

2022

# Reasons for living following an acquired brain injury: A mixed thematic analysis

Parris, C.

Parris, C. (2022) 'Reasons for living following an acquired brain injury: A mixed thematic analysis', *The Plymouth Student Scientist*, 15(2), pp. 586-614.

<http://hdl.handle.net/10026.1/20104>

---

University of Plymouth

---

*All content in PEARL is protected by copyright law. Author manuscripts are made available in accordance with publisher policies. Please cite only the published version using the details provided on the item record or document. In the absence of an open licence (e.g. Creative Commons), permissions for further reuse of content should be sought from the publisher or author.*

# Reasons for living following an acquired brain injury: A mixed thematic analysis

Catalana Parris

Project Advisor: [Dr Alyson Norman](#), School of Psychology, University of Plymouth, Drake Circus, Plymouth, PL4 8AA

## Abstract

Considering the prevalence of acquired brain injury (ABI) and the concerning statistics around the associated risk of problematic substance use, impacted mental health, and suicidality (3-4 greater risk of suicidality in those with TBI), and the lack of qualitative, recent, and UK based research. This study aimed to explore what people's reasons for living after ABI were. Individuals living with ABI were recruited via BABICM (British Association of Brain Injury and Complex Case Management) to participate in semi-structured interviews. A mixed thematic analysis was conducted on the transcripts using the themes from Knight, Norman and Simpson (2020) as a framework for a deductive analysis and then a reflexive inductive thematic analysis was conducted.

The participants (four British males) had experienced a TBI (average time since injury 26 years). Two overarching themes of *Lost and maintained sense of self*, and *ABI is a hidden disability*, and five main themes *Acceptance*, *Support networks*, *Experiences of low mood and suicidality*, *Protective factors and coping strategies*, and *Overcoming challenges and posttraumatic growth* were identified along with several subthemes. Suicidality was a comparatively minor theme and did not underlie all the other themes as in the Knight et al. paper. The themes that emerged were focused on factors that impact recovery and rehabilitation (positively and negatively), wellbeing and mental health more generally. The data might point toward suicidality in this population being reduced or prevented through a comprehensive package of support, long-term case management, acceptance, and various protective factors.

**Keywords:** Brain injury, ABI, TBI, Suicide, Suicidality, Substance use, Protective factors, Coping strategies

## **Introduction**

### **Statistics and background information**

Based on statistics from the United Kingdom in 2016-2017 there were approximately 350,000 hospital admissions for acquired brain injury (ABI). This number equates to approximately one hospital admission for an ABI every 90 seconds, and worryingly these figures are indicative of a 10% increase in ABI admissions since 2005. Although men are still 1.6 times more likely to experience an ABI as women, incidence rates among women have been steadily increasing and are now 24% higher than they were in 2005 (Barnes, Bennet & Etherington, 2018; Headway, 2018). ABI is an umbrella term that covers any brain injury that is acquired after birth (but does not include injuries sustained in utero). Causes of ABI include accidents or other injuries involving a blow to the head (often vehicular or involving a sports or domestic violence injury) in which case it is termed a traumatic brain injury (TBI), but they can also be caused by strokes, infections, or the brain being deprived of oxygen for an extended period. Globally speaking it has been estimated that approximately 50% of the population will experience a TBI during their lifetime (Maas et al., 2017). Severe TBI has a mortality rate of approximately 30-40%, and out of approximately 100,000 strokes in the UK per year, 38,000 of them are fatal which makes ABI one of the leading causes of death and disability (Rosenfield et al., 2012; Stroke Association, 2020).

### **Consequences and implications of brain injuries**

Unfortunately, many of those that survive the initial brain injury are then left with profound cognitive, emotional, psychosocial, and physical consequences and impairments. This can include but is by no means limited to difficulties with communication, memory, executive functioning (e.g. planning, organisation, attention, impulse control), various other cognitive abilities, personality and behavioural changes, aggression, difficulties with interpersonal and social interactions, and wider systemic issues such as an impacted ability to reintegrate into the community and maintain employment, housing and relationships (Barnes, Bennet & Etherington, 2018; Maas et al., 2017). Physical health, functioning and mobility are sometimes significantly impaired due to conditions like paralysis or severe hemiplegia (weakness, stiffness or loss of control of one side of the body). However, the seemingly less extreme symptom of fatigue which is very commonly occurring can also greatly impact functioning, engagement and general quality of life (Belmont, Agar, Hugeron, Gallais & Azouvi, 2006; Cantor et al., 2008).

