

Sorrow, Coping and Resiliency: Parents of children with Cerebral Palsy share their experiences

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Abstract

Purpose: To explore the grieving, coping and resiliency experiences of parents of children with CP and to investigate the suitability of chronic sorrow theory as a framework to understand those experiences.

Method: This study combined focus groups with a web-based cross-sectional survey to explore chronic sorrow in parents of children with CP. Eight parents of children with CP participated in focus groups. The discussion was transcribed verbatim and thematic analysis was performed. A further 94 parents participated in the web-based survey study in which they completed the Adapted Burke Questionnaire on chronic sorrow. A content analysis of responses was used to confirm the primary qualitative analysis.

Results: The reports of parents in the focus group were consistent with chronic sorrow theory, as were the responses of parents to the web-based survey. Some parents found the diagnosis itself a distressing time whereas others found it a relief. Parents reported that times of medical and allied health intervention were particularly challenging.

Conclusion: Chronic sorrow theory is a useful way of understanding the experiences of parents of children with CP. It is recommended that health practitioners are mindful that, even years after diagnosis, parents of children with CP may experience intensified chronic sorrow symptoms following a triggering event and that this is normal.

Keywords: cerebral palsy, parent, grief, chronic sorrow, coping

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Parenting Children with CP

Cerebral palsy (CP) is the most common physical disability in childhood [1]. Cerebral Palsy (CP) is a neurodevelopmental condition that involves the disruption of the normal development of movement and posture and is caused by a non-progressive neurological lesion early in life (in utero or in infancy) [2]. The disruption to normal motor development may result in activity limitations and/or secondary musculoskeletal problems. In addition to motor disability, CP often also includes disorders of sensation, perception, cognition, communication and behaviour. Parenting a child with CP brings additional challenges to the parenting experience such as increased burden of care [3] and healthcare management responsibilities. Parents of children with CP are at risk of increased parental stress [4], increased anxious/depressive symptoms [5-7], decreased psychological wellbeing [6, 7] and decreased health [6].

The theoretical framework of chronic sorrow theory may be a useful context in which to understand the experiences of parents of children with CP because it is a theoretical framework that normalises parental experience. Chronic sorrow is defined as the periodic recurrence of grief-related emotions associated with an ongoing disparity between desired and current reality due to a loss experience [8]. Chronic sorrow theory has been found to usefully explain the experiences of parents of children with other disabilities including epilepsy and neural tube deficits yet there is a paucity of current research [8-11]. According to chronic sorrow theory, grief-related emotions return when triggering events bring the disparity between ideal and actual into focus. This cyclic grieving process is normal and healthy with many parents demonstrating resilience by developing an array of effective coping strategies termed internal management methods. Parents may also access assistance

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and intervention from health professionals which is termed external management methods in chronic sorrow theory.

The central aim of this study is to explore the grieving, coping and resiliency experiences of parents of children with CP and to investigate the usefulness of chronic sorrow theory in understanding those experiences. The approach taken is primarily qualitative including a thematic analysis of focus group data and a content analysis of a wider survey study.

Method

Design

This study comprised of two parts. Firstly, focus groups were conducted with parents of children with CP to gain a rich data set for qualitative analysis. Secondly, a web-based survey of parents of children with CP was also conducted to provide some confirmation of the main qualitative analysis in terms of the grieving experiences of a wider array of parents. This study was conducted in conjunction with research into parenting and the parental acceptability of a parenting intervention for parents of children with CP which is reported elsewhere [12]. The analytic methodology used for the focus group data is thematic analysis, a widely used descriptive qualitative methodology that is not theoretically bounded [13]. A content analysis of the responses of parents in the survey study was conducted as well as examining descriptive statistics and the correlation between chronic sorrow symptoms and child age. Chronic sorrow theory guided the analysis.

