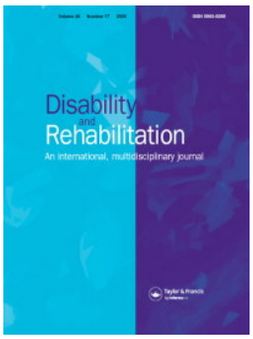

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RESEARCH ARTICLE

Exploring the lived experience and support needs of mothers with Acquired Brain Injury

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ABSTRACT

Purpose: This study sought to explore the lived experience and support needs of mothers who acquire a brain injury (ABI). Despite the increasing number of women sustaining ABIs, some of whom may be mothers of dependent children, there continues to be an over-representation in research of men with ABI.

Materials and methods: This paper focuses on Cycle One of a three-cycle Feminist Participatory Action Research (FPAR) study. Narrative interviews with ten mothers with ABI were conducted and analysed.

Results: Four themes were identified from analysis: (1) "The only person in the world": the hidden nature of brain injury leads to feelings of loneliness and isolation; (2) "I'm not in the next chapter, I'm in a whole different book": loss of self and altered identities following brain injury; (3) "Sometimes you just have to fall short": conflicting emotions of motherhood; and (4) "You just have to get on with it": determination and perseverance.

Conclusions: This study highlights the challenges facing mothers with ABI and acknowledges their diverse and multifaceted experiences. It sheds light on the conflict they experience between the need to focus on self-care and recovery while also trying to meet the demands and expectations of motherhood.

➤ IMPLICATIONS FOR REHABILITION

- Specific education and training on the hidden sequalae of Acquired Brain Injury (ABI) would help healthcare professionals and employers to be more responsive to the needs of mothers with ABI.
- Engaging in peer support can help to prevent feelings of loneliness and isolation and provide a validating and empowering experience for mothers with ABI. Facilitating peer support groups is recommended.

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Mothers; Acquired Brain Injury; Feminist Participatory Action Research; Identity; Interdependence

Introduction

Acquired Brain Injury (ABI) is a major global health issue that can have devastating impacts on individuals and their families [1]. It is an injury that occurs in the brain after birth and is an umbrella term that includes injuries caused by an external force (Traumatic Brain Injury or TBI) or an internal force, such as illness or disease (Non-Traumatic Brain Injury or non-TBI). Whatever the cause, a brain injury is often sudden and unexpected, and the impact can be life changing [2]. It has been referred to as a hidden disability and a silent epidemic [3], as many of its sequelae are invisible, with emotional, cognitive and psychosocial challenges, such as lack of empathy, irritability, fatigue, difficulties with problem solving, and reduced concentration.

ABI is one of the leading causes of death and disability worldwide [4–6]. Due to advances in medical treatments, more people are surviving significant injuries, with an estimated 27.16 million new traumatic brain injuries (TBIs) and 48.99 million prevalent cases globally in 2019 [7]. In the Republic of Ireland, there are approximately 19,000 new ABIs annually, and an estimated 120,000 people living with a disability as a result of brain injury [8]. To date, no gender-specific data have been reported on the incidence of ABI in Ireland.

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Services for people living with ABI in Ireland have been inconsistent across the country, with long waiting lists and limited access to rehabilitation. In response to this, there have been a number of drivers for change in neurorehabilitation services, including the *National Policy and Strategy for the Provision of Neuro-Rehabilitation Services, 2011–2015* (Department of Health and HSE, 2011), the *Model of Care* (National Clinical Programme for Rehabilitation Medicine, 2018), *A Trauma System for Ireland 2018* (Department of Health and HSE, 2018), and *Sláintecare Report May 2017* (Committee on the Future of Healthcare, 2017). Recommendations included having a three-tier model of care, based on complexity of need and Managed Clinical Rehabilitation Networks (MCRNs) to facilitate and promote communication between and across services. In addition to these policies, Acquired Brain Injury Ireland, an NGO providing services, support and advocacy for individuals and families affected by ABI, launched a 'Right to Rehab' campaign in 2022, advocating for all those with disabilities such as ABI to have rehabilitation and support to live in their own homes.

Despite these policy developments, implementation has been extremely slow, with many of the recommendations for services and supports not yet implemented. Along with the lack of resources to fund new services, the lack of data on the ABI population has implications for policy development, service planning and delivery [9]. This study provides additional evidence on a specific subgroup within the ABI population, to support and inform the timely implementation of current policy recommendations.

Research on parents with ABI

Acquired Brain Injury does not only impact the individual who is injured. It can affect family and friends, and extensive research on the impact of ABI on families has been undertaken in the past forty years. Research from the late 1980s and early 1990s [10,11] focused on the challenges faced by families, with an emphasis on burden and stress. In later years, the focus shifted to resilience and how families cope [12,13]. Despite the differing perspectives of researchers and diverse views on the nature of the impact, there is general consensus that an ABI has a life changing impact on all family members, involves role changes and readjustments, can lead to social isolation and financial difficulties, and causes a degree of burden and stress [2,14–18].

The impact of ABI on individuals and families when the person injured is a parent is a relatively recent focus of study, which is surprising considering the increasing number of adults under the age of 65 who are surviving brain injuries and are likely to be parents to young children [19,20]. There appears to be more focus on adults' working roles rather than their personal or parenting roles despite the societal value placed on parenting and its impact on health outcomes [21].

The brain injury research that does focus on parenting adopts the perspective of the parents or partners of individuals with ABI. There is limited research on individuals with ABI who are parents themselves, and when there is, the focus is often on the impact on the partners or the family system. Most parenting studies do not include gender as a subject of analysis, with many either integrating mothers and fathers in the sample or not specifying the gender of the parents included. A scoping review of literature highlights that a small proportion of studies focus solely on fathers with ABI (10) or mothers with ABI (11).

ABI research has been dominated by research on males with ABI due to the higher percentage of men sustaining ABI [22,23], however more research needs to be conducted on women to ensure improved rehabilitation outcomes for both men and women [24]. While the broader literature on parenting following ABI commonly addresses themes of grief and loss, parent–child relationships, and role changes, gender-specific differences are apparent. Studies focusing on mothers predominantly emphasise child protection and task-based parenting [13,25,26], whereas those concerning fathers primarily highlight burden and stress [27,28]. Themes of interdependence, loneliness, peer support and financial difficulties found in literature concerning fathers or parents in general [20,29,30] are not explored in literature on mothers.

