

## Experiences of challenges and support among family members of people with acquired brain injury: a qualitative study in the UK

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## **Experiences of challenges and support among family members of people with acquired brain injury: a qualitative study in the UK**

**Mark Holloway, David Orr & Jo-Clark Wilson**

### **Abstract**

*Primary objective:* Family members (FM) are affected by the impact of an Acquired Brain Injury (ABI) upon their relatives and play an important role in rehabilitation and long-term support. This study explores how families are affected and integrates their views on the formal/informal support received as a consequence of ABI.

*Research design:* A qualitative research design was employed to capture the lived experience of FM of people with ABI.

*Method:* Semi-structured interviews were conducted with 16 FM of people with severe ABI. Participants were chosen from respondents to a UK national online survey of affected individuals. Interview data were analysed using inductive thematic analysis.

*Results:* Family members' experiences are complex, enduring and are affected by the context in which the ABI occurs as well as by formal/informal support. Grief experienced by FM is ambiguous, develops over time and FM perceive little option

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but to remain involved. Experience of formal and informal support is noted to vary significantly in availability and quality, poor support exacerbates difficulties and isolates family members.

*Conclusion:* Greater understanding of the lived experience of FM is needed to support more effective responses to both them and the individual with ABI, integrating services and families to improve quality-of-life.

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## **Introduction**

Severe Acquired Brain Injury (ABI) is associated with long-term changes to an individual's abilities [1, 2]. Physical and communication difficulties are common, as are negative changes to self-identity [3-6]. Executive impairments and difficulties in controlling behaviours are invisible but impact significantly upon day-to-day functioning [7, 8] and the person may have limited or no insight into their condition [9, 10]. Multiple, complex and interrelated factors influence outcomes [11]. Functionally, severe ABI is associated with reduced independence, capacity to work and likelihood of employment [12-14]. Individuals affected by ABI are over-represented in prison and homeless populations [15-18].

Improved acute medical management of brain injury has increased rates of survival [19] and the consequences of severe ABI are usually significant and chronic [20, 21]. Service provision varies internationally but difficulties in adequately meeting need are noted even in countries which invest more in health and social care services [22, 23].

Early research described how severe ABI was a condition that affected the family [24, 25]. Depression and anxiety, psychological distress and reduced life satisfaction and quality of life were common among families of people with ABI [26-29]. Other research explored family functioning, the burden on the caregiver, and the role of family resilience in promoting the rehabilitation of the injured person as well as

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assisting other family members to adapt [30-34]. Family members often have to adjust to manage difficult behaviours and cope with changes in relationship status and life satisfaction [35-38].

Quantitative work has predominated in studies of ABI's impact on family members, but qualitative studies exist which have yielded important insights [35, 39-47]. Some have explored effects on the family relationships of parents of children with ABI, or of children of parents with ABI. Parents may face isolation and challenges in managing their own emotional distress whilst caring for their children; they report using various coping strategies, often including disengagement and avoidance [48]. Children may also struggle to process their emotional reactions, sometimes suppressing their feelings of loss to protect the injured parent [45] or experiencing anger or difficulty with self-expression due to the complex nature of the loss [49].

Further studies have explored family members' experiences of hospital and of the transition from hospital to community. Family members report significant needs for support from rehabilitation and other health and social care services, but research has shown that frequently these are inadequately met. Often significant gaps in services were encountered (particularly when transferring between inpatient units, or between inpatient and community services), a cohesive plan was lacking, and services needed to do more to support hope for relatives and engage them in the process of rehabilitation [41, 42, 50-53]. Needs changed over time in ways that

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services often did not appear to plan proactively for, from the immediate aftermath of emergency medical response through pre-discharge planning, return to the community, and ongoing support [54]. However, most qualitative studies have followed up family members' experiences of services over a relatively short-term timespan post-discharge, meaning that the 'big picture' perspective over a longer period is under-explored.

Studies of longer-term post-ABI adjustment have focused on living with challenging behaviours [35, 44]; Tam et al.'s research is particularly interesting in that the 6 family members interviewed averaged 17 years of experience of life following the injury. This research has provided important insights for health and social care professionals by revealing the complexities of adjusting to the condition, and how services might provide better support. Little work has however been undertaken to establish family members' experiences of ABI and related services, over time, seeking the perception and judgement of relatives to define what approaches they would find supportive.

