

## Supporting individuals with an acquired brain injury: An interpretative phenomenological study exploring the everyday lives of caregivers

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# **Supporting individuals with an acquired brain injury: An interpretative phenomenological study exploring the everyday lives of caregivers**

## **Abstract**

Acquired brain injury (ABI) is one of the most common causes of disability and death globally. Support from informal caregivers is critical to the wellbeing and quality of life of people with ABI and supports the sustainability of global health and social care systems. This study presents an in-depth qualitative analysis of the experiences of 8 British informal caregivers supporting someone with ABI. Semi-structured interviews were conducted with narratives transcribed verbatim and analysed using Interpretative Phenomenological Analysis (IPA). Three superordinate themes were generated: making sense of brain injury; being consumed by caregiving; and the changing self. These data highlight the impact of caregiving on caregiver's illness perceptions and sense of self. By identifying negative and positive changes in caregiver's sense of self, and dilemmas regarding the care recipient's behaviour, we address less understood aspects of caregiver experiences. Caregiving can pose both challenges to the caregiver's sense of identity and an opportunity for self-growth. Some caregivers exhibit resilience throughout their journey, with post-traumatic growth more apparent in the later stages of caregiving. Illness perceptions shape caregiver wellbeing and family dynamics, and indicate the need to address stigmatisation and discrimination faced by ABI survivors and caregivers. Although some caregivers acquired positive meaning and enrichment from their caregiving, previously described challenges of ABI caregiving are supported. Overall, our findings support the need for timely psychological/mental health support for caregivers, caregiver education, and the provision of short breaks from caregiving.

**Keywords:** informal care; interpretative phenomenological analysis; acquired brain injury (ABI); illness perceptions; sense of self; caregiving challenges

## Introduction

Acquired brain injury (ABI), i.e., any injury to the brain occurring during someone's lifetime, is one of the most common causes of disability and death in adults (Maas et al., 2022; Menon & Bryant, 2019), often requiring long-term rehabilitation, support and care (Peoples et al., 2011). An ABI can be non-traumatic in origin, e.g., an internal event such as stroke or brain tumour, or traumatic, e.g., due to an external event such as an assault or vehicular accident (Feigin et al., 2010).

ABI can affect a person's physical, cognitive, social and/or emotional functioning, with some people being impacted in all these domains of functioning, and some in fewer (e.g., Ellis et al., 2013; Quinn et al., 2014; Satink et al., 2015). Physical, cognitive, social and emotional challenges can persist for months or years post injury (Jourdan et al., 2016) (sometimes a lifetime), and require specialised care and support (Kreitzer et al., 2018). ABI ranges in severity from mild (generally with time-limited, resolving symptoms such as dizziness, nausea, headache) to moderate, severe (with long-term symptoms such as fatigue, sensory problems, seizures and physical/cognitive impairment; e.g., Brickell et al., 2018; Merriman et al., 2019), up to catastrophic (expected to result in permanent loss of brain function; Neal et al., 2018). Individuals with catastrophic ABI are often excluded from research due to the profound nature of their impairments, leading most studies on the effects of brain injury to concentrate on those with moderate to severe brain injuries (Ponsford et al., 2014). Following moderate and severe brain injury, individuals may have executive function difficulties (Jourdan et al., 2016) and may experience significant functional limitations affecting their activities and participation (e.g., communication, mobility, interpersonal relationships). Due to its long-term impacts, moderate-severe ABI is a chronic health condition (Kreitzer et al., 2018; Masel & DeWitt, 2010).

Given the serious impacts of moderate-severe ABI, survivors often rely on informal caregivers, i.e., family members, friends or neighbours, to provide unpaid help and support with various aspects of daily living (including psychological, nursing, or instrumental support) (Kreitzer et al., 2018; Quinn et al., 2014). The support provided by caregivers is critical given the growing trend for early discharge from hospital and treatment and rehabilitation at home (e.g., Department of Health, 2014; The Scottish Government, 2019). However, as the occurrence of ABI is typically sudden and unexpected, families are generally not prepared for their new role as a caregiver, and they experience a range of impacts (Bäckström & Sundin, 2010; Greenwood et al., 2010; Satink et al., 2015). Caregivers express uncertainty about this rapid and unexpected change to their life and many have little prior knowledge or understanding of ABI (Lond & Williamson, 2022). The consequences of stroke and other brain injury have largely been described in terms of changes to physical function, however cognitive and emotional impairments are notable (e.g., Hackett et al., 2014; Merriman et al., 2019), whilst being less visible. Caregivers have to face a range of complex changes to someone; cognitive, emotional, behavioural and physical (Chan et al., 2009; Merriman et al., 2019).

There is compelling evidence that caregiving is a social determinant of health (Public Health England, 2021). Research has shown that caregivers of adults with a range of chronic health conditions may experience depression, fatigue, burden, burnout, anxiety, lower subjective wellbeing, and poorer levels of physical health compared to non-caregivers (Brickell et al., 2018; Manskow et al., 2017; Saban, 2016) and this is shown in studies of those caring for someone with an ABI (Feigin et al., 2010; Lond & Williamson, 2022). Compared with caregivers providing care to people with other chronic conditions (such as dementia), ABI caregivers typically report comparable or lower quality of life and mental health outcomes, and similar or higher levels of burden and grief (Jackson et al., 2009; Marwit & Kaye, 2006). The grief experienced by ABI caregivers is multifaceted (with caregivers often expressing the

feelings of ambiguous loss) and develops over time (Gamgee et al., 2023; Holloway et al., 2019). A qualitative meta-synthesis of 39 studies exploring the impact of ABI caregiving on caregiver health and wellbeing (Kokorelias et al., 2020) identified a range of physical and psychosocial challenges that caregivers face (e.g., physical tiredness), and evidenced that ABI caregivers find it difficult to maintain a personal life alongside their caregiving role. Given the care required by individuals with ABI, caregivers face persistent negative health consequences tied to the extended caregiving duration (Iwata & Tadaka, 2023).

