their life and they can tell me about what it is like for them to have cerebral palsy.

Results
The analysis of the data I collect will highlight a number of issues that the children with cerebral palsy think are important. At the end of the study, these results will be disseminated to the children involved in the research should they wish this to happen.

Recording information
Interviews will be recorded so that they can be analysed later by the researcher and their supervisors. Only the researcher and involved supervisors will listen to recordings. All information will be confidential and it will be stored according to NHS guidelines. Recordings will be destroyed at the end of the study. If you do not wish the interview to be recorded, your child can still take part and the researcher will write down the answers during the interview.

Right to withdraw
You and your child have the right to withdraw from the study at any point. Choosing to withdraw will not affect any healthcare or service involvement now or at any time in the future.

What happens next?
An information sheet for your child is enclosed. Should your child wish to take part in the study then please phone the researcher on 07981475203 / 01294 323072, alternatively you can inform the clinician who gave you this information form, or you can complete and return the enclosed opt-in form. A freepost envelope is enclosed.

If you wish to take part then the researcher will arrange a suitable time to meet with you and your child, at this point, you and your child can ask any questions and if you still wish to participate then you will be required to complete consent/assent forms. At this meeting, an appointment will be made to carry out the interview with the child, or you may complete the interview then to avoid having to meet again.

Expenses and payments
Unfortunately we are unable to refund travel expenses.

What are the potential benefits to taking part in the study?
Your child may find it helpful to be able to talk with an unfamiliar adult about how they feel about having cerebral palsy.

Will my child's participation be kept confidential?
Yes. We will follow ethical and legal practice and all information about your child will be handled in confidence. Any data collected and used in the study will be anonymised.

In the event that a child discloses any information which would give cause for concern, then as a duty of care immediate action would be taken.

If the information in Part 1 has interested you and you are considering allowing your child to take part, then please read Part 2 before making your decision.

Part 2

What will happen if I or my child does not want to carry on with the study?
If you or your child decide to withdraw from the study, then you will be thanked and the data collected will be destroyed. This will not affect any care or involvement with other services now or in the future.

What if there is a problem?
If you have a concern about any aspect of the study, you should speak to the researcher who will do her best to answer your questions (Tel: 07981475203 / 01294 323072). If you remain unhappy and wish to complain formally, you can find out about how to do this by telephoning the NHS helpline on 0800 224488. Alternatively, further details can be obtained from any NHS organisation or your local citizens' advice bureau.

Will my child's participation be kept confidential?
All information which is collected about your child during the course of the research will be kept strictly confidential, and any information which leaves clinic will have any names or addresses removed so that your child cannot be recognised by the data collected.

The information we collect during the interview will be anonymised and stored on a secure password protected computer. No-one will be able to identify your child from the data we collect. The researcher and their supervisors who are also involved in the research will have access to the anonymised data so that it may be analysed. Only the researcher will have access to your identifiable information and this will not be stored with the data collected during the interview, ensuring that your child's data remains unidentifiable.

If your child's interview has been recorded, the recording will be destroyed when it is typed into the computer. This will happen as soon as possible following completion of the interview.

What will happen to the results of the study?
The results of the study will be anonymised and published as part of my thesis. The study may be published in a scientific journal following completion of the course. All data collected will be anonymised and your child's data will be unrecognisable. You can receive a summary of the results of the study should you wish to do so.

Who is organising and funding the research?
The research is organised through the university of Glasgow. It is sponsored by NHS Ayrshire and Arran and funded by the University of Glasgow. The researcher is not being paid for including you in this study.

Who has reviewed this study?
All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. The study has been reviewed and given a favourable opinion by the West of Scotland Research Ethics Committee.

Further information and contact details
If you wish to seek further information about taking part in research in general, you can contact Dr Shields (01294 323425) or Dr Teer (01294 323072) who will be happy to answer any questions you may have.

If you would like to discuss this study further or you wish your child to participate then please contact the researcher **Donna Redford on 07981475203 / 01294 323072.**

If you wish to obtain advice as to whether to allow your child to participate, you can speak to the researcher or any other health professional with whom your child is involved.

