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## CLINICAL PSYCHOLOGY & NEUROPSYCHOLOGY | RESEARCH ARTICLE

# Maternal narratives about their child's identity following acquired brain injury

Gerard A. Riley<sup>1\*</sup> and Selina Balloo<sup>1</sup>

**Abstract:** The aim of this study was to explore differences in how mothers perceive the identity of their child after acquired brain injury and the emotions associated with these different perceptions. Five mothers of children who had sustained a brain injury were interviewed and the data were analysed using thematic analysis to obtain the mothers' narratives about what had happened to their child's identity as a result of the injury. Three general narratives are described: *a child with problems*, in which the problems of the child dominated the perception of the child's identity and the post-injury child was viewed as fundamentally different from the pre-injury child; *an improving child*, in which the child's progress and achievements figured prominently, and the post-injury child was viewed as having an identity continuous with that of the pre-injury child; and *an improved child*, in which the post-injury child was viewed as fundamentally different and improved compared to the pre-injury child. These narratives were associated with different emotional responses: *A child with problems* was associated with a sense of burden, grief and anxiety about the future. These emotions were relatively absent from the other two narratives, and *an improving child* was associated with a sense of relief, pride and optimism.

**Subjects:** Behavioral Neuroscience; Behavioral Sciences; Psychological Science

**Keywords:** acquired brain injury; narratives; identity; family relationships; family carers

### ABOUT THE AUTHORS

The authors have an interest in how families cope with brain injury and degenerative neurological disorders. A major strand of their research, picked up in the present study, is how some family carers perceive continuity in the person (and in their relationship with that person) before and after the onset of the condition, whereas others perceive discontinuity. The research has focused on the impact of this difference on how family carers cope emotionally and on the quality of care that they provide.

### PUBLIC INTEREST STATEMENT

In this study, mothers of children with a brain injury were asked to describe what their children were like before the injury and what they are like now. Some mothers felt that the child was completely different, and their descriptions of the child after the injury focused on the child's problems. They felt burdened by these problems; they grieved for the pre-injury child they had lost; and they worried about the future. Other mothers were able to focus on the progress and achievements of their child, despite ongoing problems. They felt relieved about the progress made, optimistic about future progress and were proud of their children. The child was seen as the same child despite the injury, and there was no grief for a lost child. The study suggests that there is a connection between how mothers view their child after a brain injury and their emotional experience of the injury.

## 1. Introduction

Some of the negative outcomes arising from acquired brain injury (ABI) are mediated by the impact that the injury has on the identity of the individual (i.e. conceptualizations of the relatively enduring characteristics of the individual that are used to differentiate that person from others) (Ownsworth, 2014). ABI can result in losses and alterations in social, cognitive, physical and emotional functioning, which may, in turn, have an impact on how the person functions in education, employment, leisure and social activities, and family life. These consequences may then alter the person's self-identity (i.e. the person's private cognitions that define their identity to themselves); their social identity (i.e. how they are identified in terms of their position within social networks and relationships); and their public identity (i.e. how others identify and characterize them) (Gelech & Desjardins, 2011; Ownsworth, 2014). These changes in identity may, in turn, have a significant impact on the person with ABI. Negative changes in identity are associated with social withdrawal (Riley, Dennis, & Powell, 2010; Simpson, Mohr, & Redman, 2000), reduced quality of life (Secrest & Zeller, 2007; Vickery, Gontkovsky, & Caroselli, 2005), poor emotional well-being (Carroll & Coetzer, 2011; Ownsworth et al., 2011; Secrest & Zeller, 2007) and disruptions to family relationships (Gill, Sander, Robins, Mazzei, & Struchen, 2011).

Most of this research into identity after ABI has addressed identity changes when the injury has occurred in adulthood and research on the issue in relation to ABI occurring in childhood or adolescence is limited (Ownsworth, 2014). In relation to self-identity, there is evidence that children with an ABI tend to have lower self-esteem than their peers (Hawley, 2012). In relation to social and public identity, Mealings and Douglas (2010) interviewed adolescents about their return to school after ABI and reported that some experienced social rejection by former friends and differential treatment from teachers; and several qualitative studies have found that many parents feel that others in wider society do not understand the impact of the brain injury on their child (Brown, Whittingham, Sofronoff, & Boyd, 2013; Jordan & Linden, 2013; Roscigno & Swanson, 2011).

There are also a number of qualitative studies of maternal experiences of child brain injury that suggest that mothers' perceptions of the child's identity (i.e. part of the child's public identity) can be significantly challenged by ABI. Relevant themes from these studies include experiencing the post-injury child as being very different from the pre-injury child; a sense of loss and grief for the pre-injury child; and a sense of needing to build a new relationship with the post-injury child (Brown et al., 2013; Clark, Stedmon, & Margison, 2008; Collings, 2007; Guerriere & McKeever, 1997; Jordan & Linden, 2013; Roscigno & Swanson, 2011). However, these themes have emerged as part of an exploration of the wider experience of being the mother of a child with an ABI, and consequently there is a lack of detail about the impact of the ABI on maternal perceptions of identity. No previous study has attempted a systematic and focused exploration of the issue. Rather, relevant material in previous research has emerged as snippets of information that have not been integrated into a meaningful whole. Previous studies have also not explored, to any great extent, individual differences in maternal perceptions of identity, even though such differences are highly likely (Wongvatunyu & Porter, 2008).

The investigation of this issue is an area that merits particular attention. Some of the themes identified by this earlier research (e.g. loss and grief for the pre-injury child) suggest that how mothers perceive the identity of their child may have a significant emotional impact on the mother. Furthermore, maternal perceptions of the child may have a significant impact on the child's progress. Self-identity is developed and shaped by our interactions with others, and how others interact with us is determined by the identity they attribute to us (Gelech & Desjardins, 2011; Goffman, 1963). Parental perceptions of identity may have a particularly potent impact on the child's self-identity because of the critical role they play in the development of that identity (Bohanek, Marin, Fivush, & Duke, 2006; Ownsworth, 2014). The child's self-identity after ABI is, in turn, likely to have important consequences for their social functioning and emotional well-being. This expectation is based on the evidence from adult ABI, mentioned earlier, that negative changes in self-identity are associated with various negative social and emotional outcomes, such as social withdrawal (Riley et al., 2010)

and poor emotional well-being (Carroll & Coetzer, 2011). The expectation is also consistent with the theories underlying several psychotherapies (e.g. psychodynamic therapy Bowlby, 1977; Kohut, 1971 and cognitive therapy (Beck, 1967), according to which parents play a critical role in the development of the child's self-identity which, in turn, has a lifelong impact on emotional well-being and social functioning.