Caregiver burden can impact upon the recovery of brain injury survivors, i.e., brain injury survivors whose daily life is characterised by strained relationships and by unsupportive family members show less improvement on disability rating, level of functioning and employability scores (Sady et al., 2010; Sander et al., 2000). Research shows that distressed caregivers can diminish the effectiveness of post-acute rehabilitation for care recipients (Sander et al., 2012). A mixed-method systematic review of 117 studies (Gaugler, 2010) focussing on the experiences of stroke caregivers showed that although caregiver depression, stress and health status did not significantly change over time in quantitative evidence, the qualitative studies inferred a more dynamic view of ABI caregiving (see also for example: Whiffin et al., 2015). Bermejo-Toro et al. (2020) also found that factors such as the time since injury and the level of dependence of those with ABI can predict caregiver challenges over time, i.e., over time patients' dependence levels change, and caregiver challenges may also shift. Therefore, recognising the dynamic challenges and support needs of caregivers of brain injury survivors following discharge to home is important both in terms of addressing caregiver wellbeing, but also in supporting care recipient's recovery.

Research demonstrates that caregiving can also have benefits, such as a sense of pride derived from the role or increased resilience/strength in the face of adversity (Quinn & Toms, 2019), however, studies identifying positive experiences for ABI caregivers are limited (e.g.,

Las Hayas et al., 2014; Mackenzie & Greenwood, 2012). For instance, a quantitative study conducted with Spanish ABI caregivers evidenced that caregiving can be a source of satisfaction and was significantly related to the quality of life and post-traumatic growth of the caregiver (Las Hayas et al., 2014). A mixed-method systematic review of 9 nine studies (Mackenzie & Greenwood, 2012) exploring positive experiences of stroke caregivers concluded that caregivers did identify positive experiences of caregiving, providing a more balanced view of their role. It has been also shown that factors such as social support and the survivor's level of awareness of deficit may be important for rehabilitation outcomes (Ownsworth & Clare, 2006) and for caregiver satisfaction in their role (Ergh et al., 2002, 2003), i.e., in caregivers with low social support, the survivor's unawareness of deficit was adversely related to caregiver satisfaction. The literature regarding ABI caregivers' outcomes (e.g., burden or gains) mostly quantifies these various phenomena in terms of incidence of psychological disorders or scores on scales to measure perceived outcomes; such studies assume the specific challenges or gains that hold significance for caregivers. However, there is dearth of literature that explores how ABI caregivers make sense of their own experiences (e.g., Gamgee et al., 2023; Ghosh-Cannell et al., 2023; Townshend & Norman, 2018; Whiffin et al., 2021).

The concept of self or identity defines who or what an individual is (Stets & Serpe, 2013). The only existing informal caregiver identity theory (Montgomery & Kosloski, 2009; Savundranayagam & Montgomery, 2010) conceptualises caregiving as a series of transitions emerging from a change of roles and identity (e.g., an adult child becoming a caregiver for their parent). Although this theory provides an important theoretical lens to help understand the role of self/identity in informal caregiver experiences, caregiver sense of self has rarely been studied (Hughes et al., 2013; Zarzycki et al., 2022).

Illness perceptions and how these influence coping and health outcomes have typically been studied in patient samples (Dempster et al., 2015; Rogan et al., 2013). Understanding of caregivers' perceptions of their care recipients' illness and the importance of these perceptions to caregiver outcomes is limited. There is some evidence (predominantly quantitative, and not within the ABI caregiver population) that illness perceptions play a significant role in caregiver stress (e.g., Pakenham, 2001), wellbeing (e.g., Bassi et al., 2016) and positive aspects of caring (Parveen & Morrison, 2012).

Within the field of ABI, research has mainly focused on the patient outcomes, with fewer investigating the experiences of their unpaid, typically family, caregivers. It is important to gain a deeper qualitative understanding of caregiver perceptions of self and of the illness and their effects, in the context of ABI so that support can be put in place. This paper reports findings from a qualitative study exploring these factors.

## **Method**

### ***Design***

In line with the exploratory and inductive nature of the study, a cross-sectional qualitative design with semi-structured interviews aligned to the Interpretative Phenomenological Analysis (IPA) framework was employed. IPA was chosen as it is committed to an idiographic level of analysis, is appropriate when exploring experience within specific small samples and in developing knowledge from a 'bottom-up' approach. Richness of the data rather than the sample size is prioritised as it allows the interpretation of the participants' experiences (Larkin et al., 2011; Smith et al., 2009).

### ***Participants***



Purposive sampling was applied, as recommended by Smith et al. (2009) for studies employing IPA. Participants were identified via the *Headway Brain Injury Association* and *Stroke Association* and had to identify as the primary caregiver. All participants were family members who identified as a primary caregiver (N=8) of a person who had sustained an ABI as an adult, including parents supporting their adult son or daughter (N=4), spouses (N=2) and a sibling and her spouse who were supporting their brother(-in-law) (N=2). Six caregivers were female, two were male. Caregivers' age ranged from 43 to 65 years and the age of individuals with the ABI ranged from 22 to 70 years. All caregivers identified themselves as White British. Caregivers had provided support to their care recipient for between 1 and 13 years. The severity of the ABI was classified as moderate/severe (as self-reported by the caregiver). Table 1 summarises participants' characteristics.