Appendix 2.3: Opt-in Slip

Researcher
Donna Redford, Trainee Clinical Psychologist
Department of Psychological Medicine
Academic Centre
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow
G12 0XH

Telephone: 01294 323072 / 07981475203

If you have read the information sheets and would like to reply then please complete this opt-in or out slip and return it in the enclosed free-post envelope.

My child ……..(Name) and I have read the information sheets dated 15.08.11

☐ We would like to participate in the study. I consent to you contacting me to arrange a time to discuss the study further.

Please provide telephone number if possible…….

Thank you for taking the time to consider taking part in the study and for your reply.

Appendix 2.3: Assent Form – Child: 8-10 years

Study Title
'What is it like to be a child living with cerebral palsy?'

Donna Redford, Trainee Clinical Psychologist
Department of Psychological Medicine
Academic Centre
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow
G12 0XH

Telephone: 01294 323072 / 07981475203

Please tick:

☐ Someone explained to me what the project is about

☐ I read and understood the information sheet and the explanation given to me.

☐ I asked the researcher questions about the study if I didn't know what something meant.

☐ I know that I don't have to take part in the interview and that I can stop anytime I want to.

☐ I know that our talk will be recorded and that the researchers will listen to it later, but I know that no one else will be allowed to listen to it.

☐ I know that if something I say is put into the study then no-one will know I said it because my name will not be in the study.

☐ I would like to take part in this study.

Name of Parent/Guardian…….Date……
Signature…….
Name of Participant……Date……...
Signature…….
Name of Researcher……Date……..
Signature……

Appendix 2.3: Assent Form – Child: 11-12 years

Study Title
'What is it like to be a child living with cerebral palsy?'

Researcher
Donna Redford, Trainee Clinical Psychologist
Department of Psychological Medicine
Academic Centre
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow
G12 0XH

Telephone: 01294 323072 / 07981475203

Please tick:

- ☐ I read the information sheet and the explanation given to me.
- ☐ I asked the researcher any questions I had about the study.
- ☐ The researcher helped me to understand what will happen.
- ☐ I know that our talk will be recorded and that the researchers will listen to it later, but I know that no one else will be allowed to listen to it because it is private.
- ☐ I know that if something I say is put into the study then no-one will know I said it because my name will not be in the study.
- ☐ I know that I don't have to take part in the interview and that I can stop anytime I want to.
- ☐ I would like to take part in this study.

Name of Parent/Guardian…….Date……
Signature…….

Name of Participant……Date……...
Signature…….

Name of Researcher……Date……..
Signature……

Appendix 2.3: Parental Consent Form

Donna Redford
Trainee Clinical Psychologist
Department of Psychological Medicine
Academic Centre
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow
G12 0XH

PARENTAL CONSENT FORM Version 2: 15.08.11

Title of Project: A qualitative analysis into children's experience of living with cerebral palsy.

Name of Researcher: Donna Redford (Trainee Clinical Psychologist)

Please initial box

1. I confirm that I have read and understood the information sheet dated 15.08.11 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my child's participation is voluntary and that my child is free to withdraw from the study at any time without giving any reason and without their medical care or legal rights being affected, and that all information relating to them will be destroyed at the point of withdrawal. ☐

3. I understand that the interview with my child may be audio-recorded, and that the recording will be kept in a locked filing cabinet and listened to only by the researcher and their supervisors. It will be transferred to a secure computer as soon as possible at which point it will be anonymised. ☐

4. I understand that some quotations from the interview may be used in the write-up and future publication of the study, but that there will be no way of identifying the child as all names and personal information will be removed. ☐

5. I understand that if my child discloses information that causes concern for their safety, then the researcher who has a duty of care, would have to take action to ensure that my child is safe. ☐

6. I agree to my child taking part in this study. ☐

_____	_____	_____
Name of Patient	Date	Signature
_____	_____	_____
Name of Person	Date	Signature

Appendix 2.4: Interview Schedule

Title: An investigation in to the experience of living with CP.

