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The experiences of wives following acquired brain injury (ABI). A qualitative analysis exploring realisations of change following the ABI of a “loved one.”

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ABSTRACT

The experiences of family members following Acquired Brain Injury (ABI) are well established, with spouses in particular facing multiple relational and personal changes. Qualitative studies have analysed accounts pertaining to a range of sequelae, however, “change” itself has yet to be addressed. This study explored the experiences of realisation of change for married women living with their husbands following ABI. Nine participants took part in semi-structured interviews focussing on becoming aware of changes in both their spouse and themselves post-injury. An Interpretative Phenomenological Analysis (IPA) was completed, arriving at two overarching themes; “bravery to face changes” and “lost and trapped in an unsolvable maze,” with accompanying subthemes. Participants generally experienced realisation of change gradually, in some cases finding strategies to control their exposure to distress. They often referred to “acceptance,” which held varied meanings, and metaphors appeared to aid personal meaning making. Relationship changes generated both dilemmas and the feeling of being trapped. Overall, this study contributes greater insights into the experiential mechanisms underpinning realisation of change in spouses after brain injury.

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Introduction

Family members regularly take on caregiver roles and support rehabilitation following the Acquired Brain Injury (ABI) of a loved one (Baker et al., 2017; Gagnon et al., 2016). Studies have identified double the population prevalence for long-term depression, somatic symptoms, marital dissatisfaction and anxiety for these caregivers (Brooks et al., 1986; Hall et al., 1994; Kreutzer et al., 2009; Kreutzer et al., 2016), alongside challenges adapting to lifestyle and relationship changes (Jackson et al., 2009). Caregiver burden, family functioning and poor

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mental health have been found to be the top three factors influencing negative outcomes in caregivers across 62 studies, with healthy relationships contributing to better outcomes (Baker et al., 2017).

Family systems are theorised to shift towards homeostatic maintenance in the face of change (Verhaegue et al., 2005). This may be particularly challenging following ABI where attempts to achieve homeostatic maintenance could also result in negative interactional patterns (Bowen et al., 2010). This generates a tension between the emotional safety of sameness versus the threat of potentially permanent, unwanted post-injury changes within the system (Yeates et al., 2013). Circumstances contributing to family system functioning include caregiver strain and the ABI patient being female (Gan et al., 2006). Furthermore, caregiver burden has been linked to the self-awareness of the injured person (Rubin et al., 2020). These types of patterns and processes provide insight into the challenges faced by those living within a family system changed by ABI and may be considered within therapeutic interventions (Yeates et al., 2013).

Bowen et al. (2010) and Yeates et al. (2010) highlight that some post-ABI impairments change with social context (such as memory deterioration when angry), demonstrating the potential systemic influence on injury sequela. ABI can be seen as partially socially constructed (Yeates et al., 2008), with family life cycle, gender and contextual limitations (such as socioeconomic status) contributing to understanding injury expression (Yeates et al., 2010). Such findings contribute to social work practice (Baker et al., 2002), family interventions (Wilson et al., 2009) and in eliciting secure attachments (Yeates et al., 2013).

The family sense-making that arises when confronted with traumatic events related to acquired brain injury has been explored through narrative analysis (Whiffin et al., 2015). Perception of change by family members was sometimes observed to contrast with actual changes, highlighting the potential for dilemmas or confusion to arise. Participants also compared the past and present, reflecting on aspects of relationships previously taken for granted. These findings provide insight into the ways families might try to make sense of change, with scope to further explore the sense making process across the threshold of realization or perception of change, not just after such realisations have formed.

Across the literature, it is noted that spouses and partners may experience their loved one's ABI differently to other relations (Kratz et al., 2017). Specific changes include intimacy and sexuality (Kitzmuller & Ervik, 2015; Rosenbaum & Najenson, 1976), difficulties with the physical demands of care (Gosman-Hedström & Dahlin-Ivanoff, 2012), loss of social networks, personality changes and reduced emotional support (Bodley-Scott & Riley, 2015). Where the injured partner displays unpredictable mood swings, a "Jeekyll and Hyde" experience is reported, with uninjured spouses feeling "married to a stranger" (Wood, 2005). Marital roles have been noted to shift towards a parental nature, and some couples were found to respond aggressively towards each other (Gosling & Oddy, 1999).

Qualitative studies have applied a range of methods including grounded theory to explore marriage after stroke (Anderson et al., 2017), and Interpretative Phenomenological Analysis (IPA) to capture detailed experiences (Bodley-Scott & Riley, 2015; Brunsden et al., 2017; Gosman-Hedström & Dahlin-Ivanoff, 2012). Findings span a multitude of responses and experiences within post-injury life; hope, feeling overwhelmed, marital change and the “unknown” appear prominently. Whilst all participants across these studies would have faced changes in their lives following their spouse’s injury, the specific experience of noticing or realizing such changes has not been studied in detail.

