

Citation for published version:

Clare Coppock, Scot Ferguson, Anna Green, and David Winter, 'It's nothing you could ever prepare anyone for': the experiences of young people and their families following parental stroke, *Brain Injury*, Vol. 32 (4): 474-486, March 2018.

DOI:

<https://doi.org/10.1109/THMS.2015.2445105>

Document Version:

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"It's nothing you could ever prepare anyone for": the experiences of young people and their families following parental stroke

Clare Coppock, Scott Ferguson, Anna Green & David Winter

ABSTRACT

Aims: This study sought to explore the experiences of young people (aged 8-16) and their families following parental Acquired Brain Injury (ABI), with the aim of developing an understanding of the ways in which members of a family make sense of events post-injury, and to consider the implications of different perspectives on adjustment and coping.

Design: The study applied a qualitative approach using a thematic analysis methodology.

Procedure: Individual semi-structured interviews were conducted with ten individuals from three families affected by parental stroke.

Results: Findings suggested that post-injury, families experienced a period of uncertainty in which they were required to renegotiate their roles and adjust to the loss associated with parental stroke. Additionally, the psychosocial wellbeing of young people was negatively affected, whilst protective and coping strategies were recognised.

Conclusions: The research offers an insight into the processes that may contribute to patterns of interpersonal relating that could negatively impact on adjustment. Provision of adequate information, psychological and practical support during recovery may therefore be crucial elements of supporting young people and their families in adjusting to the challenges posed by stroke.

INTRODUCTION

Acquired Brain Injury (ABI) is a growing public health concern. Stroke is the second leading cause of death and the third leading cause of disability worldwide [1]. In addition there are estimated to be in excess of 10 million people affected by Traumatic Brain Injury (TBI) arising from motor vehicle accidents, falls, and assaults [2]. ABI also includes, amongst others, injuries resulting from brain tumour, meningitis, encephalitis, hydrocephalus, and anoxia [3, 4]. Moreover, medical advances have resulted in increased numbers surviving ABI, and consequently living with associated disability [4]; over 43% of survivors of TBI, and as many as 50% of survivors of stroke experience long-term disability [5, 6]. Premorbid lifestyle factors can also influence recovery following injury and may place individuals at risk of further injuries [e.g., 4, 5].

The prevalence of ABI is increasing, particularly in developed countries including the UK [e.g. 1]. Lifestyle factors including smoking, poor diet, and lack of exercise are placing individuals at increased risk of cardiovascular conditions and stroke [5]. Changes to occupational and leisure activities may account for the increased prevalence of TBI; these can include, but are not limited to, increased numbers of car owners and consequently increased prevalence of road traffic accidents (RTA) [e.g. 1], increased participation in contact sports/extreme sports, and increased drug and alcohol use which may facilitate risk taking behaviours [7].

Finally, recent estimates suggest that 348,934 individuals in the UK were affected by ABI in 2013/14, representing a 10% increase since 2005 [3], with an annual incidence in excess of 500 per 100,000. Based on UK hospital admissions it has been estimated that stroke and traumatic brain injury (TBI) account for up to 84% of ABI [3]. It has been estimated that per annum, stroke costs the National Health Service (NHS) £8.9 billion [8], whilst TBI is thought to cost the NHS in excess of £5.1 billion [9].

ABI can result in significant behavioural, cognitive, emotional, functional, social, occupational, and physical impairment. Deficits resulting from ABI are heterogeneous; they vary depending upon the site of the injury and the neural pathways affected [e.g., 4]. Given the sudden onset and frequently irreversible

consequences of ABI, it is unsurprising that affected individuals face a significant period of recovery and a complex adjustment process [e.g., 4, 10].

Research suggests that when a parent has experienced an ABI, both the patient and their family members may be particularly vulnerable to experiencing psychosocial difficulties [11 - 23]. The following section summarises the impact of parental ABI for the individuals themselves, their spouses, and their children. Where existing literature allows, the impact of stroke, TBI, and other types of ABI will be differentiated from one another.

Experiences of Parents with an ABI

It has long been acknowledged that adults with an ABI may experience anxiety, depression, behavioural disturbance, and emotional dysregulation [e.g. 4, 5, 10]. However, with the exception of depression, few studies examining the impact of parental ABI have measured the prevalence of different psychosocial difficulties for the parent with the injury. Sieh and colleagues [18] measured depressive symptomatology at four time points during the first three years post-stroke. Approximately 25% of their participants affected by stroke (n = 7) experienced clinically significant symptoms of depression during this time period. Similarly, van de Port and colleagues [13] identified that 21% of parents who had experienced stroke (n = 6) were experiencing clinically significant symptoms of depression three years after their injury. In TBI literature, Uysal and colleagues [20] reported that 19% (n = 3) of parents with TBI were found to be experiencing clinically significant symptoms of depression; furthermore, this was significantly higher than counterparts affected by chronic illness.

Parents with an ABI have also described experiencing relationship difficulties [11, 12, 15, 18, 22]. Charles and colleagues' [22] Multifamily Group (MFG) evaluation included one family affected by parental stroke; in this instance, the parent affected by stroke had scores indicative of dysfunction on measures of marital and family functioning. Their findings were similar for individuals affected by TBI (n = 3), and other types of ABI (n = 2). Transcripts of the MFG sessions described this parent's experiences of a reduction in their social relationships, missing out on experiencing their children growing up, and perceived reduced capacity to parent. Parents with

other types of ABI also described similar changes, in addition to having concerns that changes to their parenting were impacting their relationships with their children [22]. Kieffer-Kristenson and colleagues' [11] cross-sectional study of families affected by parental ABI (n = 35; 60% stroke, 26% TBI, 14% other) also suggested that the parent with an ABI may experience marital dysfunction, parental distress, parenting stress, and impaired parent-child interactions. Findings were similar in TBI literature: for example, Pessar and colleagues [12] reported that 42% (n = 10) of parent-child relationships were negatively affected, and they found a significant correlation between the child's age and frequency of parent-child relationship difficulties. Uysal and colleagues [20] found that among parents with TBI, specific changes to parenting style included becoming less actively involved with their children, becoming less encouraging, having lower expectations of their children, and being less strict than the parent without a TBI.