Table 1 Caregivers' and ABI survivors' characteristics

No.	Caregiving	Fictive name	Age	Gender	Relationship type	Time caring
1	Caregiver	Paul	60	Male	Father	10 years
	Care recipient	Julia	28	Female	Daughter	
2	Caregiver	Josephine	63	Female	Mother	4 years
	Care recipient	Luke	43	Male	Son	
3	Caregiver	Emma	43	Female	Mother	3 years
	Care recipient	Tom	22	Male	Son	
4	Caregiver	Alice	65	Female	Mother	12 years
	Care recipient	Joan	35	Female	Daughter	
5	Caregiver	Ceri	65	Female	Wife	7 years
	Care recipient	Harry	70	Male	Husband	
6	Caregiver	Siân	64	Female	Wife	1 year
	Care recipient	Dylan	66	Male	Husband	
7	Caregiver	Florence	56	Female	Sister	13 years
	Caregiver	Will	59	Male	Brother-in-law	
	Care recipient	John	59	Male	Brother(-in-law)	

### ***Data Collection***

Prior to recruitment, full ethical approval was obtained from the University Ethics Committee at Bangor University (reference number 2019-16561-A14834). Informed consent was obtained from all participants. Interviews were conducted in an authorised room at the university with one exception where, at their request, one caregiver was interviewed in their own home. Respite care and travel expenses, where these were incurred, were reimbursed for the participants. The first author (MZ) conducted all of the interviews. Congruent with gathering information about individuals' lived experience, interviews were participant-led, exploring topics that were personally significant, i.e., an interview guide with prompts was used to help frame the discussions (e.g., feelings about caring). Interviews were recorded using an encrypted voice recorder, transcribed verbatim and further supplemented by reflective process notes. Interview length ranged from 60 to 180 minutes (M=112 mins).

### ***Analysis***

Interviews were analysed using IPA, following the broad analytical steps described by Smith and colleagues (2009). Transcripts were read and re-read to enable immersion in the data. Line-by-line analysis noted descriptive, linguistic, and conceptual elements of the data which facilitated the next stages of identifying emergent themes and identifying connections between them within one person's account. Analysis continued consecutively across the remaining transcripts, before identifying patterns across transcripts to develop superordinate themes. Analysis was iterative and continued throughout the write-up.

The first author (MZ) conducted the analysis, meeting frequently with the other authors (DS, MP, VM) to discuss the focus, organisational structure, and quality of the analysis. Authors discussed themes to ensure that the analysis satisfies the quality criteria for

qualitative research (Tracy, 2010), including for instance ensuring the credibility of the results generated (e.g., that themes were well represented in the transcripts), resonance (e.g., the applicability of findings presented in relation to policy and practice contexts) and coherence (i.e., with the research design, methods, and presentation of findings aligned cohesively).

### ***Reflexivity***

During the research process, reflexivity was considered and discussed. Reflections of the first, key author (MZ) can be found in S1 Supplementary Material.

## **Findings**

Three superordinate themes provided rich phenomenological insights into the experiences of the ABI caregivers.

1. Making sense of brain injury
2. Consumed by caregiving
3. Changing self

The superordinate themes and their subthemes (in bold) are presented, with illustrative quotes from the participants (pseudonyms are used).

### **Making sense of brain injury**

This superordinate theme reflects on caregivers' perceptions of brain injury and includes three subthemes: understanding brain injury; living with limitations and losses; and living with an 'invisible' condition.

### *Understanding brain injury*

Caregivers provided varying explanations of care recipients' changed behaviours. There was a strong sense of caregivers' dilemma in considering whether their care recipient's behaviour was purposeful, arising from their personality, or whether it was an unintended consequence of their brain injury. For example, tiredness could be considered as dispositional laziness, forgetfulness as due to cognitive impairment or as intentionally manipulative. Such caregiver perceptions indicate a deeper struggle in interpreting and distinguishing between the effects of ABI and for example possible manipulative tendencies of ABI survivors.

And I've just phoned you 10 minutes ago, why didn't you put it in your prompts? 'You know I've got brain injury!' So, she, she uses it as a tool. [...] I know what she's like and manipulative as well. (Paul)

It just feels like sometimes he knows what he's doing and that's again frustrating because he knows what he's doing to get away with it. (Florence)

Caregivers alluded that they either took over some tasks that care recipients could no longer manage due to ABI (e.g., managing finances), or they assumed additional responsibilities when the recipients adopted a 'sick role' and gave up certain tasks (Parsons, 1975). Emma and Josephine attributed their sons' behaviours to the brain injury and believed that as caregivers they were able to distinguish between ABI-consequent behaviour or unrelated characterological/manipulative behaviour and the assumed 'sick role'. However, neither Emma nor Josephine could specify explicitly what underpinned their ability to distinguish between these, and felt it was based on their intuition. These caregivers contrasted their own perceptions with those reportedly held by other family members who – according to them – did not

understand the nature, or consequences of, living with the (person with) ABI. Caregivers also identified differences in illness understanding and recovery expectations amongst family members, which could lead to tensions, as illustrated by Emma, who reflects on the way her husband responded to their son:

Okay, if they can't understand something, keep finding other ways, you know, it's not their fault. It's your fault. And so, I guess that kind of understanding helps, whereas my husband didn't have that at all. And then I think he thought I was naive and just didn't realise Tom was being lazy. And I know he is a bit lazy as well, but he was struggling, and it was a lot. (Emma)

### *Living with limitations and losses*

The cognitive and physical consequences of ABI were widely acknowledged by caregivers. Reflecting on their experiences, caregivers reported that these limitations and losses elicited a variety of intense emotions, including anger, sadness, grief, surprise, fear, and shame.