Participants

In order to participate in the focus groups parents had to meet the inclusion criteria of having a child aged from two to 12 years with a paediatrician's diagnosis of cerebral palsy (Gross Motor Function Classifications I – V). Eight parents participated. Participants for the

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focus groups were recruited from the Queensland Cerebral Palsy and Rehabilitation Research Centre database via letters and telephone calls. See Table 1 for participant characteristics of the parents participating in the focus groups.

[Insert Table 1 about here]

A further 94 parents participated in the web-based survey study. Participants for the web-based survey were recruited from the research database of the Queensland Cerebral Palsy and Rehabilitation and Research Centre (QCPRRC) at the Royal Children's Hospital; the Queensland Cerebral Palsy League; and the New South Wales Spastic Centre with the inclusion criteria of having a child aged from two to 12 years with a paediatrician's diagnosis of cerebral palsy (Gross Motor Function Classifications I – V). See Table 2 for participant characteristics of the parents participating in the web-based survey.

[Insert Table 2 about here]

Procedure

This study was approved by the Royal Children's Hospital and Health Service District Ethics Committee (HREC/09/QRCH/28), the University of Queensland Medical Research Ethics Committee (2009001351) the Queensland Cerebral Palsy League's Ethics Committee (CPLQ-2007/09-1033), and the New South Wales Spastic Centre Human Research and Ethics Committee (2009-12-06). Informed consent was obtained from all participants.

Two parent focus groups were conducted and both were facilitated by the first and second authors. The focus groups were recorded and transcribed verbatim by the second author. A complete list of the questions asked by facilitators in relation to grief, coping and resiliency

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can be found in Appendix A. Parents were also asked about parenting and the acceptability of a parenting intervention and this is reported elsewhere [12].

Parents completing the web-based survey completed the questionnaires online from their own home. The study website included information about the study and prompted participants to provide consent before proceeding to the questionnaires. It was clearly stated that parents were free to withdraw from the study at any time. All data collected was stored anonymously. For the purposes of this paper, parent responses on the Adapted Burke Questionnaire were analysed qualitatively to confirm thematic analysis of the focus group data.

Materials

Family Background Questionnaire (FBQ). The FBQ is a brief demographic questionnaire [14] that was completed by both focus group and web-survey participants.

Adapted Burke Questionnaire (ABQ). The ABQ is a measure of chronic sorrow symptoms and it is an adaptation of Burke's Chronic Sorrow Questionnaire (CSQ) [9]. Parents rate the intensity of eight mood states including grief, shock, anger, disbelief, sadness, hopelessness, fear, and guilt on a four point scale. A higher cumulative score indicates increased chronic sorrow symptoms. This chronic sorrow score was used in the quantitative analyses. In addition, the ABQ offers parents the opportunity to describe in their own words any additional mood states that they have experienced and triggering events. These verbal descriptions were used in the content analysis. The ABQ has good reliability ($\alpha = 0.90$ for parents, $\alpha = .89$ for fathers, $\alpha = .91$ for mothers) [9]. Parents were instructed to complete the ABQ according to their current mood state in relation to their child's diagnosis of Cerebral Palsy. The ABQ was completed by participants in the web-based survey.

Data Analysis

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The focus group data was analysed qualitatively using descriptive thematic analysis. Patterns within the data (themes) are identified and reported so that the data set is organized in an understandable manner that maintains the rich detail of the data set [13]. Focus group transcripts were analysed line by line, broken into discrete parts and grouped together by similarity of content and/or meaning. Analysis was continued until saturation was reached. Thematic analysis of the focus group data was performed by the second author and confirmed by the first. Both authors agreed on the emerging themes. In addition, a content analysis was performed on the responses of participants in the web-based survey on the ABQ (i.e. on their descriptions of additional mood states and triggering events) Descriptive statistics were calculated using the statistical program SPSS 18.00.

Results

Focus Group Data

A total of seven themes emerged from the thematic analysis. These seven themes consistently emerged across the two focus groups. Themes are summarized in the following Table 3 and discussed in detail below.