One exception to this is the study of Whiffin et al. (2015) which identified expressions of continuity when facing potential change, with changing events being considered an ongoing occurrence. Whiffin et al. (2017) suggest steering away from a rigid conceptualization of change, for example seeing post-ABI experiences in terms of “loss,” or as related to specific ABI sequela (such as Bodley-Scott & Riley, 2015). They argue that approaching change in this manner places constraints on our understanding of the unique experiences of ongoing adjustment. Consequently, whilst current findings cover the broad impact of ABI on relatives highlighting the presence of “change”, there is a gap in the literature regarding a deeper understanding of specific experiences of realisations of change.

The current study

This study aimed to explore the experiences of wives when noticing and making sense of changes following their husbands’ ABI. Specifically, we sought to increase understanding of experiences underlying the established pattern of deterioration in emotional wellbeing for spouses and partners of injured individuals. Here, “changes” refer to both the immediate differences resulting from ABI sequelae and longer-term implications triggered by the onset of injury.

This study addressed the primary research question; what is the experience of realisations of change for the wives of men affected by ABI? Within this, the study also explored a secondary research question; what personal meanings are drawn from these experiences? The participants involved were either attending a support group or in contact with specialist ABI services when recruited. The study aimed to provide a reflective account, providing rich detail in addressing the two research questions and building upon prior phenomenological research in this area (Bodley-Scott & Riley, 2015; Brunsden et al., 2017).

Method

Methodology and design

To elicit in-depth accounts of experience, a qualitative approach using Interpretative Phenomenological Analysis (IPA) was adopted. IPA is idiographic, aiming

to elicit focussed detail and generate “rich” data from case-by-case exploration, followed by an in-depth analysis (Braun & Clarke, 2013; Smith et al., 2009). IPA is based upon phenomenology, capturing the nature of an individual’s experience (in this case, the accounts of wives of ABI patients) and how they have attached personal meaning to their experience (Smith et al., 2009). Analysis employs the double hermeneutic wherein participants provide their own interpretation of their experience, and the researcher reflexively interprets this (Smith et al., 2009).

Data were collected by the lead researcher (CGC) via semi-structured interviews using a topic guide (Appendix A). This covered seven areas, each with prompting questions, which aimed to prevent interview content steering away from the research question. While the topic guide represents the range of pre-empted questions used, this varied for each interviewee as the conversation was intended to “flow” naturally. The topic guide was developed with the Patient and Public Involvement (PPI) member of the research team who had their own experience of a loved one sustaining an ABI. Their input helped generate meaningful interview questions for those with lived experience.

Participants

Nine participants were recruited via purposive sampling through local services supporting individuals and families following ABI. This number reflected the participants available and willing to take part. As guided by Smith et al. (2009), the sample size was considered appropriate for gathering the depth of detail required for IPA, whilst guarding against the amount of data becoming a barrier to highly detailed and focused analysis. Inclusion criteria were:

- The onset of ABI for the spouse of the prospective participant occurred at least one year prior to recruitment.
- The prospective participant had a continued relationship (within a marriage/couple) with the injured person.
- The prospective participant had appropriate fluency in English, due to the reliance on expression of language for the analysis.

Exclusion criteria were any circumstances potentially impairing capacity to consent or take part in an in-depth, potentially emotional interview.

Twelve participants were approached by either a member of staff from the service or by the lead researcher at a support group. Nine participants were recruited (three via support groups and six via service staff). Of the three who declined participation, one did not wish to discuss the interview content, one reported being too busy and one cancelled their interview due to illness.

All interviewees were female, White British and married. The age range was between 50 and 73, and the length of spousal relationships ranged from 13

to 52 years. Eight had late teenage or adult children. As this study focussed upon meaning making, participants were asked directly about the nature of their spouse's ABI, summarised in [Table 1](#). All injuries were adult-onset and all participants had a relationship with their significant other prior to the injury. Time since the injury ranged from 1.25 to ten years, presented in [Table 1](#) with pseudonyms applied.

Given the wide range of time since injury onset, variations within the data may be pre-empted. A summary is provided ([Table 1](#)) of participant descriptions of their spouses' injury type and impairments, highlighting a range of physical, cognitive and personality sequelae.

Procedure

Ethical approval was provided through the Social Care Research Ethics Committee (REC), London and the Health Research Authority. General Data Protection Regulation (UK Government, 2018) was adhered to. Initial introductions for potential participants communicated the study purpose and the interviewer's (CGC) training level. Confidentiality was outlined to participants in the Participant Information Sheet prior to providing consent. Upon consent, participants provided demographic information and then took part in the semi-structured interviews. These explored what it was like to realise that both their lives were changing, whether there had been moments where they perceived themselves differently and what the changes meant for them, with prompting questions to elicit detail. Interviews lasted around 1 h 10 min on average, with the shortest being 1 h and the longest 1 h 25 min. Field notes were taken by the researcher to manage the data collection process but were not used for analysis. Eight interviews took place at the participant's home, with one taking place at a local community day service. Only the researcher and participant were present in the interview. No interviews were repeated.

Table 1. Time since injury and described impairments since injury.