The study described in this article was undertaken with family members with between 2 and 28 years' experience of ABI. It explores their accounts of their experiences, and what helped or hindered them in adjusting to the changes post-injury. The analysis aims to assist service providers to better understand family members' own perceptions of their needs and how these can be used to improve

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service provision. This study goes beyond previous work in asking relatives not only about the challenges they faced, but also specifically to consider what helped them and what their experience of informal and formal support was, whether good or bad.

## **Methods:**

### ***Participants***

Participants were selected from a cohort of respondents to a UK national online 30-question survey of family members of individuals with ABI, undertaken as an earlier part of the first author's doctoral research [55]. The survey was distributed nationally via Headway (a UK brain injury charity), the Child Brain Injury Trust, United Kingdom Acquired Brain Injury Forum, the Brain Injury Rehabilitation Trust, the Brain Injury Social Work Group and the British Association of Brain Injury Case Managers, and these organizations both directly brought it to the attention of relevant individuals in contact with them, and promoted it through their websites and Facebook groups. There were 110 responses to the survey, 48 of which expressed willingness to participate in a single follow-up interview. Sixteen were excluded as they were previously known to the first author in his professional capacity, and, for this reason, might not speak freely about their experiences of care. From the remaining 32, a final sample of 16 participants was identified using purposive sampling. The selection criterion was response to survey questions asking relatives to rank their perception of the severity of post-injury difficulties experienced using Likert scales; those rating the difficulty as more severe were included. This approach

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to recruitment enabled access to potential participants across a wide geographical area and through a range of intermediate organizations. However, it may not have reached those who were unaware of or not in current contact with such organizations. Potential bias may also have been introduced to the sample by unknown factors which may have influenced the decision to respond or not to the survey.

Demographics of the research participants and their injured relatives are displayed in Table 1. Time since the ABI ranged from 2-28 years, with a mean of 10.875 years. Fourteen of the 16 people with ABI were unemployed; no affected individual was in full-time employment or education. Descriptions provided by relatives of duration of coma and length of Post Traumatic Amnesia indicate all affected parties sustained moderate to severe ABI [56]; four of the sixteen resided in specialist long-stay ABI rehabilitation/care facilities. Fifteen of the sixteen interviewees were female. Fifteen of the sixteen individuals with ABI were male. Seven relative respondents were mothers and 7 were partners. Road traffic accidents were the most common cause of injury (10/16).

### **Design and procedure**

Fifteen of the sixteen interviews took place in the participant's home and one in a public location (as preferred by the interviewee). The interviews averaged 127 minutes in duration, ranging from 68 to 181 minutes. The responses from the earlier



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online survey informed the design of the semi-structured interview schedule.

Participants were asked about the history of their family prior to the ABI, the impact of the ABI, the immediate aftermath and the subsequent changes that occurred for the non-injured relative. Participants were asked to describe formal and informal support provision and specifically and what they had found helpful/unhelpful.

Examples of the questions included:

1. Describe your life today. What is different from before the brain injury?
2. In terms of help, what has worked for you? What do good services do well?
3. What would you advise someone who had a newly brain-injured relative?

The interviews were audio recorded and transcribed verbatim. Data were analysed qualitatively using inductive thematic analysis to identify key semantic themes, using the analysis processes suggested by Braun and Clarke [57, 58]. This form of analysis is a regularly used, non-theoretical, qualitative methodology, which aims to create a data-driven (rather than theory-driven) and rich understanding of participants' experience. The transcripts were repeatedly read for purposes of familiarisation, then initial descriptive codes were generated to classify each data segment. These codes were then brought together into overarching themes, and a process of reviewing and refining followed. Themes were examined for content fit and compared back to the original data set to check accuracy, before finally defining the set of themes that would structure the data presentation. The first author completed the analysis process in regular discussion with the second author regarding the coding process, development of categories and the development and

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refinement of themes. Table 1 provides an example of the sub-themes/codes that formed one theme "experiences of poor support".

**Insert Table 1 here**

Ethical approval for the study was sought and granted by the University of Sussex Research Ethics Committee (ref. ER/MH373/1). All names and potentially identifying information have been changed. A numeric code has been allocated to each participant to enable their contributions to be followed.

## **Results**

Six themes were identified using the Inductive Thematic Analysis approach. These were: 'the existing context'; 'the all-encompassing challenge'; 'loss and grief'; 'unavoidable duty'; 'experiences of poor support'; and 'positive support and change'. Sub themes are identified within the main themes.