Often it was the neurocognitive consequences of the brain injury, not the physical/functional consequences (such as impaired mobility), that were emotionally challenging. For example, Siân found the damage to Dylan's executive functioning frustrating and disruptive to her own life (e.g., interfering with daily planning); Paul had to deal with Julia's unpredictable mood swings ('depressive cycle'), and John's lack of appetite control, acquired Brown syndrome (a disorder of ocular motility, i.e., rapid eye flickers or wandering gaze), and other problems with behavioural control meant that Florence and Will monitored him constantly as he could eat improperly/inappropriately or could not control his gaze in social situations.

Also, he will take food, waste bins, dust bins and even animal's food. He won't ask for food. He will steal food. It doesn't matter whether it's mouldy or in a dustbin. He will take it and eat it. (Florence)

So, there's no no control with the hunger. And having no taste and no smell doesn't help either. (Will)

Functional limitations, in contrast, were seen to restrict caregivers and brain injury survivors in continuing with pre-ABI activities (e.g., getting out of the house, meeting with other people away from home, doing or planning things together). For example, Ceri referred to her husband's limited mobility:

I mean, his limited mobility is bound to have an effect. You know, when before we were working, we had this dream of getting a camper van. He always wanted to have a camper van to go for the weekends and stuff. We haven't got a camper van and it's probably me not [being] so keen because he needs help at home. (Ceri)

Caregivers reported a sense of loss due to the fact that many unique aspects of their relative's personality and behaviours were seen to have changed. This was found to be a painful experience, reflecting the processes of grieving.

I think certainly in the early days, especially because he wasn't himself, he is a lot more now, a lot more now, which makes me feel extra bad about feelings that had been, because it just wasn't him. It was just somebody else stumbling around the house. And

you know, just looking at him and looking at everything he lost was really, really hard.

(Emma)

### ***Living with an invisible condition***

The responses of others (including those of strangers) and their perceived lack of awareness and understanding of living with a brain injury featured heavily in caregiver accounts. Whilst not all of their care recipients had an invisible condition, the invisibility of many symptoms, such as cognitive impairments which underpinned behavioural changes (as seen above), was considered as contributing to a lack of public understanding.

The invisibility of the brain injury and its consequences was often thought to be the reason why the caregiving role was questioned by people in the community, with some challenging the existence of the care recipients' health condition and consequent need for care (e.g., an assumption that if the brain injury survivor does not display physical symptoms of disability, they do not need any care). The behavioural consequences of an invisible health condition were a source of stigma or discrimination against the care recipient, as expressed by caregivers Josephine and Alice. Challenges to the need for caregiving and stigma/discrimination toward the care recipient were perceived as unjust.

... And then trying to explain to people the same thing and if you've got something physical people can see but you can't see it in him. I'm not just mad, all the people I've seen – they've got stressed and angry [with him]. You see this in all different kinds of places. He can walk away in the middle of the conversation because he's got brain injury. (Josephine).

If you say that he's going through food bins, eating, they say, 'Well, obviously, they're not eating...' ...that he's being starved [by us]. So again, it looks like we're not looking after him, we're not caring for him, all we're there [for] is taking his money. (Florence).

As seen previously, caregivers were conflicted about attributing their recipients' behaviours to ABI, potential manipulation, or adopting a 'sick role'. On the other hand, this subtheme highlights how carers advocate for the often-invisible nature of ABI and address stigmatisation issues. This shows intricate dynamics between recognising ABI's impact and differentiating it from other behavioural sources; differentiating process which is not entirely clear.

### **Consumed by caregiving**

Caregiving was found to be all-consuming, with a negative impact on the caregivers' physical health and mental wellbeing. For some this generated an expressed need for short breaks from the care giving role.

### ***Consumed by the caring role***

Prioritising the brain injury survivor's needs led to feelings of exhaustion and helplessness, impaired self-care and impacted negatively upon relationships within the wider family network. Siân depicted this by saying that 'all is based around caregiving', leaving little or no space for the life beyond the caring role. Alice, herself suffering from diabetes, stated that:

It's [my diabetes] never been easy. But suppose you shove it to the back of your mind. This [caregiving] is more important than... you know. I know people say you're supposed to put yourself first because if you're not well you can't help anybody else.



But I think I've stuffed the diabetes for now. I've got more important... Joan's [the care recipient] more important than the diabetes. (Alice)

The expression of helplessness was manifest through depressed mood and a sense of the suspension of other aspects of life, such as one's career or personal development. For some caregivers who were routinely carrying out their role, putting effort into repressing intensive, negative feelings, the interview offered an opportunity to voice their innermost feelings and resulted in them verbalising their sense of burden. Paul, for instance, spoke about the anxiety and depression he had experienced since caregiving which had required him to seek pharmacological intervention. Emma's account also revealed overwhelming emotions:

But there were moments where you almost couldn't move because you're just hit by a big - not even a wave - it would just be like a big thump of overwhelming combination of nothingness and depression, all in one go probably just because you can't take all the feelings and they just, you know, hit you like that. (Emma)

Ceri described a transfer of anxiety from her husband, Harry, to herself, leaving her with a feeling of constant alertness and fear of what the future might hold. Similar feelings were expressed by Emma, Siân, Florence and Will.

