

ORIGINAL ARTICLE

Lockdown life - experiences of partners of individuals with an acquired brain injury during the COVID-19 pandemic: a qualitative study

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Abstract

Objectives: The present study sought to investigate the experience of individuals living with their partner with an acquired brain injury (ABI) during the first lock down period of the COVID-19 pandemic.

Method: Semi-structured interviews were conducted with seven partners of individuals who had sustained a range of ABIs. Interviews were transcribed verbatim and thematic analysis was carried out by two of the researchers exploring the unique narratives.

Results: ABI occurs within a relational framework, which means that it has repercussions not only for the individual but also the entire family system. COVID-19 prevented family systems (living separately) from coming together which negatively impacted them; however, it also slowed life down, with many people working from home with flexible arrangements in place which participants found to be beneficial. Three main themes emerged from the interview data: partner focus, slowing down and support networks. The narratives identified the struggles of having to continue their partner's rehabilitation when face to face services could not visit the home, the importance of establishing routine, the positives of a slower paced life (due to COVID-19) that enabled them to build stronger relationships with their partners, and the difficulties of being separated from family and loved ones.

Conclusion: This research suggests that it is imperative to consider individual experiences and choices. Some families benefited from reduced treatment and a slowed pace of life, whilst others may find this overwhelming and burdensome. The study makes recommendations for supporting couples after an ABI during the ongoing pandemic.

Keywords: COVID-19 lock down; thematic analysis; qualitative research; acquired brain injury; partner research

Introduction

The first reported case of the respiratory syndrome corona virus 2 (SARS-CoV-2 or COVID-19) in England was reported on the 31st of January 2020 and the first death from the virus was documented on the 5th of March 2020 (Tang et al., 2020) after the virus originated in the Chinese city of Wuhan in November 2019. The virus has since spread across the globe and caused a world health emergency. Many countries had to react by implementing strict controls in an attempt to avoid a possible health system break down due to the rapid spreading of the virus from person to person (World Health Organization & Mission China Joint, 2020) and its high morbidity and mortality rates. Since the 23rd of March 2020, in England, the public faced varying degrees of lock down measures to reduce the spread of the COVID19 virus. During the lock down periods, vulnerable

individuals (e.g. those with an underlying physical health condition that would put them at risk of serious illness from the virus) were advised to ‘shield’ and stay at home due to increased risk to their health if they contracted COVID19. Individuals were otherwise only permitted to leave their home to access essential items, such as food and medication. Individuals with an Acquired Brain Injury (ABI) were considered to be within the vulnerable group.

The National Institute of Clinical Excellence (NICE) guidelines estimate that annually, in England and Wales, 1.4 million patients are seen in emergency departments with suspected ABIs. Of these, 200,000 are admitted for further treatment (National Institute for Health and Care Excellence (UK), 2014), and ABIs remain the most common cause of death and disability in the UK for those aged between 1 and 40 years of age (National Institute for Health and Care Excellence (UK), 2013). ABIs can be the cause of many permanent cognitive, behavioural, psychological and emotional symptoms, that are often life altering for the whole family system (Muenchberger et al., 2008). Brooks (1991) coined the phrase ‘the head injured family’ to highlight that the impact of ABI symptoms are not limited to the person who sustained the injury.

The impact of ABIs occur within a relational framework (Checklin, Fernon, Soumilas, & Stephens, 2020; Jumisko, Lexell, & Söderberg, 2007). The repercussions on a relationship with a significant other can also influence the patient’s recovery process (Jumisko et al., 2007). Family members, especially partners, may need to quickly adjust to a new and unfamiliar role, providing a level of support they are likely to have never anticipated, prior to the injury (Frias et al., 2020; Jackson, Turner-Stokes, Murray, Leese, & McPherson, 2009; Jumisko et al., 2007). As a result, this may potentially lead to high levels of stress and burden (Cheng, Chair, & Chau, 2014; Leathem, Heath, & Woolley, 1996). Following injury, research has suggested that partners will often put their spouses first and their own feelings and needs second (Öhman & Söderberg, 2004; Engström & Söderberg, 2004; Kratz, Sander, Brickell, Lange, & Carlozzi, 2017). Additionally, partners report feeling the need to be ‘constantly available’ for the individual with an injury, and report feeling guilty when they had to leave for work (Jumisko et al., 2007).