**(Insert table 2 here)**

### ***1 The existing context***

#### ***1.1 Sudden and unexpected events***

Family members' experience of their relative's journey through ABI invariably started traumatically and unexpectedly. In some cases, they had to make decisions about treatment or continuing life-support, whilst in emotional turmoil. Such

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circumstances were entirely outside their previous experience. This often set the tone for their ongoing involvement with services.

*I basically got a phone call saying, "We're taking her in for surgery, it'll be at least seven hours. She might survive, she might not"... He said, "She could come out paralysed, blind," .... He said, she had a 50/50% of survival and all that. So he said, "just make your way over here and tell your parents to come," (02)*

### *1.2 Pre-existing roles and context:*

For some, the ABI occurred during periods of upheaval or difficulty, further complicating developments. Other relatives' ability to cope with news of the injury and its consequences varied. Their responses further influenced the participants' perceptions of feeling supported and being able to cope. The consequences of ABI were therefore set into a pre-existing context of roles, difficulties and responsibilities for both the injured person and relatives, which shaped views, resources and coping for post-injury life.

## **2. The all-encompassing challenge**

### *2.1 Dependency on family support*

ABI outcomes are extremely varied, and participants described how the range of their relative's support needs presented seemingly all-encompassing challenges.

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Physical and cognitive impairments might require substantial – even round-the-clock – care, but even some who were physically able to function without assistance did not because of executive impairment:

*He wouldn't function without me. He'd like to think he would function without me. He can't. He won't motivate himself to eat. (07)*

When unable to initiate activity or to make a choice autonomously, individuals required their family members to step in:

*You have to prompt him to have a shower, you have to prompt him to use shower gel, because he will just stand under the shower. (01)*

*The choice is there and he can't cope with choice. (07)*

These instances did not reflect a choice not to act by the injured party, but rather an inability to plan and initiate action, requiring specific support that could only be provided by the family member.

## *2.2 Behaviours that challenge*

Behaviours such as impulsivity, aggression or disinhibition also led to challenges for family members, as they often became responsible for mediating in the injured individual's dealings with the wider world. Sometimes this called for providing careful, draining explanations of dramatic actions; other times, family members found themselves resorting to subtle management techniques to avoid these difficult interactions:

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*He went into a stare and this woman was getting really, you know ... really embarrassed [...] so I just stood in front of him, so he was literally staring at my back, so she didn't feel uncomfortable and then I didn't have to explain it. So you have to kind of watch him. (01)*

This could lead family members to feel they needed to be constantly alert, ready to head off or respond to situations that might arise.

### *2.3 The added burden of loss of insight*

The demands of these caregiving roles were often exacerbated when individuals lacked insight into their behavioural difficulties [59, 60]. Family members were therefore not engaged in a fully shared endeavour with the injured party; rather, the responsibility fell primarily or entirely to them. It could be confusing, saddening or frustrating when their relative seemed able to show understanding of their condition, but not apply this knowledge in practice:

*I think the hardest thing as well is his lack of insight means that he doesn't really, despite the fact that he can articulate those deficiencies really well, he makes no connection [...] I get upset because of what he achieved and who he was and how clever and brilliant he was to someone sat with a blank piece of paper not able to make the connection between – he doesn't know. (09)*

Family members often had to develop their own strategies over time to deal with these challenges.

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## *2.4 The unpredictability of the future*

Prognosis after the ABI only unfolded gradually and the all-consuming nature of caregiving meant that though many participants expressed concerns about the future, often they could consider little more than the immediate situation. Longer-term planning became too much:

*I don't really look ahead, I take each day. I honestly don't know. (07)*

While participants identified the need for forward planning to create support structures, their ability to do so was limited by factors such as unavailability of support from services or other relatives, and by difficulty in conceptualising how the injured party could be supported in the future.

