

Parenting a child with an ABI

**The experiences of parenting a child with an acquired brain injury: A metasynthesis of the qualitative literature**

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### **Abstract**

**Objective:** To systematically review and then synthesise the qualitative literature on the experience of parenting a child with an acquired brain injury (ABI).

**Design:** Systematic literature review and metasynthesis

**Methods.** A systematic search of the literature was conducted in four databases. Papers which met the inclusion criterion were assessed for quality using the Critical Skills Appraisal Programme (CASP) tool and then synthesised according to Noblit and Hare's (1988) guidelines for metaethnography.

**Results.** Of the 4855 papers retrieved, 17 met the inclusion criteria. Synthesis resulted in three themes: (1) Disconnection: Cut off from internal emotions and isolated from others; (2) Seeking understanding and support to manage in an insecure world; (3) New parent to a different child.

**Conclusions.** Having a child with an ABI leads to many challenges for parents. These include feeling insecure, isolated from others, and struggling to adapt to the different roles required to parent their different child. Clinical implications highlight the need for specialist support that is ongoing after discharge, including specialist knowledge and understanding of ABI and opportunities for peer support.

## **The experiences of parenting a child with an acquired brain injury: A metasynthesis of the qualitative literature**

### **Introduction**

A significant proportion of those who experience acquired brain injury (ABI) are children. For example, within the UK, the Neurological Alliance [1] estimate that as many as 200,000 children have an ABI every year and 30% of attendances at accident and emergency departments for a head injury are children. ABI can have considerable consequences for the child, resulting in impairments in physical, cognitive, emotional and social functioning. For example, children with an ABI are more likely to exhibit behavioural problems [2-4] and are at increased risk of mental health difficulties such as depression, anxiety and obsessive-compulsive behaviours [3,5-9] They can also have problems with schoolwork, learning and friendships [3], probably due to impaired neurocognitive skills and reduced pragmatic skills and social problem solving [10]. Coupled with physical impairments these difficulties lead to restricted social participation [11]. ABI in younger children is also associated with worse long-term neurocognitive and psychosocial outcomes [12,13], perhaps due to the impact of the ABI on a child's developmental trajectory [12]. Hence ABI has significant implications for children both immediately but also for future development.

Parents of children with an ABI provide important support in managing the resulting difficulties [14]. Given the impact that ABI has on children, it is not surprising that it also affects parents' lives. This review focuses specifically on parents of younger offspring (under 18) as parental stress after paediatric traumatic brain injury (TBI; for example caused by an accident or a trauma) is reported to be greater when children are living at home than when grown up and living elsewhere [15]. Whilst moving out of home occurs at different ages, the transition to adulthood is often defined as age 18 in line with common cultural and

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legal norms. Consequently, this review will consider 'children' as up to and including age 18.

The quantitative literature suggests parents experience high levels of psychological distress [16] including anxiety and depression [17] and worsened physical health [18]. Shudy et al. [18] found that parents of children who are critically ill or injured experience a high level of stress, anguish, helplessness and aggravation due to role alteration and loss of control, creating a sense of helplessness. This pattern of high stress is similar for parents of children with TBI [19,20] and persists over time [19]. Additionally parents of younger children can experience guilt for not protecting their child after a TBI [14].

This higher risk of psychological and physical health difficulties may in part be due to the high level of burden that parents experience [21,22] including relinquishing paid employment in order to care for the injured child as well as significant financial implications due to the cost of aids and hospital visits [19]. In addition parents own social activities are often reduced [19] which is likely to reduce emotional wellbeing [23,24]. Given that social relationships are helpful in managing difficult emotional experiences [25], parents are at risk of being left without key coping mechanisms at a time of high psychological distress.

Furthermore, experiencing high levels of distress may influence the ability to parent not only the child with ABI, but also any siblings. Parental psychological distress can have detrimental effects on child wellbeing generally as well as affecting parent-child relationships [26,27] and may lead to siblings experiencing behavioural and social difficulties and problems at school [28]. Thus it is important to understand the impact of having a child with an ABI on parents, not only to support their wellbeing but also to support the rehabilitation of the child with ABI and the psychological wellbeing of any other children in the immediate family.

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In summary, the quantitative literature shows that paediatric ABI has significant implications for parents, which has the potential to affect the psychological wellbeing and coping of all the family. It is therefore crucial that the experience of parents is understood in order to provide appropriate support. A body of qualitative research has explored parents' experience in depth but it is yet to be synthesised. Thus, this review will be completed in the form of a metasynthesis, which aims to enrich knowledge through synthesising the findings of research studies and producing additional interpretations [29], which together provides a fuller understanding of the phenomenon in question [30] and has the potential to generate helpful results for informing practice. It moves beyond describing qualitative research in a narrative review to the reinterpretation of data in published studies [31]. The aim of this metasynthesis is to increase understanding about the experiences of parents with a child with an ABI.