It is imperative to consider the relational impact of an ABI in order to systemically support the individuals recovery. A relational focus seeks to assess the impact that the ABI has on the individual and their relationships with others. A study of male partners (following their wife’s ABI) by Brunnsden, Kiemle, & Mullin (2017) highlighted feelings of helplessness, with the males reporting a range of emotions (described as an “emotional-rollercoaster”) and having very little time to consider their own needs. In spite of the negative aspects of their new caring role, the male partners described feeling a ‘sense of duty’ to their partner, wanting to ‘stand by her’ to ensure she was supported. Relationships can therefore be under immense pressure post injury, with many studies reporting a significant sense of loss experienced by both the individual and their partner (Braine, 2011; Brunnsden et al., 2017; Buckland, Kaminskiy, & Bright, 2020; Kratz et al., 2017). It is therefore important to explore loss from both perspectives, as partners can feel a ‘two-fold’ loss as they personally grieve for their own losses, as well as the losses their loved ones are experiencing (Buckland et al., 2020). In the area of ABI research, subjective experiential changes are becoming more recognisable as vital ways in which to attempt to understand recovery and rehabilitation (Abrahamson, Jensen, Springett, & Sakel, 2017; Couchman, McMahon, Kelly, & Ponsford, 2014; Muenchberger et al., 2008).

While COVID-19 put many aspects of daily living on hold, ABIs continued to occur. Patients continued to present at hospital after experiencing, strokes, traumatic brain injuries, tumours and infections, yet visiting was banned and family systems experience further strain. Prior to COVID-19 many localities when discharging patients from hospital provided ongoing face to face community rehabilitation delivered by a multidisciplinary team. However, the lock down period put a temporary stop to community rehabilitation, and patients discharged just prior to this period, or at the time of the first lock down, were faced with restricted/limited service input and a general sense of uncertainty across the nation. To the authors knowledge, no other qualitative studies have been completed exploring the impact of the lock down on partners of those with a brain injury in

the UK. There has been one qualitative study published assessing the experiences of partners of individuals who had a stroke, however, this was in Singapore (Liang, Chan, & Ibrahim, 2022). This study indicated positives such as an increase in the time available to spend with family due to the COVID-19 restrictions and the kindness of hospital staff. There has also been one UK-based study that reported that carers of individuals with a range of difficulties were at a higher risk of depression with the key predictor being feelings of loneliness during the lock down periods (Gallagher & Wetherell, 2020).

To further explore the issues raised above, this study was completed with partners of individuals who had sustained an ABI and were at home, acting as informal carers, during the first national UK lock down. The overall objective of the current study was to explore partner experiences of supporting and caring for an individual with an ABI, during the lock down period, in absence of face-to-face community rehabilitation and social visits. The analysis aimed to highlight the experiences of partners within this unique context, and to amplify their unheard voices by documenting their descriptions of their personal experiences. This study expands the current literature on partner experiences post ABI, and provides further support for the continued implementation of systemic family-centred approaches to care.

Methods

This was a qualitative study, using thematic analysis to explore and further understand the lived experiences of being in lock down with a partner who had sustained an ABI. The narratives of those interviewed were explored to understand how meaning was created within the context of participants unique experiences (Hesse-Biber & Leavy, 2011). Qualitative methods can provide a platform for individuals who may otherwise remain unheard. They can explore complex relationships and uncover a range of personal interpretative meanings given to different situations (Sofaer, 1999). The study takes a critical realism lens that views reality as independent, with individuals socially constructing their knowledge of this reality (Clark, Lissel, & Davis, 2008). Critical realism posits that individuals reality is created through their descriptions of their experiences. It proposes that the various social phenomena that people experience exist in a system of different “layers” of reality, which are continually in a state of flux as systems and mechanisms interact (Clark *et al.*, 2008).

Participants

Participants were selected from those who were currently open to a specialist community rehabilitation team in the National Health Service (NHS) in England which caters for patients with neurological conditions at the time of study recruitment. All participants had partners who were actively involved with the community team at the point of data collection. Using convenience sampling, staff in the team were asked to make partners of individuals they were working with aware of the study. From this 13 potential participants were contacted who expressed an interest and 7 agreed to participate. Although this sample is relatively small, basic meta themes have been found to emerge from samples of as few as six (Fugard & Potts, 2015; Guest, Bunce, & Johnson, 2006; Murray, 2010) and other research studies have found that they can draw conclusions from research with similar populations and sample sizes (Tam, McKay, Sloan, & Ponsford, 2015). Furthermore, for a small study such as this, the research indicated that as few as six interviews are acceptable, especially as there is no definitive conclusions around sample sizes (Fugard & Potts, 2015).