## **3. Loss and Grief**

### *3.1 Family member loss of identity*

Participants highlighted both the injured party's losses and their own. Their relatives' loss of abilities, hopes and roles affected them deeply, but they also noted that the responsibilities they themselves had assumed had caused important losses, not only of opportunities but of valued identities. Widespread lack of understanding of ABI created a mismatch between family members' reality and others' perceptions that heightened the sharpness of loss, in ways both isolating and frustrating:

*Sometimes when people say, "Oh well, at least you didn't lose him," I think "Oh God, you're so naive." Of course I lost him. I lost him, I lost my identity – he didn't just lose his. Yet no-one thinks about that." (09)*

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The distinctiveness of ABI, where the physical person remains but their personality and cognition may be dramatically altered, can give misleading impressions to others:

*I think that's what makes it quite isolating is because of this picture that's been created – that's where people say "God, Terry's doing well, isn't he?" You say, "Yeah, absolutely, everything's great," because it's too tiresome to – you sound like you're complaining. (09)*

### *3.2 Complicated Grief*

For participants, reconciling the person they knew pre-accident with the physically unchanged individual post-injury posed difficult psychological challenges. They spoke of how that individual '*vaguely resembles [...] but isn't him*' or '*learn[ing] to love this stranger*'. Participants spoke of the '*continuous bereavement*' they were now living.

*It's a bereavement without any closure and you are left with all the 'belongings' of the past and they are still there because this person has some association with them but they don't belong in the same way. There is a bereavement but there is no closure. (13)*

The process of adjustment to this unwelcome grief state was constantly disrupted by reminders of pre-accident personality characteristics or behaviour, which could be '*very upsetting when you get a glimpse*' (06). Sudden but fleeting reappearances by

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'the real person' sustained grief by momentarily bringing 'what was' into 'what is'.

This continually reawakened the dilemma that

*you never properly grieve for what you've lost because you can't, because you haven't but you have. (09)*

Participants found that it was not straightforward to rely on support structures that would usually help people through loss. The distinctive needs of people with ABI meant that they tended not to 'fit' service structures and eligibility criteria; similarly, their family members felt that the ongoing 'bereavement' they were experiencing was poorly understood. Many also gave up seeking informal support from friends, family or neighbours:

*You think, "Well, I'm not talking about this." They heap on you more pain because they make you feel inadequate or stupid because they don't understand and they don't want to. (16)*

*I don't talk to them anymore about it. They just, they can't take it on board. (11)*

Family members perceived that others could not understand the complexities of ABI or feared too much might be asked of them:

*Everybody says to you that you are so lucky that he is still alive, he can walk, and you think, "You have got no idea." No idea at all. (16)*

*If you tell them, they think you're giving them some responsibility. You're actually not. It's your responsibility, you just need to share it with somebody. (06)*



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They were left reluctant to confide in others, even for emotional support.

### *3.3 Questioning the value of life*

The magnitude of loss and grief, and limitations of available support, led 7 of the 16 participants to suggest that it might have been better if their relative had not survived:

*Can you remember when we were in the hospital and we said, "Dad, it doesn't matter how you wake up, just come back to us?" And I went "Yeah, I remember all of that," and she said, "God, how naive were we?" And I was like "Whoa," that she – and she said, "There, I've said it. I've said it out loud, there you go. We were naive." (09) (mother recounting conversation with daughter about their injured husband/father)*

Though all participants continued to profess love for their relative, had fought hard for their survival and access to services, and dedicated themselves to that person's needs at considerable cost to their own well-being, for some the situation forced them to wonder about the value of the life being lived.

## **4. Unavoidable duty**

### *4.1 Inescapable duty*

Participants reported a sense of duty but also of having no choice over their ongoing involvement with the individual affected by ABI:

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*You just keep going and going. People say, "How do you do it?" You do it because you have no choice really. (11)*

For many, this stemmed from an uncertain reciprocity:

*There are lots of times when I want to walk away, but I can't, because I know he would do the same for me. (04)*

*I think it's to do with ... if it was yourself you would absolutely hate that somebody would walk away from you or not help you. (13)*

This inescapable duty reflected the need for someone to act as a link between the injured person and services. This might mean accompanying them to appointments so that information could be retained and acted upon, monitoring and smoothing over difficulties in social settings and recognising and addressing the need for specialist input. This extended to maintaining the person's relationships with family or friends:

*I'm the one that has to make contact with the boys. "It's been a week now. Can you speak to [your son]?" "Can't do it, can't do conversation." [...] I don't know what it is, empathy as well, nothing, there's nothing there. (07)*

Even when the individual is abstractly aware of the need to act to sustain relationships or seek professional input, there are many ABI-related reasons why they may not be able to do so. Family members assume the role of 'go-between' to integrate the person with the wider worlds of professional support and social networks.