ABI is often referred to as a hidden disability since many of its effects are not always outwardly observable and are difficult to measure or quantify (e.g. deficits in planning, organisation, working memory, impulse control) (Simpson, Simons & McFadyen, 2002). Due to this hidden nature individuals living with ABI are sometimes evaluated by professionals (and society at large) based on criteria and standards that do not consider their unique situation and unseen needs. This is further compounded by a general lack of knowledge around ABI meaning those with ABI often do not receive equitable treatment or the reasonable adjustments that they perhaps should (Holloway & Norman, 2022; Norman, 2022; Norman et al., 2020). Additionally, those with brain injuries sometimes lack awareness and insight into their own condition, so can be unaware (or sometimes in denial) that they have certain impairments, so in a sense it can be a hidden disability even from those who have it. This can be detrimental to rehabilitation as it is difficult to accept assistance let alone ask for help

or practice self-advocacy if one is not aware (or in agreement) that it is needed (Owen, Freyenhagen, Martin & David, 2017). However, there is some support for the idea that lacking insight and non-acceptance of the severity of their conditions (motivated denial) can be beneficial to recovery and rehabilitation (Barco, Crosson, Bolesta, Werts & Stout, 1991; O'callaghan, Powell & Oyebode, 2006; Fleming, Strong & Ashton, 1996). This denial can be a way to deal with the cognitive dissonance (Festinger, 1957) that results from the disparity between the premorbid sense of self and the new post-injury sense of self (Deaton, 1986). Another facet to this hidden status is that symptoms can manifest months or even years post-injury and due to the time lapse they are often not associated with the original ABI and therefore can be overlooked by the individual or even misdiagnosed or by professionals (Menon, Schwab, Wright & Maas, 2010).

### **Complex relationship between substance use and ABI**

Considering the list of severe and life changing consequences of an ABI then it is of little surprise that there is an association with post-injury substance use. The available literature supports an association between ABI and alcohol and substance use as a coping method post-injury. This appears to be at least in part to avoid the negative thoughts and feelings associated with their injury, and as self-medication for the associated physical and mental health symptoms (Adshead, Norman & Holloway, 2021; Knight et al., 2020; Olsen & Corrigan, 2021).

The literature suggests a possible multidirectional relationship as individuals who engage in substance use are thought to be more likely to experience a TBI than those who do not engage in substance use and substances are often a factor in brain injuries being acquired (West, 2011). Anecdotally speaking one can understand how that this might be the case as there is more likelihood of engaging in risky behaviours or vehicular accidents when under the influence of substances. It is established that substance use often occurs both pre and post-injury in the population living with TBI however despite being a well-researched topic there is still not a definitive answer about which direction of the relationship is stronger, some researchers have concluded that risky substance use is more likely to cause a TBI (Ponsford, Alway & Gould, 2018; Rogers & Read, 2007) but others disagree (Bjork & Grant, 2009; Graham & Cardon, 2008) and a consensus has not yet been reached.

It is unclear whether the neurological sequelae (complications arising from damage to the central nervous system) caused by the ABI are a causal factor in post-injury substance use or whether it is caused by the psychosocial affects associated with the injury. Such as feelings of isolation or lack of social connections (long suggested to be causal factors in substance misuse) which in turn negatively affect self-esteem and mood (Alexander, Beyerstein, Hadaway & Coombs, 1981; Olsen & Corrigan, 2021; Christie, 2021). It appears that post-injury substance misuse may affect one's ability to engage with rehabilitation and can exacerbate some of the already present physical and cognitive impairments which can cause a cyclical pattern whereby the individual self-medicates with substances to deal with the disappointment that their rehabilitation is not progressing faster inadvertently self-sabotaging their progress (Corrigan, 1995; Olsen & Corrigan, 2021; West, 2011).

### **Mental and neurological health**

There is a fairly large body of research that supports the link between ABI and an increased risk of developing mental health difficulties (Chan, Toccalino, Omar, Shah & Colantonio, 2022; Waltzman, Daugherty, Sarmiento & Proescholdbell, 2021). Depression and anxiety are commonly referenced in the literature but those with ABI are also believed to be three times as likely to experience psychosis than the general population and endure high rates of PTSD (Batty, Rossell, Francis & Ponsford, 2013; Stein et al., 2019). Chan et al. (2022) described TBI and mental health symptoms overlapping and potentially exacerbating each other. The authors used depression as an example and noted how it can intensify the experience of the physical effects of TBI (e.g. fatigue and headache) but that if left untreated physical symptoms can in turn exacerbate depression. The relationship between TBI and mental health may also be multidirectional as those with mental health difficulties are more likely to experience a TBI (Simpson & Tate, 2005). In those that develop mental health difficulties post-injury it is unclear whether the cause is neurological changes/deficits or the result of situational, social factors and systemic factors (Perry et al., 2016).