The inclusion criteria were: i) had been living with their partner for the duration of the first lock down period (inclusive of 23/03/2020–04/07/2020), ii) be in a self-identified relationship (did not need to be legally married) with the patient who had sustained an ABI of any sort, iii) patient is currently open to the community specialist rehabilitation team, and iv) age 18 years or above.

Not all patients open to the service at the time of recruitment lived with a partner, and whilst all patients open to the service had complex physical illness or injury, not all had ABIs (i.e. other presentation were spinal injuries, peripheral neuropathy) and so were excluded.

This study sought to understand the experiences of the partners and not the patients whom had sustained a brain injury, therefore no demographic information was recorded regarding the patient. This decision to omit patient demographics was also to reduce potential burden while they were receiving input from the therapeutic team as including their demographic data would have required consenting them into the study. The partners were involved with the patients care and therefore were also known to the service. Members of the team working with the patients asked their partners if they would be willing to be contacted by a member of the research team. They were only contacted if they agreed. Four out of seven of the participants were female, there were a mix of heterosexual and homosexual relationships, and all couples were cohabiting.

Design and procedure

The manuscript was structured in line with the 32 item Consolidation Criteria for Reporting Qualitative Research (COREQ) (Tong, Sainsbury, & Craig, 2007). The participants were sent a detailed information sheet prior to consenting to take part. All seven interviews were completed remotely over the telephone in August 2020 by two of the researchers (EB and PC) and averaged 21:46 minutes in duration and ranged from 12:50 to 29:37 minutes. The semi structured interview schedule was created from a targeted review of the literature, and reviewed and edited by a patient panel group (experts by experience) who had a range of physical health conditions including ABIs (see Appendix A). The interviews were audio recorded and transcribed verbatim by the researchers (EB and PC). The participants were sent a debriefing sheet following the interview that thanked them for participating. Ethical approval for the study was sought and granted by the National Research Ethics Committee (NRES) Cornwall and Plymouth (IRAS 285675). All names and any potentially identifiable information were removed. The study was conducted in accordance with the tenets of the Declaration of Helsinki.

Analysis

The analysis followed the rigorous, six-stage process suggested by Braun and Clarke (2006) for inductive thematic analysis to identify semantic themes. This method allowed the researchers to search both within a data item and across the data set “to find repeated patterns of meaning” (Braun & Clarke, 2006) with the use of an iterative process, allowing for a rich understanding of the participants experiences. The approach was flexible, as it did not make any prior assumptions or use a theoretical framework, and instead followed an inductive process to explore the data.

In an attempt to reduce researcher bias, the analysis was completed by two researchers (EB and PC) with each phase set out by Braun and Clarke (2006) completed separately before comparing ideas (Morse, 2015). The interviewers (EB nor PC) were not a member of the patients treating team at the time of the interview. In step one, the two researchers (EB and PC) independently familiarised themselves with the data. EB and PC transcribed the data in the first instance and then engaged in repeated reading, ensuring to read through each transcript fully prior to generating descriptive codes or identifying patterns. In step two, the researchers generated initial data driven codes by systematically working through the entire data set to organise the data into meaningful groups. This was completed using the latest version of the NVivo software. In step three, the researchers sorted the codes into potential themes and collected relevant extracts that represented the emerging themes. In step four, the researchers reviewed the themes and ensured that they formed a coherent pattern. Thereafter, the researchers reviewed the themes in relation to the entire data set to ensure they accurately reflected the meanings in the data and to assess for content fit. In step five, the themes were defined and refined. Finally, in the sixth step, the report was completed.

Results

Three major themes were identified using the inductive thematic analysis approach. The major themes were ‘partner focus’, ‘slowing down’, and ‘support networks’.

Theme 1: Partner focus

All seven participants reported that their primary focus, during the lock down period, was on their partner with an ABI. Participants displayed a need to ensure their loved one was safe, comfortable and cared for. A common reason for the focus on their partner, stated by the participants, was the ceasing of face to face rehabilitation services during the lock down period. Participants appeared to take on the role of a multidisciplinary team in an attempt to provide support for their partner, in the absence of services. Across all interviews, however, this was not seen to be a negative experience.