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#### *4.2 Fighting for services*

This often included advocacy, with family members sometimes playing key roles in the progress made during rehabilitation. One injured individual's mother, finding that he kept pulling out his feeding tube, insisted that he didn't like it and it should be kept out for 24 hours, against the protests of the clinical team:

*I said, "I'll feed him." So I got him eating again and discovered that he could actually swallow. (06)*

Often such roles were assumed not out of choice, but because relatives became painfully aware of the inadequacies of staffing and knowledge available within services. Some participants expressed little doubt that without their constant involvement, these injured individuals would be utterly isolated, dead or in prison.

#### *4.3 Personal sacrifice*

Fulfilling this duty came at significant personal cost:

*I wouldn't leave him and I know he wouldn't function if I wasn't here but, I don't know, it's not ... sorry, I get upset ... I've given up a lot and I know there are things that I can't have that I would like. (07)*

*The other thing that I have suffered with, this is why I have to have my job and I have to have my work, is my lack of freedom. (06)*

However, participants saw this role as inescapable; when support was available from someone else, it assisted but did not remove the responsibility. Even with access to a

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specialist brain injury case manager, participants were clear that their involvement would still be required.

## **5. Experiences of poor support**

### *5.1 Variable and poor quality of care in hospital*

Participants mostly reported positively on their experiences of hospital Intensive Treatment Units (ITUs). They valued the specialised and life-saving work undertaken there, and the one-to-one nursing intrinsic to such units. Once stabilised and outside ITU settings, however, participants were more critical of hospital provision marked by poor communication, inadequate staffing, and lack of knowledge of ABI. They found that they needed to step in to address needs that ward staff were neglecting:

*I changed Jake's bed, I bathed him on the ward, otherwise I don't think it would have happened, to tell you the truth. (03)*

*And the first night they had him on the general ward we went home and he fell out the bed. [...] what had to happen was that at night they put a mattress on the floor and he kept crawling off the mattress and so my husband had to go and stay the night with him and sleep alongside him on the mattress and somebody had to be there all the time during the day because they just didn't have the staff to cope. It was as simple as that. (06)*

Though similar behaviour is common post-injury, many participants found that general wards had no strategy to manage it.

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### *5.2 Poor communication*

Sometimes important information was not transmitted to relatives:

*I don't understand how he can have been in the hospital for six days and had two brain scans and no-one would have thought to themselves, "Oh, this could have long-term implications." I mean to be honest, I don't know. (08)*

*The only contact I had with regard to brain injury was there was a scrap of paper with the Headway number stuck on a noticeboard. End of story. And in desperation, I phoned it. (14)*

Other times, the prognoses given were either overly optimistic or too pessimistic. Though it is generally impossible to predict outcomes accurately and in detail in ABI, this was not necessarily communicated to family members:

*Without the information you can make the wrong plans as well. If you know where you stand right from the beginning, I just think it puts you in such – a much more powerful position to be able to make the kind of changes you need to make so that you can get on with your recovery. (08)*

Lack of information or communication left family members at a disadvantage in embarking on this new stage of their lives.

### *5.3 Poor professional knowledge and understanding*

Matters rarely improved once in the community. Participants commonly reported the 'complete lack of understanding' by practitioners who 'don't have any training in

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[ABI]'. Service gaps were encountered and inter-agency communication was ineffective without the active involvement of the relative:

*I think that's probably where the handover from the NHS to the Social Services needs to be better, needs to be clearer. (05)*

Though participants found that they needed to be closely involved to tackle service failings and lack of knowledge, they nevertheless had an uphill struggle with professionals for that to happen. Expertise stemming from their intimate knowledge of the person affected by ABI could be dismissed as over-protectiveness or being excessively controlling:

*The worst problem is the cognitive stuff, which you kept saying "He's not right, he's not the same." "You are imagining it, you are a mother." No, I do know my own son. (16)*

*I know, yes, they do it to make sure people are telling the truth and honest, but you sit there, pour your heart out to people and they treat you as though you are liars, basically. That's how they make you feel. (07)*

#### *5.4 Professionals who exclude family*

Rather than benefiting from the insights that family members could bring to care and rehabilitation, or even just maintaining positive engagement with the family, professionals in these and other cases had contributed to perceptions that the family members were not valued or believed.