### **Hopelessness and suicidality**

Often underlying some of the difficulties with mental health and substance misuse are feelings of hopelessness which are common post-injury (Simpson & Tate, 2002). Sadly, hopelessness is a powerful risk factor for suicidality and is thought to be even more predictive of suicide than depression. It is worth noting that hopelessness is often a feature of depression, but is also independently predictive of suicide (Beck, Brown & Steer, 1989; Beck, Steer, Kovacs & Garrison, 1985; Oyesanya & Ward, 2016; Simpson, Tate, Whiting & Cotter, 2011). Sadly, the research points toward those with TBI being at increased risk of experiencing suicidal ideation and suicidal behaviours and those with TBI are thought to be 3-4 times more likely to take their own lives than the general population (Bahraini, Simpson, Brenner, Hoffberg & Schneider, 2013; Madsen et al., 2018). There also appears to be an element of chronicity with some individuals experiencing suicidality (though usually transiently) for decades post-injury particularly among those who experienced severe TBI (Knight et al., 2020; Teasdale & Engberg, 2001).

How much of this suicidality is caused by the injury and the resulting neurological trauma or by a complex interaction between physical, emotional, behavioural, social and cognitive factors is unclear. Certainly, those with comorbid substance abuse, psychiatric conditions or hopelessness are in a higher risk category for suicidality than those without any comorbidities (Brenner, Homaifar, Adler, Wolfman & Kemp, 2009; Simpson & Tate, 2002; Teasdale & Engberg, 2001). Bessell, Watkins and Williams (2008) looked at the interaction between rumination, depression and over general autobiographical memory recall in those living with TBI and found that overgeneralised autobiographical memory may reduce problem-solving ability which then causes frustration and low mood. This contributed to rumination which caused individuals to dwell on the injury and what had been lost which in turn contributed to feelings of depression and hopelessness one might then infer that this cycle could also contribute to suicidality. Being treated as disinterested or non-compliant by services and experiencing a lack of understanding from their support networks may increase feelings of hopelessness, post-injury substance misuse, depression, and even suicidality in those with ABI (Norman, 2022; Norman et al., 2020). Barriers to engagement are not always obvious to wider society or many professionals (e.g.

difficulties planning, organising, remembering appointments and commitments, motivation fatigue (Douglas, 2010; Maas et al., 2017).

### **Protective factors and things that facilitate recovery**

There has been some research on what might be acting as protective factors for those living with an ABI against this potentially devastating and very final outcome, this is an important avenue for further research as it could help to inform interventions utilised during rehabilitation or information provided to individuals living with ABI (and those supporting them) in the hope of reducing suicidality. The research by Brenner et al. (2009) on a sample of US veterans living with TBI found that “having a sense of purpose and hopefulness regarding the future”, “social support” (from friends, family, peers, and pets), and “religion/spirituality” were protective factors for their participants. Similarly, Knight et al. (2020) found that “hope” and “spirituality” were also protective factors for their Australian sample and further identified a theme of “reliance (others)” which had a subtheme “support from social network”. Knight et al. also found that “perceived sense of others loss” and “personal positive attributes” acted as protective factors. The above list is not dissimilar to some of the factors that the general population find protective against suicidality. More recent research by Downing et al. (2021) looked at factors that facilitate recovery and found themes around good support networks, positivity and engagement, and quality of care and found that those factors tend to lead to better rehabilitative outcomes. This supports the idea that with the right support and rehabilitation posttraumatic growth can be fostered (Powell, Gilson & Collin, 2012)

### **Research gap and research aims**

Given the quite alarming statistics and the established associations between ABI and subsequent risk of impoverished mental health, substance use, feelings of hopelessness and suicidality gaining a better understanding of what might be contributing to this or acting as risk or protective factors is urgent. Research is lacking, especially so for anything qualitative and UK based. To the best of the author’s knowledge the only qualitative studies investigating this are Knight et al. (2020) from which this research is inspired and Brenner et al. (2009). The present study employed a qualitative design using a UK demographic in the hope of contributing to this important area of research. The aim was to improve our understanding of people’s reasons for living after an acquired brain injury (ABI), and to explore what might be acting as protective or risk factors. A semi-structured 1-1 interview format and qualitative analysis will be conducted.

## **Methods**

### **Participants**

The design of the study and relevant materials were approved by the research subcommittee for BABICM (British Association of Brain Injury & Complex Case Management - an organisation dedicated to improving and maintaining best practice standards in complex case management) (See Appendix A). Ethical approval was then obtained from the University of Plymouth Ethics Committee. The recruitment strategy was purposive and involved a BABICM senior case manager contacting other suitable BABICM case managers to ask them to participate in the study with their clients. The inclusion criteria were one year post ABI, aged between 18-65, and psychologically stable and cognitively able to participate in the interview (suitability was assessed by their case managers). The resulting sample (n=4) consisted of four male participants aged between 39-56 (one participant said “mid-forties” so a mean

was not able to be calculated) the injuries were all acquired between 22-28 years ago ( $m = 26$ ). All four participants had TBI resulting from road traffic accidents (RTA), however one participant also went on to develop subsequent ABI via infections at the surgical site. The aim was for a larger sample however time constraints prevented data saturation from being achieved (Braun & Clarke, 2013; Fusch & Ness, 2015)