Version 3

Introduction

- My name is X, I work as a psychologist and I am interested in finding out more about people with cerebral palsy.
- Remind the child that they agreed to help me with my research, check whether they still want to.
- So we are going to talk about cerebral palsy
- Some of my questions might sound silly, but I just want you to tell me what it is like to have cerebral palsy
- You are the expert on cerebral palsy so that's why I want to know what its like for you to live with it
- There are no right or wrong answers, nothing you say will be said back to your parents or school unless it seems that you or someone else is at harm.
- If you want to stop at any point then tell me and we can stop
- I'm very forgetful so I am going to record what we are talking about so that I don't forget anything, is that ok? If you don't want me to record the interview then I could write down what we say.

Sometimes I might ask you to tell me a bit more about something, is that ok?

Opening Gambit:
The aim of this interview is for me to find out what its like to live with cerebral palsy, and since you have cerebral palsy I think you might be the best person to tell me about it.

I don't really know you so I was hoping to find out a bit about you. I thought maybe you could start off by telling me a bit about yourself. I would really like to find out a bit more about what you like and dislike, a bit about your family, friends, school and hobbies. If you want to draw while we talk that would be really good too.

I would like to ask you some personal questions, for example, about your health and things that worry you or you find difficult, is that ok?

It is important to remember that there are no right or wrong answers, what I really want to know is what you think is important since you are the person who has CP. I hope that what you tell me about your life might be able to help other children that have cerebral palsy.

For all sections – the poster will be used to help children talk about their lives and areas we wish to address.

1. **What is their understanding of CP and how it effects or will affect them.**

I don't know much about CP, but I would like to find out about it. You know lots about it, so I was wondering if you could tell me what you know about it?

- What do you know about CP?
- What is CP?
- How does CP make like different for you?
- Will you always have CP or will it go away when you are older?
- Does having CP mean that there are some things you can do better/some things you can't do that other people your age can do?
- What is good/bad about CP?
- If I had a magic wand and could take CP away, what would be different in your life?

2. **How does CP affect a young person's life?**

I would just like to start by asking about your family and friends.

- Tell me about your family. Tell me who's in your family?
- Do you have any brothers or sisters? How do you get on with them?
- What kind of things do they like doing? Do your parents have different rules for you and your brothers/sisters? (jobs/chores)
- Do you do things different from your brothers/sisters because of CP?
- Tell me about your friends. Do you have a close friend?
- What kinds of things do you like doing with your friends?

3. **What have their experiences been like growing up with CP?**

If you think back to (age), has CP made things good or bad for you?

- What do you think other people think about CP?
- Do you think you have ever been treated differently because of CP?
- Has anyone ever been nice or mean to you because you have CP?
- Do you talk to people about having CP? About how it makes you feel?

4. **How do they think it will affect them in the future?**

I am also interested in talking to you about the kind of things you would like to do when you grow up

- Have you thought about what you might do when you grow up/leave school?
- Do you think you will be able to do that?
- Is there anything that might make this difficult or stop you doing this?
- Is there anything that worries you maybe about leaving school? Or at the moment?
- What are you looking forward to doing when you grow up?

Closing comments

So we have talked a lot about you and CP and it has been very interesting for me to hear about your life. I was wondering though if you think that I have forgotten to ask you something that you would have liked to tell me about?

What has it been like talking to me today?

Appendix 2.5: Example of an analysed script

Theme	Page no./ Line no	Key words/Phrases
Conflicting sense of self		
Conflicting self	7/290	Can do everything else like other people…way I go upstairs is different
Desire to be the same	9/397	'I would love that, I would love that, I would just like to have all the bad things taken away'
	9/400	'I could do stuff like other people, I wouldn't have a walker, I wouldn't have a wheelchair'
	9/403	'I would not have operations, I would not have anything, I would just love to do it that way'.
	19/830	'I would like to do everything the way that other people do them, instead of the way I do them'
	19/841	'In gym I have to put the way that other people do them to the way I do them'
	19/844	'the teachers say your going to have to do it your way, you're going to have to do it your way'
	19/867	'But I would like to try it their way instead of always putting it to my way'
	20/870	'would just feel like I would be the same' (if I did it their way)
	20/884	'I wanted to walk in…and em stop having these operations, it would feel like I'm like everybody else'
Sense of being different	1/39	'I need a walker, in school everybody else can walk straight, fine, but I can't.
	5/196	'they can wear Ugg boots, everything like that, I cant, I cant wear ugg boots'
	1/43	'I think he's got it different from me, cause I think he's mental'
	2/48	'What I don't like about it is that I find I'm different from everybody else'
	2/51	'Everybody else can run'
	2/85 2/87	'I put myself compared to say one of my friends'