While there is a paucity of research on mothers and fathers with ABI, research that includes the perspectives of the fathers or mothers themselves is even more limited. In fact, these authors found only two studies on fathers with ABI that included the voice of fathers [28,29] while no studies on mothers with ABI included their voice. There is, therefore, a significant gap in the literature concerning the lived experience of mothers with ABI. In addition, the importance of Public and Patient Involvement (PPI) in research is increasingly recognised, with particular emphasis placed on ensuring that the perspectives of

seldom-heard populations are meaningfully represented [31]. These considerations provided the impetus for the present study, which sought to engage and empower mothers with ABI to share their experiences of living with ABI, whilst continuing to fulfil their maternal role. Furthermore, the findings aim to raise awareness of the unique needs of this population and to underscore the importance of their inclusion in the development of policy and rehabilitation services.

The concept of motherhood, often regarded as a personal choice, identity, or way of life, has also been described as a 'social institution' [32–35] that is culturally and historically constructed and designed to produce the highest number of new humans at the lowest cost [36]. Hays (1996) [37] introduced the concept of *intensive motherhood*, characterising it as the belief that childcare is the mother's primary responsibility; that parenting practices should be child-centred, expert-guided, emotionally absorbing, labour-intensive, and financially demanding; and that children are inherently sacred, innocent and pure [37]. This cultural discourse—suggesting that mothers should devote their time and energy unconditionally to their children [38,39]—is not only reinforced informally through social networks but also formally embedded in institutions such as social services, medical and educational systems, and government agencies [40]. Intensive motherhood has thus become the dominant ideology in modern Western societies [41], reinforcing the assumption that women bear primary responsibility for family caregiving [42–45]. Although contemporary Irish family policy increasingly promotes shared parenting, statutory frameworks across social services, healthcare and family support continue to position parents as the primary agents responsible for children's wellbeing (see for example, *Supporting Parents: A National Model of Parenting Support Services* from Department of Children, Disability and Equality, 2022). And given the persistence of gendered caregiving patterns [46], these institutional arrangements may inadvertently reinforce the ideology of intensive motherhood, whereby mothers are expected to prioritise their children's needs above their own.

For mothers with disabilities, research suggests that intensive mother ideology is particularly difficult to navigate. Women with disabilities often have fewer resources and encounter multiple barriers, including poverty and the inaccessibility of public spaces [47–50]. Such barriers contribute to reduced economic and social status and limit access to education and health care [51]. Consequently, these constraints may shape how women with disabilities perceive themselves as mothers and may negatively affect their capacity to parent [52,53]. This study sought to address the lack of recognition of the needs of mothers with disabilities and the limited focus on parenting in brain injury rehabilitation [54] in order to inform rehabilitation services for this underrepresented group.

Methods

The purpose of this paper is to report on the first cycle of a three-cycle Feminist Participatory Action Research study, which explored the lived experience and support needs of mothers with ABI in Ireland (see Figure 1). The other cycles of this research will be reported on in a separate article. Cycle One of this study, and the object of this paper, aimed to answer the research question: how do mothers with ABI perceive the impact of their ABI on themselves and their families and what helped them to adjust.

Feminist Participatory Action Research (FPAR) is an emancipatory action research, that focuses on ideas of empowerment, emancipation and democracy. While the purpose of action research is to influence or make a positive change to something that is being researched, FPAR attempts to contribute to the social justice agenda and recognises power relations that are gendered, classed and racialised [55]. Reid and Frisby (2008) [55] proposed dimensions of FPAR that included: 1) centring gender and women's diverse experiences while challenging forms of patriarchy; 2) accounting for intersectionality; 3) honouring voice and difference through participatory research processes; 4) exploring new forms of representation; 5) reflexivity; and 6) honouring many forms of action.

Recruitment of participants

For Cycle One of the study, reported here, recruitment commenced by placing flyers and advertisements inviting mothers to participate in the research in two recruitment sites, a hospital rehabilitation centre and a community-based information and support agency. Anyone interested in learning more about the

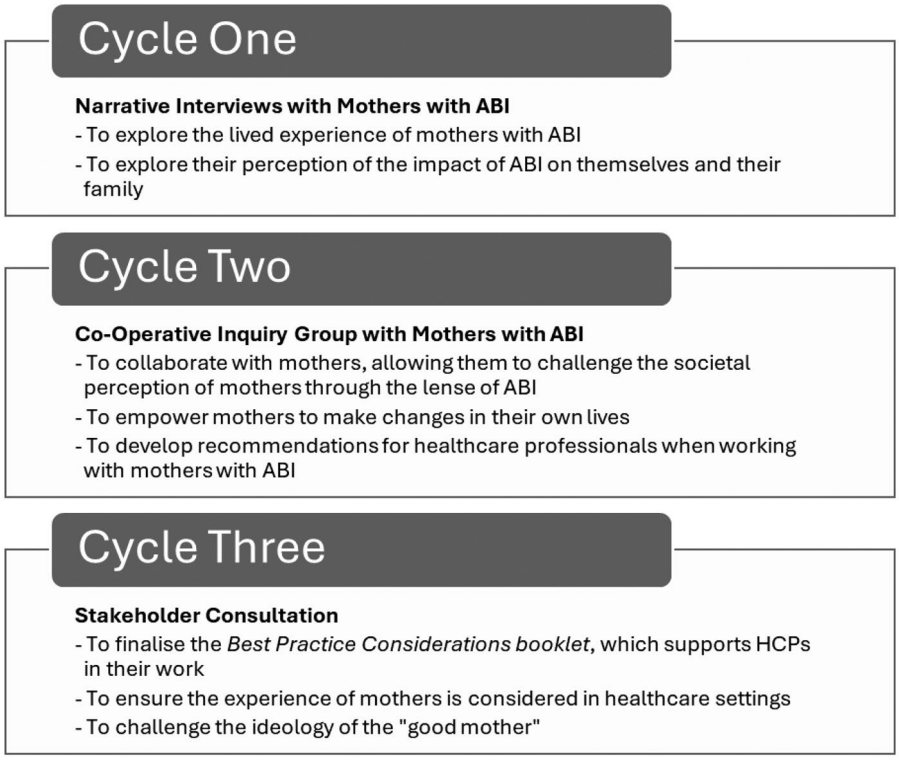

Figure 1. Research design overview.

research was invited to call the first author to discuss the research and ask any questions before consenting to participate. Participants were recruited using a purposive sampling approach, and the study had the following inclusion criteria: 1) women with ABI who were mothers to children of any age; 2) mothers who had at least one child before their ABI; 3) mothers who had their ABI at least two years prior to the research; 4) mothers who were attending or had previously attended either of the two rehabilitation services from which ethical approval was obtained; and 5) mothers who had a diagnosis of ABI – as reported by them.