### **Design**

This was a qualitative study using a semi-structured interview format to allow for more expansive answers and natural conversation but also some degree of standardisation across the interviews. The interview schedule was designed by the researchers and consisted of six open ended questions which aimed to explore some of the challenges and difficulties that those living with ABI experience, and to further explore any experiences of depressive or difficult thoughts, suicidality, coping strategies, sources of support and hopes and aspirations (see Appendix B). This study drew inspiration from a previous study conducted by Knight et al. (2020) and was interested in any similarities or differences with their data. To this end a mixed thematic analysis (Fereday & Muir-Cochrane, 2006) was conducted first taking a deductive approach using the themes from the Knight et al. paper to complete a framework analysis (See Appendix C) and then afterward a separate inductive analysis following the six stages outlined by Braun and Clarke (2006).

### **Procedure**

The recruitment process involved a BABICM senior case manager (and member of the research supervisory team) contacting suitable BABICM case managers to ask them to act as interviewers and participate in the study with their clients. Those interested were provided with a detailed PDF document (see Appendix D) which included an explanation of the rationale for the research. To ensure standardisation, rigour, and responsible and ethical research the document also included a step-by-step guide (including a flow chart for easy reference), guidance on conducting semi-structured interviews and points of flexibility, instructions on when to issue the information sheet, consent form, and debrief sheet in, a copy of the interview schedule, and a demographic information sheet. Links to instructional videos on how to record using Zoom and upload files to OneDrive were also provided.

The decision was made for case managers to conduct the interviews as they already had established rapport with their clients and were familiar with one another's communication styles. Communication, memory and insight deficits are not uncommon among those living with ABI (Coelho, 2007; Douglas, 2010) so it was felt that case managers would be able to provide some verbal scaffolding if needed to obtain the richest most detailed data from the participants. Furthermore, the sensitive focus of the research (investigating experiences of low mood and suicidality) meant that case managers were best placed to monitor for any signs of psychological distress.

Prior to the interviews the participants were provided with the information sheet (see Appendix E) and allowed to ask any questions, and then issued the consent form (see Appendix F) if they wanted to proceed. The interviews were then conducted and recorded using Zoom video calling software and each lasted between 29-70 minutes. Following the interview participants were provided with the debrief sheet and given the opportunity to ask questions (see Appendix G). The interviewers then uploaded the recordings, consent forms and demographic information sheets to a OneDrive folder which they were provided temporary access to. All data was then retrieved

and stored securely in a password protected file on a password protected laptop until the point of transcription at which point all identifying information was removed to ensure anonymisation.

Transcription was completed with the assistance of Otter transcribing software (Otter ai, 2016) but was then carefully manually reviewed and checked for accuracy (see Appendix H). The transcription method was “intelligent verbatim” meaning that the transcriber retained some discretion in editing, e.g. background noise and some filler sounds with no significance were removed but some paralinguistic features such as significant pauses or words that were emphasised were noted (Hickley, 2018). Following transcription, a mixed thematic analysis was conducted (Fereday & Muir-Cochrane, 2006) first taking a deductive approach and then a reflexive inductive analysis was completed using the six-stage process as outlined by Braun and Clarke (2006; 2013; 2022).

After the transcription and deductive analysis were completed an additional step was taken to obtain a secondary data source in the form of a short statement (or in one case a telephone call) from the various case managers about their perspective on current or historical experiences with low mood, suicidality or other mental health concerns for their clients (see Appendix I). The scarcity of references to suicidality within the transcript data was somewhat surprising based on previous literature so the researchers speculated that either insight or memory issues might have been a factor.

### **Analysis Procedure**

It is important to note that as a researcher one is never entirely neutral in how they approach and interpret research and despite my intentions and feelings that this research is situated within a contextualist epistemology and an ontological position between critical realism and relativism I will have undoubtedly been influenced by my life experiences (Silverman, 2013). Having personal connections to some of the issues investigated in this research meant that I likely hold various assumptions and potentially biases, many of which may be unconscious. Further detail can be found in the reflexive statement (see Appendix J).

A mixed thematic analysis approach was used, first a deductive analysis was conducted using the themes found in the Knight et al. (2020) paper as a framework to analyse the data and look for any similarities. The thematic map from the Knight et al. paper was converted into a thematic table (see appendix C). There were six main themes from the Knight paper which were all connected with suicidality (risk or contributing factors, chronic yet transient suicidality, protective factors, and reliance on self and others). Each transcript was then reviewed multiple times to achieve familiarity and then systematically analysed using the Knight et al. themes as a framework, an inductive analysis was then conducted to look for new themes.