“I was doing everything with [them]. . . so that was hard . . . but obviously as the time went on, you sort of spread your time out a little bit more and do other things apart from rehab . . . physio, speech therapy . . . I was doing all that meself, cos we didn’t . . . see anybody for weeks. So me whole day was just taken up in . . . like . . . focusing on [them] really” (01)

Due to the new role partners had of now having to support their partner with their rehabilitation in the absence of services there was a concurrent fear, expressed by participants, that the patient would lose the gains they had made prior to the lock down period. The participants commonly reported anxieties in relation to how they could best support the individual to continue with their rehabilitation, not necessarily to make further gains, but at least to maintain the progress they had previously made.

“That’s all . . . all I did for weeks was just concentrate on [them]. Just so [they] wouldn’t lose what [they had] already gained, if that makes any sense? I didn’t want [them] to go backwards . . . I don’t want you to lose those skills and . . . things you’ve picked back up” (04).

The participants were somewhat expected to fill a large gap left by services when face to face visits were suspended to reduce potential spread of the virus, which caused anxiety and stress for some, as they felt unskilled in their new role. Regardless of anxiety, all the participants ensured that their partner engaged with the rehabilitation plans shared by professionals in lieu of face to face contact.

“ . . . just by doing what we could really . . . so I mean I’m not, obviously I’m not a physiotherapist, so it was just trying to keep it simple. Just doing some of the exercises that we had already been taught . . . and just trying . . . not over do things really but . . . but also not having [them] just . . . sitting there not doing anything at all so . . . trying to walk that line really of how far can we go with . . . because obviously I don’t want to injure [them] and just working within [their] . . . capability really . . . Like I said I’m not a physiotherapist so we just had to be as careful as we could”. (05)

The participants lives began to revolve around their loved ones ‘ . . . the structure of the day was planned around [them]’ (03) and this left very little time for themselves ‘I didn’t do anything for myself, to be honest . . . nothing . . .’ (01). The participants viewed this focus on their partner as a necessity, and some even used this as a way to reduce boredom; ‘I’d be even more bored if I had nothing to do’ (01). This recurrent theme showed that the participants main focus was on the individual with the ABI, highlighting the love and care they directed towards their partner’s recovery. This may, by some, be perceived as a negative, however the participants spoke only from a

place of concern and love for their partner and none of the participants centred this experience as a burden.

The timing of the lock down was a positive for all participants in relation to their partner's injury and as it allowed them the time to focus on their recovery and have their partner be the main focus of their attention. All participants reflected that the lock down allowed them to be fully present for their partner as they no longer had the additional stresses of leaving home for work. This meant that many did not have to make a difficult decision around leaving their work role or having to ask for long periods of leave.

“even if I had been working, and there had been no lock down, I would have come out of work anyway to look after [them] . . . So that would have been done anyway, I'm not worried about work like. That's the last thing on my mind” (07)

All participants were either working from home during the lock down or were furloughed. This gave the participants a unique opportunity to be available to support their partner without the 'normal' financial stressors or professional pressures.

“ . . . I was furloughed from work, that helped a lot because [they had] literally only come home . . . then that afternoon I got a phone call to say we wasn't returning to work . . . So I think that helped, because if I'd have been in work, and [they] had only just come home . . . I'd have been a bit . . . wary of leaving [them] . . . so I think, it . . . fell into place . . . quite well really.” (01)

The participants described the new focus on supporting their partner, in the absence of face to face support from services, as a routine they had created in reaction to the lock down. The lock down also uniquely created a situation where they could be home supporting their partner without any of the 'normal' competing demands. Initially, the participants described their 'new normal' as challenging, however, later reflected on the benefits in terms of focusing on their loved one's recovery and spending quality time with them post injury. Routines varied on their partner's level of care needs, however all the participants appeared to quickly adapt.

“I think the most challenging thing really was with work, because erm . . . we were used to having active work lives . . . I think that was mainly the only part that either of us struggled with, because you haven't got that routine or regulation there have you . . . so that was a little bit . . . of a challenge because . . . there was no regulation to maintain, so it was basically a free for all and you could do what you want . . . we wanted to keep some sort of stability . . . some sort of normality going. Some sort of routine basically”. (06)

The routine not only reduced boredom within the context of the covid19 lock down, but also served to reduce the participants anxiety by providing a focus, and a goal for each day; “it kept my mind busy” (03). All those interviewed had adopted some form of routine around their partner and their recovery that gave structure to their day and maintained a semblance of normality during the lock down period.