Pseudonym	Time since husband's injury (years)	Participant answers to question "What happened to cause the brain injury?" on the demographic information form.
Debbie	5.5	Stroke: Reduced tolerance and difficulties processing information.
Maureen	6	"A bleed on the brain": Aphasia and depression.
Sheila	4	Sudden fall: Unconscious for seven weeks and required surgery (shunt). Impairments included short-term memory & mobility.
Tina	10	Car accident (TBI): Resulted in impaired memory alongside personality change, including lack of empathy and patience.
Iris	1.25	Fell off a ladder and suffered skull fracture: Mood and anger changes, deaf in one ear.
Alice	4	Ischaemic stroke and haemorrhage: Fatigue, mood swings, cognitive impairment, left hand side weakness.
Hazel	10	Stroke: Right-sided weakness and memory problems.
Florence	3	Hydrocephalus (diagnosed late), right side of body collapsed, surgery (shunt) then suffered two haemorrhages: Loss of movement/bodily control, memory impairment.
Grace	6	Stroke: Impairments with mobility, energy levels and mobility.

Analysis

IPA emphasises the importance of reflexivity, referring to the self-awareness of one's own experiences and assumptions; acknowledging and bracketing their potential influence throughout the IPA process (Smith et al., 2009). The lead researcher who undertook the analysis was a female Trainee Clinical Psychologist studying at doctoral level, with ten years' experience working with vulnerable populations. An IPA workshop was attended prior to the study commencing, and the research team oversaw the study design and theoretical application of IPA. This involved feeding back on adherence to the method throughout the analysis, aiming to ensure that themes at all levels of analysis reflected lived experience and stayed close to the research question. A reflective journal was also maintained to aid reflexivity (Wagstaff et al., 2014).

Audio recordings of four interviews were transcribed using a transcription service, and five by the lead researcher. Transcripts were not returned to participants for feedback during this study. All transcripts were entered into Microsoft Excel to support coding. Interviews were analysed independently and then explored across accounts.

Analysis involved reading and re-reading each transcript to ensure immersion and generate linguistic, descriptive or conceptual notes (Smith et al., 2009). Emergent themes were then drawn from individual transcripts and clustered to generate superordinate (overarching) themes. This involved consideration of common experiences among emergent themes, supporting the derived superordinate themes (Smith et al., 2009). Reflections continued to be logged throughout the process of analysis.

Table 2 outlines the analytic process for the development of the two main themes derived from the analysis of individual transcripts. Prominent quotes were identified and coding involved revisiting and adapting emerging themes from the initial notes taken. Superordinate themes for each case were explored and developed where similar or related experiences were present across accounts.

Forty superordinate themes were accumulated in total from the data. If present within five or more interviews (over half the accounts), they were considered potential cross-cutting themes. These were grouped together to identify common aspects of experience, which generated subthemes across accounts. Subthemes were then grouped based on interpreted commonalities to form the main themes.

Once complete, the results were discussed with the PPI team member, to determine whether someone with lived experience related to the initial findings. Participants were then provided a summary of the findings. Whilst all participants were offered the opportunity to provide feedback on the results, this was only provided by two. These participants reported feeling that the results closely reflected their experience, consistent with our aim to

Table 2. Examples of analytic process; each quote leading to a key subtheme and main theme.

Quote	Coding	Reflection	Emergent theme	Subtheme	Main theme
"(I was) ... scared really scared because I thought ... is he ever going to get his language back and how is he going to function as a person again ... " (Debbie).	Intense fear at the realization of ABI impairments on perception of spouse as a functioning "person."	Impression of sense of threat with managing the unknown and unexpected nature of impairments, expressed through repetition of word "scared." Loss of language holds the weight of whole "personhood." Reflected that this description may be a further expression of the fear related to it.	Witnessing perceived loss of personhood	Holding the emotion of unexpected change	Bravery to face changes
"As time has gone on and things improved, you've seen him being perfectly okay with somebody else, then 'he can't help it he's got a brain injury'wears a bit thin on occasions." (Iris).	Realization that spouse has more self-control than may have been initially thought. This may limit unconditional acceptance of ABI sequelae. This quote is tentative and in third person; perhaps to distance the self from elicited emotions in the interview itself.	Implied exhaustion with use of the same explanation no longer alleviating emotions following spouse's behaviour. Feelings of possible frustration are said indirectly; she may have felt unsure about expressing a potential criticism of her spouse in the interview setting?	Evolving recovery with changing explanations.	Perceiving unfolding events	Bravery to face changes
"You have to pick yourself up and say, right ok, this is what you've got, this is what you've got to deal with, what are you going to do." (Sheila).	Experiencing pressure to carry on regardless of emotional experience. Was there a different manner in which she "got on with it" on this occasion compared to pre-"breakdown"/ emotional overwhelm (described earlier in the interview)?	Wondering whether there were any further realisations here that led to picking herself up? Sense that may have restarted same strategy? Recognition that this experience easily relates to psychological theories.	Realisation of inevitability leading to persistence	Discovering acceptance	Bravery to face changes
"That is like, the marriage has ended, and you're at, the whole axis has changed, I'm now his carer, and he's like a dependent, that's not a partnership	Direction of marriage has changed, role change, no longer travelling through life together, like marriage has ended yet a carer-dependent dynamic remains.	Own sense of sadness that this is described in such a specific way; that this description must have been difficult to say out loud.	Marriage ending to make room for dependency	Being alone in a partnership	Lost and trapped in an unsolvable maze

(Continued)

Table 2. Continued.