And it still makes the future shaky, because it still leaves me thinking: Well, you know, I still need to be there. I still could have to stop everything anytime. (Emma)

Resentment towards a situation in which life was consumed by caregiving was common, often accompanied by a mix of frustration, anger, and guilt. Consuming aspects of the caregiving

role included: the sense of lost freedom, a diminished social life (and for some, social isolation) and 'living two lives', i.e., feeling that they could not be open with their true feelings towards family members or other people; either because of 'protective buffering' of the other family members or because they felt other family members would not understand or support them, or because voicing their feelings might have made it look as though they were struggling or failing in their caregiving role.

We're actually more tied because of John and he thinks, 'So?', you know... he doesn't realise or whether he does realise, and he doesn't care - we don't know because he won't say - he just... he says, 'So?' and he just carries on, he doesn't realise how much William and I have given up and we've tried to tell him. (Florence)

### ***Recognising the need for a break from caregiving***

Although the caregivers made sacrifices and often neglected their own mental and physical health, they realised that they needed breaks from caregiving to attend to their own's needs (e.g., have quality time alone, sleep more) and to sustain their caring role. Caregivers found different ways to have breaks. Breaks could arise from receiving relief support from family or from the care recipient engaging with activities (e.g., gym).

[You] recharge your batteries, because you're completely drained and so tired... er, we went on a cruise, and I think we slept more than we... instead of just sunbathing, we actually stayed in our room and slept. (Will)

I've been trying to just do more for me, you know, less thinking about what will make all the children happy and what's good for them [including the care recipient] and just

thinking a bit more about, you know, what I might want to do, what makes me happy?

And I've been trying to do a bit more of that. (Emma)

In the context of supporting someone with ABI, caregivers highlighted that a longer break, such as a holiday taken together with the care recipient (and not apart from them) may prove challenging. Florence and Will mentioned having taken a break jointly with John and how it had not provided them with sufficient rest as they still had to 'monitor' John's eating behaviours and social contacts, and that they did not spend quality time alone together as a married couple.

...and in 13 years I think we've only [had] 3 holidays without him. (Will)

Because we still take him at times as well. But when we go abroad with him, you know, we have to book basically, a separate villa, with its own little pool and things like that.

Because it's about staring with the kids and stuff. So, that's a big problem... (Florence)

## **Changing self**

Here we reflect on the impact of caring for someone who has experienced ABI on the caregiver's sense of self: firstly, caregiving viewed as a threat to self (subtheme 'Identity shift'); secondly, caregiving as an opportunity for self-growth (expansion of self; subtheme 'Post-traumatic self-growth').

### *Identity shift*

Some caregivers spoke about the different ways the care recipient's brain injury had influenced the feelings, attitudes or beliefs they held about themselves. For example, Emma and Josephine questioned their self-identity, and their roles as mothers as well as their moral convictions about sustaining life and dying. It was seen that conflict around sustaining life and dying delves into existential and moral dilemmas. These types of dilemmas challenged some carers' core beliefs and values, such as for example the 'maternal instinct' to protect one's child at all costs. Internal debate between wishing for an end to suffering and the inherent desire for one child's survival underscores not only multidimensional nature of caregiver stress and guilt, but also identity shift.

I never wanted him not to be there anymore. But I think part of me sometimes gets thinking, 'just do it, you're going to do it' [to die], you know, and it doesn't mean I wanted him to die. But in a way it must have been that, but I didn't want that. To have had those thoughts about somebody, especially your own child, it's an awful thing.  
(Emma)

Emma's account reflected both the process of grieving for her brain injured son with two main attributes: her unfulfilled expectations about how his life could have been and the loss of his identity, but in addition grieving for herself, with doubts expressed especially about her role as mother, and guilty feelings for not being the mother she had hoped to be (e.g., anticipating her son's death). Emma's specific experience prompted feelings of being 'closed off' emotionally to everyone else, anxiously perceiving the world as an unpredictable place underpinned by a constant alertness (e.g., that one of her loved ones might die unexpectedly). She had begun to recognise that these traumatic changes made her a 'different person'. At the time of the

interview, when Tom's recovery was much advanced, she still recognised permanent traces of trauma: awareness of the fragility of life, distant alertness that something bad could happen to her children and self-healing processes (described later). She was reflecting on her traumatic experiences with the hope of re-establishing herself anew (see subtheme 'Post-traumatic self-growth').

I feel that maybe a part of me changed a lot. And it's been very hard to get close again to everybody else because it was just such a big thing. And I think because I didn't know that - I mean the prognosis - in the first interview with the doctor, that neurologist, he started talking about, you know, death, epilepsy and sudden death and nobody had a clue with Tom... for a good period of time I had no idea if he would still be awake in the morning, you know and it was... when you have to, when you have to live with that and get through it, it does change you and other things. I don't know, I suppose I can't let go in the same way you can't relax, and you don't want to fully enjoy it because you worry it might be taken away from you... (Emma)

Josephine observed how her sudden crying during the interview reflected her sense of hopelessness - her inability to change Luke's condition, grieving for her son having realised that his injury cannot be undone, that the recovery potential that she referred to in her interview was low. These realisations filled her with intense despair which triggered doubts about the future, e.g., concerns about the ability to continue caring.