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Confidentiality was perceived as a further way of excluding participants from the conversations and planning that was needed to meet the needs of the person with

ABI:

*It's a huge blanket. It's a war. It's a weapon. If I have ever – if anybody says confidentiality, I say, "Look, there's no point in worrying about our Sean's confidentiality. His life is decided by strangers who know everything about him." What's there to be confidential about? He needs help. We need help. I will stand on top of the Empire State Building and broadcast my entire life if I thought something could be sorted out for him. (14)*

Yet despite families' experiences of being excluded, these same family members were expected to provide the input to prevent deterioration, often with minimal support:

*And then because he was walking and he was on his feet and he was, you know, they had a big meeting and they wanted him to, wanted us to send him home and leave me to deal with him. (06)*

*I asked the social workers to come. They came from older people's services and she said to me, "Oh well, you seem to be doing a good job and you're a therapist so you know more about it than me." She said, "You know, we haven't got the resources for the old people, let alone this." (06)*

Even when participants were the only party supporting the injured person, and when the injured person's capacity to make decisions regarding their own needs was

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questionable, they found themselves cut off from key information and discussions between professionals. Often these professionals lacked knowledge of the person's pre-morbid functioning and/or of ABI, both of which might have been provided by family member input.

Exclusion of family members was felt particularly keenly as professionals often seemed to show little interest in their relative as a person. This signified a lack of care from the very *'people who really need to know that he's not been stupid and thick and all the rest of what he's been called over the years'* (12). A number of participants described staff calling their relative with ABI 'stupid.' Several episodes of striking insensitivity were recounted; more than 25 years later, one mother recalled the use of de-humanising language about her son, whose ABI resulted from a suicide attempt, and the attitudes it seemed to reflect:

*Lots of people saying either nothing or cheerfully saying. "No hope" or one nurse described how somebody – they kept referring to him as "a hanging": "We find with a hanging –" you know? I think – not an appropriate word to be using to me. (14)*

The failure to treat both the person with ABI and their family members empathically, on an interpersonal level, seemed for participants to underlie many of the other failings of which they spoke.

## **6. Positive support and change**



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### *6.1 Specialist knowledge*

Notwithstanding these difficult experiences, all participants also had positive reports about some of the support they had received. They were particularly appreciative of the benefit of specialist knowledge and facilities, as in this comment on the expert report from a medical specialist:

*Me reading that and what she put in that and everything, I felt as if she'd lived with us for the last 12 months. It was unbelievable. (03)*

Participants identified the value of this specialist training, and the ability to identify issues and make connections that it could confer. While some praise for professionals was about the outcomes they achieved, much of it was related to process. Attitude, approach, and commitment to genuinely including the participant were highlighted as much as knowledge and experience. One example of this referred to an art teacher who made adjustments to the person's needs:

*Lisa's very set in her ways and she doesn't like using anything except a 9B pencil and she won't do this, that and other, and the teacher, she's recognised that already. (02)*

After years with little purpose or structure, Lisa now sells her artwork and has increased social contact; this was in part attributed to the teacher having realised and accepted that Lisa would not stay in her class unless the approach was adapted to suit her.

### *6.2 Empathic Understanding and humanity*

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Empathy was highly valued:

*The social worker actually is another person who has been amazing, very young girl, but she just really understands and really gets it. (04)*

Feeling that the professional understands, or at least makes every effort to understand, the situation of the participant was key to forming supportive relationships. For most interviewees, there were few professionals who had managed this, but those few were highly valued.

Participants' expectations were realistic and they recognised the limits of what professionals could provide. Sometimes that was simple humanity and a sense of connection:

*The social worker who – I mean, I couldn't fault her, the girl – she couldn't provide services that didn't exist. And what I can say about her is, she sat and cried with me on occasions because I was in bits and – just soft, soft girl. (14)*

Above and beyond outcome, these practitioners were seen to care and recognise the participants' situation, even if sometimes they were also unable to provide an answer:

*I think the parents really need somebody that they can talk to. It's not somebody who is going to give you an answer, it's just somebody to understand and say, "Yes, I know." (16)*

For the interviewees, professionals who saw it as a central part of their role to take the time to understand and empathise were enormously valuable.

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### *6.3 Practical help and 'presence'*

Though it was noted above how frequently participants found others could not comprehend their situation, they described how non-professional input, from family, friends or neighbours, could be extremely important. This might take the form of practical help, but sometimes this was just 'being there'. One mother said of a friend:

*We could have phoned him at 2am. and said, "We are in terrible bother here," and he would have come and he was lovely, but he was a friend who lived nearby. I think it's very hard for a stranger to come in and actually tune into what it's about and how... (13)*

Participants received significant support from wider family and the community, particularly soon after the injury. When these others were felt to understand their needs, it was invaluable to feel that there was someone they could rely on.