Quote	Coding	Reflection	Emergent theme	Subtheme	Main theme
any more ..." (Hazel). "It's a vicious circle although it's not actually a circle because ... you feel even worse trying to explain to them how upset they've made you so you stop." (Tina).	That the experience of bereavement (previously described in the interview) was a repetitive realisation, where emotions experienced at ABI onset are re-experienced and may appear again. This quote indicates that she sees no way to change this pattern aside from to "stop," does this mean giving up?	Sense of never-ending nature of experience of bereavement. As the marriage is ongoing, this evokes a feeling of being trapped.	A cycle of grief and powerlessness	Navigating a changed marriage	Lost and trapped in an unsolvable maze
"Quite frightening, erm, because you wonder what you've done wrong and you can't think of a single thing that you've done ... if you can't think of something that you've done wrong then there's no way that you cannot do it again." (Tina).	Powerlessness to prevent anger as she can never predict the trigger. Sense of being able to get managing moods right "there's no way"; perhaps trying not to upset spouse is experienced as an unachievable task?	Researcher sense of confusion and powerlessness and non-direction when listening, also that this would have been anxiety-provoking. Impression of "what do I do now?"	Confusion and powerlessness in response to newly observed anger	Balancing dilemmas	Lost and trapped in an unsolvable maze

keep themes closely linked to and embedded within participants' accounts (Smith et al., 2009).

Quality checks included Yardley's (2000) characteristics of "good" qualitative research, which are considered useful principles, albeit non-specific in terms of practical application (Smith, 2003). These covered sensitivity to context, commitment and rigour, transparency and coherence, impact and importance.

Results

The analytic process arrived at two main themes; "bravery to face changes" and "lost and trapped in an unsolvable maze." These themes were built from a foundation of subthemes and capture the essence of the vast range of experiences forming them. "Bravery to face changes" was derived through similarities between the three subthemes "holding the emotion of unexpected change," "perceiving unfolding change" and "discovering acceptance." The main theme

“Lost and trapped in an unsolvable maze” was also formed of three key sub-themes. These were “being alone in a partnership,” “navigating a changed marriage” and “balancing dilemmas.” These two main themes and underlying subthemes are further elaborated below, with further analytic examples in [Table 2](#).

Bravery to face changes

Participants described bringing realisations on the periphery of awareness into acknowledgement, an emotionally evocative undertaking:

I wouldn't say I enjoyed my life but I wasn't thinking of leaving him ... I think I felt quite empowered I think it was a very brave decision and I think I felt good daring to think it. (Maureen).

The above quote is an expression of Maureen's recognition that she may have been holding back from a potentially life-changing realisation (that she could choose to leave her spouse). Her feeling of “empowerment” and “daring” elicit a sense of bravery through facing previously avoided thoughts. When enduring this, participants experienced the subtheme “holding the emotion of unexpected change” in managing their initial realisation and tolerating emotions in response to their spouse's injury. Iris described approaching this using a strategy from a previous bereavement:

It's almost like you go up to the pain and you pat it, and then you run away like mad, and then when you are feeling a bit stronger, you go back and you do it again and very, very gradually over time, that, you learn to live with it ... you know you recoil from it ... you can't deal with all that in one go, you'll go crazy. (Iris)

“Recoiling” from pain emphasizes the enormity of facing distress associated with realisations of changes and the need to try and regulate this. The physicality of Iris' description emphasises fear of emotion being overwhelming; that this is an entity that needs to be approached delicately. [Table 2](#) highlights a similar experience of “sitting with” emotion for Debbie, as she identifies fear for the future upon realization of the extent of her spouse's impairments. The feeling of being settled within a married role was also overturned upon realisation. For some, this led to the security of “wifeness” being challenged:

I'm the home maker ... when I realised that maybe he might leave me or subsequently did I not want to stay ... what a fool I was to have bought into that sort of married life ... (Maureen).

For Maureen, beliefs and values of marriage were challenged and accompanied an experience of disempowerment and self-criticism (“fool”). Her prior commitment to marriage may have also elicited an experience of feeling trapped. From this, it is also plausible that post-injury life was experienced more intensely from the position of the home maker role (or as a woman).

Additionally, the experience of temporality since the injury included a gradual or “unfolding” experience of realisation of change, a second subtheme. This was generated through multiple events with different attached meanings. Iris’s quote in [Table 2](#) demonstrates how ongoing realisations meant that sense making around the nature of the injury was malleable. Iris experienced a personal change around how much ABI could explain her spouses’ actions. Over time, participants reported change in perception of both themselves and how they relate to others:

... .they also say stupid stuff like you know, what doesn’t kill you makes you stronger, I don’t agreeI think sometimes what doesn’t kill you makes you weaker (Tina).

In contrast, Maureen described:

I am quite an independent personit was it was very hard to be under control so it was connecting a bit with myself really, you know feeling empowered (Maureen).

Whilst taking differing perspectives, these two quotes suggested changes to Maureen and Tina’s sense of identity. For Maureen, there was a drive to move forward, whereas for Tina, it was potential exhaustion and “weakness” within post-injury life.