### **Method**

#### **Design**

This review uses a metasynthesis approach to answer the research question: What are the experiences of parents of children with an ABI? In order to find relevant papers the following eligibility criteria were developed and applied: (1) The paper described a research study using a qualitative approach; (2) The study focused on the experiences of parents of an individual with an ABI who was between 0 and 18 years of age<sup>1</sup> at the time of injury; (3) The study was published in English due to financial restrictions for translation; (4) The study was published in a peer-reviewed journal, thus offering quality assurance.

Studies were excluded when: (1) The views of parents could not be separated from the views of others (for example, partners); (2) The information was a thesis, dissertation or a book due to access restrictions and lack of quality control via peer review; (3) Papers

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<sup>1</sup> One paper included two grandparents [32]

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excluded children with ABI acquired at the time of birth because the parents had no experience of their child prior to injury; (4) The focus of the research was focused on the experience of an intervention or more specifically on the child (e.g. school re-integration or social participation) rather than the general phenomenon of being a parent to a child with an ABI; (5) The paper did not specify the age of participants or included participants over 18.

### **Literature Search and Selection of Papers**

After consultation with specialist librarians, relevant literature was searched in three databases (PsycINFO, PubMed and Web of Science) on 17 March 2015 and an additional search was conducted in CINAHL in February 2017 but with an upper date limit of March 2015 in line with the other databases and thus the results represent the literature available up to that point. Search terms were identified by consulting relevant literature, specialists in neuropsychology and brain injury organisation websites (e.g. The Child Brain Injury Trust, The Children's Trust and The UK Acquired Brain Injury Forum).

Searching covered combinations and variations of the terms: “qualitative”, “parents” and “acquired brain injury” (ABI). For example, to find qualitative papers, general terms such as qualitative or interview were utilised as well as specific approaches such as “narrative analysis” or “thematic analysis”. To find papers related to parents, terms such as mother and father were included. For ABI terms included brain injury, stroke, brain haemorrhage and brain tumour. Table 1 gives a full list of free text search terms. As well as free text searching, medical subject headings in CINAHL, PubMed (MeSH headings) and PsycINFO (Thesaurus headings) were used (see Table 2). Limiters were placed in databases when this was available, “peer reviewed”, “human subjects”, or “English language” and all terms were ‘exploded’.

TABLES 1 AND 2 ABOUT HERE

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The following number of papers were identified in each database: CINHL 975, PsycINFO, 600; PubMed, 736; and Web of Science, 2544. Of a total of 4855 papers 1359 were duplicates across databases. Therefore, the titles of 3496 papers were reviewed against the eligibility criteria and 2789 were excluded. The abstracts of 707 papers were then examined against the criteria, resulting in the exclusion of a further 481 papers. The full texts of the remaining 226 were read and 15 papers identified that met the inclusion/exclusion criteria. Forward citation searching (searching for papers which cited the 15 papers) was performed via Google scholar which resulted in one further paper, as well as reference list searching which resulted in another paper that met the criteria. Thus, 17 papers were included in the review. The systematic process of identifying papers is summarised in Figure 1.

INSERT FIGURE 1 ABOUT HERE

### **Characteristics of Included Studies**

The 17 studies were published between 1997 and 2015 from six countries: Australia (n=4), Canada (n=2), New Zealand (n=1), UK (n=4), Sweden (n=3), USA (n=2), and South Africa (n=1). Three studies included a range of ABI aetiology [33-35], nine studies focused solely on TBI [32,36-43], four were focused on brain damage after a brain tumour [44-47], one study looked at hemiparesis specifically [48]. When papers met the inclusion criteria but not all findings were relevant to the research question the data of interest were extracted. For example, information regarding parents' reactions was extracted from studies about brain tumours, but themes about managing cancer treatment were excluded.

Thirteen studies included both mothers and fathers although two did not specify respective numbers and one just specified primary caregivers. Five studies looked only at mothers, one included two grandmothers [32]; given that grandmothers made up less than 7% of participants this study was included. The ages of children with ABI ranged from one

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month to 18 years; both genders were represented. Of those studies that reported time since injury, parents were interviewed up to 12 years post-injury but only one study included parents of children over 6 years post injury [40]. Two papers used the same data to answer two different research questions. Given that these had a very different focus and the second added additional data directly relevant to the research question, both were included but caution was taken to avoid undue influence of these participants on the metasynthesis [49].

In terms of data collection methods fifteen studies used interviews, one a focus group and two open-ended questions in a questionnaire. One of the papers that used interviews also used observations. All papers met the requirements for qualitative analysis as described by Sandelowski & Barroso [50], i.e. the analysis produced interpreted themes. The analysis process varied in the level of interpretation and data transformation from content analysis to phenomenological analysis. The aims of the papers included general exploration of experience and emotional responses, informational and/or support needs, coping and adjustment, challenges, experiences of post-trauma and existential issues. Table 3 summarises the demographic and methodological details of the papers.