“at first we had . . . everybody was ringing, y'know? From every department you can think of . . . giving me exercises regimes to do with [them], and it was like “oh my god how am I going to fit all this in” . . . because it was everything. It was physio, it was OT . . . it was speech therapy and then it was things . . . from the [service name], they were telling me to do this . . . and it was like . . . how am I going to do all this? But it was just a case of . . . just getting into a routine where you don't have to do everything every day. Just do something different every day . . . and . . . you can do it”. (01)

The couples began to really enjoy their new routines, and they reflected on them positively, recalling the benefits that routine and consistency provided on a daily basis. This again highlighted the dedication that the participants had to their partners and the commitment they had to their recovery. The participants therefore focused on their partner and their recovery, and in some cases, this was driven by fear and anxiety. However, the rituals that this provided for them both somewhat reduced their anxiety by providing them with a routine during a time of global and personal uncertainty.

Theme 2: Slowing down

The theme of slowing down and realigning values was evident in all interviews. The enforced lock down allowed the couples to take time to reflect and provided a safe space to process the traumatic event that had occurred (their partner's injury). They no longer had time pressures, in terms of pre-injury commitments, and therefore relished the opportunity to slow down and appreciate their lives more. In this way we can see participants expressing how their values shifted during the lock down period.

“... it seemed to almost increase our quality of life almost... I think during normal... what they now call normal life, where you go shopping, you do this and... you almost without thinking about it, you fall into that life where you sit there with your phone and whatever. But it totally changed all that. It made me rethink... different things... what were important and things like that ...” (06)

Participants appeared to benefit from this worldwide compulsory reduction of pace. “It's made... me a lot calmer, and... it's made me a better person to be honest with you.” (07). Slowing down the pace of life was not only of benefit to the participant, but they observed benefits in their loved one, identifying that this was now important for the long term (not just the lock down period). “It just meant everything slowed down so it was a calmer pace of life, it was an easier pace of life... and I think that probably helped with [their] recovery as well.” (03)

Expressed repeatedly across all interviews, participants shared a desire to live more in the present moment. “I think it's given everybody a chance to take stock of your life really because we're all on that treadmill” (02). This slower pace was evidently in juxtaposition to the participants previous routines. It appeared that prior to the lock down, many lived incredibly busy lives, visiting their significant other at hospital whilst trying to balance their work and social life alongside this. Others were busy taking their partner to groups and appointments, or being home to let the rehabilitation staff in. “So I've gone from running at like 100 mile an hour to nothing.” (01) This allowed participants to spend quality time with their partner and other family members, such as children that lived at home.

The lock down period allowed for the primary focus to be on the individual; a positive factor which was uncovered across those interviews. Lock down appeared to create a safe space for the individual and their partner to begin to adjust to their 'new normal' post injury. This appeared to give somewhat of a positive distraction from the anxiety that the pandemic posed.

“the focus was all about just making sure [they were] ok... so the actual sense of lock down wasn't a particular issue or it didn't seem to be an issue to us it was only much later on, erm... as [they] started to get better, that we started to realise that you couldn't go out and do all the things that you normally do. But in a sense, it created almost for us, like, a little safety bubble for [them]”. (03)

Within this theme of 'slowing down' was also the impact which this change in pace had on the couple's relationships. Many of those interviewed said that the lock down period and the “forced

togetherness” had “definitely brought us closer together” (03), and that they now “do talk more” (05). This extra time allowed the couples to strengthen their relationships in a space without competing interests; “we were just in together. And . . . and in some respects its . . . it’s brought us closer together” (01). They described engaging in more activities together than before the injury and focusing on one another’s needs.

“before [they] had the [injury] and all this . . . it was just like erm . . . Just like any normal married couple . . . [they would] watch his things on the telly and I’d watch my things on the telly. But now we seem to watch more things together” (04).

The couples tried new activities together which they had not done in the past and may not have done if they were not to experience recovery within the lock down.

“working in the garden, or planting, for [them] sitting and planting . . . just sitting in the garden with a cup of tea . . . has been lovely, because . . . it’s an opportunity to chat and look at nice things and just slow down . . .” (03).