Underlying the inevitable need to approach difficult emotions, “acceptance” was also prominent across accounts, forming a third subtheme. At times this may have appeared the only option, as demonstrated in Sheila’s quote in [Table 2](#), and “acceptance” held subtly different meanings across accounts. In Iris’ case, it elicited temporary “normality”:

What was normal before, is gone, this is the new normal, it’s not necessarily the only normal, butanother normal will come, and then hopefully another one after that, but in the meantime, this is the normal (Iris).

For Iris, finding the “new normal” may have created peace with the present whilst allowing for further change. Having found this perspective, future realisations may be experienced differently to those occurring nearer the onset of injury.

Lost and trapped in an unsolvable maze

In realizing the implications of change, participants reported struggling to make sense of feeling the permanency and insolvability of challenges they faced. Expressing these experiences appeared challenging at times, indicated through the many metaphors used across accounts. A particular example is Tina’s description of a “vicious circle” in [Table 2](#). Here, she expressed re-lived realisations as a harsh-yet-predictable pattern but then noticed that their lives had become unpredictable. This evoked insecurity, adding a sense of “viciousness” to a situation with no redeeming pattern. Use of metaphor also indicated

moments of participants actively making sense of their “lifeworlds” during the interview process.

You have a hole like a ... waste paper bin or something of screwed up pieces of paper which are all the rubbish that you've had to deal with ... you get lost underneath the piles and piles of paper and you're not there anymore, the person you were before has completely changed. (Tina)

Tina's metaphor may have been an expression of built-up tension, described as rubbish swamping her identity. This experience seemed to be one of losing sense of self through persisting through an endless, insurmountable personal load.

Nonetheless, such experiences seemed poised alongside hope for further recovery, contributing to the subtheme “balancing dilemmas.” At times, this balance was thrown by the reality of their spouses' injuries:

Whilst there's hope, there's also a fear ... a thought that nothing's going to change. (Florence)

The fear Florence mentioned evoked a sense of powerless and an unsolvable, tentative position between hope and fear, perhaps highlighting the inadequacy of either path in approaching post-ABI life. Other dilemmas included an internal swing between viewpoints:

Accept that appointments don't always work, shunts don't always work, umm, yes there's hassle in life ... we're lucky to be here. (Florence)

This quote described acceptance of emotionally difficult realities, however maintaining these views long-term may have felt more personally challenging. Florence balances this with a sense of luck, perhaps to counteract the challenges on the opposing side of this dilemma. Where balancing dilemmas centred around hope for further recovery and awareness that this may be unlikely, some endeavoured to take themselves away from the dilemma altogether:

To be honest, at that point you dare not think too much because you don't want to have two and two making five and, you're overthinking it and thinking it's worse than it is ... you don't know whether or not it's going to change, you just don't know. (Iris)

Iris expressed how the unknown seemed less threatening than overthinking, yet tolerating uncertainty was also uncomfortable. There was an underlying awareness of needing to face the “truth,” yet fearing the personal consequences of realisation.

I'm still I'm still aware that there's a possibility that I suppose he could have another stroke, I think you live in fear a little bit of fear ... I'm still trying to not be not be so pandering I suppose, you know if I think he's going through a bad time then I want to help but sometimes I know that that's not the best solution, that he needs to do this journey on his own at times. (Debbie)

Nevertheless, for some the unknown was also a source of fear. For Debbie, she described the constant potential for further ABI-related complications in their future, adjusting the “journey” (Debbie) they were navigating through. Part of her experience was figuring out how to help, potentially within her changed role, whilst navigating moments where her husband also requires independence. This captures the continuous thoughts and reflections that accompany being “lost in the maze.” Across accounts, conflict managing the dilemma between the potentially feared “truth” and the unknown aspects of post-ABI life posed a prominent internal task when experiencing realisations of change.

Participants also experienced realisation of being both married and alone, as emphasised through Hazel’s quote in [Table 2](#). This built into the subtheme “navigating a changed marriage.” Through her spouse’s dependency, Hazel expresses a transition from wife to carer, which contradicted expectations of how marriage “should” be experienced, enhancing emotional separation. Within this, participants reported noticing themselves having become stuck in a continuous “regime” (Grace) to accommodate post-injury life. This was expressed as like looking out at the world rather than being in it:

I feel like a goldfish swimming round in a medical bowl ... there’s never no release you know ... (Grace).

Despite this, participants also established commitment to their spouses, perceiving the relentlessness of the “maze” as a personal choice:

You still make that decision to stay, you’re putting yourself back in the trap (Tina).

The nature of providing ongoing support, however, contributed to navigating how to cope with the onset of realisations around marital change. At times, this was evaded, with realisation being both described as something “that creeps up” (Hazel) yet experienced with emotional intensity:

Just suddenly something hit me and I just went into overload ... nothing in particular seemed to trigger it ... it was just natural progression ... I’d been pushing myself too hard (Sheila).