INSERT TABLE 3 ABOUT HERE

### **Quality appraisal of papers**

Only peer reviewed studies were included to ensure they met a minimum quality. However, in addition, the Critical Appraisal Skills Programme (CASP) (Public Health Resource Unit, 2006) tool was used to assess quality (see Table 3 for CASP ratings). The CASP is a 10 point assessment criteria for qualitative research which includes two screening questions and a further eight questions. For example: ‘Was the recruitment strategy appropriate for the aims of the research?’; and ‘Have ethical issues been taken into



consideration?’ The papers were rated out of three for each criterion [51] giving a maximum score of 24. The scores ranged from 17 to 24.

### **The synthesis process**

The analysis was completed systematically according to Noblit and Hare’s [29] guidelines for a metaethnographic approach. Every effort was made to preserve the meanings and concepts of the original studies [52]. The papers were read repeatedly to gain familiarity with the main concepts and metaphors. A summary of key concepts in each paper was produced along with details of study design. The relationship between studies was then considered, looking for recurring common concepts. Following that, the studies were translated into one another by checking the concepts and themes in each paper against each other to develop further understanding. Britten et al. [31] suggest using first and second order constructs [53] as a way of distinguishing between everyday understandings that are participants’ own reports (first-order) and constructs used by researchers that interpret the participant data (second-order). Finally, the translations were synthesised to create new understanding or reinterpretations (i.e. third-order constructs).

## **Results**

Three themes emerged from the analysis: (1) Disconnection: Cut off from internal emotions and isolated from others; (2) Seeking understanding and support to manage in an insecure world; (3) New parent to a different child.

### **Theme 1. Disconnection: Cut off from internal emotions and isolated from others**

Disconnection was evident both in the way many parents managed their intense emotions and in their relationships with partners and other children. Parents were also left feeling socially isolated as others were unable to understand their experience.

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Parents experienced intense and prolonged emotional reactions to their child's injury both immediately and years afterwards. This included depression [32], anxiety [33,38], stress [39,42], guilt, anger [40,48] and post-traumatic responses [32,36] to such intensity that parents were left feeling emotionally exhausted. As one participant described: 'at times the hurt can come on so instantaneously it takes my breath away...I sometimes wonder when I'm not going to be sad' [48, p. 269]. These emotions were so intense that parents often ignored or avoided them in order to cope [34,38-40,46]. Other coping strategies included alcohol or drug use [35]. While such strategies were recognised as helpful in the short-term by some parents [34], as being disconnected from emotions meant they could manage the practical burden, they became detrimental in the long-term [34,39].

Although some studies found that the couple relationship was crucial to coping and adjustment, for others the theme of disconnection was observed within family relationships. As the needs of the child with an ABI were prioritised [45], parents struggled to invest in other family relationships [34,39]. As a result, some reported conflicts in their couple relationship such as disagreements over parenting and behaviour management given their child's changed needs [40,45] or frustration at the lack of reciprocal support or appreciation [38,40]. This was exacerbated by different coping styles and reactions [38,46,47].

Alongside the couple relationship, parents noticed the impact on their relationship with other children [34,43,45,46]. Some recognised that they were forced to neglect siblings' needs at times [46] despite recognising the siblings' distress [38,45,46]: 'Everything revolved around Josh [affected child] and Josh's wellbeing, so for Andy [sibling] he was starting to get a bit cheesed off with it' [47, p.746]. Even years post-injury, some parents felt they were more attentive to the child with ABI with a more intensive relationship, in contrast to emotional distance with the sibling [45,46], despite efforts to counteract this [38,45].

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In contrast other parents talked about feeling more connected and closer as a family unit [34,36,42,45] because of their shared experience. For example, 'now it's more like us, it feels like we are more we' [45, p.375]. However, this intra-familial closeness contrasted with wider disconnection, as parents felt isolated and detached from society [32,34,36,41,45]. They felt misunderstood or judged by friends, family and professionals who could not truly understand what it was like to be a parent of a child with an ABI [32-34,38-40,46]. For example, one parent explained that: 'The pain and loss we experienced .... was made so much worse by having no one to talk to who we felt understood' [34, p. 287].

Some parents felt their child's difficulties were not recognised, understood or accepted by family and friends because they were not obvious [32,40-43]. Specific judgements about their child for example as manipulative or intentionally lazy or inappropriate advice based on a lack of understanding were particularly difficult [39-41]. The resultant barriers to their child's full social participation made parents feel disillusioned, frustrated, dismissed and sometimes avoided by others [36,39,40].