### *6.4 Acknowledging uncertainty*

In those early stages, participants felt there was more benefit in knowing that things would not be as they had been, than in being given specific information that – depending on the unpredictable course of recovery – might or might not turn out to be accurate:

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*He also helped us – he put a plan in place. He was like, “You know–” he just gave us really good advice. He was like, “Your life isn’t going to be the same” and this was the first time anyone had ever said this. (08)*

*The most important thing is knowing from the beginning where you stand and not – by not giving people the information, I think I gives them false hope that it’s going to all get magically better... I don’t think it does anyone any harm and it does a lot of good if people, from the start, know this is a big deal and it will probably change a lot of aspects of your life and the sooner people can deal with that, the better. (08)*

Though this information was hard to hear, participants saw value in being included and being prepared for the long-term nature of the injury. They found they had little option but ‘learning along the way’, and they noted that they too had contributed to the learning of the professionals working with them. ‘*She [social worker] has learnt a lot along the way as well’ (04)*, as one put it.

### *6.5 Flexible approach*

Some of this learning sprang from flexibility and commitment needed to meet the very individual needs of the person with ABI. One man, despite being placed in a highly specialised unit, repeatedly and violently smashed furniture and toilets, but the centre found ways to adapt: ‘*Their way of looking at it was, “well, what’s the answer to this?”*’ A stainless-steel toilet was imported from overseas to replace the broken porcelain ones, demonstrating that ‘*Their philosophy was we will build it*

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*right, what he needs.'* (13) Changing the service to meet the injured party's needs, rather than vice-versa, here enabled significant behavioural change and functional improvement. This could be reflected in smaller, interpersonal interactions too, and was greatly valued by participants:

*He asked me what the behaviours were that were upsetting people. I says, "Well, he laughs inappropriately" and I always remember this, he says, "Well," he says, "in here, I laugh inappropriately," and he started laughing. 'Course our Sean went into hysterics. Three of us were sitting in his office with tears dripping off us. And I just – you know, you just met somebody that is clued in. (14)*

Though this professional was ultimately unable to provide a service, this moment of acceptance and connection was remembered and prized decades later. Other positive tales consistently highlighted staff who knew how to adapt standard ways of working to suit the injured person and family members, whether it was GP appointments being made available immediately, changed timings of rehabilitation work so that children or other family could join in, or being available at the end of the phone each morning to say how the previous night in hospital had gone.

## **Discussion**

This study explored themes emerging from the accounts of family members who could look back on years of involvement with the relative with ABI. The findings inform understanding of the key challenges they encountered, their responses, and

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both positive and negative experiences of the support they received. This could help professionals become more aware of what family members are facing, so they can respond more effectively and support suitable service provision.

ABI presents multiple, complex challenges to relatives, the extent of which cannot be underestimated. The person's support needs absorb the attention of family members, such that the challenges become all-encompassing for them. Risky or socially challenging behaviours in particular, usually resulting from the cognitive and executive impairments, places constant and, at times, overwhelming demands on family members. This is exacerbated by feelings of isolation.

Family members also highlighted the following:

- lack of insight left family members feeling that they were struggling to 'manage' the person whose wellbeing they were so focused on, rather than struggling alongside them;
- the uncertain and unknowable prognosis and functional outcomes, particularly in the early years post-injury, impeded proactive planning and left family members managing day-to-day;
- failings of services to work in a joined-up way, left family members to learn for themselves how to act as links between services and individuals;
- family involvement was required, as there was no individual or service that would take responsibility for the totality of needs and difficulties

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- if family members stopped providing support the person with an ABI would likely deteriorate further;
- many impairments were 'invisible' to others and therefore discounted;
- lack of understanding of the condition from family and friends, many professionals, and the wider public;
- failure to integrate real-world functional and behavioural changes into plans made by professionals;
- failure to integrate the relative's knowledge and needs into plans;
- failure by professionals to deal humanely with family members.

Adjusting to this new reality was further complicated by family members' own experiences of complex grief. ABI was experienced as a partial or incomplete bereavement, with no recognised ceremonies to provide 'closure' or 'resolution' [61] and where the person they had lost remained present, though changed. Interviewees with more years of experience post-ABI explicitly highlighted this lack of closure; they made clear that the ambiguity [62] of the loss they had experienced meant adjustment was a continual process. Almost half of interviewees expressed ambivalence about the value of the life the injured person was now living; though this sentiment has also been identified in research with other life-changing conditions [63, 64], it is often enormously difficult, even taboo, for family members to acknowledge openly and underlines the challenges with which they are dealing.