The focus of many existing papers has been the psychosocial impact of ABI; few studies have directly explored the experiences of parents with an ABI. Themes identified by Charles and colleagues [22] during their MFG evaluation included uncertainty about recovery, and the need to establish coping strategies; these findings are reflected in general ABI literature [e.g. 24].

Experiences of Spouses of Parents with an ABI

Spouses of parents with an ABI may also be vulnerable to experiencing psychosocial difficulties, including depression [11, 13 - 15, 18, 20]. Sieh and colleagues [18] identified that 50% of spouses (n = 28) experienced depressive symptoms during the first 2-5 weeks following their partners' stroke. Similarly, van de Port and colleagues [13] identified that over half of spouses (n = 15) were experiencing clinically significant symptoms of depression three years following their spouses' stroke; these findings suggest that spouses may be at risk of depression in both the short and long term. Findings in TBI literature are less consistent; Pessar and colleagues [12] identified clinically significant levels of depression in 87.5% (n = 14) female spouses, and 37.5% (n = 3) male spouses, but Uysal and colleagues [20] reported that none of the spouses in their study (n = 8) reached the clinical threshold for depression.

Experiences of caregiver strain and relationship difficulties following ABI are widely documented [11 - 15, 18, 22]. Spousal ratings of the quality of their marital relationship following stroke is low [13, 18], with some evidence to suggest that this may decrease over time [18]. These findings were supported by Visser-Meily and colleagues [15]; whilst mean spousal ratings of marital satisfaction in their study were initially 'high', they fell below the cut-off and deteriorated over time in the first year following stroke.

Additionally, changes to parenting behaviours have been documented in spouses of individuals affected by TBI [12, 20]. Pessar and colleagues [12] found that 29% (n = 7) of spouses reported that they experienced frequent problems with reduced parenting performance [12] whilst Uysal and colleagues [20] identified that spouses demonstrated less warmth and acceptance towards their children in comparison to their non-affected counterparts.

Finally, themes from Charles and colleagues' [22] MFG evaluation suggested that spouses of parents with ABI (n = 6; TBI = 3; ABI = 2; stroke = 1) felt alone, and struggled to manage the demands of caring for their spouse whilst simultaneously supporting their children to adjust. Whilst findings are limited, they reflect general stroke literature that has identified caregiver strain in relation to spousal caregiving following stroke [25].

Young People's Experiences of Parental ABI

Finally, young people have also been identified as at risk of psychosocial difficulties following parental ABI [11 - 23]. After parental stroke, 13-14% of young people have been identified as experiencing clinically significant symptoms of depression [14, 15], 13-30% experiencing internalising symptoms (e.g. withdrawal, anxiety, depression, somatic symptoms) [13 - 16], 17-26% experiencing externalising symptoms (e.g. behavioural difficulties) [13 - 15], with experiences of stress [13, 18] also having been documented. In longitudinal research, these symptoms were found to persist over time [15]. Research regarding parental TBI has suggested that 20% (n = 5) of young people have been identified as experiencing frequent problems with 'acting out', 41% (n = 10) have been identified as experiencing relationship difficulties, and 16% (n = 4) have been identified as experiencing frequent emotional problems [12].

Uysal and colleagues [20] observed significantly more depressive symptoms in young people affected by parental TBI (n = 18) than their unaffected peers (n = 26), even in instances when individuals' scores fell below the clinical threshold. Similarly, Niemelä and colleagues' [19] Finnish cohort study identified that by 21-year follow-up, 23% of young people with a parent with TBI had accessed psychiatric services in comparison to 13% of their non-affected counterparts. Kieffer-Kristensen and colleagues [11, 23] examined psychosocial wellbeing in 35 young people from families affected by parental ABI (60% stroke; 26% TBI; 14% other). 46% young people were identified as scoring above the clinical cut-off for Post-Traumatic Stress Disorder (PTSD) [11, 23], which was significantly more than in a control group of young people with a parent suffering from chronic illness. They attributed these differences to the frequently traumatising nature of ABI and the presence of secondary stressors, such as family disruption and parental role change.

Whilst the psychosocial impact for young people is well documented, the relationship between parental injury variables and the subsequent impact on young people is less clear. Injury variables such as cognitive dysfunction (including impaired attention, memory, information processing, and/or communication difficulties) and physical disability have not been shown to be predictive of psychosocial outcomes for young people who have a parent with an ABI [11 - 15, 18]. However, depressive symptoms in parents affected by stroke have been positively correlated with poorer outcomes for young people [13, 18], even when parents' scores were subclinical [13]. This association has been identified at 2 months [18], 1 year [18], and 3 years [13, 18] post-injury. Furthermore, these findings are consistent with research investigating young people's adjustment to parental chronic illness [e.g., 26, 27], and the finding that within the general population parental depression is a risk factor for young people's psychosocial difficulties [e.g. 28].

Van de Port and colleagues' [13] cross-sectional study of families three years following parental stroke identified that parental independence and ability to perform activities of daily living following stroke was negatively correlated with stress in young people [13]. Specific changes to young people's roles and responsibilities that have been documented include fulfilling direct caregiving activities [13], taking on

additional household chores [13, 17], and having greater concern for their parents' wellbeing compared to pre-injury [17, 21]. However, Visser-Meily and colleagues [14] reported that increased caregiving by young people following parental stroke was not associated with increased stress. These seemingly conflicting findings may suggest that undertaking additional roles and responsibilities may not directly result in increased stress, but observing parental loss of ability and increased dependence on others may be particularly challenging for some young people.

Interestingly, compromised functioning and emotional wellbeing of the parent without ABI appears more predictive of poorer psychosocial outcomes for young people [11 - 16, 20]. Specifically, depression and caregiver strain in the parent without the ABI have been positively correlated with depression in young people, whilst being negatively correlated with young people's functioning [14]. Spousal depression was also found to be predictive of young people's functioning at two months [18] and one year post-stroke [15, 18].