	2/91-2	'they can sit like that, but I would sit like that' 'I tend to get a sore back'
	5/213 5/226	'They can run faster than me' 'They can get a heel strike'
	6/262	'Well they can walk, they can like, they can have their own, they don't need to use a walker in school'
	16/715 16/720 16/723	'What my friends can do and I can't do, so they can go walk and different, they get treated differently from me so'. 'But I have to, I've got a wheelchair, they don't' ''because they can walk further..and if I put me compared to X, you could see that I stand differently'
	18/796	'I have to use different things, I have to be taken out of class for appointments'
Being treated differently	8/341	'I get treated differently' (cause I have a walker/wheelchair)
	22/1004 22/1006	'It's just the way some people treat me compared to others' 'its not fair'.
Independence/Autonomy		
	8/343 8/349	'I have a walker, I have a wheelchair, I cant just go around doing my own thing' 'I'd like to just quit them all, and do it my way for once'
	14/594	'Sometimes go out and play in the cul-de-sac'
	16/730 16/733 16/735 16/737 17/740 17/742 17/744	'They can walk further and they don't need someone to be right beside them' 'They can go off and wander by themselves' 'But I need to be with somebody' 'Which is not fair' 'It's like I'm a kid' 'It feels like I'm not growing up at all' 'It feels just like I'm a kid, a wee kid, XX age, XX is my age, and he's just getting to wander by himself'.
	18/785	(RE being away from Mum) 'It would feel good, it would feel like I would be with my friends' 'And I could do stuff, I could do stuff with myself, which I can, but it feels like em I'm just a kid, I cant do anything, Like I'm locked somewhere I'm not allowed to go out there'.
Overprotection		
	17/752	'I'm not allowed to wander away by myself

		like XX can do'
	17/755	'I've got to stay near Mum and Dad so'.
	17/757-761	'Feels like I'm a wee kid…feel like I'm a wee kid, I'm getting left all alone in the house…with Mum and Dad when X and X is away out'
	17/763	'I just feel like I'm the youngest child…it feels like I'm a wee kid, not who I am, I'm not growing up'.
	17/776	'Outside and play outside the cul-de-sac and not get Mum, well Mum would check on her, but not as much as she checks on me'
	18/779	'If I was out on my own, she still checks on me'
Emotions		
Hiding feelings	20/913	'Well I've not said it, but I think it' (not expressing feelings)
Worry	25/1111	'Well maybe that em sometimes I might not cope outside school'
	25/1114	'I just don't think that I would cope'
Insight	24/1062	'I don't know' (if be able to be a midwife)
		'I don't know that would affect me as well as what I have'
Relief	26/1159	'It feels good to get all that out and like talk to someone'
Dealing with others		
Lack understanding	21/936	'They're all saying yeah, but they don't know what it is'
	21/945	'Cause everybody else, like XX doesn't understand'
	21/960	'but some doesn't understand my life'
	22/994	'well mostly my family, but sometimes they don't understand'
	22/999	'I would love to talk to someone who has the way I feel, not X cause he doesn't understand me either
		'Like someone who has it like me'
Isolation	21/927	'they don't know how to deal with it'
		'I'm all alone, I don't have anybody on my side'
	21/938	'I'm their, their enemies, and I'm just going at them and I'm the only one fighting'
	18/801	'It just feels like I'm not part of class, I'm not part of the world, it feels like I'm just alone