This time together in the home after the traumatic injury allowed the couples some quality time to be together and to appreciate this difficult time; “we’ve managed, and we’ve become closer” (02). This also appeared to positively impact the mental wellbeing of the participants, “Yeah . . . the positive side has been that it’s brought us closer together . . . and that gives me a lift as well” (07). One participant expressed an appreciation of the lock down as it afforded them time to spend at home with their partner, “I’d say that was one of the positive things (laughs), that we were able to shut ourselves away and nobody could get out” (06). This protected time allowed couples to reassess their values and what is important to them and their family; “. . . life gets fogged over by things that we think are so important and when you sit back and look at it, they’re not important at all . . .” (06). The participants therefore took advantage of the reduction in pace and used this time to reconnect.

Theme 3: Support networks

All participants were fortunate to report having a wider support system in place who helped them emotionally and physically in varying degrees. Many of the participants highlighted how they were aware of their privilege in having a variety of support networks, and they reflected on the many individuals who do not have such support. Participants recalled how family and friends would be “at the end of the phone” (05) if they needed to speak about their feelings, with many arranging regular zoom calls to check in on the couple. Other participants, who did not leave their homes, recalled how neighbours and family dropped by with shopping to ensure that they had the essential items. All the participants expressed their utmost appreciation for their support systems, which included immediate and extended family, services, neighbours and friends.

“my daughter in law, she always pops in in the morning and checks on him and makes sure he’s alright. So we have . . . have got like a good . . . a good family . . . that at the drop of a hat, they’re . . . I mean, they’re here.” (01)

Some participants praised the services that offered their partner with an ABI support. These services attempted, in lieu of face to face contact, to try and provide a continuous level of support throughout the lock down.

“well we have a smashing support network, as I say, [they go] to that care centre and they’ve rung every single week asking if we were alright for shopping are we alright for medication and things like that” (02)

One participant reported how not having people call to the house, and only being able to speak to people on the phone, was actually helpful in their situation. They felt that this was the right amount of support for them, and that more support would perhaps have been overwhelming. This participant demonstrated a depth of insight into their own personal needs, reflecting that lock down had facilitated a protection when they were in a vulnerable position emotionally.

“I knew there were people that I could talk to, I had friends that I could offload on to as well. And to be honest at that time I didn’t really want to see people. I was happy to talk on the phone . . . I think it would have felt a bit too much because it would have felt very . . . I think deep down I was very vulnerable . . . I just automatically went into sort of . . . power mode. I gotta get through this, gotta get [patient] home, gotta make sure [patients] ok. So, I think at that point, I didn’t want anybody, sort of . . . slowing me down if that makes sense?”. (03)

This theme unearthed a mixture of emotions across the participants than ranged from gratitude to grief. Participants reflected on how helpful having protected ‘couple time’ together in the home was and how it was beneficial for their own personal processing of the shock after the ABI. Many benefitted initially from this protected time to reflect as a couple and to reconnect after a time of separation while their loved one was in hospital. However, others lamented and grieved the lost time with other loved ones, “When you’ve got a good friend’s group . . . its missing them I guess” (06), and the difficulty of not being able to spend time with their extended family “the most challenging part . . . is not being able to go see your parents . . . and your grandchildren” (01) and “. . . you can’t see family . . . we’ve found that really hard” (02). Participants reflected on the different emotional and physical supports they received and how they were grateful to their support networks for their help during the lock down and their partner’s recovery.

Discussion

This study explored the themes deduced from the accounts of partners of individuals who had sustained an ABI, and their experience of being in lock down together during the COVID-19 pandemic in the UK. The study highlighted a number of key findings, unearthing the personal challenges, coping mechanisms and the positive and negative experiences of the lock down period on their loved one’s recovery. The use of thematic analysis uncovered three main themes: (1) Partner focus, (2) Slowing down and (3) Support networks.

Previous research has shown how partners assume care for an individual with an ABI because of the love they feel towards them (Engström & Söderberg, 2004; Jumisko *et al.*, 2007) and this was evident in the discussions with the participants in this study. The participants did not complain about their new role, as it was felt to be a necessity born from the care and love they had for their partner with an ABI. All participants described having to take on the role of a rehabilitation assistant during the lock down period in the absence of face to face clinicians and service provision. Those interviewed wanted to adapt to this role change, knowing it would benefit their partner (emotionally, physically, cognitively), and the wider family network, in the longer term, which replicates previous research done in this area (Brunsden *et al.*, 2017). However, participants did reflect on the role being difficult at times, due to facing the struggles and demands associated with being an informal carer, which was further impacted by the lack of face to face support from community services. The authors were acutely aware that the couples were fortunate to be in the position where the individuals with an injury had a caring partner who was willing and able to provide support in lieu of services. The study therefore does leave questions to be addressed in

regards to patients who, post-discharge, had no option but to self-isolate alone, and how they managed to progress with their rehabilitation goals without the support of a partner or carer present.