This lack of recognition was not limited to the impact on the child with the ABI, as parents also experienced a lack of society's understanding of the impact of the ABI on all the family [32]. As a result, many parents felt they did not fit or belong with parents without a child with an ABI [40,48]. This meant that, although family and friends were important to help some parents cope [36,39,41-43,47], for others, they were not able to provide the emotional support required as they could not connect with parents' experience. For this reason, some parents wanted to connect with others in similar situations [34,39,48]. For example, talking to other parents on the ward was helpful for some [38] although not for others [44] when survival and recovery was uncertain [32]. A lack of peer support opportunities within the community was noted [39,40].

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Sharing the emotional burden with professionals offered an outlet [37,38] and could be helpful in validating their experience [35-37]. However, some parents felt that professionals did not understand the social and cultural factors that affect families and their unique perspectives as they focused on a narrow medical approach rather than a holistic view [36,39]. This meant that professionals often missed what was important to families. Some parents sought counselling but opinions varied on its necessity and provision for this also varied [35].

### **Theme 2. Seeking understanding to manage in an insecure world**

This theme reflects parents' need to obtain stability and security in an unstable and frightening situation. They sought to understand the situation and ensure their child received appropriate care.

Having a child with ABI resulted in fear and anxiety, initially due to uncertainty of the child's survival [32,37,40,43]. This was often followed by immense relief and feeling grateful on realising their child was alive, for example, on regaining consciousness [33,35,40]. However, this was often mixed with shock, confusion, and devastation on realising the extent of the ABI [33-35,47] and not knowing how long the medical, cognitive and behavioural changes will continue [43]. This realisation happened over time as parents came to recognise the extent of and permanence of the ABI [36,39,41]. One parent described this process after their child's injury, 'everything was day to day,,first, please God let him live...ok, he is going to live. Please God, don't let his brain damage be really bad..you get greedier and greedier...after that you just want a little bit more and a little bit more' [43, page 14]. Additionally parents expressed fears about the future for their child [37,40,42,48] as to how the ABI would affect them (e.g. academically, [41,47]) and how society would accept them [34,48].

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Parents' fears and uncertainty were experienced in the context of re-evaluating core values, views, priorities and fundamental assumptions about life [33,38,42,45,46]. Parents were confronted with ideas that life is unpredictable, unstable and dominated by fate or divine intervention and therefore experienced a loss of control or helplessness [33,34,42,43,46]. For example one parent stated, 'I think until something horrible happens to you, you kind of go through life thinking you have a bit of control and you think, if I am a good person and I try hard, and I work hard and I look after everybody and I try to be a good mother, things will go pretty well. But it doesn't work like that. Your stability goes out the window and what you've always based your life on you can't do it anymore because it's not there anymore' [33, p. 110].

Some parents attempted to manage their anxieties, uncertainties and changes in life perspective by considering themselves lucky that their child survived or wasn't as seriously affected compared to others [40,43], by breaking down rehabilitation into small manageable milestones [34,38] or drawing strength from their spirituality [42]. Parents were also assisted in managing uncertainty by consistency in staff caring for their child [32,34,44] which was also important in order to build relationships [35,38]. Trust and a feeling that staff cared were important elements of this for some parents [32,34,39,44]. This linked to parents' need to ensure that their child was receiving quality care. There seemed to be particular anxiety and criticism of care at times of increased uncertainty, such as transition from higher staffed intensive care wards to less intensive and difficult to access community services [32,34,36,38,39].

As part of quality of care, many parents stressed the need for information and understanding [32,34,37-39,41,48]. This included information about ABI [37], medical procedures [37,54], prognosis [40], support available [34,37,40,47], behaviour management [40], as well as practical issues such as car parking [44]. However, parents in one study

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recognised a conflict between receiving and not receiving information, as both could cause exasperation and fear: 'You want all the information. But you don't want to know either'[44, p. 100]. Knowing typical emotional responses was also seen as helpful: 'well it's like, your feelings change all the time, from day to day, even from minute to minute at the beginning. It would have helped to know that what we felt was normal not madness' [34, p. 288]. These information needs were particularly important as many parents had little or no prior knowledge of ABI beyond television shows, which led to confusion [32]. When these information needs were met, many parents reported feeling relief and reassurance, and were less frustrated, fearful and apprehensive [35,44,47].

It was essential that information was accessible so parents could understand the language and have the opportunity to ask questions [32]. Unfortunately, many felt that the information provided was insufficient [32,39,48] and some believed staff felt they would not understand or did not require the information [35]. Increasingly the parents in one study [39] described increasingly independent sources of information accessing books, the internet and talking to other parents.

Parents also stressed the importance of when and how the information was delivered as heightened emotions made it difficult for parents to absorb information [32,44,47]. Written information was helpful for this reason and telephone access for opportunities to ask questions once the information had been processed [40,47]. Many parents responded positively when information was given honestly, sensitively but frankly with empathy and compassion [32,34,44].

Uncertainty about prognosis or when professionals were proved incorrect led to increased stress [36,38,39]. On the other hand, parents wanted acknowledgement of the uncertainty and respect for their need to maintain hope and positive thinking [33,38,39,45] as

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noticing progress and maintaining hope was often important in holding things together [41].