		in my wee world, that I've got no-one to care for me. Well I do have people, but it just feels like I'm a wee kid, alone in this big world'
I'm different	18/820	'It feels like I'm alone, it feels like I'm a different person…than everybody else'
Negative experiences	21/920	'some went the other way and went 'oh look at this wee one, she cant do what we can'
Frustration	9/364	'Other people think its good cause they want a shot of my wheelchair, they want a shot of my electric wheelchair, and I'm like this, you wouldn't like this. You would not like to have this'.
	9/368	'Its rubbish, I cant do stuff, I cant do stuff like other people'
	9/370	'And its not fair'
	20/889	'they just think it's great cause I've got an electric wheelchair'
	20/897	'But not to me it's not'
	20/898	'could you get out and let me in there, and I'm like, I cant get out, I cant do this!'
	20/904	'You would not like to have this, you would not like to have what I've got'
	20/907-910	'And what I would like to say is that like I wish, I wish I was born, but wish I wasn't born like this'.
	20/913	'Well I've not said it, but I think it' (not expressing feelings)
	22/962	'some will just think, oh yeah it's great to sit around'
	22/965	'I would just love to go and walk, I would love to show them how to not great it is'.
	22/971	'they just think it's great being pushed around.….but sometimes you wish you could get up and walk'.

Appendix 2.6: MRP Proposal

MRP Proposal

A qualitative analysis into children's experience of living with cerebral palsy

Abstract

Introduction: Research suggests that children with disabilities are at increased risk of experiencing psychological difficulties. Cerebral palsy is the most common cause of physical disability in childhood and one that has been investigated mostly from the stance of the parent. Given this, the current study aims to investigate the experience of living with cerebral palsy from the perspective of the child.

Design & Method: A qualitative cross-sectional design will be adopted; data will be collected via semi-structured interview.

Participants: Children diagnosed with cerebral palsy aged 8-12 years attending mainstream school will be invited to participate.

Analysis: Data will be subjected to Interpretative phenomenological analyses.

Discussion: Implications of the results for clinical practice and future research are considered.

Introduction

Research suggests that cerebral palsy is the most common cause of physical disability in childhood (Parkes et al., 2008; Parkes & McCusker, 2008) with prevalence rates in the region of 2 to 2.5 per 1000 children and an estimated ten thousand new cases diagnosed every year in developed countries. Cerebral palsy is a non-progressive developmental disorder present from birth or early childhood. It has no cure, and can affect multiple domains, including language, cognition and praxis. Moreover, it has been associated with behavioural and emotional difficulties, epilepsy and learning disabilities (Aran et al., 2007; Rapin, 2007).

Concerning emotional difficulties, it is estimated that as many as 10% of typically developing children of five years and over may experience mental health problems (Parkes et al., 2008). Children who have a disability, are proposed to have a higher risk of developing such problems (Rutter et al., 1970; Goodman, 2002). For example, Goodman and Graham, (1996) reported that over 50% of their sample (N= 149; age range 6 to 10 years) of children with hemiplegia experienced psychological problems and Parkes et al., (2008) reported that approximately 25% of their sample of 818 children (age range 8 to 12 years) with cerebral palsy were found to be experiencing psychological difficulties.

While there could be many reasons for an increased incidence of psychological difficulties, one consideration is that of overprotection. Wood et al., (2003) propose that when children are not allowed to, or are prevented from, engaging in age-appropriate tasks, they may develop a sense of helplessness. Consequently, they may have a sense of dependency on the parent, which may then result in anxiety. Children

with disabilities may be unable to complete certain age appropriate activities or be perceived to be unable to complete them. This could contribute to the increased risk of developing psychological difficulties.

Another concern is that of participation. Parkes, McCullough and Madden (2010) report that participation in society such as meeting friends, eating out, taking part in activities etc is important for children in terms of allowing a smooth transition from child to adulthood. Consistent with other research in the field, the results of their study suggest that children with cerebral palsy experience reduced frequency of participation in a variety of activities when compared to typically developing peers. This may therefore be an issue impacting upon psychological well-being.

Rationale

To date, much research has focused upon the important issue of functional ability, however with advances in medical technology and children now being expected to reach adulthood, the focus of research has shifted to that of the experience of parenting and parental quality of life (Aran et al., 2007; Parkes & McCusker, 2008). Such research findings are varied, with some evidence of the experience being stressful (Brinchmann, 1999), and others suggesting that it can have a positive affect on the lives of parents (Davis et al., 2009).