The role of “carer” was also considered to remove the reciprocity that was previously in their relationship, forming the subtheme “being alone in a partnership.” This is highlighted further through the loss of seemingly small, habitual interactions that may have maintained a sense of connection prior to injury:

I miss it a lot ... somebody just saying, putting their arm around you and saying “cor that was a lovely meal”, you know a few, little things really that, have gone. (Florence).

Florence’s quote reflects lost interactions within the marriage, leading to a feeling of “missing” something despite her spouse being physically present. Notably, one account contrasted with the experiences of the majority. For Alice, relief and acceptance were prominent:

If this is as good as it gets, that's good enough for me ... the essence, the essential [name] is still here, he might be impaired ... but ... he's still managing to make me laugh ... (Alice).

From Alice's quote, recognition of the sustained identity and interpersonal moments which had remained the same post-injury may have contributed to finding acceptance. Such expressions may emphasise historical relationship commitment, which could make the potential challenges of post-injury life appear manageable:

All of the lovely things we have done is great, and if we never do anything again that's fine (Florence).

Florence expressed a sense of peace with how the future may have changed, alongside recognition of the "lovely" aspects of the past potentially supporting this feeling being elicited. In addition to Alice's recognition of her spouse's "essence," these experiences suggest that realisation of change can also include acceptance, commitment and moving forward, despite any accompanying challenges.

Discussion

This study sought a "deep," subjective interpretation of the personal meanings related to wives' experiences of realisations of change. The findings add to the literature by focussing on a previously unexplored element of the post-ABI experience. The two main themes derived were "bravery to face changes" and "lost and trapped in an unsolvable maze," each formed from three sub-themes. These key subthemes captured how realisations come to pass, sometimes involving an "unfolding" of multiple experiences over time. Personal dilemmas were also acknowledged, including anticipation of impending realisation and tolerating the unknown.

Connecting themes

A connection between the two main themes may be present. In particular, feeling lost and trapped may be a circumstance requiring great bravery. Consequently, elements of the subthemes may connect the main themes, providing insight into the shared and unique interwoven phenomenological "lifeworlds" of participants' realisations of change.

Multiple experiences of change were also seen to instigate ongoing realisations for years following ABI. For some, there was a point of making sense of post-injury experiences after a prolonged "build up" of feelings. Participants experienced parallels with previous experiences of bereavement alongside a gradual unfolding of experiences, generating different realisations relating to themselves and their spouse. Some realisations were around marital roles and

feeling trapped within post-injury life, experienced as a monotonous “regime” for some, yet lacking predictability for others.

Participants appeared to try and find a balance between varying tensions and dilemmas. These included hope balanced with fear of the unknown, alongside striving for change balanced with acknowledging personal acceptance. Participants often felt alone in their partnerships, yet maintained persistence and hopefulness for further change.

The two main themes emphasise experiences of disconnection, concurring with recognition of role change and loss of partnership. Notably, entering a carer or parent-like role could be challenging yet was not always experienced negatively. Within this, realisation of aspects of continuity post-ABI seemed to accompany a closer relationship.

Participants also experienced unsolvable boundaries within post-injury marriage; they tried to solve “in the moment” challenges whilst personally managing their sense of permanency. This internal and endless dilemma could be difficult to make sense of and some participants used metaphors to help communicate their experience.

Bravery was important in allowing participants to realise changes. The emotionally laden nature of this included reliving realisations and “daring” to realise personally aversive aspects of change. Newfound questioning occurred around marriage, in particular societal expectations concerning perceived duty and responsibility as a wife were being brought to the forefront. Furthermore, holding realisation at bay until feeling personally ready may allow some meaning-making strategies to be developed. For example, through metaphors or recognising similarities to, or continuity with, previous experiences.

Relationship to pre-existing findings

Thematic similarities exist between these findings and those of other studies. Bodley-Scott & Riley’s (2015), recognition of the role of perception of injured spouses’ personal control could form part of the “unfolding” experience of realisation, especially where non-injured spouses notice newfound areas of control. This indicates a niche for the experience of realisation in contributing to spouses’ perceptions around facing their loved one’s post-injury sequela. Furthermore, Brunsden et al. (2017) include a main theme of imprisonment, similar to the main theme “lost and trapped in an unsolvable maze” within the present study, alongside further thematic overlaps relating to hope and experiencing the unknown. Given this parallel, loss of freedom and the resulting grief could be an extension of this theme worthy of further exploration. Brunsden et al. (2017) included a male sample with injured wives, suggesting experiential commonalities across gender. Questioning marital roles, however, remains specific to this study’s sample of women. It is plausible that this reflects the contribution of sociocultural context around women’s roles upon individual

“lifeworlds.” Given the non-comparative nature of IPA however, only tentative suggestions may be drawn. Nevertheless, the importance of socially derived discourses as a basis for constructing meaning is emphasised.

Within this study, accounts referred to finding “acceptance,” a “new normal” and noticing personality traits that have remained unchanged post-injury. While these lie within the context of change, they also hold similarities with the notion of striving for continuity, as previously noted by Whiffin et al. (2017). Realisations of continuity regarding some aspects of pre-injury life add another dynamic to experiencing realisation of change, one of which might alter the nature of the realisation experience. Here, change went beyond ABI impairments alone, for example questioning marriage and observing self-change. This emphasises the potential limitations of applying a binary notion of post-injury change (either changed or unchanged) and the need for a more nuanced understanding as argued by Whiffin et al. (2017).