[Insert Table 3 about here]

Parental experience: Grief. Parents spontaneously discussed grieving. They reported a sense of sadness for lost opportunities, both for the parenting moments that they were expecting to have and will not have and for their child's lost potential had they not had CP. Parents also reported a feeling of injustice that anyone should have a child with a disability as well as feelings of guilt, frustration and exhaustion. Parents particularly reported feelings of exhaustion and frustration in relation to their child's development. For some parents, grief was associated not with the diagnosis per se but with the slow developmental progress of

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their child over time. Parents also discussed related loss experiences such as the loss of friendships when friends didn't understand their new situation.

“Coming to terms with the fact that I waited for so long to have a baby and then I got the baby, and the baby is premature and now he has disabilities. So, it's that expectation of wanting a healthy baby and not getting one.”

Mother of a 6 year old boy with Cerebral Palsy GMFCS level II

“I think you do move beyond the grief after the first sort of three or four years, but you always grieve for the lost opportunity”

Mother of a 10 year old boy with Cerebral Palsy, GMFCS level V

Parental experience: Worries for the future. Related to the process of grief, parents reported a strong sense of worry and concern for their child's future. This included worry about how their child will continue to socialize with peers as they age and enter High School, job prospects and how to prepare their child for wider society. Parents also reported concern for their other children and the roles that they may need to fulfill in caring for their sibling in the future.

“He's getting bigger, he's getting heavier. What's going to happen when he leaves school? What role is my five year old going to inherit at some point with his brother? I can't help but...worry about those things and while we can afford to provide at the moment for him and his needs, there's going to be a point where I retire...how [do] we support him in the future?”

Father of a 10 year old boy with Cerebral Palsy, GMFCS level V

Triggering events: Diagnosis both a challenge and a relief. Parental feelings around the time of the diagnosis itself were mixed. A number of parents reported that the time immediately after the diagnosis was one of the most emotionally difficult times. However, for other

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parents the diagnosis itself was a relief because it lifted their feelings of uncertainty. Further, for some parents worry about their child's development began early in life following a premature birth and hence the diagnosis itself, when it came, was not unexpected.

“Interestingly for us, the diagnosis in some way was a bit of a relief because you know we had this child...constantly falling over we knew that there was something going on...”

Mother of a 12 year old boy with Cerebral Palsy, GMFCS level I

Triggering events: Hospitalisation and treatment a challenge. Parents agreed that periods of hospitalization and medical treatment were emotionally difficult times and were challenging for the whole family.

“I think for me it has been when he had to have treatment. You know, he has got to go to the hospital and had to have... [injections].. and you know, the casting and everything like that. Because I know that it's scary for him and he doesn't like it.”

Mother of a 6 year old boy with Cerebral Palsy, GMFCS level II

Triggering events: Challenge of coping with others. Parents discussed the challenge of coping with the reactions of others to their child. A number of parents reported that they lost friendships after the diagnosis of CP or after their child was born preterm. Parents also discussed the challenges of coping with comments from the public, including sometimes well-meaning comments that nevertheless got in the way of them having a normal family day out with their child.

“People constantly surprise me... when [my child with CP] was born prematurely, my best friend drifted away. On my assessment, she couldn't cope with the disappointment of me not having the pregnancy and the child that she wanted me to have. And so she just drifted away because there was no connection anymore... That was a total surprise.”

Mother of a 10 year old boy with Cerebral Palsy, GMFCS level V

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How parents cope: Stay positive. Parents emphasized the importance of staying positive. They reported that it was important to be optimistic, to take the time to enjoy the progress their child is making (however small) and to stay strong for their child. Parents reported that it was important to develop an array of coping strategies because different coping strategies worked at different times. Suggested coping strategies included seeking support from family, friends and partner, seeking professional assistance, seeking satisfaction at work, using encouraging quotes and comfort food.

“I try and deal with it in a positive way and do what we can do.”