In spite of these findings, Visser-Meily and colleagues [14] identified that whilst 54% of young people received at least one type of support following parental stroke, frequency of support was correlated with severity of the stroke, rather than young people's experiences of adjustment difficulties or psychosocial problems. Since illness variables such as cognitive dysfunction and physical disability have been identified as poor predictors of young people's psychosocial outcomes, injury severity may be an unreliable way of identifying young people in need of support.

Qualitative research has identified that following parental stroke young people may have experiences of feeling glad to no longer live with their parent [22], and disliking or avoiding them [18, 22]. Experiences of loss and grief have also been documented [16, 17, 21, 22]. Adaptation to parental personality change has been identified as particularly challenging, with some young people describing a dislike for their parent post-injury [16, 22]. Nonetheless, positive changes to relationships have also been described, including being able to spend more time with the parent with ABI [16], and increased family cohesion [21]. Similarly, positive outcomes for young people have been identified, including re-evaluating life, developing sense of self through

maturation, and the acquisition of new skills [21].

Some young people described experiencing their parent without ABI as the most stressed family member [16], and young people often described not wanting to overburden either parent [16, 21]. It has been hypothesised that changes to the parent with ABI are more readily accepted in the context of associated disability, whilst changes to the parent without ABI are more difficult to comprehend and young people may expect their parent without ABI to function in the same manner [11].

Following MFG intervention for stroke, young people described benefitting from the opportunity to relate to other people in similar circumstances [22]. However, it was also noted that certain disclosures about family life, including the presence of violence, were not made until the ninth session [22]. This highlights the importance of building a trusting relationship with families and may negate the efficacy of short-term interventions or ad hoc support offered to young people and their families. In addition to the support from healthcare professionals, families described the value of social support in maintaining routine during the acute phase of ABI [17]. However, it has also been acknowledged that social support may decrease over time, and young people and families have also described feeling isolated [16, 22], with some young people preferring not to disclose their experiences to others [17, 21, 22].

Summary

Existing research indicates that following parental ABI, all family members may be vulnerable to developing psychosocial difficulties. Furthermore, findings suggest that not only does parental ABI have the propensity to result in significant psychosocial difficulties for young people, but the complex and distinctive features of ABI also place young people at greater risk than those affected by parental chronic illness. There is a growing body of literature regarding the experiences of families affected by parental ABI. Systemic variables and interpersonal processes appear to have significant implications for young people's wellbeing following parental ABI. Specifically, the disruption that ABI can cause to family life, and individual roles and responsibilities, appears to pose a threat to the psychosocial wellbeing of young people.

Given the increasing prevalence of ABI and therefore the growing number of families affected, it remains important to continue developing an understanding of the experiences of this population. Furthermore, despite increasing attention being given to the experiences of different family members following ABI, few qualitative studies consider the perspectives of multiple family members and explore the implications of different perspectives and experiences within the family system.

Aims

This study was a preliminary investigation into the experiences of families affected by parental ABI in the UK. A qualitative approach underpinned by the epistemological position of constructivism was used. Constructivism supposes that individuals actively make meaning from their experiences [e.g. 29], so this was considered an appropriate framework within which to identify the perceptions and interpersonal processes occurring within families affected by parental ABI.

METHOD

Recruitment

Purposive sampling was used to identify potential participants. The lead author contacted ABI specialists from local services, who considered the suitability of their service users as potential participants. Participants were recruited from local Headway branches (UK brain injury charity), and an NHS ABI service in the South East of England.

Families in which a parent was at least one year post-injury, and experiencing moderate to severe functional impairment following ABI, were eligible to take part. Individuals experiencing mild ABI or those who were not accessing services were excluded from the current research, although it is noted that they may also experience significant difficulties and require additional support [e.g. 4]. This inclusion criterion was largely constrained by the services from which participants were recruited. The NHS ABI service support individuals following severe ABI whilst Headway generally support individuals with moderate to severe ABI; both services receive referrals due to ongoing clinical needs. Furthermore, narrowing the inclusion criteria was anticipated to strengthen the validity of findings.

Additionally, individuals with significant or unmanaged sequelae including mental health difficulties, cognitive difficulties, behavioural difficulties, and communication difficulties were also excluded from the study. Whilst these types of difficulties often constitute an inherent part of ABI, the decision to exclude these individuals was based upon primary need and risk. The authors felt that in these instances access to appropriate support should be prioritised and participants should not be exposed to additional stressors that may be associated with the research process. Furthermore, since these variables may restrict engagement in the research process, defining the sample population reduces the number of variables that may confound results. Being from a two-parent family was not an inclusion criterion and therefore the inclusion of a parent with ABI was necessary in order to establish multiple perspectives within the family system; consequently it was imperative that it was both appropriate and viable for parents with ABI to be able to take part in the research. It is, however, acknowledged that the findings of the current study may therefore underestimate the difficulties faced by families.

Eligible families included at least one parent with an ABI, and one child aged 8-16 years old. Young people under the age of eight years were excluded; this is due to the developmental difficulties that young people under the age of eight may experience when asked to consider the viewpoints of others, a skill that requires perspective taking [30]. Additionally, young people over the age of 16 years were excluded. It is acknowledged that even adult children of parents with ABI may experience significant psychosocial difficulties, however, the criteria were narrowed in order to reduce the number of confounding variables that may dilute findings. The upper age limit was imposed since there is typically a significant period of transition for young people between the ages of 16 and 18 years, which can influence family dynamics, for example, older adolescents often exhibit increased disengagement from their families and have a reduction in shared activities [e.g. 31], whilst individuation and a need for privacy become increasingly important [e.g. 32]. Furthermore, within the UK young people over the age of 16 years can move out of home without their parents' consent [33]; therefore they have greater opportunity to create distance from the family system if they are unhappy with family functioning. It is acknowledged, however, that there will likely be marked differences between the

experiences of young people at the lower age limit and upper age limit due to the relative influence of chronological age and social, cognitive, and emotional development. Limits were not imposed with regard to maximum family size, or the ages of parent participants.