The findings portray multiple interpersonal and intrapersonal experiences of discrepancies between participants actual aspects of post-injury change, and those they may perceive to be personally acceptable but are not present. This is consistent with a systemic application of the Y-shaped model (Gracey et al., 2009) as presented by Bowen et al. (2010). Relevant findings include realisation of changed interactions when comparing their pre- and post-injury relationship, alongside sitting between knowing the unwanted truth or tolerating the unknown. A further discrepancy may arise between being a wife as an equal partner and a carer. Spouses may attempt to manage such discrepancies in unsustainable ways, such as continuously striving for recovery or even revising their pre-injury assumptions about the marital relationship. Such strategies to manage discrepancies could mean that some necessary adjustments feel personally unacceptable. Alternatively, other strategies for managing discrepancies could focus on experiences of resolution or continuity, which might contribute to resilient emotional health, or other positive outcomes for both spouse and injured partner.

The current study also describes one couple being brought closer together. Prior research has focused on negatives such as post-injury problems and losses (Baker et al, 2017; Whiffin et al., 2021). This negative focus risks hindering recognition of potentially optimistic outcomes and associated mechanisms in future studies, such as those reflected in traumatic growth research (Hallam & Morris, 2014).

Methodological considerations

Applying Yardley’s (2000) framework for consideration of quality, strengths of the current study include alignment between the underlying epistemology, research question and method (coherence). The results also successfully convey unique subjectivity and commonalities of experience which may have clinical applicability. The importance of recognising sociocultural factors, such

as gender, was also noted (sensitivity to context). The reflective journal aided transparency around the analytic process, whilst analysis accumulated these interpretations across accounts, ensuring impact and importance. Furthermore, the PPI research team member supported the development of a meaningful topic guide. The PPI research team member and two of the participants also provided confirmation of how the findings resonated with their own experience, supporting the potential impact and importance of the analysis. Furthermore, the COREQ (Tong et al., 2007) was followed to ensure reporting quality.

In terms of limitations, given the quantity of data, timescale, and the IPA methodology undertaken, saturation of the analysis was neither pursued nor achieved. A further limitation of this study is that information on nature and severity of ABI was gathered anecdotally from participants, compromising objectivity. While IPA does not aim for generalisability (Smith et al., 2009), having further medical details may aid transferability of findings and comparison with other studies, or within systematic reviews. Nevertheless, the injuries described were significant enough to seek ongoing rehabilitation and all could be perceived to have experienced long-term consequences following ABI (Table 1).

A 23-year age range was present within the sample, reflecting different stages in the family life cycle (Rolland, 1987), and indicating some heterogeneity (Smith et al., 2009). The inclusion of the potentially divergent needs and concerns of those in later life as well as middle-aged (Gosman-Hedström et al., 2012) also introduces potentially problematic heterogeneity into the analysis that was not considered in the design of this study. Given that realisation of change has not been explored previously, broad, mixed gender inclusion criteria were applied, however only married women opted in. While this improved homogeneity and the analysis allowed for each participant to be seen as unique (Smith et al., 2009), male experiences remain unrepresented (Brunsden et al., 2017).

Participants were also all seeking help when they took part. This may have contributed to the expression of losses and challenges within the results, as they may have been seeking support for these. Consequently, the experiences of wives who are not seeking or receiving professional involvement were not collected.

Additionally, time frame between injury onset and the interviews for some participants could bring memory recall into question. Should this have been the case, some accounts of experience could potentially differ from events at the time. Whilst methodologically sound within IPA (Smith et al., 2009), future research could consider a prospective study exploring the emergence of perceptions over time.

Implications

Experiences of realisation of change may be considered as part of the “ripple” effect following ABI, including the questioning of marriage and relationships.

This study explored beyond specific ABI-related changes to consider identity change within the non-injured spouse, questioning relationship roles and dilemmas when facing difficult realisations. This relates to family systems theories, in particular how a system adjusts in a homeostatic manner (Verhaegue et al., 2005). Spontaneously achieving a return to homeostasis following ABI may prove insurmountable (as recognised by Yeates et al., 2013), requiring the development of a “new normal.” The “new normal” has been previously considered in a thematic analysis exploring multigroup family therapy (Couchman et al., 2014), demonstrating further commonality across studies and within clinical practice. Here, family therapy groups led to a sense of connectedness, identity and increased knowledge for families, supporting their definition of a “new normal.”

In the current study, the “new normal” captured the experience of one family member, rather than the group. If the Y-shaped model were applied clinically, sensitivity to different meanings of the “new normal” to all family members in the system would be required, in order to navigate the complexities of individual and systemic experiences of discrepancy (Bowen et al., 2010; Gracey et al., 2009). Park’s (2010) model of meaning making is also relevant here, where addressing personal beliefs (such as the belief that they need to strive to re-achieve pre-injury life) could aid a sense of acceptance.