Ethical considerations

Ethical approval was granted by the two recruitment sites, the National Rehabilitation Hospital and Headway Ireland, two organisations working with adults with ABI in both inpatient and community settings. This research involved collaborating with adults with ABI who had some level of cognitive impairment. There were specific ethical issues to be considered before conducting interviews, including the risk of retraumatising participants. All participants had their injury at least two years before the study began and they had either moved on or were trying to move on with their lives, not focusing on the difficulties in the initial stages of their injury. By asking them to discuss how it had affected them and what would have helped them at the time, there was a possibility of them reliving painful memories. Interviews therefore needed to be undertaken with an empathetic approach, reassuring participants that they could cease the interview at any time. A distress protocol was developed in the event of a participant being very distressed (see Appendix A). Due consideration also had to be given to potential child welfare and protection issues that could arise during the research process. The consent form had to clearly state the responsibility of the researcher to report any concerns in accordance with the Children First Act, 2015.

Ensuring that the purpose of the research was fully explained to participants so that they could give informed consent was crucial as the research involved people with cognitive impairments. It was important to be cognisant of the Irish Health Service Executive (HSE) National Consent Policy (National Office for Human Rights & Equality, 2024) and the Assisted Decision-Making (Capacity) Act (2015), which ensures

the presumption of capacity for all individuals and emphasises the need to support people to make their own informed decisions. The consent form and information leaflet (Appendix B) for the study were designed to facilitate an understanding of the research for people who may have cognitive difficulties. The information leaflet included information for two cycles of research, Cycle One of which is reported here.

Narrative interviews

Narrative interviews were undertaken by the first author with women who had acquired a brain injury in the course of engaging in a motherhood role. Interviews took place in person and lasted approximately 60–90 min. Interviews were recorded with a dictaphone. A narrative interview is a form of qualitative research that focuses on people's stories. In keeping with the emancipatory and collaborative focus of Feminist Participatory Action Research (FPAR), narrative interviews allowed for participants to have control over their own stories [56]. Unlike semi-structured interviews or quantitative questionnaires, narrative interviews do not have a pre-set list of questions or topics to discuss. Rather, they allow the researcher to elicit the person's story and prioritise the meaning the person attributes to their own story [56], thereby illuminating the reality the person constructs for themselves. This aligns with the collaborative nature of FPAR, ensuring participants had the opportunity to make their own contribution to the research rather than being led by the researcher. This method also facilitated rapport building with participants, engaging them in dialogue and helping them to feel comfortable enough to tell their story. Narrative interviews are more conducive to the development of this trusting relationship between the researcher and the researched [57] and therefore is a significant strength of this study.

Participants were given an information leaflet and were required to sign a consent form before the interviews began. A distress protocol was developed in the event that any participant was distressed and needed to terminate the interview. For some participants who had aphasia, conducting narrative interviews was more challenging. Utilising social work practitioner skills and experience throughout the interviews helped to ensure that they were able to tell their story in their own words as far as was possible. Strategies such as writing down words, drawing pictures and using gestures helped to ensure understanding between the researcher and participants.

Data analysis

All interviews were recorded and transcribed by the first author, and each participant was assigned a randomly selected pseudonym to protect confidentiality. Braun and Clarke's (2006) [58] framework for thematic analysis was used to analyse the data, which was analysed manually, with the use of Microsoft Excel to ensure rigour and validity. Six steps were undertaken for thematic analysis (see Figure 2): 1) transcripts were read through by the first author to become familiar with the data; 2) initial codes were generated by the first author, by reading through the transcripts line by line, searching for ideas and characteristics within the data; 3) codes that shared some unifying features were clustered together in an Excel spreadsheet (by the first author) to reflect a meaningful pattern in the data [58]; 4) codes and themes were reviewed by all authors and re-organised to ensure a set of themes that accurately reflected the data. Researchers engaged in reflexive data analysis, using their experience and expertise to critically interpret the data and ensure the credibility and authenticity of the themes generated. Samples of interview text and themes were shared with authors two and three to provide an 'external check' [59] and to ensure credibility of the analytical process; 5) themes were named and defined by the first author; and 6) analysis was completed by all authors and findings were reported, with quotes to support the results.

Transcription of data included verbal output (spoken words) only. During interviews with some participants who had aphasia, communication aids such as pictures and gestures were used by the first author to interpret the meaning behind the verbal output. While these creative methods provided the necessary scaffolding to support engagement, data analysis still took place within a system that continues to privilege articulacy [60].

Feminist Disability theory [61] was used to guide analysis. While the overall thematic analysis was deductive and guided by a theoretical framework, the generation of codes, or coding framework, was