It does affect you because you don't want to see... well, it affects because you can't do anything. [pause, crying] Sorry. [...] And then you wonder how much longer you can carry on. (Josephine)

### ***Post-traumatic self-growth***

As noted, caregiver's wellbeing was challenged, however, for some, these challenges offered opportunity for reflection. Oftentimes, it was a healing process of the burdened or traumatized self that could be termed as a post-traumatic self-growth. Five of the eight caregivers revealed that the experienced trauma or burden enabled them to become stronger and to grow (Josephine, Florence and Will's accounts did not refer to self-growth). Caregivers reported they found a sense of strength (e.g., ability to cope with challenging situations) or developed a different outlook on life (e.g., they started valuing life more), and that this experience, which could be termed post-traumatic self-growth, happened subsequently to the traumatic change in self experienced (see subtheme 'Identity shift' above).

Alice noted the inner strength she gained following her daughter's stroke/brain injury.

Yeah. I'm stronger than I thought I was. (Alice)

Emma's caregiving journey described as moving 'from paralysing to *almost* fine' depicted how she moved from a grieving and traumatised state following Tom's brain injury to a mode of healing the self which was perceived as a 'strength'. She noticed that 'that little bit of her', i.e., the previous burden and trauma in herself, was 'changing and just kept getting better'. Despite ongoing awareness of the fragility of life and anxiety, she recognised that it was possible to enjoy life as a 'different person', as a brain injury caregiver. This post-traumatic growth was facilitated by the positive progress in her son's condition, i.e., he gradually became less dependent on her (practically and emotionally), reducing the caregiving duties and changing the nature of the caring responsibilities (from nursing to emotional care).

Well, because we've moved so far down the road, I guess, anything I wanted to change has changed already. You know, I think, thankfully and luckily, we have got to that point. Yeah, the overriding thing is just wanting things to carry on getting better or at least just stay the same. And just that that little bit of me just to get better again really.

(Emma)

Paul reflected on the sense of trauma, anxiety, and depression that he developed as a result of his daughter's brain injury and the all-consuming nature of his caregiving. For him, being consumed by caregiving was purposeful - caregiving became a way to grow as a person and to find new ways to appreciate life. He mentioned frequently that he chose to be a caregiver, i.e., that he knew from the ABI onset that he would want to do that for his daughter.

But it's something that I learned from, you know, nearly 10 years of experience with her now, you know [...] in helping her, I find that I'm helping myself. (Paul)

## **Discussion**

This study explored the everyday lives of caregivers supporting someone who had an ABI. The findings are presented as three superordinate themes: making sense of brain injury; being consumed by caregiving; and changing self. Firstly, changes in the caregiver sense of self are notable in this study - providing care was seen as both a threat to self and an opportunity for self-growth, with the latter likely developing over time for some caregivers. Secondly, this study highlights the importance of illness perceptions to caregiver experience and wellbeing.

Caregivers' retrospective and reflective accounts point to change over time in how caregivers consider the illness impact, and their care recipient's needs. Thirdly, the study confirms previously described challenges and needs of ABI caregivers (e.g., Kokorelias et al., 2020), for example for recognition and support from others including the lay public, for short breaks from a caring role.

### ***Impact on the sense of self: post-traumatic growth and resilience***

Subjective experiential changes are increasingly recognised as important factors underpinning recovery and rehabilitation following ABI, and this may also include the changes in the caregiver sense of self (e.g., Abrahamson et al., 2017; Whiffin et al., 2019). Changes in caregiver sense of self were evident in caregivers' narratives (see superordinate theme 'Changing self'), a dynamic process recalled throughout the caregiving career. In a study conducted by Abrahamson et al. (2017), where 41 brain injury survivors and their caregivers were interviewed, the authors recognised a phenomenon of the 'self-identity disintegration', characterised by an awareness of the profoundly different life in the post-injury existence for both ABI survivors and caregivers. For example, our findings show how caregiver struggles with navigating the line between prolonging care recipient's life and alleviating their suffering (Holloway et al., 2019) underlie self-identity disintegration. Although there are several studies exploring the sense of self or identity in ABI survivors (see for example a qualitative meta-synthesis of 23 studies by Levack et al., 2010), only a small number of studies have considered the changes to the caregiver's sense of self (Abrahamson et al., 2017; Couchman et al., 2014; Whiffin et al., 2019). What was clearly evidenced in our data is that caregiving following the care recipient's brain injury can be an opportunity for caregiver's self-growth, i.e., changing sense of self. The superordinate theme 'Changing self' presents the positive aspects of the caring role, uncovering factors that may promote wellbeing for ABI caregivers. Consistent with