Information tailored to parents' needs seemed important in facilitating understanding and reducing uncertainty.

### **Theme 3. New parent to a different child**

Most of the papers discussed the need to adjust to being parents to a changed child. Along with grieving for the 'lost' child, parents tried to understand their new child and changed relationship.

A common finding was parents' pain and grief of the loss of the past child due to changes in cognitive ability, behaviour, personality and temperament. For example, 'This is not the same kid that went into the coma. Where is that...that used to be mine? He's not there, he's gone. And the bottom line is you almost treat it like a death. That child is no more... You have to go through a grieving process. You have to let go of what you had because he'd not the same child. His name is the same, he may look the same, he may not look the same. That's what really happens, is this huge sense of loss, just sometimes overwhelming sense of loss' [33, p. 109].

At first some parents aimed for maximum if not complete recovery [35]. However, many parents realised that the changes were most likely to be permanent [39] and that their child was profoundly different from the pre-injury child [33]. The pain of this realisation was only ever partially or temporarily relieved [34]. The impact of the brain injury often became apparent on arrival home [32]. At this point, parents had to begin to come to terms with a new and different child [32,34,36] and adjust their expectations of their child's future [39,48]. A parent described realising that 'This isn't going to go away. This is going to be a lifetime. There is nothing that is going to fix this' [48, p. 267]. As a result, some parents felt robbed of the child's potential and idealised the pre-injury, 'perfect child' [34,39,40], making

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comparisons between pre and post injury [43]. However, other parents reported their child's recovery met their expectations which supported the grieving process [39].

Given the changes in the child, some parents reported the need to reconstruct another view of their child [32,33]. For example, they sought to understand their thoughts, feelings and reasons for behaviour, whether it could be attributed to the ABI, associated trauma, developmental stage or other life stresses [40,41,43]. In response parents altered their own behaviour and communication to try and compensate for their child's deficits [33]. Some felt that if they could not understand their child it was stressful and confusing [40] and greater emotional support was needed [32].

Many parents also reported a changed relationship with their child [33,36,38,45]. For some this meant a rupture and insecurity in their relationship, feeling like strangers to each other. However, others felt they had become closer to their child due to the time spent together and enhanced mutual appreciation. Parents had to adjust to a new way of relating to their child, for example, by finding behaviour management strategies for unpredictable behaviour [40,42,46]. Coping with behavioural changes was reported in one study [32] as the most concerning for parents in which they often felt unsupported. Parents also recognised that their own fatigue and emotional experiences (see theme 1) were making it harder to be consistent, provide structure and have time to teach their child new skills [40]. Parents reported a level of over-protectiveness, remaining alert to risks of further injury and guarding their children, particularly if told by professionals to be extra careful or watchful early in recovery [32,38,41-43]. Parents often felt uncertain about promoting independence versus protection from discomfort or more pain [32,40].

The new parent-child relationship involved many new roles while maintaining their parental role. Brown et al.'s [40] study identified a loss of their parenting role within the



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hospital environment. Being involved in care and decision-making reinforced the parent role and contributed to increasing confidence and ability to cope and reduced stress and anxiety [32,35,37,38,44]. However, some parents preferred not to be involved in specific care provision, for example bathing a child with intravenous therapy, or in specific decision-making, deferring to clinicians' expertise [32,35]

As the child progressed, parents took on increasing responsibility [32], sometimes in quasi-professionals roles [39,45,54]. This included acting as trainers to coach new skills and teachers to support with homework, taking on social work and advocacy roles by reorganising and networking services and managing legal proceedings and benefits [34,39-42,48] and acting as medical assistants in observing symptoms and administering medication. They were also therapists, handling difficult questions and children's responses as well as interpreters for the wider family, friends and community. Some parents reported feeling inadequate in these unfamiliar roles due to uncertainty about techniques [45] and a fear of injuring the child [34]. The mothers in Shortman et al.'s study [47] described drawing on the responsibility of their maternal role to help them to cope.

Discharge was an important time in adapting to being a different parent but one that came with conflicting [38]:

You feel so alone and you feel, like I say, you're dealing with all this stuff that you've not got a clue really what you do, you know what I mean...it's like have you got a manual for this child? Because I don't know who he is and I'm trying to look after him and, as far as they was concerned, they'd sent him home...you just feel so alone and you're with this child that you don't really know what you're dealing with [32, p.308].

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For some parents this meant giving up other important roles and activities that they previously undertook such as their employment, to become a full-time carer [33,40,42]. To help adopt these daunting roles, parents reported a number of helpful interventions. For example, trial periods at home before complete discharge and staff providing appropriate information, which decreased anxiety and increased confidence [32,35,38].

### **Discussion**

This review highlights the challenging nature of having a child with ABI including social isolation, the insecurity of the situation and the challenges of adjusting to different roles required in parenting a changed child.