Moving from the perspective of the parent to that of the child, Mitchell and Sloper (2001) reported that there was a paucity of studies investigating the views of children with learning disabilities. In Garth and Aroni (2003) it is stated that "children's understanding and experience of the world is different from their parents" (Thomas &

O'Kane, 1998. P564). A suggestion supported in a review of quality of life literature by Varni et al., (2005) who found that the discrepancy between parent and child reports can result in a 'hidden morbidity' in areas such as emotional functioning. Moreover, Dickinson et al., (2007) report that in article 7 of the 2006 UN Convention on the Rights of Persons with Disabilities; it states that children with disabilities should have the right to express their views on matters concerning them.

In recent years there has been some research focusing on the perceptions of children and young people. Maher et al., (2008) investigated the quality of life of 11-17 year olds with cerebral palsy. Their findings suggest that a majority (67%) of the sample (N=118) had quality of life scores less than would be expected for typically developing children. However, Dickinson et al., (2007) also investigated quality of life using self-reports of children with cerebral palsy, and report that children had similar quality of life to those in the general population. Considering such inconsistency in findings, it may be argued that Dickinson et al's results are more representative of the population of children with cerebral palsy than those of Maher et al., in that the sample was larger and it was formed by children from 6 different European countries thus increasing ecological validity. In comparison, Maher et al's sample was smaller, it spanned a larger age range and all children lived in South Australia. Studies employed different measures in assessing quality of life and clearly each represents a different age group within different populations of children with cerebral palsy and as such this may account partly for the difference in findings.

In another study, Davis et al., (2008) employed qualitative analysis to investigate quality of life from an adolescent and parent perspective as they attempted to design a

measure of quality of life for adolescents with cerebral palsy. Their results highlighted a variety of themes that appear to affect quality of life, including physical health and acceptance of disability. While the Davis et al., (2008) study may appear similar to the current one, it differs in that this study is designed to investigate the experience of living with cerebral palsy with an emphasis on psychological functioning and does not aim to concentrate on quality of life.

It seems that with the recognition of the importance of children's views, combined with the finding that parent and self-report data demonstrate low levels of correlation (Livingston et al., 2007) more studies are tending to access the views of children directly. The discrepancy between self and proxy reports is recognised within quality of life literature (Verrips et al., 2000; Eiser & Morse, 2001) and Verrips et al., postulate that the observable nature of the rated construct may be an important factor influencing discrepancy between self and proxy ratings.

Much research employing children's own views have been concerned with quality of life (Dickinson et al., 2007; Davis et al., 2008; Maher et al., 2008) and many studies have employed standardised measures as opposed to less structured methods to obtain such information. However, such designs do not capture the personal view or subjective experience of living with cerebral palsy and as such these studies are restrictive in terms of the data they collate.

With quality of life and more specifically psychological well being in mind, the proposed study aims to investigate what it is like to be a child living with cerebral palsy. Existing research documents that children with cerebral palsy are at increased

risk for psychological difficulties, however, such research has failed to identify why this may be the case. There is a dearth of studies that focus upon the experience of children with cerebral palsy, with the majority of research focussing upon the experience of the parents.

This is the first study, as far as is known, to adopt a qualitative approach to examine the experience of living with cerebral palsy from the perspective of the child. Such an approach will allow children to guide the conversation with issues that are important to them. Previous research has found that employing standardised measures has not addressed all areas that impact on quality of life (Davis et al., 2008). Therefore, it is proposed that adopting a semi-structured interview will allow more flexible communication of what is considered to be important to the child, rather than what is deemed important by the researcher. It is argued that the view of the child is important, and that the results of the study may provide rich data that will enable a more holistic view of children with cerebral palsy. Moreover, the data may identify issues that are indicative of why children with cerebral palsy are at increased risk for psychological difficulties.

Aims and Hypotheses

Aims

The study aims to explore young people's experience of living with cerebral palsy.

Objectives

a. To explore young people's experiences of living with cerebral palsy, what it means to the individual, how it affects their life in general, and how they think it impacts upon their relationship with family and peers.

b. To contribute to the emerging evidence base detailing the view of the child as opposed to the parent or caregiver.