To investigate maternal perceptions of their child's identity, the present study adopted a narrative approach focusing on the stories that mothers told about how the ABI had changed their child. In the process of helping us to make sense of events and understand why people responded to events and circumstances in the way that they did, narratives help us develop a sense of both ourselves and others; and a sense of our own identity and the identity of others, in turn, shapes the stories that we tell (Bluck & Habermas, 2000; Bruner, 1990; McAdams, 2001). Families co-construct narratives about shared experience that similarly shape, and are shaped by, the identities of the family and the individuals within that family (Bohanek et al., 2006; Kellas, 2005; Trees, Koenig Kellas, & Roche, 2010). Narratives about serious illness and acquired disability are very frequently developed: they are needed because they provide the individual and the family with a way of explaining to others what is happening, and because the condition challenges their identity and the narrative helps them redefine their sense of self (Barker, Lavender, & Morant, 2001; Frank, 2013; Skinner, Bailey, Correa, & Rodriguez, 1999; Smith & Sparkes, 2008; Trees et al., 2010). Focusing on the mother's narrative about the changes in her child following the brain injury should thus provide a window on how the mother perceives the identity of her child.

In summary, adult ABI can have a negative impact on social and emotional functioning that is mediated by negative changes in self, social and public identities. In the case of child ABI, there has been relatively little investigation of identity change and its impact. One aspect of this that merits attention is changes in parental perceptions of the child's identity. More general research suggests that the child's self-identity is likely to be shaped by these parental perceptions; and some qualitative studies of child ABI suggest that mothers' perceptions may be significantly challenged by the ABI and that these altered perceptions may be associated with negative emotional outcomes for the parents. However, these possibilities have not been explored in any detail in previous research. There is little detailed information about the content of these perceptions of identity, how they may relate to the emotional experience of the ABI, how they may differ across mothers, or how the child may shape, and be shaped by, these identities.

The present study explored some of these issues, using a narrative approach involving five mothers whose children had sustained an ABI. Specifically, the aims of the study were to gain information about the content of maternal perceptions of their child's identity following ABI, using their narratives about change following the ABI as means of gaining this information; to explore how these perceptions and narratives differed across individual participants; and to investigate the emotional experience of the ABI connected to these narratives. In order to contain its scope, the study did not investigate how the children may shape, and be shaped by, the ways in which their mothers identified them.

## 2. Method

### 2.1. Qualitative approach

Following the recommendations of Squire et al. (2014), the focus and epistemological assumptions of the narrative approach adopted in this study are made explicit. The focus was on the content (specifically, what the narrative said about the way in which the participant perceived her child's identity) and emotional context (i.e. the connections between the narratives and the emotional experience of the participant) of the narratives, not on the structure or performance of the narrative. The narratives were viewed as a medium for understanding the experience of the participant, and not as a medium for understanding how narratives were used to construct that experience. It was assumed that external realities shape experience and narrative, and that experience is not wholly

defined by language and narrative. It is acknowledged that the content and emotional context of the narrative provided by the participant is likely to have been influenced by other factors such as memory, willingness to disclose and the social interaction with the interviewer. Despite this acknowledgement, the focus was on providing a description of the participants' narratives, rather than on additional interpretations of the accounts. Detailed family narratives about serious illness and acquired disability appear to be developed regardless of any involvement in research (Barker et al., 2001; Fisher & Goodley, 2007; Frank, 2013; Skinner et al., 1999; Trees et al., 2010), and so it was considered likely that the narratives would be sufficiently rich and detailed without the need for additional interpretation by the researchers that would introduce concerns about its credibility. At the same time, it is acknowledged that the researchers have influenced the representations of these narratives provided in this study, in terms of how the interviews were conducted and in terms of the themes that were extracted. Finally, although it was assumed that external realities shape the narrative, the relationship between those external realities and the narratives was not investigated (e.g. through the collection of more objective data from the participants or other sources). This would be more appropriately investigated in later studies when more is understood about the different ways in which mothers perceive their child's identity after ABI.

## 2.2. Participants

A convenience sample was recruited through the Child Brain Injury Trust, a UK non-governmental organization supporting children with a brain injury and their families. Participants were required to be mothers of children who had sustained a brain injury. Inclusion/exclusion criteria relating to the child were that the brain injury had occurred after they had entered formal education (i.e. at least four years old); the injury had occurred at least 12 months prior to the mother's participation in the interview; the child was under the age of 18 at the time of the interview; and the child did not have any additional concurrent serious medical condition. It was required that the child was at least 12 months post-injury because it was anticipated that it would take some time for mothers to develop a consistent and settled narrative about their child following the injury. The child was required to be of school age at the time of the injury because the study included a focus on whether identity had changed following the injury, and so the child needed to be old enough for the mother to have formed a clear and detailed perception of their pre-injury identity. Inclusion/exclusion criteria relating to the mother were that participants needed to have the intellectual capacity, and to be sufficiently fluent in English, to participate meaningfully in the interview; and that they were judged sufficiently emotionally robust not to be put at risk by participating in an interview that had the potential to be upsetting.

Given the complexity of narratives about important events in people's lives and the wish to explore differences between the narratives of the participants (Squire et al., 2014), the intention was to recruit a sample of no more than 10 participants (Morse, 2000). In the event, five mothers took part. Some details about them and their children are contained in Table 1. All names in the table and in the text are pseudonyms. For all the children, the brain injury had necessitated a stay in hospital of at least one week and, at the time of interview, all still had significant residual cognitive, emotional, social and/or behavioural difficulties arising from the injury.

## 2.3. Ethical approval

The study was approved by the University of Birmingham ethics committee and by the relevant committee of the Child Brain Injury Trust.

## 2.4. Interviews

Participants were asked to describe their child before and after the injury. To facilitate these descriptions, participants were asked to talk about the child's strengths and weaknesses, and their likes and dislikes; five adjectives that described the child's personality; how they got on at school, both academically and socially; how they related to other members of the family; and how they related to their friends, peers and others in the wider community.