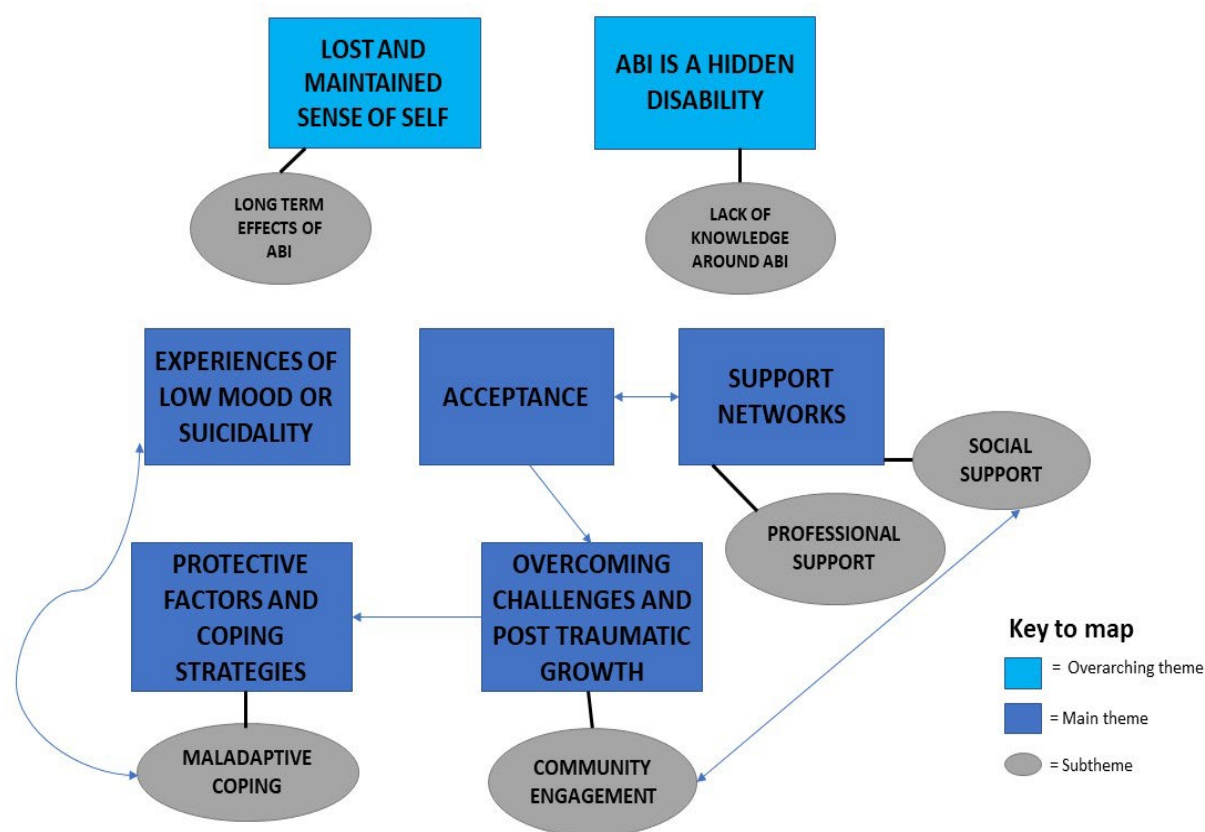
The inductive analysis followed the six-stage process outlined by Braun and Clarke (2006; 2013; 2022). Stage one was reading through the data multiple times to achieve familiarity and noting down initial thoughts and impressions. Stage two was generating codes by systematically reviewing the data and identifying meaningful words or sections. Stage three involved searching for themes among the codes by categorising them. Stage four involved reviewing the initial themes and checking to make sure they were relevant to the research and coded extracts. Stage five



involved refinement of the themes and further analysis of how the themes and subthemes connected and convey the story of the data, and finally naming and defining the themes. At this point a thematic map was created to help in visualising and understanding how the themes and subthemes related to each other. Stage six involved selecting relevant quotes and extracts that allow the data to tell its story and further analysis of those extracts in relation to the literature.

## Results and Discussion

The mixed deductive and inductive approach thematic analysis of the interviews revealed two overarching themes of *Lost and Maintained Sense of Self* and *ABI is a Hidden Disability* and five other main themes of *Acceptance*, *Support Networks*, *Experiences of Low Mood or Suicidality*, *Protective Factors and Coping Strategies*, and *Overcoming Challenges and Posttraumatic Growth* and a number of subthemes. See thematic map (Figure 1) for a visual illustration.



**Figure 1:** Thematic map which illustrates the overarching themes, themes, subthemes, and connections between them.

***Lost and maintained sense of self*** was an overarching theme and represented the awareness that participants had about the disruption in their self-narrative and the things that have changed since the injury (e.g. physical and cognitive abilities, parts of their personality, level of independence, and their ability to engage in employment). It included ideas around the loss of one's premorbid identity and skills, regression to a less mature self, no longer feeling a sense of belonging, awareness of the things

the injury has taken from them or prevented them from doing. It also captured the parts of themselves that remained postinjury and the acknowledgement of various helpful traits, qualities and strategies they had retained from their preinjury selves. This maintained sense of self was discussed as a protective factor and something that helped preserve friendships so connects with the protective factors and coping strategies theme and the social support subtheme.