Plan of Investigation

Participants

Participants will be children (8-12 years) with a diagnosis of cerebral palsy who are listed on the support needs register within Ayrshire and Arran. From the group of children identified, only those who attend mainstream school will be invited to take part. To aid the identification of common themes within the collected data, purposive sampling will be employed and participants will all be functioning cognitively at a level which allows attendance at mainstream school.

Inclusion and Exclusion Criteria

Inclusion/Exclusion

Children attending mainstream school, aged 8-12 years with a diagnosis of cerebral palsy will be included. Children must be able to communicate in English.

Justification of Sample Size and Age

As the study will employ qualitative methods and an idiographic mode of investigation, a small sample size is generally deemed as acceptable. Smith and Osborn (2003) propose that sample size, should be concerned with providing

sufficient data to explore any differences and similarities between accounts, while at the same time not producing an excessive and unmanageable amount of data. A range of recommendations exist relating to potential sample sizes when using IPA (Smith et al., 1999; Smith & Eatough, 2007) and as such the current study aims to recruit a sample of eight participants since this is consistent with proposal that a sample of six to eight is suitable for post-graduate studies.

The study will target children aged 8 to 12 years as it has been suggested that difficulties can be exacerbated during this pre-adolescence phase when typical developmental shifts with regards to decision making tend to happen (Holmbeck et al., 2002).

Recruitment Procedures

Participants will be recruited via the support needs register which contains details of children within Ayrshire with cerebral palsy. If insufficient numbers are identified with Ayrshire, then we will access the registers held within other health boards. It is anticipated that the sample size should be achievable, as within Ayrshire and Arran there are a pool of approximately 15 children.

Guardians of identified children will be approached and informed of the study by a health professional with whom they are already involved. Invitations will be followed up with a phone call from the researcher asking whether or not they wish to participate. If they do wish to participate, then the researcher will arrange to meet with the parent and child in order to build rapport, clarify the procedure and answer any questions they may have.

Parent and child will be asked at this meeting to complete consent and assent forms regarding participation. They will be informed that the interview will be recorded and transcribed for the purpose of later analyses, and that their identifiable information will be removed from the written transcription. It will be explained that the transcription will be read by the researcher and supervisors and that the interviews and transcription data will be stored securely for a period of five years to allow analysis and replication by others, following which it will be destroyed.

If consent and assent are achieved then a suitable appointment will be arranged for the interview.

Data collection

Interviews will be carried out on an individual basis. If the parent is not sitting in on the interview then they will be asked to remain within the waiting area; if the child becomes distressed at any point, then their parent will be available to them. Initially, interviews will begin with establishing rapport, then socio-demographic information will be collected and the Strengths and Difficulties Questionnaires (SDQ; Goodman, 1999) and Gross Motor Function Classification Scale (GMFCS; Palisano et al., 1997) will be completed. The child will then be reminded of the purpose of the interview and will be told that they can stop for a break or stop completely at any point if they decide they do not want to carry on. Interviews will last for approximately an hour, and they will begin when the child informs the researcher that they are ready. The SDQ will take approximately five minutes to be completed by the parent.

Acknowledging the importance of building rapport for the purpose of facilitating communication during the interview, the researcher has considered using games to aid engagement and reduce anxiety. Bruce (2007) employed a 'poster' icebreaker that involved the child filling in a poster with details regarding their family, hobbies, school and friends with the researcher. Since the current study will enquire about such topics, it will adopt this as an icebreaker; however a choice of games will be offered to play initially as a means of engagement for children who appear to require it.

Interviews will employ a semi-structured approach with an interview schedule acting as a guide. This method of data collection is often chosen when employing qualitative research (Reid et al., 2005) and it should facilitate flexibility within the interview and allow the child to tell their story (Smith & Osborn, 2003). A non-directive approach will be adopted, thus allowing the interview to be directed by the participant (Smith & Eatough, 2007) who can highlight areas they think are important to them. Prompts such as 'can you tell me more about ' will be used to encourage elaboration on topics.

Interviews will be recorded and then later transcribed by the researcher. As there may be difficulty achieving the sample, the interview will be piloted with seven year-old children. It is estimated that transcription and analysis will take approximately 7 hours per interview (Smith & Eatough, 2007) therefore total transcription and analyses will take approximately 56 hours.