During the recruitment period, fourteen families expressed interest in participating, three of whom took part in the research. Of the identified families, reasons for non-participation included severity of ABI sequelae ($n = 4$), presence of other life challenges ($n = 3$), and geographical constraints ($n = 1$). Two families opted not to take part, and preferred not to give a reason. One family dropped out following the initial interview, without giving a reason for discontinuation.

Ethics

Ethical approval for the study was granted by the University of Hertfordshire Ethics Committee and the London-Central NHS Research Ethics Committee (REC). Research and Development (R&D) approval was also gained from the local NHS Trust. Informed consent was obtained for all participants, and parental consent was sought prior to young people consenting themselves. In accordance with the Mental Capacity Act [34], capacity for parents with ABI to give informed consent was assessed via professionals at research sites and during initial face-to-face interviews. Only individuals deemed to have capacity were included in the research. Confidentiality and anonymity were maintained throughout.

Data Collection

Demographic data and information about the ABI was collected from parents during a brief informal interview conducted prior to the individual research interviews (summarised in Tables 1 and 2). In order to protect participant confidentiality, pseudonyms have been assigned. Specific impairments were subsequently evaluated using self-report information about social and occupational functioning gathered during the initial meeting with participants. This information was used to classify severity of impairment on the Glasgow Outcome Scale (GOS) [35].

<Table 1>

<Table 2>

Interviews

Participants chose the time and location of interviews. All families opted to complete interviews in their own homes; prior to the interview, the lead author ensured there was an appropriate room within the family home in order to maintain the privacy and confidentiality of participants throughout. All participants were given the opportunity to have an additional family member present throughout the interview, but all declined. The mean length of individual interviews was 48.2 minutes (SD = 12.2).

Interviews were semi-structured and orientated around individuals' perceptions of themselves and others in their family, in addition to their perceptions of the ABI. Interviews were facilitated by a Perceiver Element Grid (PEG) [36]. The PEG is a matrix that can be used to support the identification of an individual's views and perspectives, in addition to identifying how the individual believes they are perceived by others. An example PEG can be found in Appendix 1. Whilst it is not within the scope of this current paper, the use of the PEG methodology for this population is evaluated by the authors elsewhere [37]. For clarity, Table 3 provides examples of interview questions and possible prompts.

<Table 3>

The interview questions encouraged participants to use three levels of cognitive functioning. The first level identified individuals' perceptions and reactions to events through asking participants to describe their own views and opinions. The second level required participants to use reflective functioning in order to imagine how other people in their family would respond to each of the interview questions [e.g. 38]. Finally, participants were encouraged to externalise the ABI. Externalisation encourages individuals to separate the problem from the person [39]; in this instance it was used in an effort to support participants to consider the ABI as separate from the parent who had been affected by it.

Participants were given the opportunity to draw or write their responses, in addition to discussing their responses with the first author. It was important to consider

interview methods that were accessible to participants of different ages and abilities. None of the participants chose to use drawings. The majority of participants (n = 7) chose to discuss their answers, whilst three participants wrote some of their responses down.

Following the completion of the interview, participants were debriefed and given the opportunity to ask questions. All families were offered personalised information packs containing details of local organisations offering support for individuals affected by ABI, and emotional wellbeing services suitable for both adults and young people of different ages.

Data Analysis

A Thematic Analysis (TA) [40] was conducted to identify themes in the data occurring between families. All interviews were transcribed by the first author in order to facilitate familiarisation with the data. The interviews were subsequently read, and the audio recording listened to over at least two occasions. Initial thoughts were recorded alongside the transcript and a research diary was used to reflect upon observations. Following this, a coding process was initiated. Similar codes were clustered using a thematic map, after which preliminary themes were defined by the first author. Since findings specific to individual families have already been reported elsewhere [37], for the purpose of this paper themes were required to be evidenced in more than one family. Furthermore, this was considered an appropriate way of enhancing the generalisation of findings and drawing conclusions from the research.

It was acknowledged that interpersonal processes occurring between the researcher and participants will have influenced data obtained, and that the authors' own processes of construal may influence data interpretation. In order to strengthen the reliability and validity of codes and themes, the second and third authors coded a section of a randomly selected participant's transcript. To minimise subjectivity, verbatim quotes have been presented to describe findings relevant to each theme. Participating families were also given the opportunity to comment on the themes generated in the research. Two of the three families opted to take part in this stage of the research process. Both families agreed that the themes reflected their experiences, and no points of disagreement were highlighted.

RESULTS

Participants spoke in depth about experiences of uncertainty, role adjustment, psychosocial difficulties, loss, and coping. The five themes identified from the TA were defined as follows: 'It's nothing you could ever prepare anyone for'; 'I need to do things I've never done before'; 'I've been more stressed'; '...that person wasn't there any more'; and '...fight if there is a chance to fight'.

'It's nothing you could ever prepare anyone for'

All families were affected by the sudden onset of ABI that did not appear to have been preceded by an obvious period of ill health. The contrast between the days preceding and succeeding the ABI were acknowledged, for example, '...in one night, everything changed' (Carina), 'I didn't know it was gonna come to me' (Joyce), and "...Monday and Tuesday I was fine, I was coming out [of hospital] and suddenly I collapsed again" (Leo).

Participants recognised their lack of knowledge about the epidemiology of ABI, thus finding it difficult to anticipate prognosis and the impact of the injury. One young person explained that '...I knew it was like a life risk but I didn't know how it can be caused, I didn't know what the consequences could be, I didn't know like you have to have all these tablets' (Oliver). This uncertainty was not limited to the acute event but prevailed through rehabilitation, with another participant citing how difficult it was for others to anticipate recovery: '...my husband, he thought within six months I'd, you know, I'll be okay' (Joyce).

Young people's lack of knowledge surrounding ABI appeared to be perpetuated by parental efforts to protect their children. One participant cited this explicitly, stating that '...for me it was protection, to not tell everything that was going on' (Carina); however, these sentiments were reflected in other families, for example, '...I didn't want to upset them and I thought if I was crying then they would worry' (Susan).