In the theme of disconnection: cut off from emotions and isolated from society, it was clear that parents had to find a way to manage their intense emotional experiences, with some disconnection in order to cope. This has some parallels with the emotional numbing that can occur after a trauma [55]. Use of distancing and avoidance as a defence against overwhelming emotional experiences has been found to be more likely when parents are experiencing high levels of stress [56].

Parents' social activity reduced and parents reported feeling isolated and different from others. This reduced social activity may be due to burden [17,19], but the current findings also suggest that parents have difficulty connecting with others who do not understand and feel alone. While high levels of distress and trauma echo experiences of having a child with any chronic illness (for example, paediatric cancer [57]) the high levels of disconnection from others does seem particularly salient for these parents. This occurred, even when attending community groups for parents of children with a developmental disorder, which suggests there is something distinct about the ABI experience.

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The second theme of seeking understanding to manage in an insecure world, reflects findings from parents of children with chronic illness who similarly needed normality and certainty [58]. Information could go some way to provide certainty but, as with other chronic illness [59,60], this was often felt to be lacking. Hawley et al. [3] found that over 70% of families with a child with a TBI had unmet information needs and some parents of more severely injured children were unable to take information in even when it was given. The findings in this metasynthesis highlight the need for information to be accessible in how and when delivered, as memory for medical information is generally poor [61]. When combining this generic retention problem with parents' extreme distress, it is not surprising that little information is absorbed. Furthermore, the current findings demonstrate how delivery interacts with parents' coping mechanisms, such as the need to maintain hope and how information assisted parents in anchoring themselves throughout the uncertainty.

The experiences described in the final theme of adjusting to being a parent to a different child and the loss of the child they knew, seemed more prominent for parents of children with ABI than other chronic illnesses (e.g. [58,60]) where onset of a condition is more gradual or indeed is present from birth, but is similar to the experience of family members of adult ABI survivors ([62]. The quantitative literature has highlighted the significant burden that parents experience in their caring role after paediatric ABI [19]. However, this review also highlights the wide range of these new roles and the different ways they contribute to burden. Many parents of other chronic conditions may identify with increased roles and adaptation to parenting styles and in some cases, a changed child in their emotional wellbeing and physical health [60]. However, after ABI there are additional cognitive and neuro-behavioural changes, associated relationship changes, and greater loss of the child's previous identity which add to the complexity of parenting a child with an ABI.

## **Limitations**

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There are a number of limitations to consider. First, although the results were drawn from participants from six countries, most of which were economically developed countries with arguably similar socio-cultural backgrounds. This may be in part due to the restrictive inclusion criteria of English language articles. In addition, (where reported) the ethnic origin was predominantly white. The results may not therefore apply to parents from different ethnic and/or cultural backgrounds. Second, the predominance of mothers might bias the results towards maternal experiences. This requires further research specifically looking at fathers' experiences, especially given some parents highlighted differences in coping styles between mothers and fathers.

Third, there was variety in the age range of children, time since injury and ABI aetiology. The age of children at ABI onset ranged from early infancy up to 18 years old. However, all of these parents are still parenting a child who, in the western cultural framework, is usually dependent on them, although in different ways. Time since injury also varied, though all except one study (of those which stated time since injury) were within 6 years of the injury and the one study outside this, the findings did not appear particularly different. The range of types of ABI has also indicated the similarity in parents' experiences, however half the studies focused on TBI, so may be biased towards this sub-group.

### **Clinical Implications**

As in other paediatric illnesses (e.g. leukaemia; [63]) parents reported that professionals were often focused on physical health and neglected psychosocial implications. This suggests the professionals were working from a predominantly biomedical model and there might be benefit from greater application of biopsychosocial models (e.g. [64,65]) which adopt a wider systemic understanding of the family's coping to include interpersonal, in addition to intrapersonal, variables.

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As part of a greater psychosocial focus, this review emphasises the need to support parents through this traumatic and overwhelming experience, not only during acute care but through discharge and in the community. There is a clear need for professionals to recognise the emotional journey of parents, and for parents' grief to be acknowledged and validated to support this process and reduce feelings of guilt. There is also an argument for suitably trained professionals to provide emotional containment as some parents thought nurses were either too busy or not appropriately trained to respond to their needs. This could involve training nurses directly or other professional groups such as clinical psychology providing direct support or supervision to ward staff.

This review suggests that interventions for parents might be beneficial. However, the choice of evidence-based interventions for parents caring for a child with a chronic illness is limited [66,67], particularly psychosocial interventions. On reviewing the chronic illness literature, Morawska, Calam & Fraser [67] recommend that parenting interventions should include linking the illness with a child's behavioural and emotional adjustment, as well as with parenting strategies. They also emphasise the importance of addressing parents' information needs. Both of these recommendations are supported by the findings of this review. However, it is important to recognise that parents of children with ABI have distinct needs, as discussed previously, which may require specifically tailored interventions. The limited evidence base suggests such interventions have significant benefits for children and parents (for example [68,69]).