Mother of a 2 year old boy with Cerebral Palsy, GMFCS level I

“But I look at the glass half full and say that “Well, it’s only his walking, everything else is fine”. So, get over [it] and deal with it. I’ll give him a set of wheels and he can do the rest of the things. For me the glass is half full.”

Mother of a 8 year old boy with Cerebral Palsy, GMFCS level IV

How health practitioners can help: Be honest and give a plan of action. Parents agreed that they wanted health practitioners to give them honest and accurate information and to explain what the information means for their particular child. Parents also felt that it was important to develop, with parents, a plan of action so that parents aren’t left with a “What next?” feeling soon after diagnosis. Parents emphasized that different people cope differently with the initial diagnosis and so the amount of honest information and the detail of the action plan will need to vary from family to family. Parents wanted health professionals to consider their emotional needs at the time of diagnosis.

“give you an idea of perhaps what to expect...[that] It might be in the range of anything from this to this, and... why...”

Mother of a 6 year old boy with Cerebral Palsy, GMFCS level II

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“A really individual and tailored approach, according to what the family’s needs are... as well as what our emotional state is...”

Mother of a ten year old boy with Cerebral Palsy, GMFCS level V

Web-based Survey

Parents responding to the web-based survey had a mean score on the ABQ of 9.98 (SD = 6.44). This is consistent with symptoms of chronic sorrow found in other populations of parents of children with disabilities including parents of children with epilepsy (M = 10.45, SD = 7.9) [10] and mothers of children with neural tube defects (M = 7.09, SD = 5.63) [9]. The emotion endorsed most frequently on the ABQ was sadness, experienced by 98% of the parents. Full responses to individual items are listed in Table 4.

[Insert Table 4 here]

ABQ scores were not significantly correlated with child age, $r = -.14$, ns.

Parents are also able to identify additional emotions on the ABQ that they are also experiencing. The most commonly identified additional emotions were frustration (identified by 17 parents or 18.1% of the sample) worry (identified by 10 parents or 10.6% of the sample) and joy (identified by 4 parents or 4.0% of the sample). The ABQ also asks parents whether their feelings worsened at specific times thus identifying triggering events. Parents were able to respond in their own words to this question. The content of their responses was subjected to a qualitative analysis and three themes emerged. Parents reported that their feelings worsened when there was a medical intervention such as surgery or botox, a medical appointment, an allied health appointment or new diagnosis (reported by 22 parents or 23.4% of the sample). Parents also reported that their feelings worsened when their child failed to reach a developmental milestone, when parents compared their child to peers/siblings, or at times of a specific transition (e.g. starting school) (reported by 18 parents or 19.1% of the

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sample). In addition, some parents reported that their feelings were constant with one parent describing them as present, “every hour, every day” (reported by 6 parents or 6.4% of the sample).

Discussion

The aim of this study was to explore parental experiences of grief, coping and resilience in parents of children with CP and to investigate whether chronic sorrow theory provides an appropriate framework to understand those experiences. The results of this study are consistent with research demonstrating enhanced parenting stress in parents of children with CP [4-7]. Further, this study suggests that the theoretical framework of chronic sorrow theory may be useful in understanding the experiences of parents of children with CP [8-11]. Parents in the focus groups spontaneously discussed emotional experiences consistent with chronic sorrow including an ongoing sense of loss and feelings of sadness, frustration and guilt. Parents in the web-based survey were found to be experiencing a level of chronic sorrow symptoms consistent with other parents of children with disabilities such as epilepsy [10] and neural tube defects [9]. The overwhelming majority of the sample, 98% of the parents, reported continued feelings of sadness in relation to their child’s diagnosis. Further, chronic sorrow symptoms were not related to child age suggesting, consistent with chronic sorrow theory [8-11], that chronic sorrow symptoms persist as the child ages and do not remit with time.