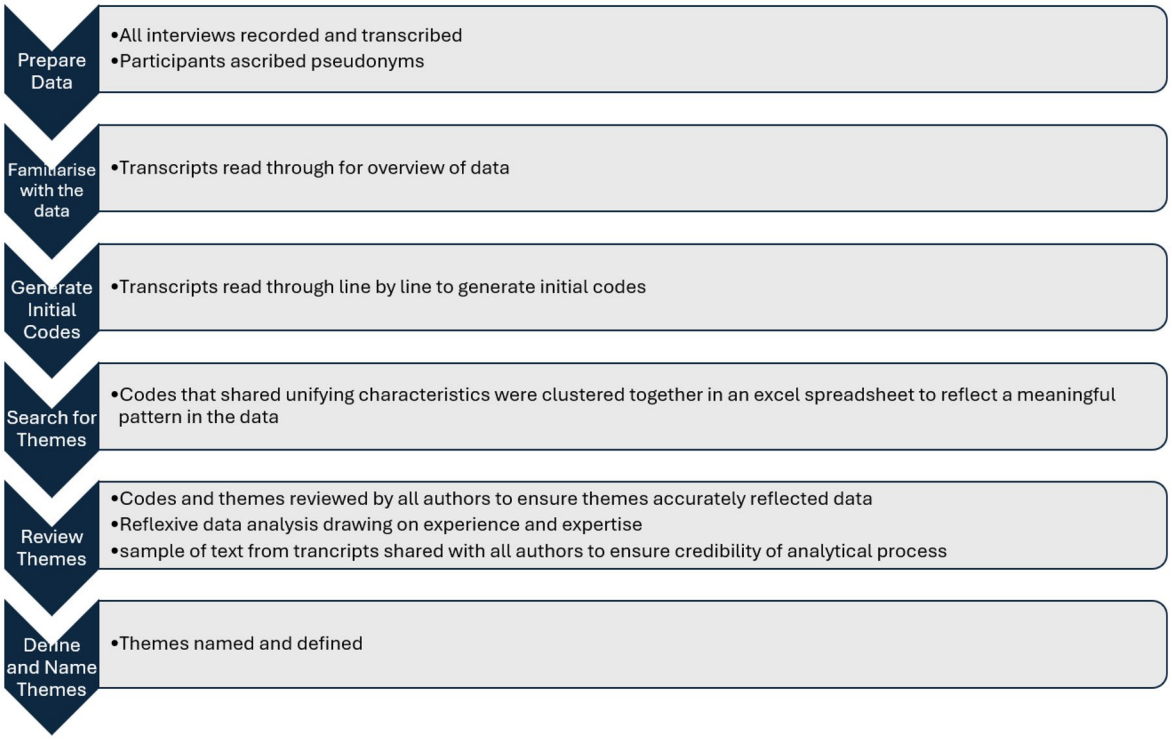

Figure 2. Overview of data analysis process.

inductive, being guided by the data. This was to ensure that any and all issues raised by participants were incorporated and analysed, with nothing being omitted if not deemed to 'fit' with the theoretical framework. This also allowed for the possibility of adding to the theory, generating new concepts and ideas to extend and enhance the theory. In practice, the generation of codes is not a linear or binary process, and the researcher is always influenced by their epistemological position. Thus, coding can be neither fully inductive nor deductive [62].

Feminist Disability Theory, first coined by Garland-Thomson [63], critically analyses how people with physical, cognitive or psychological differences are collectively imagined as defective and excluded from an equal place in society [61]. Three main concepts of the theory are intersectionality, interdependence and identity. Intersectionality focuses on women's divergent experiences, broadening our understanding of women with disabilities but also of societal structures and norms and the interplay between them. Interdependence focuses on the value of reciprocity (people recognising each other's needs and relying on each other) above the neoliberal ideology of autonomy and independence, which can lead to feelings of shame and low self-esteem, particularly for those who receive care. The concept of identity is central to Feminist Disability Theory, focusing on the dynamic nature of identity, which can change at any moment.

Data generation and authorship

Author 1 was responsible for research design, recruitment, conducting narrative interviews, leading the data analysis process and drafting the article for publication. Authors 2 and 3 provided support and guidance with the development of the research design, contributed to data analysis and drafting of the article for publication.

Results

Profile of participants

Interviews were conducted until theoretical sufficiency was achieved, in other words, until it was deemed that the research question had been answered [64]. Ten interviews were undertaken in total. Eight participants

were in their thirties at the time of injury, and two were between the ages of 55 and 65. Five of the 10 were in relationships, while the other five were either separated or widowed. Half of the sample did not return to work following their injury, while the other half were working either part-time or full-time. Table 1 highlights the type of injury, time since injury and brain injury sequelae of participants. While more specific details, such as type of employment, socio-economic status and geographical background would have been helpful in providing a richer context for participants, it was felt that the risk to their privacy outweighed the potential benefits. The relatively small number of mothers with ABI, particularly within two agencies in a country with a small population, makes privacy more difficult to maintain and safeguards had to be put in place to protect, in so far as possible, the anonymity of research participants by limiting identifiable data.

Themes

Four themes were identified following thematic analysis of interviews (see Figure 3). These included: 1) "The only person in the world": Hidden nature of ABI leads to feelings of loneliness and isolation; 2) "I'm

Table 1. Profile of participants.

Profile	No. of mothers
Time since injury	
2–4 years	**6**
5–7 years	**4**
Type of injury	
TBI	**1**
Non-TBI^	**9**
Brain injury sequelae	
Physical impairments	**4**
Fatigue	**8**
Aphasia	**5**
Memory problems	**2**
Sensory overload*	**8**

^Non-TBI included stroke, tumour, and post-concussion syndrome.
*Sensory overload was the term used by participants, and incorporated impairments such as reduced concentration, reduced information processing speed, and reduced ability to divide attention.

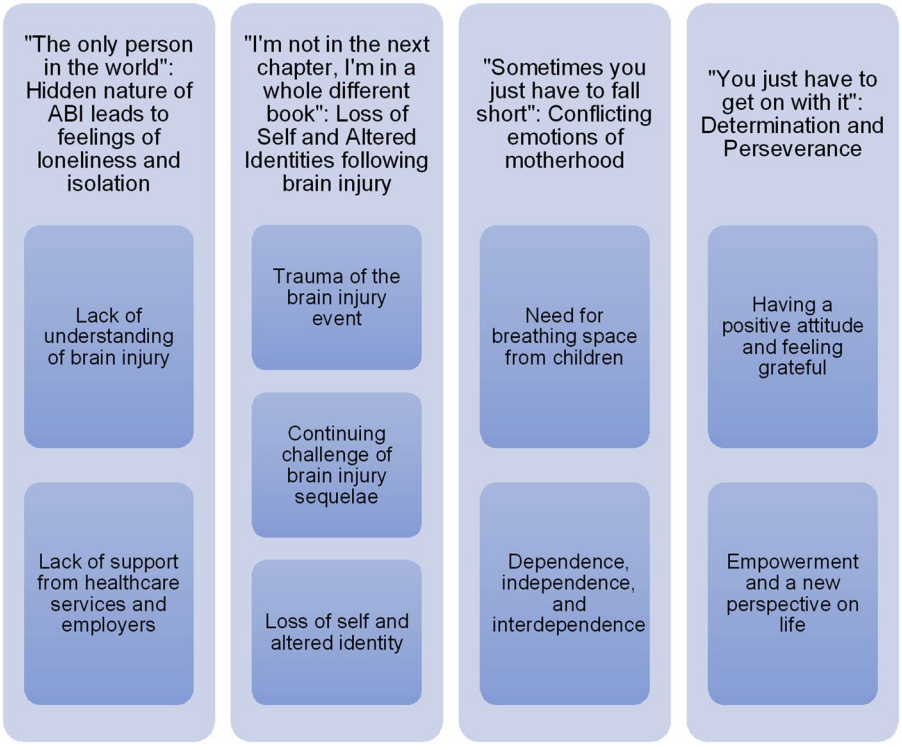

Figure 3. Themes and subthemes.

not in the next chapter, I'm in a whole different book": Loss of self and altered identities following brain injury; 3) "Sometimes you just have to fall short": Conflicting emotions of motherhood; and 4) "You just have to get on with it": Determination and perseverance.