P4- Missing my old lifestyle and job, being dependent on other people wholly for your existence I suspect, ummm co-dependence on other people being increased to such an extent where you're no longer individual. If you get what I mean with that. I mean there is no like, there is no simile to it. It is a fact of life it's that if the post brain injury is severe you are dependent on other people because what you were in premorbid existence is gone! So it's it's "guess what you're starting again mate, baby steps to learning to become independent as you can be.

P1 - Yeah. So I woke up in the hospital, not being able to kind of move, talk (small laugh/sigh), not do anything. I was like, yeah I had to learn everything. Basically, everything to be a human again. It's quite a lot.

P2 - I was literally walking to the park I'm feeding the ducks as a 21-year-old at this point with a head injury skull flap, you know no skull flap and this is what I was doing 11 years before when we moved down there from (*location removed*). So it felt like I had really regressed you know from sort of adult mode. I was back being a 10-year-old again. Which obviously was, (*laugh and exasperated sigh*) was very, very challenging!

P4 described his career preinjury having instilled characteristics and knowledge that remained with him postinjury and helped with coping and self-advocacy.

P4 - Everything that's necessary, absolutely zero that is not, that is the rifleman's code, apply that code to every day and you will find that you've got coping mechanisms that you didn't know you possessed, everything that's necessary nothing that ain't,

P4 - I was a patient with knowledge. Yeah and also my background was SF wasn't it, Special Forces, so "oh" is right crack on.

P1 - So I still have my humour still had some of my intelligence yeah it was just me as a person hadn't changed, or a lot of people get kind of angry or resentful and it changes their personality. Mine didn't change.

The **long-term effects of ABI** subtheme captured a large assortment of effects and consequences that can be caused by an ABI. Many of which are significant and enduring and relate to a changed sense of self and reduced independence. This includes but is not limited to changes or impairments with physical health and fitness, mobility, fatigue, ability to live independently, emotional regulation, personality, psychiatric disturbances, executive functioning (e.g. planning, organisation, attention), memory, communication, motivation and some unique challenges that were difficult to articulate or categorise.

P3 - Emotional problems and basically it starts off as something small and then it gets much larger. Umm just a bunch of physical physically your brain does everything in your body and your brain affects your motivation and your movement. So I put a lot of weight on during my recovery over many years and uhh you know I find it difficult but uhhh I find it difficult to get around and I'm not as fast as I used to be but that's just recovery it's been 28 years now

P4 - I stepped out of that lift and I went "where's ward 7?" from the ward one floor to an open area like this and I thought "where's ward 7? And from one floor doors opening thinking I was

36 miles up the road in (*location redacted*). I can't explain that. That's the weirdness of brain injury! [ ] How bizarre! For 3 hours I stood there!

P2 - This isn't umm an over exaggeration, I was literally living in my parents back bedroom. Umm you know for several years, having T shirts changed several times a day because of the dribble. Umm yeah and that that really isn't an exaggeration.

The concept of loss of sense of self is well covered in existing literature and has been described as the difficult realisation that one is the not the same person as they were prior to the injury and usually involves negative self-perception of post-injury functioning (e.g. mobility, cognitive abilities, emotional or psychosocial functioning) (Myles, 2004; Nochi, 1998). It emerged as a main theme within the Knight et al. (2020) paper and was also a key concept that was listed as a precipitating factor of suicidality among the sample of US veterans used in the study by Brenner et al. (2009). This literature suggests that this challenge to self-concept, and negative self-evaluation of functioning is often accompanied by feelings of low mood or depression, and impacted self-esteem and often underlies psychosocial and emotional difficulties postinjury (Carroll & Coetzer, 2011). The literature aligns with the link found in this study between the themes of loss and maintenance of sense of self and feelings of low mood or suicidality.

***ABI is a hidden disability*** was another overarching theme that captured the hidden nature of many of the consequences and problems that result from ABI and was connected to both the support networks and acceptance themes. These hidden difficulties included cognitive sequelae such as difficulties with planning, organisation, memory, impulsivity, attention and communication. The difficulties not being outwardly observable can result in those with ABI not receiving the right level of support or fair adaptations. A delay in symptoms appearing or secondary insults causing significant symptoms years later and being overlooked or not associated with the original injury was also discussed.

P3 - And most people are uhhh aware of what I've been through but you get strangers that come on with their ignorance and the fact that they just don't know what you've gone through umm and then they want to pass judgement which doesn't always help you and I don't want to say to them and express myself and explain myself as I've done it so many times I don't like doing it anymore or because you know I'll turn around, I'll walk off and you know they say "you got obviously got a low IQ, and you know there is no reasoning with you so"

P2 - I was working full time, it kind of went okay for six years, and I started getting extremely fatigued ummm and seemingly more and more drunk. So eventually I had to give up work. My family were caring for me, we weren't really getting any recognition and medical services and stuff.