Parents reported that the chronic sorrow symptoms worsened following specific trigger events, consistent with chronic sorrow theory [8]. For some parents the diagnosis was a particularly difficult time whereas for others the diagnosis itself came as a relief. All parents in the focus group reported that times of medical and allied health intervention were difficult. This is consistent with the web-survey data in which 23.4% of the sample identified

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times of medical intervention, allied health appointments and new diagnoses as the most difficult times. This makes sense when considered in the context of chronic sorrow theory as any event that brings into focus the disparity between actual and idealized life can trigger chronic sorrow. Parents in the web-survey (19.1%) also reported that their feelings worsened when their child failed to reach a developmental milestone, when parents compared their child to peers/siblings, or at times of a specific transition (e.g. starting school). This is consistent with the reports of parents in the focus group as for some parents the time of diagnosis itself was not difficult, it was more the lack of developmental progress over time that was distressing. Parents in the focus group also discussed the reactions of others as a triggering event, with even well-meaning reactions (e.g. attempts at charity) bringing their loss into focus.

The parents in this focus group demonstrated resilience, drawing from an array of coping skills (termed internal management methods in chronic sorrow theory) to manage their grief. Further, parents thoughtfully discussed how health practitioners could best support them; requesting honesty and an action plan (termed external management methods in chronic sorrow theory). Parents also emphasized the importance of tailoring needs for the individual parent by asking parents about their experiences and needs. This is consistent with chronic sorrow theory.

This study primarily took a qualitative approach in order to gather a rich data set on chronic sorrow in this population. The limitations inherent in qualitative research should be emphasised. The generalisability of the themes emerging from the focus group is, however, supported by consistency with parental reports in the cross-sectional survey. The confirmation of the focus group data with a cross-sectional survey is a strength of this paper. Further, a better understanding of chronic sorrow in parents of children with CP across time

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may be achieved through a longitudinal approach, following the adaptation of families from diagnosis across their child's life.

Conclusion

This study suggests that chronic sorrow theory may be a suitable framework in which to understand the experiences of parents of children with CP. It is recommended that health practitioners are mindful that, even years after diagnosis, parents of children with CP may experience intensified grief following a triggering event. Further, this grieving experience is healthy and normal with many parents demonstrating resilience by using an array of coping strategies or by seeking support from health professionals.

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Table 1.

Sample Characteristics of the Parent Focus Group (N = 8)

Variables	Participant Characteristics
<i>Age of child</i>	7.75 (3.35)
<i>Sex of child</i>	
Male	7
Female	1
<i>GMFCS Level of Child</i>	
Level I	3
Level II	2
Level III	0
Level IV	1
Level V	2
<i>Co-morbid diagnoses</i>	
Autism Spectrum Disorder	1
Epilepsy	1
Learning Difficulties	2
Intellectual Disability	1
<i>Type of family in which the child is living</i>	
Original family	7
Step-family	0
Sole parent family	1
<i>Relationship of participating parent to child</i>	
Mother	6
Father	2
<i>Highest level of education of participating parent</i>	
High School	0
Trade/apprenticeship	0
TAFE/college certificate	3
University degree	5
<i>Child receiving professional services for emotional or behavioural problems</i>	
Yes	1
No	7
<i>Professional assistance sought for participating parent (e.g. from psychologist, psychiatrist, counsellor, social worker)</i>	
Yes	2
No	6

GMFCS = Gross Motor Function Classification Scale

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Table 2.
Sample Characteristics of the Web-based Survey (N = 94)

Variables	Participant Characteristics
<i>Age of child (mean in years)</i>	6.68 (SD = 3.30)
<i>Sex of child</i>	
Male	63 (67%)
Female	31 (33%)
<i>Parental recall of GMFCS level as assessed by health practitioner</i>	
Level I	5 (5.3%)
Level II	5 (5.3%)
Level III	10 (10.6%)
Level IV	9 (9.6%)
Level V	9 (9.6%)
Unknown	50 (53.2%)
<i>Relationship of participating parent to child</i>	
Mother	85 (90.4%)
Father	6 (6.4%)
Foster mother	1 (1%)
Grandparent (primary caregiver)	2 (2.1%)
<i>Marital status of participating parent</i>	
Married	66 (70.2%)
Defacto	12 (12.8%)
Divorced/separated	11 (11.7%)
Never married	5 (5.3%)
<i>Highest level of education of participating parent</i>	
High School	28 (29.8%)
Trade/apprenticeship	19 (20.2%)
Vocational education/college certificate	9 (9.6%)
University degree	38 (40.4%)
<i>Employment status of participating parent</i>	
Full time	22 (23.4%)
Part time	36 (38.3%)
Not employed in paid work	36(38.3%)