Theme One: "the only person in the world": the hidden nature of brain injury leads to feelings of loneliness and isolation

Theme One reveals the sense of isolation experienced by mothers with ABI, largely due to the invisible nature of many of their sequelae and the lack of understanding from family and friends. This lack of awareness often led to insufficient support, particularly from healthcare professionals and employers. While rehabilitation services were accessible, participants' early experiences within acute healthcare settings suggested that understanding of ABI was sometimes limited, leading to insufficient acknowledgement of and support for the challenges they experienced. Even within rehabilitation services, long waiting lists and limited resources resulted in insufficient support. The hidden aspects of ABI contributed to a broader lack of recognition and lack of support, intensifying feelings of loneliness. The demands of motherhood further compounded these experiences, as participants described pressure to manage their impairments for the benefit of their children. The lack of understanding and subsequent lack of support for mothers with ABI are explored in the subthemes below.

Subtheme One: lack of understanding of brain injury. Many participants identified the invisible nature of brain injury as a primary factor contributing to a lack of understanding from family members, friends, and healthcare providers, which, in turn, fostered feelings of loneliness and social isolation. One participant observed:

> *"When they see you walking and you're fine, they think you're fine, but you're not fine. And it's hard to explain because people don't understand, because it is not a physical injury. You're trying to explain to them and they are like…you're fine."* (Ann, 2-4 years post injury).

This lack of understanding was also attributed to having an experience that not everyone can relate to:

> *"They haven't gone through what I went through"* (Joan, 5-7 years post injury)

Another participant noted that people were less interested after a certain period of time:

> *"I think the longer – the further away it goes, I think the less they understand. I think there was allowances initially maybe. You know, like, oh, you might need to have a rest, you might need to have a lie-down. Whereas now it'd be kind of like, 'What?'"* (Edel, 2-4 years post injury).

The perceived lack of understanding was frequently associated with participants' identities as mothers, particularly in the context of healthcare provision. Participants described how healthcare professionals in acute hospital services appeared more focused on their physical ability to perform caregiving tasks than on addressing their own health, well-being, and recovery needs. This emphasis on child welfare—often at the expense of recognising the complexities of brain injury—was a notable source of frustration.

Subtheme two: lack of support from healthcare services and employers. Participants expressed the view that the lack of support they received was closely linked to their identity as mothers. They felt that being perceived as capable of performing parenting duties often led to assumptions that additional support was unnecessary. This perception, combined with limited access to psychological support and peer networks through healthcare services (because of lack of availability in acute settings, and long waiting lists or limited resources in rehabilitation settings), contributed significantly to feelings of loneliness and isolation. As one participant shared:

> *"I am on my own and it is one of the loneliest places to be and there is no help out there… There really is nothing out there! It would be so nice to talk to someone who has experienced this, and I always think to myself, am I the only one feeling this… am I the only one being so dramatic?"* (Mary, 2-4 years post injury)

Another participant commented:

"No one around about me. No one…totally alone" (Helen, 2-4 years post injury)

While another noted:

"I haven't met anybody [like me]" (Joan, 5-7 years post injury)

There were some notable exceptions, with a few participants reporting positive experiences of healthcare support, particularly where peer support groups were available. However, access to such services, particularly within community rehabilitation services, appeared to vary depending on geographic location.

Participants also highlighted a lack of support in the workplace, describing unaccommodating colleagues and rigid management systems that failed to provide options such as a phased return to work following their injury:

"I had horrendous issues in my job and they wouldn't allow – like, they weren't supportive of a phased back-to-work approach. So they said it's you're either out sick or you're in full-time." (Edel, 2-4 years post injury)

Theme two: "I'm not in the next chapter, I'm in a whole different book": loss of self and altered identities following brain injury

Theme Two emphasises the profound changes mothers with ABI experienced in their sense of self following their injury. The initial shock and trauma altered their perspectives, requiring them to adapt to persistent sequelae that affected their identity. Participants particularly struggled with invisible impairments, such as reduced information processing speed, memory difficulties, and fatigue, which posed significant challenges to their self-concept. The trauma of the event, the ongoing challenges and the loss of self and altered identity felt by participants are discussed below under three subthemes.

Subtheme one: trauma of the brain injury event. The traumatic impact of a sudden and unexpected brain injury was the beginning of often profound identity change for the participants, particularly in light of their relatively young age. As one participant noted:

"I remember thinking, I am only 31… your life changes in an instant and it's so unexpected. You don't plan for this and here you are thrown into this whole other life that you didn't ask for." (Mary, 2-4 years post injury)

The shock of a sudden injury and the difficulty in accepting it was illustrated by a participant who stated:

"It's terrifying…I read a little bit about what happened to me…but I just stopped…I don't want to know" (Ruby, 5-7 years post injury)

The brain injury was also traumatic for family members, as participants expressed concerns for their children, particularly when they had to spend long periods in hospital away from them. Having communication difficulties was also noted as a challenge and distressing for participants, as one participant spoke sadly about the impact on her child as she couldn't speak for the first couple of years:

"[child] *is struggling with me for two or three years after the stroke, I didn't have speech."* (Doreen, 5-7 years post injury)

Participants described the trauma of the injury as being compounded by their parental role, as they had to navigate their children's reactions while also coming to terms with their own experiences.

Subtheme two: continuing challenge of brain injury sequelae. Cognitive challenges arising from brain injury, such as reduced information processing speed and reduced ability to divide attention, hindered participants' ability to perform parenting tasks, requiring them to adopt strategies to address these challenges. One such strategy was to seek help from other family members and have an "escape hatch" to allow time for rest and recuperation:

"Sometimes I just have to step out. Or if I'm making dinner, I would go into him [husband] *and say, look if you're not on a meeting can you just go in and take over the pasta, I would just have to step out… I do need to know that I can step out, that there is an escape hatch for me."* (Rachel, 5-7 years post injury)

In some cases, this caused feelings of guilt and concern about the impact of this coping behaviour on their children:

> *"I kind of feel guilty about how I handled things for them."* (Emma, 2-4 years post injury)

For some participants who had both physical and cognitive difficulties, this affected their ability to care for their children and led to feelings of guilt and an altered sense of self as a responsible adult:

> *"If something were to happen my reaction times would be severely compromised… if I was ever on my own with the children, and if they had a crisis, they would run to my mother or my sister instead of me so maybe they see me as not the responsible adult."* (Brenda, 2-4 years post injury)

Participants attributed these feelings of guilt and changes in their sense of self to the disruption of their pre-injury parental role following the injury.