Lack of knowledge appeared to contribute to the development of health anxieties. Participants from Family 2 and Family 3 spoke about experiences of misattributing

physical sensations as signs of significant ill health. For example, ‘...if I get like a mole or something, I’d be scared like “oh no, I’m getting, say like cancer” or something like that and I just worry about it for like three or four weeks and then it’s like an ongoing cycle, my heart races, I feel ill’ (Mark), and ‘...everyone gets a pain and goes “oh I’m a little bit worried” but at the time it was like “oh my gosh, I am dying”’(Susan).

‘I need to do things I’ve never done before’

Role change appeared to occur within two domains: parents with ABI relinquishing their usual roles, and other family members assuming additional roles. For example, ‘...I have to do more, start like a baby, so I have to train myself, my left side to do things because of my part of my brain it can’t do it any more’ (Joyce) and ‘...when I got to [hospital]...I was just in a chair or in a bed...[my wife] having to clean me up’ (Richard). This was also recognised by other family members, for example ‘...she’s like basically on the sofa all the time’ (Katie), ‘...he can’t work and he doesn’t really have his own money’ (Susan), ‘...he can’t take care of the family like before’ (Carina), and ‘...now all he can really do is just walk around, talk to his mates’ (Mark). In these instances a reduction in abilities resulted in previously active individuals being required to pursue a more passive role in their lives, whilst having to re-learn basic skills, and rely on others.

Parents without ABI, and young people, noticed the impact on their own roles, for example, ‘They’ve had the brain injury and you’ve got to try and re-teach them to the best that you can’ (Susan), ‘...he need help for everything he do’ (Carina), ‘I became man and woman now because I need to do things I’ve never done before’ (Carina), ‘...she’s like the carer now for him, so like if he goes to shower she’s always got to clean him, change him’ (Oliver), ‘Well now it’s like looking after four children now instead of like three’ (Mark), and ‘...just put your arm out, she can like use you as a walking stick’ (Katie).

None of the young people in the sample identified themselves as young carers, and their role changes appeared less concrete than those of their parents. Rather than being required to take on specific responsibilities such as additional household chores, their roles appeared to change in their relationships with their parent.

Newfound concerns about their parents' vulnerabilities suggested a role shift analogous with parentification whereby young people demonstrated parenting traits towards their parents. For example, worries included, '...like if anything bad's gonna happen or like if he's gonna get hit or robbed because he's, erm hasn't got that good eyesight' (James), '...you have to be patient with them and you can't like, stress them out a lot (Katie), and '...he felt unprotected because, you know [his Dad] was in hospital, I was there with [his Dad], you know he felt, I think at the beginning it was, he felt alone, he felt "I need to grow up"'(Carina describing Oliver).

'I've been more stressed'

The ABI appeared to affect the emotional wellbeing of all young people, albeit to differing degrees. Regarding how young people responded to their emotional experiences, some described feeling as though they needed to hide their feelings. For example, '...I'm kind of a guy that doesn't show his emotions to people, I'm always keeping it in, like when my Dad had the heart attack and stuff, I didn't tell none of my friends. I didn't tell anyone like kind of how I felt, I kinda like kept it in and obviously be strong for my other, like my Mum, my brothers' (Oliver), and '...I kept a lot of stuff in like at the time and erm I didn't tell anyone or anything and then like I ended up in hospital, like my face like half of it like blew up like I'd got a massive swollen face, and then like I couldn't move my right side either and then like they knew it wasn't [stroke] so they thought I was allergic to something and so I had my allergy tests and they said it wasn't anything and it, they said well it's stress' (Katie).

Parents tended to notice their children's experiences varied and this was often attributed to their ages at the time of the ABI. For example, '...[My eldest] was more cry, express himself, talk about what's happened. [My second child] was the one, he never talked, he never involved in anybody, he was close, closing down himself. [My youngest], he become, you know, a little er "oh I'm big now, I can do things"' (Carina). Leo also noticed changes for Oliver, stating "...when I had a stroke, he changed a little bit". Similarly, 'I think it was hardest for [my eldest] in some respects because he was er used to Dad doing things with him', 'because [my youngest] was younger erm he spent a lot more time with me and sort of needing Mummy', and 'It's not like [my second child] ever cried about it or, and he'd just sit and play his computer and that's about it. Get on with whatever he was doing, erm so I was a bit

concerned about that really 'cause it was kind of like well he's not showing any signs of anything (Susan). Whilst young people endeavoured to hide their emotional experiences, these descriptions suggest that for these families, parents may have continued to be aware of their children's individual needs.

'that person wasn't there anymore'

Participants described experiences of loss, in the context of their premorbid relationships. Comments included '...he's still a Dad like he cares for me and all that, but most of him now, he's like a friend now...it feels like you've lost something and it just feels like I've lost a bit of my Dad' (Mark). The experience of loss was less noticeable for Family 2. The young person in this family expressed that 'it hasn't changed her' (Katie).

Younger participants tended to describe loss in the context of activities rather than interpersonal relationships, for example, '[Dad] wasn't as fun since then...and he didn't get much to do and lots of stuff we couldn't do' (Harry). These reflections tended to be corroborated by parents without ABI. '...he's not the person he was, erm he'll never be the person he was, so in that respect it has completely changed life erm and we've just gotta get used to it really' (Susan), '...this is [him] but it's not [how he] was before, he's the same [man], but with different needs and different things' (Carina), and '...he's there for the kids but he can't do the things he can before for them' (Carina).

Particularly in families within which there appeared to be traditional gender roles, having a father with ABI appeared to result in significant anxieties. For example, '...he felt he lost his Dad, you know, he felt unprotected' (Carina), and '...Dad had been the protector as it were, y'know, he was there to look after us all, you know, and even I missed that 'cause he's- he'd always be that person if something was going on, I'd talk to him, and y'know talk through it properly more and if I was upset and, he'd try and y'know give me cuddles and that, and that person wasn't there anymore' (Susan).