**Table 1. Information about participants and their children**

Participant pseudonym	Age of mother	Occupation of mother	Number of other children in family	Child pseudonym	Type of injury	Gender	Age at time of injury	Age at time of interview	Years since injury
Mary	42	Service worker	2	Martin	Traumatic brain injury	M	5	13	8
Elizabeth	47	Clerical support worker	1	Alan	Traumatic brain injury	M	8	16	8
Laura	50	Manager	1	Emma	Stroke	F	15	17	2
Clare	48	Professional	2	Jack	Cerebral anoxia	M	4	7	3
Melissa	48	Service worker	2	Peter	Encephalitis	M	12	16	4

### 2.5. Analysis

Given the focus on the content and emotional context of the narratives, content-related thematic analysis was considered appropriate. Steps in this analysis followed those recommended by Braun and Clarke (2006). Interviews were audio-recorded and transcribed verbatim. Each transcript was read through and initial notes were made about how the mother identified the child and about other material that might be of interest. Initial notes from each transcript were then compared, looking for commonalities and points of difference. From this, potential themes were identified. Transcripts were then re-examined, and extracts relating to particular themes were copied into separate electronic files. Within each file, extracts were grouped separately for each participant. Each file was then examined with a view to refining the description of the theme, and extracts from the different participants were compared with the aim of identifying commonalities and points of difference.

### 2.6. Establishing credibility

Several measures were taken to enhance the credibility of the data collection and analysis. During the data collection phase, the two researchers met regularly to review transcripts to ensure that the questions followed the agreed interview schedule, and that the participants were being given ample opportunity to reflect on their perceptions of the child's identity. During the analysis phase, these meetings focused on reflecting on what the researchers may have brought to the process, clarifying the meanings of the themes, and ensuring that the themes were properly grounded in the interview data. Verbatim extracts from the interviews have been used extensively in this write-up of the study so that the grounding of the themes in the data is clear to the reader. The participants were sent a written summary of the findings and invited to comment. Four replied, saying that the summary captured important aspects of their experience and that it was helpful to hear that their experience was shared by others. The findings of the research were also presented to a group of paediatric clinical psychologists with experience of working with child brain injury. The expectation was that this work would have exposed them to the narratives of mothers about how their child had changed as a result of the brain injury, and that therefore they would be able to indicate the match between the findings and their own experience. Feedback suggested that many aspects of the narratives were familiar to these clinicians, but that they had less often encountered the central narrative provided by Melissa (i.e. that her child had been improved by the brain injury—see the Results section).

### 3. Results

The results are organized according to three overarching themes, each of which was associated with one or two of the participants: *a child with problems* (Mary and Clare), *an improving child* (Elizabeth and Laura) and *an improved child* (Melissa). These labels refer to the major narrative in the accounts of the corresponding participants, and capture differences across participants in terms of how they described the problems and strengths of the child, and the child's progress since the injury. Within each of these overarching themes, there are sections addressing how the participants described and

reacted emotionally to the ongoing problems caused by the brain injury (*problems and progress in overcoming them*); the contrasts between the descriptions of the child before and after the injury and the emotional significance of this contrast (*pre- vs. post-injury child*); how they described the current strengths and achievements of the child (*strengths and achievements*); and their thoughts and feelings about the child's future (*child's future*). The results are summarized in Table 2.

### 3.1. A child with problems (Clare and Mary)

The accounts given by Clare and Mary were dominated by the problems that the brain injury had caused. This dominance was evident in terms of the proportion of the interview given over to describing these problems; the strength of their emotional impact on the participant; and the way in which the problems coloured other aspects of their account.

#### 3.1.1. Problems and progress in overcoming them

Mary described Martin as “insecure”, “clingy” and “unsettled”, with a limited social life, ongoing cognitive difficulties and a limited quality of life.

He struggles with just about everything. Everyday life is a struggle from getting up in the morning, getting himself organised to school to organising to getting himself ready for bed at night. So I would say the thing from start to finish is a struggle. I think he just operates; he gets through the day and does what he needs to do and what people tell him to do. (Mary)

Mary reported that Martin had also been prone to rages in the earlier years following his injury. She acknowledged that this had subsided, but this was not accompanied by any sense of relief and was described very briefly in comparison to the more detailed account of his ongoing problems.

Clare's description of Jack focused on his aggression and impulsivity; his impatience and unpredictability; and his lack of respect for personal space and boundaries. Clare also described him as “frustrated”, “tormented” and “saddened” because he was unable to do many of the things he wanted to do, and because he was unable to control his own behaviour even though he knew it was unacceptable. Clare also described the burden imposed on the whole family by the brain injury:

Whatever we're doing [as a family], he'll come in and go [poking gesture] and you'll go

**Table 2. Summary of Findings**

	<b>Problems and progress in overcoming them</b>	<b>Pre- vs. post-injury child</b>	<b>Strengths and achievements</b>	<b>Child's future</b>
A child with problems (Clare & Mary)	Problems dominate description of child. Mother feels burdened and overwhelmed by these problems.	Child viewed as “completely different” person following the ABI. Large contrast between idealized pre-injury and trouble-laden post-injury child. Sense of loss for pre-injury child and lost future.	Descriptions of strengths and achievements not readily given, and accompanied by expression of negative emotions.	Anxieties about the future for them and the child.
An improving child (Laura & Elizabeth)	Although dealing with problems had been very stressful and there were still current problems, worst was over and child was progressing. Sense of relief and satisfaction. Some current problems viewed as being part of normal development.	Although child was changed, essentially still the same child. No current expression of loss or grief.	Readily given. Accompanied by sense of pride and pleasure. Resilience and personal growth of child in response to the ABI highlighted.	Altered expectations, but no significant anxieties about the future. Sense of optimism that the child will continue to progress.
An improved child (Melissa)	Some ongoing problems, but these not associated with any great sense of burden. Some viewed as being part of normal development.	Child viewed as essentially different. Post-injury child seen as improvement on pre-injury child. No sense of loss for pre-injury child.	Readily given. Described in terms of how much better her son compared to pre-injury child.	No significant anxieties about the future.

“whoa ok”, or he’ll just jump on you. And you’ll think, oh god, there’s not a second where that brain injury doesn’t affect all of us. (Clare)

Clare also acknowledged progress, but this was confined to his communication and mobility, and there was no mention of progress in terms of the behavioural and emotional issues. As with Mary, the descriptions of progress were short and unaccompanied by any sense of relief or satisfaction.