Subtheme three: loss of self and altered identity. The sense of loss of one's self following brain injury was very evident in this study, with many participants struggling to cope and longing to return to their pre-injury 'self.'

> *"You have lost who you would have been. There is a loss involved, you just feel like you have lost who you are. You are trying to cope and everything but definitely I am not the same person."* (Ann, 2-4 years post injury)

> *"When I look at old pictures I think that person is a stranger to me, you're not the same person."* (Mary, 2-4 years post injury)

This was compounded for those with aphasia and communication difficulties, who felt a strong shift in identity and personality:

> "*I was chatty before!"* (Doreen, 5-7 years post injury)

Many participants were either unable to return to work or had to change jobs post injury, which also impacted their sense of self and work identity. For some, this altered identity was seen as a new normal with which they had come to terms. While for others, it was accompanied by feelings of guilt and being a burden on others:

> *"I sort of feel a burden on people"* [and] *"I feel useless in a way."* (Brenda, 2-4 years post injury)

Theme three: "sometimes you just have to fall short": conflicting emotions of motherhood

This theme underscores the conflicting emotions experienced by mothers with ABI, who expressed a need for personal space to support their recovery while simultaneously striving to maintain their identity as a 'good mother' and fulfil their previous maternal role despite their impairments. These conflicting emotions were also reflected in their attitudes towards seeking help from others and in how they navigated the values of independence, dependence and interdependence. The conflicting emotions of motherhood are discussed in more detail in the subthemes below.

Subtheme one: need for 'breathing space' from children. The need for personal space or respite (referred to as 'breathing space' by participants) from caregiving responsibilities was a recurring theme among nearly all participants. Two distinct yet often co-occurring responses to this need emerged: a sense of guilt and a recognition of its benefits. Many participants articulated ambivalent feelings, simultaneously experiencing relief and self-reproach, reflecting the internal tensions associated with their maternal identity following brain injury.

Participants used a variety of approaches to obtain respite: shouting in frustration, taking time away, or asking their children to leave them alone. Some participants, commenting on their sensitivity to noise, had to physically leave the room where their children were, while others described the need to switch off or psychologically distance themselves from their children:

> "*I ask [child] how their day was and [they] are talking to me and sometimes I'm thinking 'please leave please leave'."* (Mary, 2-4 years post injury)

A feeling of guilt arose for many who adopted these approaches to find breathing space. Participants expressed their guilt for not being the same mothers as they were pre-injury and not being the same 'nurturer' that they once were:

> *"I feel bad because they are so excited, they haven't seen me and they want to tell me about their day. And I'm like… momma can't listen to you."* (Ann, 2-4 years post injury)

However, in contrast to these feelings of guilt, some participants felt there were benefits to them not being always available for their children, as it allowed their children to have more positive relationships with other family members:

> *"I think the [children] don't see me as the nurturer and they look for cuddles off their dad more so than me…It's important for wee [children] to have a good relationship with their daddy so from that point of view I'm not too concerned."* (Brenda, 2-4 years post injury)

For these participants, there was also a sense that devoting time to self-care did not diminish the love they felt for their children and was important for them:

> "S*ometimes you will fall short but it doesn't mean that you don't love them."* (Ann, 2-4 years post injury)

Another participant spoke affectionately about her child who is now an adult:

> *"I will stay with you [child] always"* (Helen, 2-4 years post injury)

Subtheme two: dependence, independence and interdependence

How dependent or independent one should be following a brain injury, particularly as a mother, was a struggle for many participants. While some participants felt they should not need or ask for help and should manage independently and fulfil their perceived obligation as mothers, others were willing to ask for and accept help, reframing the mother role as one in which both mother and child benefit from an interdependent relationship of mutual support and openness:

> *"No one is an island, nobody can do it on their own."* (Rachel, 5-7 years post injury)

> "*They*[child] *would kind of like just push me – hold my back kind of a thing, and then, I can walk no problem because it's almost – so they're like, oh, yeah, this is my job for you now."* (Edel, 2-4 years post injury)

For those who continued to fight for independence, they experienced feelings of loneliness, isolation and guilt as they were unable to share their feelings or seek help, and often masked their impairments:

> *"I just pretend that everything is fine and I try to cope."* (Ann, 2-4 years post injury)

> *"But asking for help… I kind of try not to so much. Sure I can't."* (Emma, 2-4 years post injury)

Those who sought interdependent relationships valued the support of others and adjusted to their new life post-injury.

Theme Four: "you just have to get on with it": determination and perseverance

Theme Four demonstrates the determination of mothers with ABI, and how they continued to get on with their lives despite their challenges. There was evidence of post-traumatic growth, with a sense of gratitude for having survived the injury and a new perspective on life as a result. This was particularly apparent for those with more significant cognitive and communication challenges, and those who had support from family and friends. Thus, while the overwhelming feelings among these women with brain injuries were loneliness, conflicting emotions, and loss of identity, there was also hope of moving forward and finding ways to adapt and cope with life's challenges.

Subtheme one: having a positive attitude and feeling grateful. Participants expressed their gratitude at being alive and felt it important to have a positive attitude rather than focusing on the life-altering injuries and challenges they faced. While some expressed their gratitude for surviving the brain injury

event itself, others expressed gratitude for their families, for their support and for the additional time afforded with them as a consequence of not returning to work:

> *"It could have been a good, good thing that my kids, like, they see me more regularly."* (Ruby, 5-7 years post injury)

> *"It's nice to be able to spend time with the [children] without being stressed out from work."* (Brenda, 2-4 years post injury)

Having a positive attitude was seen as contributing to their recovery:

> *"I have to focus on the positive things… obviously I know I'm lucky in lots of ways… I've definitely made progress."* (Emma, 2-4 years post injury)

Subtheme two: empowerment and a new perspective on life. In many instances, participants acquired new hobbies and interests after sustaining their injury, allowing them to explore new aspects of their personality. A participant with significant cognitive impairments started drawing after her injury and explained how it helped to calm her mind and improve her mood. Engaging in activities, either in terms of rehabilitation or socially, was also viewed as important for their sense of perseverance:

> *"It* [physiotherapy] *was something measurable, because I felt like I'm doing something, I'm making progress. So I found that really hugely beneficial."* (Emma, 2-4 years post injury)

While some persevered to accept their new post-injury life, others persevered in an attempt to regain their pre-injury abilities. Perseverance and empowerment were evident in those who took control of their own lives, being open with friends and family about their challenges rather than hiding them:

> *"My friends are all aware that if we go out I could, mid-sentence, just go quiet and not interact. I'll sit there and I might just stop talking for five minutes or twenty minutes."* (Rachel, 5-7 years post injury)

Discussion

This study explored the lived experience of mothers with ABI, emphasising their personal narratives and the broader impact of ABI on their identities, families, and everyday lives. Given the focus within the existing literature on child protection concerns [25,26], participants in this study reflected on themes of identity disruption, lack of support and of understanding, ambivalent emotions related to motherhood, and perseverance in the face of adversity. Incorporating the voices and perspectives of mothers with ABI enabled the identification of themes not previously identified in the literature, and their voices and lived experiences to be captured. This may account for why there is a lesser emphasis on child protection concerns in this study compared to other literature. This study focused on the voices of the mothers themselves, highlighting their concerns and perspectives. As we have seen, previous literature did not include mothers' voices and thus may have been influenced by societal expectations of motherhood and perceived difficulties for children when mothers are unable to fulfil expected roles.

A particularly salient finding was the internal conflict experienced by mothers as they attempted to balance recovery and self-care with the ongoing demands and expectations of motherhood. Notably, this research did not reveal child protection concerns as a dominant theme. However, changes in the nurturing role were apparent for some mothers, particularly among those with both physical and cognitive impairments or those with more acute communication difficulties. The expectation to perform motherhood and be an 'ideal' mother for children [37] was evident through the mothers' expressed concern about their ability to perform parenting tasks compared to before their injury. The pressure to be an ideal mother can have an impact on mental health, with subsequent feelings of guilt and shame [39,65].

Performing tasks and engaging in activities with children is an important role for parents which influences the nature of the parent-child relationship [66]. In this study, mothers frequently referred to the challenges they faced in participating in such activities due to post-injury fatigue and reduced capacity compared to their pre-injury selves. Communication difficulties also emerged as a significant barrier to meaningful interaction with their children. These findings align with the concept of 'disrupted parenting' following ABI, characterised by reduced parental support and less nurturing [67]. Disrupted parenting

involves changes in family routines and emotional strain resulting from parental illness [68] - an experience vividly described by mothers in this study. Their focus on a task-based definition of parenting underscores societal expectations that mothers should consistently perform parenting and caregiving roles, pervasive in the literature on parenting with ABI [69,70]. The weight of these expectations intensified the pressure on mothers to fulfil normative roles and contributed to their feelings of guilt when unable to meet those expectations.

As noted by Bourdieu (1977), the body serves as a site through which cultural norms and expectations are enacted. Acquiring a brain injury affects this body, posing challenges to how individuals navigate and embody these norms. This is particularly significant for women who may already negotiate these norms from a place of subordination, and their power is further reduced by bodies that do not conform to societal expectations [71]. For many women, embracing a new identity as a person with a disability can be daunting [72]. In this study, several mothers reported concealing their injuries and refraining from disclosing their experiences, which contributed to feelings of isolation and loneliness. These experiences might have been mitigated through opportunities for peer support or open dialogue. This affected their sense of self and their self-esteem, yet they continued to mask symptoms in order to maintain a sense of normalcy and compliance with societal norms and expectations, and perhaps to avoid being perceived as struggling or posing a risk to their children. Notably, the theme of symptom masking remains underexplored in the literature on parenting with ABI, with only limited discussion found [13] where a mother chose not to disclose the full extent of her injury due to fear of stigma and discrimination.

Some mothers in this study expressed difficulty in accepting the need for increased support following their injury. However, many recognised the value of such support and normalised it in terms of acknowledging that all human beings require help at various points in life [73]. For those who accepted help from their children, interdependence was viewed not only as beneficial for strengthening familial bonds, but also as a means of fostering empathy and relational awareness in their children, with potential long-term benefits for their future relationships [74]. The concept of interdependence remains underexplored in the context of parents with ABI. Research to date has largely overlooked mothers, with only one study addressing this issue in relation to fathers, noting adolescents' changed perceptions and the importance they placed on mutual support within the family [27]. Broader parenting literature also offers conflicting views: while some studies associate interdependence with a loss of autonomy for the parent [75], others emphasise its value for children, particularly in sibling relationships that become sources of mutual support after a parent's ABI [76].

The value of interdependence and reciprocity in relationships, in contrast to the (mainly Western) view that dependence is associated with oppression and subordination [77], is evident in this study, particularly for those who challenged the hegemonic ideal of motherhood and were able to ask for and accept help. Interdependence can enhance relationships and create a sense of mutual respect in which the intrinsically loving and interdependent nature of humankind is validated [34,50,78]. Mothers who rejected the ideal of the self-sufficient, intensive caregiver and instead embraced help from others reported feeling less isolated and more supported. Moreover, findings from this study indicate that allowing oneself to be vulnerable and open to accepting help does not increase dependence; rather, it can facilitate greater autonomy by alleviating emotional and practical burdens. Interdependence—marked by openness, vulnerability, and mutual support—emerged as a crucial factor in mitigating feelings of loneliness, guilt, and the pressure to conform to unrealistic maternal ideals [37].

A particular challenge emerges then, when those who provide care find themselves in the position of requiring care. A binary understanding of caregiver and care receiver is not helpful in situations where a caregiver, such as a mother, acquires a disability and needs care herself. This binary can prevent individuals from seeking necessary support, either due to fear of being perceived as a burden or because systems fail to recognise their dual roles. If care was understood as a fundamental human need rather than a role assigned within a hierarchical structure [79], and if interdependence was valued over the neoliberal ideal of self-sufficiency and independence [80], mothers in this study may have experienced less isolation and a diminished sense of guilt or inadequacy.