An important outcome from this metasynthesis was that not all parents had the same needs, for example regarding information content and timing of delivery and needs changed over time. Thus access to professionals that understand ABI and can tailor responses to individual family circumstances is important, especially in the community. It also suggests greater training in the wider professional community about the implications of ABI (for

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example, in schools – for further discussion see Anderssen et al. [70]). Parents also sought connection with other parents, which suggests there is an unmet need for specialist peer support groups which are accessible.

### **Future research**

The studies in this metasynthesis only included papers where all children with an ABI were less than 18 years old. However, during the searching process, it was noted that a number of papers focused on children and young adults up to 35 years old (e.g. [71,72]). Given that western cultures are changing and young people live with parents for longer [73] it would be interesting to compare the findings with parents of young adults. Additionally, further research focusing on fathers' experiences is also required. Most importantly, this review has highlighted significant unmet need for parents, and provides further evidence of the need to explore effective ways of supporting these parents and evaluating existing interventions.

### **Conclusion**

This review paper has synthesised the qualitative research on the experience of parents of children with ABI. The findings add to the quantitative literature by demonstrating why this experience is so challenging, as it requires significant adaptations to parents' relationships with themselves, their child, and their family and wider society. Parents' perspective that others did not understand their experience has the potential to leave parents feeling isolated and unsupported throughout managing this overwhelming experience. The findings therefore suggest that there is significant unmet need for support, and indicate a need for more research and evaluation of interventions for these parents.

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### **Declarations of interest**

The authors report no conflicts of interest.

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**Table 1: Free search terms**

Qualitative OR "Grounded Theory" OR "Narrative Analysis" OR "Thematic Analysis" OR Experience OR "content analysis" OR ethnog* OR "Interpretative Phenomenological Analysis" OR "Discourse Analysis" OR "Framework Analysis" OR "Conversational analysis"
AND
"Acquired Brain Injury" OR "Brain Damage" OR "Traumatic Brain Injury" OR Meningitis OR Encephalitis OR "Hypoxic brain injury" OR "Anoxic Brain Injury" OR "Brain Injury" OR Stroke OR "Arteriovenous Malformation" OR Aneurysm OR "Brain Haemorrhage" OR "Cerebral Haemorrhage" OR Asphyxiation OR Suffocation OR "Brain Tumo*" OR "Cerebral Tumo*" OR "Brain Neoplasm" OR Neurosurgery OR "Head Injur*"
NOT
Alzheimer OR "Cerebral Palsy" OR Parkinson OR Dementia OR "Multiple Sclerosis" OR "Neurodegenerative Disorder" OR "Amyotrophic Lateral Sclerosis"
AND
Parent* OR Mother* OR Father* OR Mum OR Dad OR Caregiver* OR Family OR Families



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Table 2: Additional subject headings (thesaurus terms, MeSH headings)

*Note: All terms were 'exploded' to include narrower terms*

Database	Area of searching	Subject headings	
<u>Psych INFO</u>	ABI	Brain damage	
		Brain neoplasms	
		Encephalitis	
<u>Thesaurus terms</u>		Hydrocephalitus	
		Aphasia	
		Cerebrovascular accidents	
		Meningitis	
		Anoxia	
		Respiratory distress	
		Neurosurgery	
		Parent	DE "Parent Child Relations" OR DE "Family Relations" OR DE "Parenting" OR DE "Father Child Relations" OR DE "Mother Child Relations" OR DE "Parental Involvement" OR DE "Parental Role" OR (DE "Parents")
		Qualitative	Qualitative research
<u>Pub med</u>	ABI	Brain Diseases	

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<p><u>MeSH</u></p> <p><u>headings</u></p>		<p>Brain Injuries</p> <p>Brain Injury, Chronic</p> <p>Head Injuries, Penetrating</p> <p>Brain Damage, Chronic</p> <p>Hypoxia, Brain</p> <p>Stroke</p> <p>Encephalitis</p> <p>Brain Neoplasms</p> <p>Asphyxia</p> <p>Head Injuries, Closed</p> <p>Neurosurgery</p> <p>Brain Hemorrhage, Traumatic</p> <p>Cerebral Hemorrhage, Traumatic</p>
	<p>Parent</p>	<p>Parents</p>
	<p>Qualitative</p>	<p>Qualitative research</p>
<p><u>CINAHL</u></p> <p><u>Subject</u></p> <p><u>headings</u></p>	<p>ABI</p>	<p>Aphasia</p> <p>Brain Damage, Chronic</p> <p>Hypoxia, Brain</p>

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		Brain Injuries Brain Neoplasms Encephalitis Head Injuries Hydrocephalus Neurosurgery Meningitis Anoxia Respiratory Distress Syndrome
	Parent	*Free text searching captured all results with subject headings so not needed.