### 3.1.2. *Pre- vs post-injury child*

Both participants described their pre-injury child in glowing terms. Mary described Martin as “sociable”, “outgoing”, “bright”, “happy” and “always laughing”. He was “very sporty” and “very competitive” and was very talented at football. Clare described Jack as “sociable”, “kind”, “funny”, “cute”, “adorable”, “easy-going”, “loving” and “caring”. He was “active” and “enjoyed life”. She felt that, compared to other children, he had been advanced in most respects.

Both felt acutely the contrast between the pre-injury child and the post-injury child, reporting that the post-injury child was “completely different”.

But I just think a comparison, looking at how he was, he is completely different. ‘Who are you and what have you done with my son?’ is something you want to say on a regular basis. (Clare)

You know, ‘goodbye for that Martin - hello to this Martin’. So almost instantly, I knew straightaway, so that’s how I dealt with it and I just basically dealt with it straightaway but I knew he was different. (Mary)

Clare could see that Jack had retained some of his pre-injury qualities, but somehow these qualities were different. Jack was still intelligent and articulate, and had retained his sense of humour, but it was “different” because he was sad at the same time. He was also still “very loving”, but this was “in a different way” partly because he did not now maintain much eye contact with other people: “I would still say that he is bright and funny but tormented and sad at the same time and he is still very loving but ... in a different way”.

This contrast between the pre- and post-injury child was upsetting for both participants and particularly so for Clare. She described how she tried to avoid thinking about the past because it elicited a sense of loss and grief.

We [Clare and her husband] do avoid it [thinking about how Jack used to be] because it’s painful, you know. It’s like somebody dying isn’t it? You don’t look at it every day, and it doesn’t to an extent I think time makes it easier in some respects because we’ve still got him, but, you know, have we still got him? (Clare)

Reminders of the past were difficult to deal with. Clare expressed some sense of relief that a friend of Jack’s, who was born on the same day as him, had moved away because she was a “constant reminder” of what Jack would have been. Glimpses of the old Jack in daily life could also be painful because they were a reminder of what had been lost.

You catch a glimpse [sighs] of who he used to be...you do see glimpses of him, of this, but he is totally different in a lot of ways; you know very, very different. And I think that’s probably going to be the hardest thing for me to cope with. (Clare)

### 3.1.3. *Strengths and achievements*

Both participants were able to describe strengths and achievements of their post-injury child, but their reflections served to trigger negative emotions about the situation. When asked about Martin’s strengths and achievements, Mary took some time to think of what these might be. She thought that his loving nature may have been enhanced by his brain injury, but this thought was accompanied by



an expression of anxiety that this might leave him open to exploitation by other people: “He is very loving - so maybe he might not have been that loving, very loving, yeah. He is loyal, very loyal and very trusting, too trusting - people take advantage of him”. Clare was more readily able to highlight strengths and achievements, but again her descriptions were accompanied by negative emotions. For example, she described how Jack enjoyed video games and excelled at them, but this prompted her to think of how different this was from the pre-injury child who rarely watched the television and preferred to be outside. His achievements could be difficult for her to take pleasure from because they, too, acted as a reminder of what had been lost.

As soon as you are reminded of the children [with brain injury], you’re reminded of things that they’re not going to do. Every triumph, yeah, is nice, but with kids like this, there is always more of the damage even every victory there is. Even for me as a positive person who is not pessimistic at all, it is very difficult. (Clare)

Even his progress in regaining his mobility and communication was, in one way, “upsetting” because it reminded her of when she was told that he would not walk or talk again, and of the struggle to get the treatment she felt he needed.

#### 3.1.4. *The child’s future*

Both Clare and Mary worried about the future. Mary worried about Martin’s limited social life, and what implications this would have for him in the longer term. She expected limited success in his school exams and doubted that he would ever be able to live independently.

I don’t know what the future holds. Actually I often think [about] this - what will the future hold for him? Will he always need someone around to help him? I think that could be the case. Would he be able to live alone? I don’t know. Would he, maybe, need sheltered accommodation like when he’s an adult, you know. I don’t know. Will he ever drive? No, because he’s on medication for ever. So it’s very, very hard, isn’t it I always says he is going to stay with me forever, and I actually think he will. (Mary)

Clare expressed similar concerns about whether Jack would ever “be able to cope with the real world”. She was also worried about dealing with his aggression and personal invasiveness as he grew taller and stronger.

What’s going to happen in six, seven years’ time when he’s bigger? You know these are questions that constantly catch me looking at, and then I draw myself back and say “no look at today you can’t say that he’s going to be the same person when he’s fourteen as he is now, shut up, shut up” and I have to check myself because if you didn’t, you’d be digging yourself into an early grave. (Clare)

### 3.2. *An improving child*

In contrast to the accounts of Mary and Clare, a major theme in the interviews with Elizabeth and Laura was how their child had improved over the time since the brain injury. Both described very difficult periods earlier on in the child’s recovery, and both described ongoing problems, but the major problems were described as being in the past.

#### 3.2.1. *Problems and progress in overcoming them*

Elizabeth described, in graphic terms, how destructive, aggressive and overactive Alan had been in the year or so following the injury (“an absolute nightmare”, “less than a toddler”, “violent”, “dangerous”, “like a machine, he’d go on all night and all morning”) and how stressful and difficult it had been to manage his behaviour. He was still inclined to be overactive and impulsive, and could lose his temper and behave inappropriately in public. However, there was an emphasis in Elizabeth’s account on how much better he was. Overall, Elizabeth’s assessment was that “in eight years he’s done incredibly well.”

When I look back and think, well, when he was like throwing things and he was biting and he

was kicking; now he can sit down and he can have a conversation with me. He can make me a cup of tea. Eight years ago I didn't think he'd ever do this. (Elizabeth)

Laura described how, after her stroke, Emma had become socially withdrawn, angry, tearful and depressed. The stroke had also caused cognitive problems which continued to affect her at school. This had been "really, really intense and hard emotionally" for Laura herself. Again, however, there was an emphasis on how the problems were improving. Although there were still days when Emma would become very upset and although she still had to deal with her cognitive problems, "we are coming out of the other side" and "it's been getting better all the time". Emma was about to start a job and take driving lessons "which, six months ago, she wouldn't have contemplated". Laura expressed relief and pleasure at this progress.