***Lack of knowledge around ABI*** was a subtheme of *ABI is a hidden disability* and included lack of knowledge and understanding from professionals, the public and to some extent friends and family, and not being listened to by professionals. It also captured the link between the need for lived experience and user voice in research and policies but only some user voices getting heard.

P2 - It's also about Trepanation Syndrome as well, because neuro professionals, I've experienced them saying bollocks it's not a thing. I was like how can you say it's a not a thing I spent 10 years not being able to stand up and dribbling and you're telling me it's not a thing!

P2 - There was the conversations I was having in the (*location removed*) with with boffins, right, I was saying the top of my head is loose. Yeah, when I was when I was able to sort of communicate and stuff because I was, you know, I was so incoherent a lot of the time. The top of my head is literally loose and they're saying, Yeah, we can tell the plate is not quite, you know, the bone, the bone flap is not quite fixed in place but that's not the cause of that. Even though I would often sit there with my head between my knees so the bone flap would lift off my brain and I'd be more coherent. It would give me headache, but I'd be more coherent and they said, no, that's not the cause of it. And then when I went to see him (*unspecified other professional*) he said exactly the same thing, he'd been planning on giving me bone grafts from all over my body and putting them inside my skull. And he just chucked his notes in the bin and said, we'll fix that in place. That's that's the cause of the problem. And so, partly what helped me move forward was kind of this knowledge that I had been right (*small laugh*)

P2 - There's a lack of user of voice. And, you know, as a user voice I can kind of fit in very well, what there isn't, is the people who need to use communication software who may be disinhibited, but that is often a means of communication anyway. [ ] They're the people's voices that need to be heard as well and they should be part of the process.

ABI being a hidden disability is a well-established concept in brain injury literature and it is not uncommon for individuals to have no outward physical indications of their ABI (sometimes after a recovery period) yet they are often left with invisible yet significant cognitive, emotional or psychosocial difficulties (Knight et al., 2020; Simpson, Simons & McFadyen, 2002). There is also evidence to support the subtheme found about the lack of understanding by both the general public and professionals about the wide-ranging implications and consequences of ABI and the ramifications that creates in terms of emotional distress and lack of access to support and care (Norman, 2020; Norman et al., 2020; Odumuyiwa et al., 2019; Ponsford, Kelly & Couchman, 2014).

**Acceptance** was an important theme that emerged during the inductive analysis and was connected to several other themes including ABI is a hidden disability, support networks, and protective factors and coping strategies theme. It was discussed by each of the participants and captured both acceptance and non-acceptance of condition, delayed acceptance of condition or condition severity, and accepting or not accepting the lifelong nature of their condition. The theme also captured statements around accepting or not accepting help and how that changes throughout the recovery process, and the importance of accepting and asking for help. The theme also included other forms of acceptance such as acceptance by a romantic partner post-injury, and the general increased acceptance and understanding of disabilities and mental health today.

P4 described their non acceptance of condition, and professionals not sharing details of the severity of their condition helping facilitate their recovery and preventing them from extreme emotional distress and aggression.

P4 - I know knew that I was injured but at one stage no one ever sit down and said "right, this is what's happened to you dah dah dah dah you know CT's. Because then you know I would have been out of shape, or maybe would have have gone "Oh no, I'm really badly injured". At the push, yeah, because I've been shown the clinical information and GCS {*Glasgow Coma Score*} and all that etc. Then then if I'd have been shown how severely injured I was, maybe that would have stuck. So them by them not saying, right, this is my prognosis, basically, you're knackered mate. You're never going to be running over the hills and far away. Your career is finished, then I would have gone on a complete downer! Then I would have gone on the old wobbly war! Yeah, I would have become\_very aggressive!

When P4 was asked by I3 “*was that a good thing*” (about their non-acceptance of the severity of their condition) they replied “*I suppose ignorance is bliss*” suggesting that non-acceptance/lacking insight into the severity of their condition acted as protective factor for them.

P4 - So it's it's guess what you're starting again mate, baby steps to learning to become independent as you can be with the help that's being provided to you but you've got to accept that help

P4 - Umm and the other one is, if you need help ask for it, yeah you go “heelllppp” and ask people

P4 - so if you need help guess what well ask! “Help!!” It's a word that we don't use and we should! Do you need help, ask for it! It's not rocket science!

P1 - And also, kind of (*unspecified professional name removed*) she'll know when she does need to get involved even if I don't want her to.

P3 - I was always one that wouldn't listen to people, I wouldn't take on people's advice. But since my brain injury I've had to listen! If I wanted to get better, I've had to listen! Especially to my case manager! I always listen to her (*both laugh*)

P3 spoke about acceptance in terms of mental health and reducing stigma.