scarce previous research, mainly outside the brain injury caregiving context (e.g., Hallam & Morris, 2014; Thornton & Perez, 2006) but with some studies in the context of brain injury (e.g., Powell et al., 2012; Simpson & Jones, 2013), caregivers manage to find positive meaning and enrichment in distressing circumstances. As evidenced in findings, the difficult experiences of caregivers can, for some, result in post-traumatic growth and increased resilience. In the meta-synthesis of 30 qualitative studies focused on caregivers providing care to someone with a traumatic brain injury (Whiffin et al., 2021; p. 17), ‘the incredible positive potential’ exemplified by some caregivers was highlighted. In the context of the current study findings, we highlight that ‘the incredible positive potential’ may be underpinned by caregiver resilience and post-traumatic growth. In the UK, despite the general inadequacy of long-term services for caregivers and ABI survivors (Norman et al., 2023), certain interventions have demonstrated effectiveness in enhancing positive outcomes for caregivers/care recipients. For example, interventions such as the Brain Injury Family Intervention have improved family resilience and well-being (Bushnik et al., 2015). The resilience of those supporting relatives with TBI or spinal cord injury has been also shown to be crucial in coping with caregiving challenges (Simpson & Jones, 2013). Additionally, social communication partner training has been effective for adults with severe chronic TBI and their caregivers, enhancing communication skills, which are a component of caregiver support and resilience (Togher et al., 2016). These findings indicate that targeted interventions can significantly aid caregiver resilience and post-traumatic growth in the ABI caregivers. It is also important to distinguish between caregiver resilience and post-traumatic growth. *Resilience* is understood as the ability to adapt or to improve one’s own conditions following experiences of adversity (Limardi et al., 2016). *Post-traumatic growth* is the experience of positive change resulting from very hard personal crises (Tedeschi & Calhoun, 2004). We propose that resilience may be seen as a resource factor that caregivers may develop during the course of caregiving, whereas post-

traumatic growth unfolds later in the course of caregiving and is subsequent to the traumatic change in self experienced (see subtheme ‘Changing self’ above), the reflection on how caregivers coped with challenges and on their attempts to incorporate the trauma/challenge into their life (Jones et al., 2020).

### ***Illness perceptions***

As noted at the outset of this paper, there is a gap in research on caregiver illness perceptions with respect to ABI caregiving. Our study findings reveal that illness perceptions have an important impact on caregiver wellbeing and on their relationships with other family members (see superordinate theme ‘Making sense of brain injury’). It is clear that the occurrence of an acute-onset health problem with chronic consequences, like ABI, affects not only patients but also caregivers, whose perceptions and responses, may in turn enhance or impede a patient’s own coping responses and consequent adjustment to illness (Karademas et al., 2010; Weinman et al., 2012). Caregiver’s different ways of ‘making sense’ of the brain injury were a source of dilemma / uncertainty regarding the care recipient’s behaviour: is their behaviour a product of their personality or intentional (where they assume the ‘sick role’; Parsons, 1975), or an unintentional consequence of brain injury? Inevitably, caregiver responses to the care recipient, both behavioural and emotional, are dependent on their illness perceptions and beliefs. Caregivers reported inadequate support in their roles in relation to learning about ABI and its impact (Holloway & Tasker, 2019). This in turn may impact caregiver ability to effectively manage the care and rehabilitation of ABI patient. There is need for information provision as well as educational training that could address caregivers’ illness perceptions.

Caregivers in this study reported differences in the interpretation of their care recipient’s behaviour and in recovery expectations amongst family members, which could lead

to tensions. ABI caregivers have to deal with cognitive and emotional impairments that are often invisible to others in addition to any physical impairments (Jourdan et al., 2016; Merriman et al., 2019). As seen in the data, caregiver's illness perceptions may have a negative impact on the relationship between the caregiver and care recipient (e.g., if the caregiver thinks that the ABI survivor is being lazy instead of being fatigued) and the relationship between the caregiver and other family members.

In a broader societal context, caregivers referred also to the responses of other people towards the brain injury survivor and caregivers themselves, that likely arise from their lack of awareness and understanding of the health condition, its consequences and the associated need for caregiving. In some cases, where the functional changes associated with brain injury are largely invisible (see subtheme 'Living with an invisible condition'), individuals living with a brain injury may not be routinely identifiable. Previous studies have attempted to explain the public's misconceptions about brain injury as experienced by professionals and families of people with brain injury (e.g., McClure, 2011). For example, misconceptions can occur because people misattribute the actions of brain injury survivors (e.g., to rudeness, drunkenness) due to the absence of visible markers of the injury ('invisible condition'). This misattribution can lead to stigma: a failure among members of the public to recognise that care recipient's challenging/problematic behaviours may result from brain injury (McClure, 2011). However, these study findings show that the stigma was also felt by the caregivers: with the members of the public failing to recognise that caregiving is needed.

Previous research shows that some people living with a disability such as brain injury experience significant and damaging prejudice (Gwyn, 2003; Riley & Hagger, 2015); an issue mentioned by two caregivers in this study in relation to the people they supported. This is particularly the case when brain injury survivors decide not to disclose their injury to others and carry disability under the mask of normality (Lupton & Seymour, 2003). This fear of

stigma or prejudice can lead people living with brain injury to self-exclude (as seen in case of Josephine’s care recipient); fulfilling to a certain degree the social outcome they anticipated (Reidpath et al., 2005). Decreasing social circles, loss of key relationships and a sense of loneliness are documented phenomenon for people living with brain injury (Claude Blais & Boisvert, 2005; Salas et al., 2018). The importance of addressing brain injury survivor’s stigmatisation and discrimination should be stressed for both brain injury survivors and their informal caregivers as such factors are crucial in terms of caregiver and care recipient’s wellbeing, and the caring relationship.

### ***Caregiving challenges***

As our data have shown, the physical, cognitive, behavioural and emotional changes that occur with a brain injury can all place significant demands on the caregiver (see superordinate theme ‘Consumed by caregiving’). Numerous issues, including anxiety, depression, emotional distress, family strain, adjustment problems, and the ABI survivor’s loss of insight (related to caregiver burden) have been documented in studies of caregivers of people with brain injury – pointing to the critical issue of identifying and addressing caregiver support needs (e.g., Holloway et al., 2019; Jourdan et al., 2016; Kreutzer et al., 2016; Norman et al., 2023). The current findings also highlight some generic needs, similar to those found amongst caregivers caring for people with different health conditions (e.g., Amer Nordin et al., 2019).