It's so nice lately to see her just, just step out a bit more, you know [to] feel that she's capable of doing what she wants to do. (Laura)

She's great, I think, at the moment; she's doing really, really well. I think she's just sort of getting into the swing of things with school. I think she's enjoying the fact that she's going into school with her friends because she feels like she's back to normal there. (Laura)

Both Laura and Elizabeth interpreted some of the ongoing problems as "normal" problems that any teenager might encounter. Contextualizing them in this way seemed to make them easier to cope with.

She was going through things emotionally. So I said to her, what you've got to remember is you're a teenager and some of this could have been just what happens. (Laura)

We still have blips. The other day she felt really tired and then really tearful, but I think Emma has come round to realise, well like all of us, if you burn the candle at both ends and you let yourself get really tired, you don't cope and that's the same with everybody. It's just a little bit more acute with Emma. (Laura)

He's really sorry when he does something wrong. But then you've got to work it out. Is it impulsivity? Is it a lack of inhibitors? Is it teenager thing? Or is it just Alan being bloody minded? (Elizabeth)

### 3.2.2. *Pre-injury vs. post-injury child*

As with Melissa and Clare, Laura and Elizabeth both described their child prior to the injury in a very positive way. Elizabeth described Alan as "sporty", "intelligent", "outgoing", "lively", "kind", "generous", a "born entertainer" and a "born leader". He was a very talented footballer and cricketer. Laura described Emma as "very sociable" "always made lots of friends", "very artistic", "bright" "really enjoyed school" and "well liked by the teachers", "a good kid at home", "fairly grounded, sensible girl", "very close to her family" and "a very kind soul".

Whereas Melissa and Clare were clear that their post-injury child was "completely different" from the pre-injury child, Laura and Elizabeth were less definite in their differentiation. Although the child had changed in some ways, it was still the same child and this had become more apparent as the problems diminished. Laura described how she had prepared herself the night that the stroke occurred for the possibility that her daughter would be very different, but this had not occurred. With the progress Emma had made, Laura felt that she had now "got her back", although in a sense she had never gone away.

I said to him [her husband] I needed to get up the next day ready to take home a child that I didn't recognise...But, as it happened, I mean she is a different child but, my god, nowhere near what I had prepared myself for, and now I've got her back...I mean I always knew she was there somewhere. (Laura)

Like Laura, Elizabeth also referred to the idea that, because of his progress, her son was now more like his true self, a self, perhaps, that had never quite gone away: “[In the context of reflecting on how much progress he had made] As I said, he’s more like Alan, he’s more like my Alan, but he’s slightly different if you know what I mean”.

In contrast to Mary and Clare, Laura’s account made no mention of grieving for a lost child or lost possibilities. Like Clare, Elizabeth described her sense of loss for the life that Alan might have had, and she described how painful it could be to see other children progressing in the way that she had expected Alan to progress. However, unlike Clare, she referred to this pain as something that had happened in the past:

I lived his life, or what I would be expecting him to be doing, through her [her niece who was of a similar age to Alan]...She was doing things that I would have expected Alan to be doing at this stage. A couple of years went by and I couldn’t do it. I couldn’t go to events that she was doing and seeing her because I kept thinking, ‘What’s Alan got?’ (Elizabeth)

Elizabeth had been encouraged by a clinician to mourn for her lost child, but she found this idea puzzling and resisted it.

Because he wasn’t dead, for want of a better reason, you couldn’t mourn him - because he was still with us. And I was celebrating the fact that he was with us, so the mourning had to go on the back burner. (Elizabeth)

### 3.2.3. *Strengths and achievements*

Both Elizabeth and Laura spoke at some length about the strengths and achievements of their child. At his most recent school, Elizabeth’s son had done “brilliantly”; he was learning to be more independent; and had managed to complete some work experience “which I thought he’d never ever do”. He was also now making decisions for himself, and expressing opinions. There was also the prospect of some limited paid work, which Elizabeth was delighted about. Elizabeth attributed much of this progress to Alan’s own resilience: “I’m just thinking – don’t ever challenge him, to say that he won’t do it - because he will. That’s what’s got him as far, that’s what’s made him what he is, determination...[he] just goes on strength to strength”. Elizabeth was readily able to highlight some of his strengths

He’s very kind, he’s very loving, he’s very sharp, you know, he really is with it. But, you know, behaviour-wise he can be spontaneous, you know. He’s very sympathetic when he has to be, and he is courageous, you know, I have to say his courage is phenomenal. (Elizabeth)

Laura also highlighted Emma’s strength and resilience as being important factors in her recovery. She also reflected on Emma’s personal growth as a result of the stroke.

I think that’s one thing that’s really changed is that she tends to see other people’s points of view a lot now, you know. She’s had to be really mindful of herself [and] her feelings and because she has to, because she’s felt like that, I think it makes her look at other people like it, too I do think, whether it be stroke or anything happen to you, you do get a perspective, don’t you, some sense of perspective on things. (Laura)

### 3.2.4. *The child’s future*

Elizabeth and Laura were less concerned about the future than Mary and Clare, and neither expressed any great anxiety about what was going to happen. Elizabeth acknowledged that she did not know whether Alan would meet the “normal expectations” of getting married, having children and getting a good job. She had developed a coping strategy of not worrying about the future and not having any specific expectations about what Alan would achieve. She felt that having such expectations would put pressure on Alan, and they would both be disappointed if he did not fulfil them.

His achievements were therefore often experienced as surprising, and this had given rise to a general expectation that Alan would continue to surprise everyone with his progress.

He always surprises me with all the things he comes out with. And, as I said, I think he will continue to do that whatever he says, whatever he's going to do. (Elizabeth)

Somewhere in his life he's going to do something that's like 'wow, that's superb'. He does these things and grows. (Elizabeth)

Despite some initial concerns about how well Emma would cope with the more advanced examinations at school, Laura had been surprised at how well she had done and now wanted to keep an open mind about what Emma might achieve in the future. Generally, she was not concerned about what Emma did so long as it was something that made her happy. She took comfort from her perception that Emma was driven to achieve. The future was seen as an opportunity for further personal growth, rather than something to be worried about.

To be quite honest, I couldn't care less [about her career choices]. I've got to that stage now where, as long as she's doing something that makes her happy, I'm happy. (Laura)

She wants things in life, you know. She definitely wants to get on, and I encourage that... I think this [part-time work] will be another thing that will be good for her, that bit of extra responsibility and it's doing something for her, away from us. (Laura)

### **3.3. An improved child**

In contrast to the other participants, a major theme in Melissa's account was how Peter had been improved by his brain injury. Unlike the others, she did not paint a positive picture of Peter pre-injury and, compared to the pre-injury child, the post-injury child was a great improvement.