Measures

Strengths and Difficulties Questionnaire (SDQ, Goodman, 1999). This screening tool provides an indication of the child's social functioning and targets areas such as conduct, hyperactivity and emotional difficulties.

Gross Motor Function Classification System (GMFCS, Palisano et al., 1997). This system is being employed to classify cerebral palsy in terms of severity.

Settings and Equipment

Data collection will take place in a clinic room with the researcher. Necessary equipment will include coloured pens and paper, a digital voice recorder, transcription equipment and possible computer software for analysis. In anticipation of difficulties in engaging children, a range of warm-up activities and games will be available for children to play with until they appear to be comfortable and ready to begin the interview.

Data Analysis

Data will be analysed using an Interpretative Phenomenological Approach (IPA). IPA has been proposed to be a qualitative method particularly suited to health psychology (Smith, 1996) and in areas where little investigation has been carried out (Smith & Osborn, 2003; Reid et al., 2005). Similar to grounded theory, this approach is not theory driven, but adopts a 'bottom-up' approach, meaning that the data are analysed without attempts to mould it into pre-existing theoretical paradigms.

The central aim of IPA is to attempt to gain an understanding of the experience of the individual from their point of view. However, it also recognises that achieving an 'insider perspective' (Conrad, 1987) is somewhat impossible, as the process of obtaining this is dependent on the researcher's interpretation of the data they receive. Indeed, Smith and Osborn (2007) propose that in using IPA there are essentially two stages of interpretation; the initial stage being where "the participants are trying to make sense of their world" and the second being where the "researcher is trying to make sense of the participants trying to make sense of their world" (pp. 51).

Health and Safety Issues

Researcher safety issues

Data collection will only occur during working hours when there are other staff members in the building.

Participant safety issues

Participants will be in child-friendly areas of the building. Questionnaires will be completed by parents in a clinic room and they will be accompanied by the researcher. Should a parent or child become upset or show signs of distress at any point during the study they will be reminded of their right to discontinue participation and they will be offered an appointment with a suitable professional.

Ethical Issues

Permission to conduct the study will be sought from the West of Scotland Ethics committee and research practice will adhere to The British Psychological Society (2009) code of ethics and conduct.

Issues to consider are as follows:

Obtaining informed consent to record interviews. Children and their parent will receive information detailing the nature and purpose of the study, this information will be provided in a child-friendly format therefore facilitating understanding. The researcher will discuss the nature of the study, the procedures involved and how the interview data will be stored, analysed and destroyed. The researcher will check with children and their parent/guardian that they fully understand what will happen within the interview and then with the information they provide. If they do understand then this will be taken as being 'informed' and they will be asked to sign consent/assent forms.

Confidentiality – data storage will conform to NHS guidance. All demographic information will be stored in a locked filing cabinet with access limited to the researcher. While all recordings will be transferred onto a computer that will be password protected. All transcripts will be anonymised and stored on the computer or in the locked filing cabinet separate from the demographic information.

Financial Issues – equipment costs, travel etc

Costings are detailed in appendices. Travel costs will be claimed from the NHS employer.

Timetable

Below is an estimation of when each stage of the research will take place.

Task	Approximate dates
Preparing ethics forms	January 2011
Applying for ethical approval	January - March 2011
Recruitment	April – June 2011
Data collection/Coding	June – September 2011
Data Analysis	September – December 2011
Write up	December – January 2012
Submission	January 2012

Practical Implications

The practical implications of the findings of the study could be considerable especially if the study identifies themes apparent with the narratives of the children that indicate potential reasons for increased incidences of psychological difficulties. Moreover, regardless of whether any such indications are achieved, the results of the study will provide an understanding of what it is like to live with a condition such as cerebral palsy. To date there has been much research concerning the quality of life of those caring for individuals with cerebral palsy, but as far as we are aware, there exists no qualitative investigation into the experience of children suffering from this condition. Insight into the experience will provide information that can be used to inform clinical practice in terms of what matters to children with cerebral palsy, such information can provide the grounds for further research, clinical intervention and policy provision.

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