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**Table 3:** Overview of included studies

<b>Author/ Year</b>	<b>Aim of study</b>	<b>Method of data collection</b>	<b>Method of analysis</b>	<b>Current age / sex of child</b>	<b>ABI type</b>	<b>Time since onset</b>	<b>Mothers / Fathers</b>	<b>CASP score</b>
Bruce & Chrisholm (2001)	To examine caregivers' experience with children who had sustained a traumatic brain injury.	Interviews	Content analysis	5-15 years 4 female, 6 males	TBI	Not reported	10 primary caregivers	17
Du Toit, Coetzee & Beeton (2013)	What is the lived experience of a mother caring for a child with a severe TBI in a disadvantaged community?	Two semi-structured interviews	Content analysis (Moustakas's method)	3-12 years	TBI	Not reported but discharged home 1- 3 years prior.	Mothers	23
Forinder & Norberg (2009)	To explore the existential issues expressed by parents of children who had been treated for brain tumours.	Interviews	Inductive thematic analysis	7-14 years 4 female:3male	Brain tumour	Off treatment for 20-38 months	Mother 7 Father7	23

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Guerriere & McKeever (1997) Canada	To explore how mothers come to terms with the multiple changes that occur in children who sustain sudden brain injuries	Open-ended interview	Descriptive analysis (symbolic interactionism)	3-13 years : 2 female, 5 male	Mixed ABI	1-2 years	Mothers 7	23
Jones, Hocking and Wright-St Clair	To explore the day-to-day occupations of parents who care for children in the home after a severe traumatic brain injury.	Semi- structured interviews and observations	Grounded theory	4-11 years	TBI	2-6 years post injury	Parents 7 4 mothers;3 fathers	23
Menezes & Shinebourne (1998) UK	To identify the short and longer term needs of parents whose children sustain severe brain injury after cardiac surgery and to determine what further measures could be of use to the family after such a catastrophe	Semi-structured interviews	Analysed using techniques from (Coffey, 1996)	Does not specify age but specifies 'children'	Mixed ABI	Not reported	Mothers 8 Father 3	21

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Ramritu & Croft (1999)	To identify needs of parents of children with ABD, admitted to a metropolitan tertiary referral paediatric hospital throughout the continuum of care	Semi-structure interviews	Content analysis	6 wks-14 yrs 5 female 23 male	Mixed ABI	1.5 years-3.5 years Mean=2 years	27mothers 7 fathers	20
Robson, Ziviani & Spina (2005)	To explore the experiences and perceptions of parents of children with TBIU in the transition from hospital to home	Semi-structured interview	Thematic content analysis	4.5-10.5 yrs	TBI	Approx. 6months	Parents: 5 females 1 male	24
Meehan (2005)	To describe the experience of mothering 3 to 6-year-old children with hemiparesis	Unstructured interviews	Colaizzi's method-phenomenology	3 to 6yrs	Hemi-paresis	Not specified	Five mothers	21
	US							

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Jackson et al. (2007) Australia	To explore coping adaptation and adjustment in families of a child with a brain tumour.	2 open ended questions in questionnaire	Thematic analysis (Creswell, 1994)	Under 18 yrs	Brain tumour	4 time points (dx to 2yrs post)	53 parents Genders unknown	21
Clark, Stedmon & Margison (2008) UK	To explore the nature and quality of family members emotional responses and any change in the family and clinical relevance of different psychological theories.	Semi-structured interview	Interpretive phenomenology cal analysis	11- 16 years 10 male	TBI: 7 Moderate / severe 7, Unclear 3	2-6 years	Mothers 10	24
Roscigno & Swanson (2011) USA	To describe the common experiences of English speaking parents of children with TBI.	Two semi-structured interviews	Descriptive phenomenology cal framework	8-20 years Gender un specified	TBI: Moderate 13. Severe	4 months – 3 years.	34 mothers 8 fathers	23

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Falk, von Wendt & Klange (2008) Sweden	To characterise the informational needs of parents & compare these to previously determined needs of parents whose children have suffered more serious injury	Questionnaire with one open ended question	Content analysis (Krippendorff, 2012; Weber, 1990)	1mth-15 yrs 24 female 33 male	Mild head injury	3 months after the injury	57 parents Does not specify gender	22
Norberg & Steneby (2009) Sweden	To capture a panorama of parents experiences of post-traumatic influence	In-depth interviews	Inductive thematic analysis	7-14 years	Brain tumour	Off treatment for 20-38 months	7 mothers 7 fathers	23
Brown, Whittingham, Sofronoff & Boyd (2013) Australia.	To add to the current understanding by further exploring the experiences, challenges and needs of parents of children with ABI.	Small focus group discussions of structured questions.	Transcribed > inductive thematic analysis	5-17 years 2 female,6 male	TBI : moderate, 4, severe 4	2-12 years	Mothers 7 (mother 1) Fathers / step-father 2	23





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