GMFCS = Gross Motor Function Classification Scale

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Table 3. *Summary of the themes emerging from the parent focus group*

Meta-themes	Theme	Summary of the theme content	Relationship with Chronic Sorrow Theory
<i>Parental Experience</i>	Grief	Parents spontaneously reported emotions consistent with grieving including sadness, frustration and guilt.	All of the experiences that parents discussed are consistent with Chronic Sorrow Theory
	Worries for the Future	Parents reported worries for their child's future including transition to adulthood and concern about the role their other children may need to play in the future.	
<i>Triggering Events</i>	Diagnosis both a challenge and a relief	For some parents the diagnosis itself was one of the most challenging times. For others, the diagnosis itself came as a relief.	Consistent with Chronic Sorrow Theory, parents reported that their feelings were triggered by events that bring into focus the disparity between their reality and their idealized life
	Hospitalisation and treatment a challenge	All parents agreed that times of hospitalization and medical treatment were a particular challenge.	
	Challenge of coping with others	Parents reported challenges in coping with the responses of others including lack of understanding from friends (and the loss of friendships) and responses of strangers.	
<i>How parents cope</i>	Stay positive	Parents stated they needed to stay positive and be strong for their child. Further, they reported using an array of different coping strategies to do this.	Parents were skilled in an array of coping skills (internal management methods in chronic sorrow theory)
<i>How health practitioners can help</i>	Be honest and give a plan of action	Parents wanted health practitioners to deliver honest, accurate information and to give a clear plan of action. Further, parents wanted health practitioners to take the individual needs of the family (including emotional) into account.	Parents wanted individual attention and honesty from health practitioners (external management in chronic sorrow

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Table 4.

The number and percent of parents of children with CP (N = 94) reporting specific mood states on the Adapted Burke Questionnaire (ABQ) in the web-based survey

ABQ Emotion	Absent	Not Intense	Somewhat Intense	Very Intense
Grief	30 (31.9%)	30 (31.9%)	23 (24.5%)	11 (11.7%)
Shock	56 (59.6%)	14 (14.9%)	14 (14.9%)	10 (10.6%)
Disbelief	52 (55.3%)	12 (12.8%)	16 (17.0%)	14 (14.9%)
Anger	35 (37.2%)	29 (30.9%)	16 (17.0%)	14 (14.9%)
Guilt	28 (29.8%)	31 (33.0%)	24 (25.5%)	11 (11.7%)
Sadness	2 (2.1%)	34 (36.2%)	36 (38.3%)	22 (23.4%)
Helplessness	20 (21.3%)	26 (27.7%)	28 (29.8%)	20 (21.3%)
Fear	18 (19.1%)	29 (30.9%)	28 (29.8%)	19 (20.2%)

Appendix A: Questions asked by facilitators during the focus group

- 1) How do you feel about parenting a child with CP? List some emotions.
- 2) I'd like you to reflect back from when your child was first diagnosed with CP up till today. When you look back at your child's development up to this point, what have been the most emotionally difficult times for you as a parent?
- 3) When you are feeling this way, how do you cope with it? What strategies do you use?
- 4) As a means of coping with negative feelings, sometimes people avoid the experience. Have you done this before? Does it work?
- 5) What support do you think would be helpful when you received your child's diagnosis?
- 6) In closing, when you reflect on being a parent of a child with disability, what are the most important things you've learned?

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