#### *3.3.1. Problems and progress in overcoming them*

Melissa's account of child's post-injury difficulties did not describe these in much detail and it was not presented with much emotion. She remarked on Peter's poor memory and concentration; his restlessness, twitching and shaking; and his poorly articulated speech. She also commented on how frustrated he would get, particularly with his communication difficulties and with his younger brother. However, like Laura and Elizabeth, she considered that some of his behaviour was due to his developmental stage rather than the brain injury.

Even now if we look at him, we have to think: Is that him being a sixteen year old teenager or is that his damage, his brain injury part of him? And it's really hard - you have to try and decipher which is which, and allow for both as well because he's a teenager too. (Melissa)

Although Peter had made some progress in overcoming these difficulties, Melissa did not elaborate on this and, unlike Elizabeth and Laura, there was no great sense of relief about it.

#### *3.3.2. Pre- vs. post-injury child*

Prior to the injury, Peter already had some specific learning difficulties as a result of infant pneumonia and displayed some behaviours that Melissa had found challenging. He was anxious and insecure when his mother was not present. He was a "fussy eater". He was also "a bit of a recluse [and] didn't mix very well", preferring to stay at home and to play on his own in his bedroom.

So, yes, he was a challenge because you couldn't go anywhere. And if you went out for the day, you knew he would ruin it in some way; he'd have a tantrum or he'd want to go home or he wasn't bothered. (Melissa)

There was a strong sense of difference between the pre- and post-injury Peter. Melissa felt that she had to re-bond with a different child: "[There's been a] big change. We've had to re-bond with a

different child because he's totally different to what he was before...It's like someone's taken him away and brought him back different”.

### 3.3.3. *Strengths and achievements*

Melissa described Peter's strengths in terms of how much better he was now in comparison to before the injury. She described how Peter had become far more sociable and adventurous, keen to try new things and new activities.

[Before the injury] If we went out for the day, he didn't want to do anything and he didn't want to go on anything, you know he was real sort of, it was hard for the others [his siblings] enjoying themselves. Whereas now we've got a completely different Peter; he'll want to try new things. He's in the sea cadets, you know, he loves it. He wants to join clubs, youth clubs. (Melissa)

Whereas before he would reluctantly do things when asked, now he was positively keen to help.

He's like a little guardian. He looks out for the twins [his younger siblings]. He'll take the dog for a walk. He'll come down and say “Do you want any help mum?” He's very helpful; he loves doing little jobs for you; he's totally different. (Melissa)

### 3.3.4. *The child's future*

Melissa did not express any anxieties about Peter's future. She expected him to become independent and to gain employment.

## 4. Discussion

The aim of this study was to explore individual differences in how the participants perceived the identity of their child after the injury and how these relate to the emotional experience of the injury. The findings suggested that there were major differences in how they perceived the identities of their child, and that these differences were associated with different emotional responses. For Clare and Mary (*a child with problems*), the problems caused by the brain injury dominated their descriptions of the child's identity and both felt burdened by them. Even when talking about progress in overcoming the difficulties, or the positive achievements and attributes of their child, their accounts were clouded by negative emotions associated with the problems. Both viewed the post-injury child as having a very different identity to the pre-injury child (“a totally different child”), with a sharp contrast between an ideal pre-injury child and a current child beset with problems. For Clare in particular, there was a sense of grief for the pre-injury child and a lost potential future. Current glimpses of the pre-injury child were upsetting because they acted as a reminder of what had been lost. So, too, were reminders of the past and of what might have been (e.g. comparisons with other children). For both Mary and Clare, the child's problems were associated with anxieties about the future.

By contrast, in the accounts of Elizabeth and Laura (*an improving child*) a major theme was the improvements and achievements of their child. Although both described very difficult periods in the earlier stages and ongoing problems, there was a sense that the worst was over and that their child was on an upward curve of progress. This progress was associated with a sense of great relief and satisfaction. Problems were understood in terms of their children being teenagers, as well as being a result of the brain injury. They readily highlighted the strengths and achievements of their child in a positive way that was not coloured by negative emotions. Both highlighted the resilience of their children in dealing with the difficulties. For Laura, dealing with the injury had resulted in some personal growth for her daughter that would not otherwise have occurred. Although both reported that their child had changed compared to how they were pre-injury (and both presented an idealized description of the pre-injury child), there was no sense that their child was, or ever had been, an essentially different person in the way that Clare and Mary described. Instead, they were the same child but different, and both spoke of having their child “back”, albeit somewhat changed. Related to this, neither expressed grief for a lost child. Similar to Clare, Elizabeth did talk about a sense of loss in relation to how her son's life would have turned out but for the injury, but this was described as

something that was no longer current and she explicitly rejected the notion of grieving for a lost child. Although both Elizabeth and Laura had altered expectations for their child's progress in the future, neither expressed any great anxieties about the future.

Unlike the others, Melissa (*an improved child*) felt that the brain injury had directly improved her son. A major theme in her account was how much better her son was compared to how he was pre-injury. There was no description of an idealized pre-injury child. Melissa described ongoing problems, but these were not associated with the same degree of negative emotions as they were for Clare and Mary. Like Clare and Mary, she reported a radical change in the child's identity such that she felt she had to re-bond to a different child. However, given her perception of how the injury had benefited her son, there was understandably no sense of grief or loss for the pre-injury child. Like Elizabeth and Laura, she was inclined to attribute some of her child's current difficulties to "being a teenager", and she expressed no anxieties about the future.

The experiences of Clare and Mary resonate most strongly with other literature about parental experiences of living with childhood ABI. Other studies have reported on the parent's sense of being faced with an essentially different child and of needing to form a new relationship with this different child (Brown et al., 2013; Clark et al., 2008; Guerriere & McKeever, 1997; Jordan & Linden, 2013; Roscigno & Swanson, 2011). Related to this, grief for the lost pre-injury child has also been reported (Guerriere & McKeever, 1997; Jordan & Linden, 2013; Roscigno & Swanson, 2011). Echoing Clare's account in particular, participants in the study of Jordan and Linden (2013) reported how painful reminders were of what had been lost, such as those provided by comparisons with other children of a similar age. Anxieties about the implications of the ABI for the child's future have been reported (Brown et al., 2013; Jordan & Linden, 2013; Prigatano & Gray, 2007). The sense of burden reported by Clare and Mary is also evident in other research (Jordan & Linden, 2013; Wade et al., 2001).