A prioritisation of autonomy over interdependence was also evident in participants' experiences within the workplace. A lack of employer support was particularly highlighted by those with hidden disabilities, as many employers struggled to recognise the challenges faced by individuals with cognitive disabilities

or to identify how best to support a "misfit" in adapting to the work environment. Employers often lack the knowledge necessary to assist neurodiverse employees and do not consistently provide formal adjustment supports [81]. This reflects a broader systemic issue: work environments frequently fail to consider the specific needs of neurodiverse employees and may even deny the necessity of accommodations when a disability is not visible [82]. Such practices stand in direct contradiction to the Irish Employment Equality Acts 1998–2015, which require that suitable facilities and accommodations be made available for employees with disabilities. Under this legislation, employers are obliged to educate themselves on the needs of employees with disabilities, make reasonable accommodations, and ensure that those needs are effectively met (Employment Equality Acts, 1998–2015).

For this group of mothers, perceptions of interdependence appeared to influence adjustment following brain injury. Findings also suggest that adjustment was associated with the availability of both formal and informal sources of support. Although half of the sample were in intimate relationships, relationship status alone did not appear to be directly associated with coping or adjustment outcomes. Some mothers who were partnered continued to experience difficulties, whereas others who were single reported relatively positive adaptation to post-injury life. In contrast, access to formal support appeared to have a more substantial influence on adjustment. Participants who had access to both formal and informal supports demonstrated greater acceptance of altered roles and identities.

Time since injury also emerged as an important factor, with mothers who were more than four years post-injury expressing more positive perspectives on their adjustment. Findings from Cycle 2 of the study [83] further indicated that participants who reported difficulties during the Cycle 1 interviews described greater adjustment by the time they participated in the second research cycle. Although inadequate support was a prominent theme across the dataset, half of the sample had access to some form of formal assistance, such as home-help services for domestic tasks. However, such support was often unavailable for up to a year following injury due to resource constraints, contributing to feelings of isolation and insufficient support during the early stages of recovery. When formal support became available, particularly in conjunction with support from partners or children, participants appeared better able to accept changes to their identity and adapt to their altered circumstances.

Informal support alone did not appear sufficient to facilitate adaptation. Mothers who relied solely on family support continued to report challenges in adjusting to post-injury life. Overall, the findings suggest that the combination of relational support (from family members and friends) and structural support (through formal services) was particularly important in enabling mothers to adapt to changes in identity, role, and everyday life following brain injury.

Limitations

This study had some limitations, particularly in terms of including participants with significant cognitive impairments and the small sample size. Some mothers interviewed had severe aphasia and consequently the narrative interview approach had to be adapted to ensure their experiences and opinions were reflected in the findings. Participants had to be asked more direct questions with a total communication approach adopted. This ensured there was sufficient data to aid analysis. Another potential limitation was the lack of diversity in participants due to the small sample size and the inclusion criteria dictating commonalities in terms of gender, motherhood status and ABI diagnosis. However, intersectionality of experience is explored in the interaction between multiple influences, including age, race, ethnicity, marital status and nature of ABI impairment. Due to the small sample size, intersectionality was not explored in depth as a key theme, but it is important to acknowledge the multitude of influences on women's lived experiences that emerged in this study and which reflect the intersectionality of women's lives.

Conclusion

Practice implications arose from this study, particularly directed to healthcare professionals working with mothers with ABI. The importance of recognising the distinct experiences and support requirements of this population is highlighted, as well as the need to advocate for sustained rehabilitation input beyond

the immediate post-injury period. It further emphasises the need for services to adopt a life-course perspective, recognising that the challenges associated with motherhood following ABI may evolve as children progress through different developmental stages. Policy recommendations arising from the study focus on education and training for healthcare professionals, particularly in acute hospital settings, where findings suggest a lack of knowledge and understanding of brain injury and its sequelae.

This is the first known study to centre stage the experiences of mothers with ABI in both an Irish and international context. The tension between prioritising self-care and societal expectations of motherhood was illuminated when examined through the concept of "misfitting" [62], which offers a critical lens on the ways mothers with ABI negotiate their identities and roles. Mothers in this study may be understood as occupying a space that does not fully align with the categories of either "disability" or "ideal motherhood." As a result, they were compelled to find their own way towards survival and adaptation. The pressures embedded within societal structures, combined with limited acceptance of diverse abilities, exacerbated their challenges and restricted the availability of support. In this sense, their brain injury can be understood as both a physical and cognitive condition and a socially constructed experience. The intersection of motherhood and brain injury highlights the shortcomings of patriarchal and neoliberal frameworks that position mothers as primary caregivers and individuals with disabilities as passive recipients of care. In contrast, the findings point to the value of a "caring democracy" [77] in which interdependence and reciprocity are privileged over autonomy and independence. This study contributes to the body of work on parenting and brain injury, underscoring the need for structural, cultural, and clinical shifts that more fully acknowledge and support the complex realities of mothers living with ABI.

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Appendix A. Distress protocol

Appendix B. Information leaflet

Information Leaflet

Study Title : **Exploring the Support Needs of Mothers with Acquired Brain Injury and their Families**

Researcher: REMOVED FOR PEER REVIEW

WHO I am looking for mothers who had a brain injury at least 2 years ago, and now live at home.

WHY The main aim of the research is to find out what life is like for mothers who have a brain injury, and to see what help and support these mothers and their families need.

HOW You will be invited to meet me for an interview and chat about your experience since your injury. This interview will last about **one to one and a half hours.**

If you want to stop the interview at any time that is ok. If you want to have a rest or to stop completely that is ok.
If you feel upset during the interview and want to stop, you can talk to me about it and arrange to meet another time, or you can leave the research altogether.

CONFIDENTIALITY

I would like to record the interview to remember everything you have said.

I will not use your real name when writing down things you say. Your name will not be used in my research or told to anyone except REMOVED FOR PEER REVIEW.
I will store all notes from the interview on my computer which is protected with a password.

If you say something in the interview about someone being harmed or in danger, I will have to tell the relevant authorities, but I will let you know first.

What happens after the interview?

After I have interviewed you and some other mothers with a brain injury, I may invite you to join with the other mothers for a group discussion. I would like the group to meet **six times -** every two weeks for three months. Each meeting should last about **one and a half hours.**

In the group we will look at what kind of support has helped and what is needed to help mothers and their families.
All of this information will then be used to provide support to mothers who have just left hospital after having a brain injury. So your experiences will be used to help and support other mothers.

Do you have any questions?

If you would like more information, you can call me on [redacted] or email at X

If you agree you take part in the study, can you please sign the **consent form** and I will contact you about the time and place for the interview.

Thank you!