Support needs of those providing care to brain injury patients have previously been shown to include: emotional and financial support, counselling and education, respite care/short breaks, peer support, equipment access, assistance with in-home care assistance (Bellon et al., 2015; Kitter & Sharman, 2015). The current qualitative findings, obtained in the British context, support these findings. Specifically, caregivers in this study highlighted the need for breaks from caregiving taken apart from their care recipient. This is perhaps not

surprising given the frequent challenging behaviours displayed by brain injury survivors (but not limited to this subpopulation) which include impulsiveness, mood changes, irritability, memory problems, fatigue, temper outbursts, anxiety; all of which having a potential to contribute significantly to caregivers' burden (Kitter & Sharman, 2015). Being able to access regular breaks from caregiving is vital for informal caregivers, helping them to relieve their stress, look after their own health, enhance their wellbeing, and enjoy a life alongside caregiving. Breaks can help sustain the caring relationship and avoid the need for crisis support (Carers UK, 2021; Seddon et al., 2021). Secondly, our findings highlight the need for information provision, due to the problems with understanding the changes involved with brain injuries and seeking information as to how to cope with the psychological and physical effects of the brain injury. Similar findings have been noted in an earlier qualitative study (Townshend & Norman, 2018). Thirdly, counselling and emotional support is important given the mental health challenges expressed by caregivers in this study (e.g., depression, anxiety, psychological trauma). Services providing breaks, counselling, information provision and educational training should be available to caregivers (Bellon et al., 2015; Chan et al., 2009; Norman et al., 2023) and responsive to caregivers' individual circumstances and the challenges they face, and delivered flexibly, given the ongoing grief and ambiguous loss often experienced in ABI caregivers (Holloway et al., 2019; Lond & Williamson, 2022). Caregiver support should be delivered flexibly to accommodate the complex emotional landscape caregivers navigate, marked by the enduring presence of loss. This qualitative study also suggests that it is crucial that services are available to caregivers along the spectrum of recovery (at the time of the incidence, during the discharge from in-patient care and during outpatient care); each 'caregiving journey' is unique and different recovery trajectories are evidenced (decline, improvement or stabilisation).

## **Limitations and strengths**

The timeframe between brain injury onset and the interviews for some participants could bring their memory recall into question. Given that previous research and our current findings show that caregiver burden and illness perceptions change over time, future (IPA and other) studies should adopt a longitudinal approach exploring the emergence of experiences and perceptions over time, in contrast to the retrospective and cross-sectional accounts presented here. A 22-year age range and a difference in time spent caregiving (stretching from 1 to 13 years) were present within the sample, indicating some heterogeneity. The inclusion of the potentially divergent needs and experiences of those in later life and middle-aged, at different points of their caregiving career, and varying relationship types to the care recipient (e.g., parental, spousal), may introduce further potentially problematic heterogeneity into the analysis and impact the findings presented. It also needs to be acknowledged that the experience of recovery for different caregivers may differ, for example when no recovery is achieved, and allied to this the support needs may be different. Moreover, due to ethical reasons, the data on the nature of the care recipient's ABI (e.g., stroke, TBI) has not been collected from caregivers.

This paper presents findings relate only to caregivers' perspective and does not explore the relational experiences, as enacted by both the caregiver and the person with ABI. This may of course present some challenges where the person with ABI has moderate-severe cognitive impairment. Future efforts to enhance our understanding of dyadic experiences would likely benefit emerging dyadic approaches for supporting a caring dyad (Lond & Williamson, 2022). Similarly, triadic experiences that include the caregiver, the person with support needs and the professionals involved in helping should be included. Exploration of caregiver challenges across the entire family/friend networks may give greater insight into caregiver needs and how to further improve wellbeing of all involved. The Most Significant Change (MSC), a dialogical,

story-based and participatory qualitative technique, may be a potentially suitable method to capture and assess qualitative accounts and changes in dyadic/triadic qualitative research (Dart & Davies, 2003). Moreover, the current body of empirical literature necessitated the inclusion of references to strokes and other types of ABI in both the Introduction and Discussion. It needs to be highlighted, however, that while stroke and other forms of ABI are frequently discussed together, the distinctions in their pathophysiology, demographic profiles, and clinical manifestations caution against treating them as fully comparable.

The study employed an interpretative phenomenological approach, enabling caregivers to identify and reflect upon the aspects of experience they considered most significant when providing care an ABI survivor, and how this caregiving experience has affected their everyday lives. Despite the abovementioned limitations, the research findings contribute to understanding the impact of ABI caregiving and caregiver perceptions on a person's sense of self and potential for a post-traumatic growth, and confirm the variety of challenges faced in the caregiver role.

## **Conclusion**

Firstly, caregiving can represent both a threat to self and an opportunity for self-growth. We suggest that resilience emerges over the course of caregiving while post-traumatic growth manifests later in the course of caregiving, following the traumatic change in self experienced. Secondly, the study emphasises the important role of illness perceptions in shaping caregiver wellbeing and family relationships. In line with the past research, addressing stigmatisation and discrimination experienced by brain injury survivors and caregivers is an important aspect for the overall wellbeing of the caring dyad. Thirdly, this study confirms the variety of challenges faced by ABI caregivers and highlights their need for recognition, support, and respite/short breaks. Especially, the significance of short breaks from caregiving (separately

from the care recipient), information provision, educational training and emotional support are highlighted.



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