On the other hand, there are also echoes in the existing research literature of some of the more positive experiences reported by Elizabeth and Laura. In a study of mothers of people who sustained their injury in early adulthood, Wongvatunyu and Porter (2008) reported that some participants focused on the progress that their child had made since the injury and their potential for further progress in the future. Parents in other studies have also highlighted the child's resilience and strength in coping with the injury (Guerriere & McKeever, 1997; Wongvatunyu & Porter, 2008), and the personal growth achieved by the child as a result of having to deal with the injury (Brown et al., 2013). Similar to the present study, Wongvatunyu and Porter (2008) also noted variation across participants in the sense of whether the child was a different child. Although some of their participants reported a sense of their child being a different person, others, like Elizabeth and Laura in this study, perceived continuity in the personhood of their children, despite the changes that had occurred. Roscigno and Swanson (2011) suggested that this perception of continuity was more likely in those participants whose children had sustained less severe injuries. Similar to Elizabeth and Laura, some participants in this study also talked about the child returning to their previous self, and having the child 'back'. Elizabeth did talk about a sense of loss for the life her son would have had, but this was described as a stage that she had worked through. Other studies have also reported a reduction over time in the sense of loss and grief (Collings, 2007; Guerriere & McKeever, 1997). Finally, some studies have noted that, like Laura, Elizabeth and Melissa, not all participants report feeling overwhelmed by the burden of their situation (Brown et al., 2013; Wongvatunyu & Porter, 2008). Brown et al. (2013) suggested that the focus on positive outcomes shown by some of their participants helped them to cope with their negative emotions more effectively. The role of positive appraisals in acting as buffers to reduce the distress created by the negative aspects of caregiving has also been suggested in the broader research literature about family carers (Tarlow et al., 2004).

The notion that positive appraisals of their child can reduce the sense of burden has been challenged. Jordan and Linden (2013) noted that some of their participants did talk about their child's resilience, achievements and progress, and expressed some optimism about the future; but they claimed that this talk was not associated with any sense of diminution of burden, and there was no

sense of the participants coming to terms with their child's injury. However, the methodology of this study may not be sufficiently robust to sustain such a conclusion. The study involved participants returning written answers to five general questions about the impact of their child's ABI on their own well-being. As acknowledged by the authors, participants were not asked whether these positive aspects of their child's situation had any emotional benefits or helped them to come to terms with the ABI. A more likely scenario is that parents differ in how well they cope with the impact of the injury (Wongvatunyu & Porter, 2008).

Although these earlier qualitative studies contain material relevant to the issue of how mothers identify their child after brain injury and the emotional associations of these identifications, the material has been embedded in an exploration of the wider experience of being the parent of a child with an ABI, and consequently there is a lack of detail about the specific issue of identity and its associated emotions. The material has emerged as snippets of information that have not been integrated into a meaningful whole. The present study has attempted a more systematic and focused exploration of the issue. This allows different aspects of the experience to be related and integrated into a more complex whole. For example, an emphasis on the problems that the child has as a result of the brain injury, coupled with an idealized identification of the pre-injury child, may make it difficult to perceive continuity in the child's identity because of the sharp contrast that is created between the pre- and post-injury child. An emphasis on problems may also make it more difficult for the mother to perceive and appreciate the child's strengths and progress, and may contribute to a sense of grief for the lost pre-injury child, a sense of being overwhelmed by the burden of caring for the child, and anxiety about the future. In contrast, a sense of the child's progress, strengths and achievements may protect the mother from feeling over-burdened by their problems, or by anxieties about the future. Together with a sense of the continuity between the pre- and post-injury child, this positive outlook may also help protect her against being overwhelmed by feelings of grief for the pre-injury child and a lost future. In making these suggestions about the ways in which different aspects of the participants' experiences may be connected, simple causal connections are not being proposed. It is likely that any relationship between two aspects is bi-directional and also dependent on other aspects of experience. Rather, the aim is to highlight some plausible potential connections that merit further investigation in future studies.

Parental reactions to living with ABI, the interpretation of parental narratives about this experience by researchers (including ourselves), the general aims and methodologies of research into families living with ABI, and the practice of those providing support and services to those families are all likely to be influenced by, and to contribute to, broader cultural narratives about the meaning of disability to families (Skinner & Weisner, 2007). In this context, it is interesting to consider the narrative differences between the participants in this study and the differences between researchers in terms of interpreting family narratives about ABI, in terms of studies of the broader cultural narratives about the birth of a child with disability (i.e. the disability is congenital rather than acquired in later childhood). Based within the broader conception of disability as weakness, inferiority and neediness, the dominant master narrative for most of the past century is that such births are a tragedy for the family (Allred, 2015; Ferguson, 2002; Green, 2007; Lalvani, 2008). The Kubler-Ross stage model of grief is widely used to characterize the reactions of parents; the parents are viewed as being in mourning for the lost 'normal' child, and any parental optimism and positivity viewed as denial (Allred, 2015; Lalvani, 2008). The family are perceived as helpless victims of the tragedy, burdened and damaged by the child, and vulnerable and in need of support (Allred, 2015; Ferguson, 2002; Lalvani, 2008). Those providing support services to the child and family often share these negative conceptions of disability (Lalvani, 2008) and consider one of their primary roles to be to help the family through the stages of grief to acceptance (Allred, 2005). Much research has focused on cataloguing the damaging impact of the child on the family (Ferguson, 2002; Lalvani, 2008). In more recent years, alongside the emergence of the social model of disability and positive psychology, a counter-narrative has been gaining strength which focuses on the ability of families to cope in a positive way with their situation, and to show positive growth and development as individuals and as a family in response to their child (Allred, 2015; Ferguson, 2002; Fisher & Goodley, 2007; Green,

2007; Lalvani, 2008; Stainton & Besser, 1998). The child can be a source of pleasure, enrichment and pride (Fisher & Goodley, 2007; Green, 2007; Lalvani, 2008; Stainton & Besser, 1998). From this perspective, the aim of support services should be to focus on the family's resources and strengths, to help them appreciate the positive aspects of living with the child, and to collaborate with them in coping positively with their situation (Allred, 2015; Green, 2007).