Nevertheless, family members also spoke about characteristics of the parent with ABI that had remained the same. For example, '...his like kindness and all that's

been the same' (James), and when asked if there was anything he would keep the same about the brain injury, one participant expressed, '...how much he cares for, cares for us' (James). Other comments included, '...it's still son, er Dad and son relationship' (Oliver), '...we've bonded like altogether all the same, we always react the same, it's like nothing's changed between, there's nothing really changed between us' (Oliver). Conversely, Harry spoke at length about his premonitory relationship with his father, expressing that he wished that '...he can be back as he was basically' (Harry).

Some participants also feared further loss, stating that '...he doesn't want to go away from us really long like for a whole day or something because he gets really upset' (James) and '...[Mum's smoking cessation] makes me happy and my Dad happy and my brothers, 'cause well, without, without my Mum, we're kinda stuck really' (Mark). These experiences appear to reflect a sudden awareness of the fragility of life.

'fight if there is a chance to fight'

Participants described experiences of perseverance and determination. In particular, families appeared dissatisfied with medical opinions and were determined to prove them wrong. For example, '...the consultant there, he said to me "I can't say that you will be able to walk again, I don't wanna say that because of your, you know, you had a stroke" and I said "look, you, you can't say that because yeah I know I had a stroke but I will show it to you, I can walk again"' (Joyce), '...[his] situation was very bad, three times they said they can do nothing...the specialist in hospital said "oh we can do nothing for [him], he can't understand nothing, he can't do nothing for himself, he can't get up from the bed and everything" and they said "you need to put him in the care home". I said "Never" [laughs]. "I married him"' (Carina). Additionally, Leo spoke about needing to live life to the full, stating '...I can't see how tomorrow changes but today is the most important day of my life'.

Families appeared conscious of the possibility of family breakdown. For example, '...I heard, and I knew, loads of people left, the marriage broke down' (Carina), and '...at any point my Mum could have just said "no" but- "no, I can't take any more" but no she's stuck with her- stuck with my Dad through this' (Mark). In these instances, it appeared as though determination and perseverance prevented this threat from

becoming a reality, for example, 'Love the person when he had the stroke, to be there for them because love can cure people, can, can give hope' (Carina), '...we're all supportive and I think if we keep being supportive, it will help and it'll just keep on helping even more but if we keep it to ourselves, it's just gonna break us more, we're gonna become more lonely and won't be able to talk about it' (Mark), and 'We've stayed together through many a bad thing...one way or another we're there for each other' (Richard).

Finally, following the ABI event, parents (both with, and without, ABI) from all families described relying on the support of others, particularly for childcare. One participant stated that, 'It was very difficult at the beginning but I had good friends' (Carina) and 'My brother, my sister came straight away' (Carina). Similarly, in Family 3, each of the children went to stay with a friend or family member. Susan described how they would have struggled without the support of a relative who took over the family business, explaining that 'without her, we would have been very, very stuck'. Having support from others appeared to enable families to remain intact and keep fighting the significant challenges with which they were faced. However, some young people described disliking the experience of being cared for by family and friends. Interestingly, whilst the majority young people referred to their friendship groups, none of the young people spoke about their own support needs. This appeared to reflected the self-reported tendency of choosing to keep their experiences to themselves. Richard was the only participant to describe the development of friendships following ABI; he spoke about making friends as a consequence of accessing community activities with the support of a carer.

DISCUSSION

Summary of findings

This paper describes the experiences of three families following parental stroke, and parallel interviews with members of the same family offer multiple perspectives of each family's experience.

The uncertainty described by participants in relation to ABI sequelae, epidemiology, and prognosis is consistent with existing research that has suggested that lack of information regarding ABI may perpetuate distress within families [14 - 17, 22]. For

young people specifically, their lack of knowledge about ABI and recovery pathways may have been perpetuated by parental efforts to protect them. Anxieties extended beyond concern for the parent affected by ABI; two young people and one parent without ABI described symptoms of health anxiety. Existing studies exploring the psychosocial impact of parental ABI on young people have reported similar findings [19, 22]; however, whilst psychosocial difficulties among spouses of parents with ABI have been well documented [11, 13 - 15, 18, 20], none have explicitly cited health anxiety as a potential difficulty and thus this area warrants further investigation. Interestingly, none of the parents with ABI in the current sample described experiences of health anxiety themselves despite existing research indicating that up to 25% of individuals attending medical clinics for physical health problems also experience clinically significant levels of health anxiety [41].

Participants from all families described changes whereby individual family members acquired or relinquished different roles and responsibilities within the family system. Given the majority of additional responsibilities were reported as being undertaken by the parent without ABI, this supports the view that there may be increased risk of caregiver strain [11 - 15, 18, 20, 22]. For the parent with ABI, role changes were described within the context of loss of skills. These findings reflect those within general stroke literature that describes individuals losing abilities, independence and freedom [24]. Existing literature regarding the impact of parental ABI have tended to focus on loss of parenting abilities following stroke [11], ABI [22] and TBI [20]. Young people in the current sample tended to describe role change with regard to more abstract phenomena such as spending more time worrying about their parent, an experience that has also been previously documented [17, 21]. Young people's roles as young people may have been compromised as they were required to pay additional attention to their parents' needs. Since this type of role change is more difficult to operationalise and quantify, it is challenging to identify associated difficulties. Nevertheless, it is noted that there can also be benefits resulting from this type of role change, for example, maturation and skill acquisition [e.g., 21]. Perception of the implications of role change may therefore be dependent upon the stage of a parent's rehabilitation, alongside family member-specific variables, for example, age, gender, and personality characteristics.

Young people's descriptions of feeling stressed and anxious were also consistent with previous research findings that suggest that young people affected by parental ABI may experience psychosocial difficulties [11 - 15, 19]. Young people spoke about avoiding conversations about the ABI and not discussing their emotional experiences; this supports existing findings that describe young people keeping emotions hidden as a means of reducing the burden on others [16, 17, 21, 22]. Moreover, it has been hypothesised that avoidance of emotional disclosure may serve the function of supporting young people to retain a sense of normality within their lives [21]. Parent-report questionnaires in previous studies have identified that parents consider their children to be experiencing psychosocial difficulties following parental stroke [13 - 15], TBI [12] and ABI [11, 17].