For relatives of individuals with an ABI there can be a significant sense of loss in relation to changes in lifestyle as a result of the injury (Buckland et al., 2020). However, during lock down, the entire UK population was restricted from engaging in social activity, therefore regardless of their partner's injury, social activity was dramatically limited, thus potentially reducing the sense of loss. This, in turn, may have diminished negative feelings felt towards the injury and/or the individual, as life slowed down, everyone remained indoors (with or without injury), and social activities were cancelled. In previous literature individuals express feelings of loss (Braine, 2011; Brunson et al., 2017; Buckland et al., 2020; Kratz et al., 2017), however in this study, more themes of gratitude and connection were vocalised. Therefore, it may be assumed that for this particular group of participants, from the experiences they shared, that partners did not feel a sense of loss at taking on the new role as an informal carer, which may have been due to the covid19 context in which they were situated.

The participants reported themes that were in line with the literature on post-traumatic growth (PTG) post injury. This is evident in the positivity ingrained in the experiences shared and the felt sense of gratitude in the accounts from the participants. PTG can be seen as a positive growth period after a traumatic event where the individual experiences a positive psychological change (Tedeschi & Calhoun, 1996). The accounts shared from the participants echoed the gratitude and positivity seen in PTG. There is research highlighting the benefits to overall wellbeing of individuals with an ABI experiencing PTG (Grace, Kinsella, Muldoon, & Fortune, 2015; Lyon, Fisher, & Gracey, 2020), however there is little to suggest that their partners also experience PTG. Research has shown a positive link between family members coping and outcomes for the individual with a traumatic brain injury (Verhaeghe, Defloor, Van Zuuren, Duijnste, & Grypdonck, 2005). Research with individuals with multiple sclerosis (MS) found that when the partner with MS experienced PTG their spouse also experienced PTG, thus highlighting the importance of intimate relationships in psychological outcomes, along with support being provided to both the individual with an ABI and their partner (Ackroyd et al., 2011).

Previous research shows how partners can present with lower mood, higher risk of mental health difficulties and higher burden after the individual with an injury is discharged home (Braine, 2011; Riley, Keeble, Yasmin, & Hagger, 2020). However, the participants in this study generally reported positive experiences during the lock down period. The forced togetherness of the lock down period that was evident in the themes, coupled with the lack of competing demands and the slowing down of life, all appeared to create a safe space for the couples to take a moment to reflect, relax and recuperate their love. Although the pandemic has been devastating for many individuals and families, in the cases of those interviewed for this study, the effects of the pandemic (lock down) appeared to create a calm from the storm of their partner's injury. Many reported feelings of gratitude and having the time to 'take pleasure in the little things'. The 'slowing down' of their busy lives also allowed the couples to engage in meaningful activities which supported the strengthening of their relationships post injury.

The results of this study suggest that going forward post pandemic, families/couples may benefit from being asked about the timing of community rehabilitation, in terms of when they wish services to be involved. Some patients may benefit from a short period of time without services, a time to adjust and be in the present moment, a time to be with family and reflect on their journey. For some, this may provide the time to adapt to being home, rather than rushing into a new stressful routine of appointments and visits. Furthermore, it is important to note that the participants in this study were all working from home or had been furloughed from their job for the period of lock down. Therefore, the pressure of having to leave the individual with an injury alone at home, so that they could return to work, was removed. This enabled the participants to have financial security and perhaps added to the positive accounts recorded in the study. This is a complex issue

to address here (from an economic standpoint), however a further suggestion going forward from this study may be that employers allow a more flexible working arrangement for their employees following partner illness or injury, as the benefits can clearly be seen within the narratives presented here. Lock down permitted this change in lifestyle, which reduced the stressors for the partner, and allowed them to return to work in a more emotionally stable state. The researchers are aware that some employers may already have this option in place for their employees, however, it is felt that the majority are unlikely to have, or be able to offer, this level of flexibility and support. Future research should consider investigating whether flexible working arrangements for partners or families in sub-acute periods results in better outcomes for the individual with an ABI.