The narrative differences between the participants in this study and the differences between researchers in their interpretations of family narratives about ABI are reflected in these broader cultural narratives about the birth of a child with disability. Indeed, the tragedy and grief aspects of the master narrative may be more readily applicable to ABI because the pre-injury child that is lost is an actual child, rather than a hypothetical hoped-for 'normal' child. In relation to the participants in the present study, the narratives of Clare and Mary (*a child with problems*) reflect the master narrative, with a strong sense of grief for the pre-injury child, burden, helplessness and hopelessness. By contrast, the narratives of Elizabeth and Laura (*an improving child*) reflect the counter-narrative. Although the experience had been stressful and difficult, there was no sense of present loss. Instead, the focus was on the child's strengths, achievements, potential and resilience, and these were a source of pleasure and pride. Similarly, for Melissa (*an improved child*), there was no sense of grief, burden or hopelessness. The cultural narratives about congenital disability are also reflected in the ABI research. It was noted earlier that previous qualitative research predominantly reflects the narratives of Clare and Mary, emphasizing grief and burden; but that there are echoes (albeit less frequent and more difficult to find) of the more positive counter-narrative exemplified by Elizabeth and Laura. The interviews in this study also provided evidence of the master narrative in the advice given by those providing help and support to the participants. Both Mary and Elizabeth had been advised by clinicians to grieve for the pre-injury child and welcome the new child. As Mary reported, she had been encouraged to say "goodbye for that Martin; hello to this Martin".

### 5. Implications

Parent-related variables (such as parenting style, parental emotional state, and family dynamics) have an important influence on outcomes for the child after brain injury (Kinsella, Ong, Murtagh, Prior, & Sawyer, 1999; Micklewright, King, O'Toole, Henrich, & Floyd, 2012; Taylor et al., 2001). The influence of how parents construct the identity of their child on these outcomes also merits investigation. The identities that parents attribute to their children may have a potent impact on the self-identity of the child, and thereby on the long-term psychological well-being and social functioning of the child (Beck, 1967; Bowlby, 1977; Kohut, 1971). The present study suggests that there may be important differences between mothers in terms of how they construct the identity of their child. An issue worthy of future investigation is whether these differences, in turn, have a differential impact on outcomes for the child. For example, mothers who are able to focus on positive aspects of their child may impart more self-confidence to their child; whereas a maternal identity that construes the child in terms of the problems they cause may have a negative impact on the child's self-esteem.

The connections between these differences in identity construction and the emotional well-being of parents also merit further investigation. Childhood ABI is associated with poorer emotional well-being of parents compared to parents of uninjured children (Hawley, Ward, Magnay, & Long, 2003; Wade et al., 2001). In the present study, there was an association between identity construction and the emotional well-being of the participants. Clare and Mary (*a child with problems*) felt distressed and overwhelmed by the problems created by the brain injury; they grieved for what they had lost; and they were anxious about the future. For Elizabeth and Laura (*an improving child*), there was a sense of relief and pride in relation to their child's progress; any grief had largely been resolved; and there was less anxiety about the future. For Melissa (*an improved child*), there was satisfaction over the improvement that had resulted from the brain injury, no grief and no major anxieties about the future. It would be worth investigating whether the associations between identity construction and emotional well-being found in this study apply more generally in the population of parents looking after a child with an ABI.



If it transpires that how parents perceive their child's identity does have an impact on outcomes for the child and on the emotional well-being of the parents, another area that would merit investigation is whether parents could be supported to construct their child's identity in a way that promotes beneficial consequences for themselves and their child. In this context, it was interesting to note that some of the participants in the present study reported that they had been advised by clinicians to grieve for the pre-injury child and welcome the new child, with the implication that the post-injury child is an essentially different person. There does not appear to be any evidence that this is helpful advice. In the context of dementia, it has been suggested that spousal carers who lose a sense of continuity of identity in the person with dementia are more likely to experience a greater sense of loss and grief (Riley et al., 2013) and to feel burdened and overwhelmed by difficult behaviours (Murray & Livingston, 1998; Walters, Oyebo, & Riley, 2010). This resonates with the experiences of Mary and Clare in the present study, both of whom described discontinuity between the pre- and post-injury identities of their child, and both of whom felt an ongoing sense of loss and grief, and felt burdened by the child's difficulties. It may be of more benefit to parents if they are supported in maintaining a sense of continuity in the child's identity.

## 6. Limitations

Because of the small sample and the methodology used, no claims are made about how representative the narratives reported in this study are of those occurring in the wider population of parental carers. As noted by the clinicians who responded to a presentation of the results, Melissa's narrative about her son being improved by the brain injury is likely to be infrequent. No general conclusions can be drawn either about the links between identity and emotional well-being. Indeed, even for the mothers involved in the study, the idea that identity and emotional well-being were inter-connected can only be offered as a suggestion rather than as a definitive conclusion: The participants obviously varied in many ways that were not explored and some of these other differences could lie behind the association between identity and well-being.

A more general limitation of the study is that there was no exploration of these broader factors that may explain why mothers in this study varied in how they appraised the identity of their child and in their emotional responses. For example, Roscigno and Swanson (2011) suggested that perceptions of continuity are more likely in parents whose children have experienced a milder injury, and it has been found that grief is associated with severity of behavioural disturbance (Zinner, Ball, Stutts, & Philput, 1997) and diminishes over time (Collings, 2007; Guerriere & McKeever, 1997). However, it seems unlikely that these injury-related variables provide a full explanation of the findings in the present study. The sons of Mary and Elizabeth were at a similar time post-injury (eight years) and both displayed challenging behaviours that had shown significant improvement, but Mary's account lacked the emphasis on progress and achievement, and lacked the associated positive emotions evident in Elizabeth's account.

## 7. Conclusion

The present study is the first to attempt a systematic and focused exploration of how mothers differ in terms of the identities they create for their children following an ABI, and the emotional associations of those identities. The findings suggested substantial differences between the participants in terms of how they perceived the identity of their child, and these differences appeared to be associated with different emotional reactions. Various potential connections between these different aspects of identity and emotional experience were suggested. These merit further investigation. So, too, does the impact that maternal identity has on how well the child progresses in response to the brain injury. If these links are confirmed, research would also be warranted on whether supporting mothers to avoid unhelpful ways of perceiving identity would benefit themselves and their children.

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