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Participants revealed that professional services had frequently failed to recognise these dilemmas and the difficulties which family members faced. All had not been told important information and experienced unsupportive attitudes, gaps and lack of access to suitable services. This started at an early stage, often when the person was moved to a general ward or around discharge from hospital, when responsibility had been abruptly shifted on to them without adequate preparation for what they were taking on. Participants found they could not assume agencies would communicate with each other, without family intervention. Though participants recognised services could not take over from them and they needed to stay involved, they found that professionals too often undermined any sense of hope that they felt and left it to them to search out and link up with suitable services. Non-specialist services were often found to be unprepared and under-resourced, and rarely seemed to focus on the individual person rather than the injury, or to show interest in or awareness of how the person had been pre-injury. Despite the expectations placed on family members, they could find themselves excluded due to confidentiality concerns or simple failure to work actively to engage them; professionals' default position sometimes seemed to be one of scepticism towards what they had to say. From the family member perspective, this meant that professionals often took decisions from a relatively uninformed position, as they failed to incorporate family member expertise into their planning [65]. These experiences took place in the context of uncertainty. Functional and behavioural changes, positive and negative, took place over time. Knowledge only develops over time as to what the person with the injury



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will be able to do. Family members' experience of this process is of lack of clarity and little support to navigate changed roles and relationships or respond to changed expectations. Action to address these failings would go some considerable way to improving the experience of support of family members.

All participants also had positive stories of support they had received and the strengths and resilience they had brought into caring for their relative and how this had developed over time. Positively viewed professionals had acted as a supportive catalyst for building these strengths. Specialist knowledge and experience was highly valued, but attitude, approach, and a focus on genuinely including the family were as important for many. Even practitioners who were unable to provide specific services were regarded positively when they successfully showed recognition and concern for what family members were going through. Taking the time to understand the family member's perspective and working at their pace were key, and indicated that the practitioner understood how complex and demanding it was to adjust to the realities of ABI. Participants were realistic, not expecting to be offered certainty where there was none, but found clear and early explanations helpful. ABI's initial unpredictability meant that family members learnt 'along the way,' but so did professionals; professionals recognising and being open to this partnership was valued.

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Practitioners were praised where they looked for ways to adapt services or practice to meet individual or family needs, by showing flexibility, finding approaches that built on the person's pre-injury interests, or – as in the story of sourcing the steel toilet – identifying how equipment could be tailored. Flexibility of this kind might mean changing staff plans to suit family involvement, e.g. including children in physiotherapy sessions, to help normalise the rehabilitation process for them [66] or altering the focus of work as family need changed.

### **Limitations**

There are limitations to this study. Though its sample size was larger than previous qualitative studies of long-term adjustment [35, 44], the findings are drawn from a relatively small and heterogeneous sample and thus cannot be directly generalized to a broader population. The recruitment process unavoidably introduced potential biases: for example, it may have excluded potential respondents who were unwilling or unable to participate in an online survey, and there is no way to know what factors may have influenced willingness to participate in the interviews. Notwithstanding this, commonalities were identified within family members' experiences. Some of the interviewed relatives had over two decades of experience of familial ABI, a potential strength but also possibly a weakness because of the changes in service provision and availability of information since the events that were described. Further research might benefit from drawing on a larger sample, incorporating objective measures of family functioning/coping, and/or using a

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longitudinal research design to ascertain factors associated with improved functioning over time. However, the aim of this study was to understand family members' experiences as they perceived them, in particular focusing on "what works/what does not work".

## **Conclusion**

Family members at different points in their lives post-ABI can provide valuable insights into what they experienced as supportive or unsupportive. Their involvement may be very long-term and their understanding key to rehabilitation and support plans and services. This study gathers perspectives from a number of family members post-ABI, providing insights into what was considered significant over time and report directly upon the experience of service use. The nature of ABI, the losses and associated grief experienced, has ramifications for service provision and delivery. An individualizing and short-term approach that does not take account of the family member's knowledge, perspective and needs has the potential to reinforce and exacerbate difficulties. The converse of this, the services and approach that family valued and found supportive was predicated upon empathic understanding and knowledge of the condition, a genuine inclusion of family and a recognition of their unique position and of their grief; process and not just outcome being valued.

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