Many research items unfortunately highlight how families and patients report feeling unsupported by services post discharge from the hospital (Abrahamson *et al.*, 2017; Brunsden *et al.*, 2017). It is interesting to note however that in this study, when services were discussed, the majority of participants reported feeling that they were supported well remotely. They felt that they were given clear instructions on how to continue rehabilitation. One participant did however report that the list of activities they were provided with, by community services, were overwhelming, and that they were unsure of how to continue rehabilitation in a safe way without the risk of injury. However, there were positive reports of services 'checking in' and ensuring that the couples had what they needed during the lock down period. The positive reports regarding service involvement may have been due to the general sense of uncertainty across the nation, with partners feeling that they had not been forgotten in the midst of the pandemic. It is likely that not all services across the UK could provide the same level of support at this uncertain time, however this study suggested that the level of support was well received. Previous research shows how difficult emotions experienced by family members are exacerbated (e.g. feeling isolated) when they receive inadequate support from services (Holloway, Orr, & Clark-Wilson, 2019). Therefore, the positive reflections on service support in this study may have aided in the reduction of these negative feelings.

Limitations

The sample size meets criteria for methodology of this nature; however, the findings were drawn from a small relatively homogenous sample and therefore the results/themes cannot be generalised to a wider population. The authors are aware that the participants who agreed to take part in the study are likely to have had a positive experience of the service and the rehabilitation received, which will not be the case for all individuals receiving care. The recruitment process introduced a number of biases that were unavoidable in this instance; however, will still have excluded potential respondents, e.g., all participants were recruited from the same service, and therefore it must be acknowledged that not all patients with an ABI and their partners, at the time of the pandemic, would report such positive experiences. The lack of demographic information on the patients receiving care can also be seen as a limitation as this may have given further insight into the variety of experience. This also limits the transferability and generalizability of the findings. Furthermore, there was a lack of diversity in the service population from which to recruit potential participants. Regardless, commonalities were still found across the partners experiences. Future research should aim to include a more diverse sample from a range of groups, including minority groups, and explore a range of services and localities. Furthermore, a comparison to a sample of patients who are not currently in a relationship, and how they have coped, would further knowledge in this area.

The findings of the present study have aimed to reduce the current knowledge gap in understanding the experiences of partners of patients with an ABI during the first lock down period of the COVID19 pandemic. A unique contribution of this study is the timing, and the relatively absent recall bias, as the pandemic is ongoing and many of these individuals continue to deal with some form of lock down measure. With rehabilitation interventions currently focused on the

individual with the injury, it is hoped that the findings from this study provide rationale for further input and research into the wider family perspective of care, the timing of community rehabilitation for some individuals, and employment issues following partner illness and injury (such as partners returning to work and flexible working arrangements). There is further need to provide more support for individuals in informal carer roles, both physically and emotionally to ensure that their wellbeing is preserved.

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Appendix A Interview Schedule

How are you finding being in self-isolation with your partner who has had a brain injury?

How are you coping with being in self-isolation with your partner who has a brain injury?

Are there any positives of being in lock down with your partner who has a brain injury?

Prompt follow up questions if needed

- Noticed any differences to your daily life post versus pre lock down?
- (if they say things are the same) is the lock down and its coverage on the news having an impact at all on your experience of living with your partner who has a brain injury
- What do you find most challenging about being in lock down with our partner?
- Is this the same or worse than before the lock down started?
- How are you coping with the challenges that lock down is producing between you and your partner who has a brain injury?
- If you are struggling, how are you managing this?

Appendix A Interview Schedule for Partners of Patients with a Brain Injury

How are you finding being in self-isolation with your partner who has had a brain injury?

How are you coping with being in self-isolation with your partner who has a brain injury?

Are there any positives of being in lock down with your partner who has a brain injury?

Prompt follow up questions if needed

- Noticed any differences to your daily life post versus pre lock down?
- (if they say things are the same) is the lock down and its coverage on the news having an impact at all on your experience of living with your partner who has a brain injury
- What do you find most challenging about being in lock down with our partner?
- Is this the same or worse than before the lock down started?
- How are you coping with the challenges that lock down is producing between you and your partner who has a brain injury?
- If you are struggling, how are you managing this?

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