Additionally, participants' experiences of loss support existing research [16 - 18, 21, 22]. In comparison to existing findings that emphasise preference for the pre-injury parent in the context of personality changes [16, 18, 22], young people in the current sample tended to speak about loss to their relationship in the context of roles and activities completed with the parent. Parents with, and without, ABI spoke about loss in the context of their marital relationships; these findings also strengthen existing research that suggest marital relationships deteriorate following stroke [11, 13, 15, 18]. Fears of further loss were also present, with young people overestimating the likelihood of further loss whilst simultaneously being aware of the fragility of life that had perhaps previously been taken for granted. Boss [42] explored ambiguous loss in the context of chronic physical illness and described the challenges associated with an individual being physically present whilst psychologically absent. In this context, ambiguity regarding prognosis and recovery post-injury has been associated with increased risk of psychosocial difficulties [42]. Where experiences of loss was less evident for Family 2, this may have reflected a difference in their premorbid relationship, particularly since the parent with ABI had previously worked away from the family home and was consequently less available. Moreover, it may have reflected a difference in ABI sequelae, since the parent with ABI reported having fewer cognitive deficits and a less severe injury than the other two participants with ABI.

Finally, families spoke about their experiences of coping and resilience. Parents in all families described social support as being essential during the acute phase of ABI, which was reflected by a reliance on others for childcare in order to enable the parent without ABI to attend to their spouse in hospital. Two families had out-of-area hospital admissions; in these instances, it was even more important that friends and relatives could support families. However, some young people described disliking being cared for by others, which may highlight a challenge faced by many families; it may be extremely difficult to attend to each family member's needs and preferences, particularly during the acute phase, when the needs of the parent with ABI must be prioritised. Parents without ABI reflected on changes in social support throughout the rehabilitation journey, with social support at the time of research interviews being associated with support to sustain family businesses, and offers of financial support. It is noted that experiences of social isolation are commonly reported in stroke literature [16, 22], with some studies identifying a reduction in social support overtime; whilst families in the current study spoke favourably of the support they were receiving, longitudinal observations would improve validity of findings. Finally, apparent determination of parents with ABI to prove medical professionals wrong appeared functional for these families. Charles and colleagues [22] identified one participant who spoke favourably about their experience of surpassing the expectations of medical professionals following stroke. However, it is acknowledged that these experiences may be a reflection of the current sample, and it is acknowledged that attitude towards recovery may not always have implications for an individual's prognosis.

Strengths and Limitations

This study has offered an insight into the experiences of families with a parent who has an ABI, a population that is currently under-represented in existing literature. The current study suggests that the sample population of families from the U.K. have had similar experiences post-ABI to families worldwide. Given the increasing prevalence of ABI and medical advances resulting in declining fatality but increased disability following ABI, the research offers valuable contribution to this field.

The elicitation of multiple perspectives within individual family systems is a strength, especially given the acknowledgement of systemic variables on family functioning

post-ABI. Additionally, the interview method that involved externalising the ABI from the parent with ABI may have supported individuals to talk about more negative aspects of their experiences that had not yet been discussed in other areas of their research interviews. For example, many participants only appeared to discuss more problematic ABI sequelae, and implications of the ABI on family functioning following this aspect of the research interviews. This supports existing research that has suggested under-reporting of family difficulties may occur due to family loyalties [e.g., 22]. Externalisation may therefore enable family members to feel permitted to speak more frankly about their experiences whilst lessening the attribution of blame. Further information regarding the use of the PEG in eliciting intrafamily perspectives, and the effect of encouraging multiple layers of reflection can be found in an earlier publication by the authors [37].

Nonetheless, the generalisability of findings from this study may be limited by the small sample size. Moreover, since only 21% of the identified families participated in the research, it is essential to consider the potential implications of sample bias. Since reasons for non-participation included additional life stressors, and the presence of significant or unmanaged difficulties was an exclusion criterion, the current findings may underestimate the difficulties experienced by families affected by ABI.

Furthermore, despite the study implementing broad inclusion criteria, the sample included families with similar demographics. For example, each participating family was a two-parent family that had not been affected by family breakdown, and had access to social support. It is anticipated that families in alternative circumstances, particularly those affected by family disaggregation, may have significantly different experiences. Similarly, further exploration of other diversity variables, including the impact of race and culture on the experience of ABI, would be valuable.

With regard to the nature of the ABI, the sample was heterogeneous, and it is acknowledged that different sequelae may drastically influence the subsequent experiences of families. It should be acknowledged that, conversely, given the nature of ABI, it would be difficult to recruit a sample with homogeneous injuries and impairments.

Clinical implications

Participants in all families described feeling as though they had insufficient information about ABI epidemiology and the prognosis of the family member with ABI. It is understood that ABI can result in a multitude of uncertainties, even for medical professionals, and therefore an accurate prediction of prognosis is not always possible. Clinical guidelines have established the need for information regarding ABI and local services to be distributed to families [e.g., 4], and many services would argue that this is already the case. Perceived lack of information may therefore be a reflection of timing, for example, information given during the acute phase of the ABI may be difficult to retain due to high levels of emotional stress and associated trauma. For individuals with ABI, the injury itself may affect their ability to comprehend and recall information, for example, due to memory and information processing difficulties. This highlights a need to re-visit information at different stages of rehabilitation, and to consider presenting information in a variety of formats. Similarly, use of written age appropriate materials to support young people's understanding would be beneficial. The suggestion that young people's uncertainty may be perpetuated by parents' efforts to protect their children may indicate that information shared with adults is not always passed on to young people. Since young people's attendance in hospital settings may also be discouraged [e.g. 14], it may be difficult for information to be provided directly by healthcare professionals, and there may be an expectation that parents facilitate discussions with their children. Supporting families to have open conversations may be beneficial for all parties in this respect. Further research into the manner in which information is distributed, and how it is received, may support clinicians in providing appropriate information and resources for all family members.