Additionally, experiences of realisations of change, such as being “pushed apart by brain injury” and feeling “trapped” might impact on attachment, establishing negative interactional patterns (Yeates et al., 2013). Spouses may cope with these experiences by adopting a more withdrawn position within their relationship (Yeates et al., 2013), due to being unable to express themselves as they did pre-injury, further compromising constructive adaptation and sense-making within the relationship.

Furthermore, the analysis suggests that realisations are changeable and occur continuously over time. Initial realisations, experienced changes and perceived wellbeing at the point of service contact are likely to be temporary, a snapshot of a dynamic process at that moment in time, that may benefit from being revisited multiple times as the family life cycle moves forward. This extends the community holistic model described by Coetzer (2008) which highlights the importance of services attending to a long-term perspective on identity change post brain injury.

Suggestions for future research

The results of the current study highlight specific gendered aspects of wives’ experiences, and future research could extend developments in family understanding. This gap in the literature has been summarised via a recent meta synthesis exploring the way social discourses about gender and disability may contribute to constructing experience (Whiffin et al., 2021). With the exception of Whiffin et al. (2015; 2017), prior research has also focused on specific changes within the injured person, rather

than the wider implications of change for families. Furthermore, younger families may be considered more vulnerable (Verhaegue et al., 2005) and have not featured extensively in research (such as Gosling & Oddy, 1999; Gosman-Hedström et al., 2012 and the current study). Whiffin et al. (2021) further elaborate this by establishing that family relationship research should include greater diversity of family members, a potential next step to extend the current study.

Notably, the current study alongside previous literature (Anderson et al., 2017; Brunsden et al., 2017; Whiffin et al., 2017; Brody-Scott & Riley, 2015; Whiffin et al., 2015; Gosman-Hedström et al., 2012; Gosling & Oddy, 1999) identifies both diverging and overlapping themes capturing the experiences of spouses within post-injury life. The findings also suggest that the experience of realisations of change are gradual and multiple, occurring as singular events unfold. A longitudinal Grounded Theory approach might be especially helpful to further understanding of these underlying processes and how family members can achieve an acceptable or even positive “new normal”.

Summary

Overall, the primary contribution of this study is the addition of a novel, rich and “deep” insight into how spouses experience and manage realisations of change, especially how these fluctuate over time, and the emotional work and effort required. In exploring realisations of change, participants experienced an emotional separation from their husbands, leading to questioning beliefs around their marriage and relationship. Participants reported feeling trapped in their post-ABI lifestyle, and experienced dilemmas around the permanency of this whilst working towards or hoping for further improvements. Realisations of change required great bravery by participants to acknowledge feared and challenging emotions. Across accounts, there were shared experiences of realisation occurring gradually across multiple events, continuing long after the onset of ABI. It is hoped that this study provides an interpretation that resonates with those experiencing similar circumstances or supporting those who have. This study also points to the need for further clinical research focussed on how families can best navigate the complexities of relationship changes post ABI, understanding the processes that people go through over time and how “positive” outcomes might be achieved.

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Data availability statement

The dataset for this study is archived at the University of East Anglia.

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Appendices

Appendix A. Topic guide

Introduction: Thank you for taking part in this interview, I am going to ask you a few questions relating to your experiences since your partner/spouse acquired a brain injury. Please let me know if you feel uncomfortable about any of the questions or if you wish to stop the interview. Are you okay to continue?

- (1) (Set scene) I was wondering if you could tell me a bit about your life since your spouse/partner's brain injury?

Prompt: What is life like for you now?

- (2) What has changed since your spouse/partner acquired a brain injury?
Prompts: What sense did you make of he/she appearing/behaving that way? How did you interpret this? Can you tell me more about [participant's reported experience]?
- (3) What did these changes mean for you?
Prompts: How did you experience these changes? Can you tell me more about [participant's reported experience]? What sense did you make of this? What did you think/feel when [participant's reported experience] happened? What has it been like to manage the changes you saw in your spouse/partner?
- (4) Could you tell me what it was like to realize that both your lives were changing?
Prompts: What was life like at that point? What thoughts and emotions did you experience? What did you do when you noticed this change? How did you see the future at that time? Have there been any other realizations of change for you since [participant's reported experience]? Are you still noticing/realizing changes?
- (5) Have there been moments since the injury when you perceived yourself differently?
Prompts: What sense did you make of this? What did this mean for you? What are your thoughts about how you perceive yourself now? What emotions do you experience when perceiving yourself in this way?
- (6) How did you manage changes in your life following the injury?
Prompts: What has helped you to manage the changes themselves? Can you tell me more about what [participant's reported experience] was like for you? What personal resources did you draw on (for example, someone adapting strategies they used to manage challenges in the past)? What was it about [participant's reported experience] that eased your feeling of [reported emotion] at that time? Was there anything that you found unhelpful, how did this make you feel? What advice would you give to your past self in those moments? Is there anything else that might have helped?
- (7) What did it mean for your relationship when you first realized the changes to your everyday life?
Prompts: How have you made sense of the different roles you take in your relationship? How have realizations of change influenced your relationship? What has this been like for your relationship with your spouse/partner? Do you perceive your relationship differently?