The findings also suggest that there could be utility in offering psychological intervention to all family members following parental ABI. Firstly, parents with ABI may benefit from direct psychological intervention, for example, to come to terms with changes in their abilities and associated role change. Acceptance and Commitment Therapy (ACT) [43] is widely used in clinical health settings [e.g. 44 - 46], and may support individuals to live a values-led life in spite of the changes that have arisen following their injury and subsequent disability. Given that recovery is

complex and variable, particularly during the acute phase, initial priority should be given to the management of high risk cognitive and physical impairment. Parents with ABI may be better able to engage in psychological intervention when they are emotionally, cognitively, and physically more stable.

Whilst young people explicitly described psychological difficulties following parental ABI, they also reported that they may keep their difficulties hidden so as not to further burden their families. Given the frequency of young people's contact with teachers and pastoral staff, education providers may be well equipped to support the early identification of psychosocial difficulties in young people following parental ABI. Consultation to schools when a family is affected by parental ABI could therefore be particularly beneficial. Integrating psychology services within schools has already been identified as an effective way to support the identification and early intervention of psychosocial difficulties among young people [e.g., 47]. Additionally, services available through schools may support young people to overcome some of the barriers to accessing mental health services, for example, accessibility [e.g. 48].

Finally, given the long established impact of spousal ABI [11 - 15, 18, 20, 22], and associations between wellbeing of the parent without ABI and presence of psychosocial difficulties among young people following parental ABI [e.g. 11 - 16, 20], support should also be offered to parents without ABI. Findings from Charles and colleagues' [23] MFG intervention suggested that meeting other families in similar circumstances enabled spouses to develop more compassion towards the parent with ABI, which may help to reduce burden from caregiving activities.

In addition to individual psychological support, there may be utility in offering a systemic approach to supporting familial adjustment to parental ABI. As per Charles and colleagues' [22] MFG intervention, a systemic approach may enable families to develop an understanding of possible maintaining factors to their difficulties, whilst offering an opportunity for individual family members to share their unique perspectives of the experience of the ABI. Furthermore there is a growing body of evidence to support the use of family interventions in the management of chronic health problems in adults, including stroke [49]. Opening up conversations within families may help to address aspects of anxiety, loss, and role change. Given the

aforementioned considerations regarding timing of psychological intervention for individuals with ABI, it would therefore also be important to consider when systemic interventions are offered.

The findings from this study suggest that familial and social support can be heavily relied upon to enable partners of those with ABI to visit hospital whilst caring for the young people in the family. Enquiring about social support will enable clinicians to identify young people and families that may lack the local support required at this difficult time. Inter-agency working and liaison with social care may be central to ensuring that all young people receive adequate support whilst their parent is in hospital, particularly if there are limited alternatives of individuals who are able to fulfil the parenting role in their absence.

Parents also spoke favourably about support received from organisations such as Headway. However, parents without ABI and young people spoke less about support available for themselves. It is unclear whether this reflected an absence of local resources, lack of awareness of local resources, or an inability to pursue available opportunities. Accessing support groups, including Young Carers (UK charity) may also assist in the reduction of anxiety through learning more about experiences of ABI [e.g., 16, 22]. Additionally, a less direct approach may also be useful. Reflecting the idea that young people may wish to retain normality within their lives, offering increased support to parents (both with and without ABI) may free up time for young people to pursue preferred social and leisure activities, and fulfil their roles as young people.

Further research

Firstly, since the current study was a preliminary investigation into the experiences of families following parental ABI within the UK, it is recommended that this research is replicated on a larger scale in order to inform clinical recommendations with greater precision.

Future studies may benefit from comparing different groups of people affected by ABI, for example, comparing different types of injury, or the experiences of families following specific types of impairment. This may support researchers to determine

whether the nature of ABI (e.g. RTA versus stroke) influences familial experiences. Furthermore, ABI sequelae in the current sample were determined via self report. Measuring specific aspects of impairment, for example, cognitive and functional ability, would be beneficial, and support comparison between groups of parents with ABI. Use of cognitive screening measures such as the Addenbrookes Cognitive Examination-III (ACE-III) [50] or the Repeatable Battery for the Assessment of Neuropsychological Status (RBANS) [51], in addition to functional measures may support the identification of a more homogenous sample, and assist researchers to draw conclusions from their findings. Similarly, further consideration of premorbid functioning, and other variables such as age at the time of injury, may offer a better understanding of the impact of the ABI for the individual.

Additionally, further exploration into the relative influence of family member demographics would be valuable. For example, the impact of a young person's age on their experience of parental ABI may be beneficial; studies offering a comparison between the experiences of young people of different age groups (including adult children) may further contribute to the understanding of the impact of parental ABI. Similarly, studies examining the age of the parent without ABI, and variables such as their level of education, may support the development of a more in-depth understanding of some of the variables that may affect individual, and familial, adjustment to parental ABI.

Finally, the current study offers insight into the experiences of three families at one moment in time. Longitudinal studies that consider different stages of the recovery pathway may offer a more comprehensive understanding of adjustment in families over time.

Conclusion

This study sought to explore the experiences of families affected by parental stroke and consider the implications for adjustment. The findings have complemented existing literature, whilst offering a unique insight into the interpersonal processes that may occur within families affected by parental stroke and have implications for coping and adjustment. Furthermore, the findings shed light on the complexities of family systems and suggest that there are a number of variables that can influence

adjustment and coping, and therefore inform support. The varied experiences of participating families indicate the need for person-centered care with individual families at the heart of all clinical decision making. It remains clear that parental ABI has considerable implications for young people and their families, and continued research is essential in order to develop resources that match the needs of this population. Through using this awareness to offer timely support, young people and their families may feel better equipped to confront the challenges with which they are faced.

DECLARATIONS OF INTEREST

The authors report no declarations of interest.

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