P3 - Yeah. Well also the mental health is bigger than, there is a lot more recognition towards it now, a lot more people are being open, you've got sports players and personalities, active personalities who would share their experiences which was never done beforehand and you know just to listen to these people and you go and watch that programme you can uhh you can uhh think to yourself “Christ I've made a good recovery”

P2 discussed post-injury acceptance by someone new (his current wife).

P2 - Umm but the point is things it felt like things were turning around, and it felt like a new start. It was this whole new relationship or is about been accepted post head injury by somebody who wasn't there when it happened.

The importance of acceptance in relation to chronic health conditions is not a new concept and Acceptance and Commitment Therapy (ACT) has a growing evidence base in terms of its benefits and suitability for helping those with chronic health conditions (including ABI) accept their new reality and better progress and engage with recovery. One of the tenets of ACT is accepting that which cannot be changed and a focus on improving functionality rather than symptom reduction aligns with accepting the lifelong nature of an ABI (Kangas & McDonald, 2011; Soo, Tate & Lane-Brown, 2011). Whiting, Deane, Simpson, McLeod and Ciarrochi (2017) looked at the role that psychological and cognitive flexibility have in recovery from TBI and found psychological flexibility to be the more crucial of the two which lends some support to employing acceptance-based therapies such as ACT to improve wellbeing in those living with an ABI.

Accepting and asking for help is another topic that frequently appears in the literature around health conditions and disabilities and some of commonly cited barriers to help seeking are worrying about being a burden to others, lack of resources/services, and fears about loss of independence and autonomy (Bredewold, Verplanke, Kampen, Tonkens & Duyvendak, 2020; Gandy et al.,

2018). Gandy et al. found that males were less likely than females to seek psychological support which is consistent with the literature around help-seeking behaviours in a neurologically intact population and aligns with statements from the sample in this study about having to learn to ask for help particularly around emotional and psychological matters.

The theme of **support networks** captured many aspects and forms of support (e.g. practical, emotional, physical, psychological, financial). The importance of good support networks as a protective factor and something that facilitates rehabilitation and wellbeing was mentioned by all four participants repeatedly. The theme also captured participant's experiences and perception of support which was sometimes positive and sometimes negative, and the importance of support for community reintegration. The theme of support networks links to the acceptance and ABI is a hidden disability themes and the community engagement subtheme.

P4 - Having positive and strong people around! Because the days when you're having a pity party, "Oh, get a grip, and get on with it!"

Support networks had a subtheme of **social support** which covered the various forms of support provided by family and friends that help to facilitate recovery and wellbeing and act as a protective factor against experiences of low mood or suicidality, and the challenges and importance of maintaining relationships post-injury. It included the logistical challenges of being relocated away from friends and family for rehabilitative care, romantic partners, the responsibilities of parenthood acting as a protective factor, and how ABI affects the wider family. P3 spoke about the impact of some of the cognitive sequelae of his ABI at the start of his recovery meaning that he needed predictably and routine to not feel overwhelmed which made it difficult to maintain his friendships.

P3 - Umm keeping in contact with family and friends, I haven't held on to all of my friends through the years over my recovery cause it happens it is a statistic that you do lose all your friends and its no wonder because in the earlier days everyone had to have an appointment to call me or knock on the door you know because I didn't like unexpected guests because I was so overloaded

P1 described how the support and contact he received from family and friends made his return home and reintegration into the community more manageable.

P1 - Ummm, well just kind of settling into the real world. Because I'd been institutionalised, I was very lucky though because I had friends and family who would visit me kind of every week. Someone would come up, so bring a bit of normality into my life. And not allow me to become too institutionalised.

P1 - Yeah, kind of easing me into real life again. Cause if I didn't have that, I wouldn't, kind of because I live in my own little bubble. If I didn't have people coming in, bursting that little bubble or showing me what real real stuffs like. Yeah, it would have been a lot harder.

*Support networks* also had a subtheme of **Support from professionals** which captured the various forms of support from different professionals that help to facilitate recovery and wellbeing and act as a protective factor against experiences of low mood or suicidality. The theme also captured the importance of having long-term relationships with professionals, praise and criticism for professionals, and questioning the knowledge and care from professionals.

P4 shared that *“having a good team around you as well that’s vital!*

P4 - So you've got the support in place. So if the you know if the things get or potentially become over or feel a bit “ahhhhh” or you feel like you’re getting overwhelmed

I1 (to P1)- I wonder whether those real long-term relationships sometimes can help with that. Because you know, you you know someone better. So I know, you well enough to trust that I don't need to get involved and things.

P1 appeared to agree with the interviewer and alluded to a recent example demonstrating the link between professional support and acceptance.

P1 - And also, kind of (unspecified professional name removed) she'll know when she does need to get involved even if I don't want her to.

P4 very firmly conveyed that he was prepared to question professionals and was unwilling to accept substandard care, negativity or pessimism from professionals and expressed how unhelpful and offensive negative attitudes are.

P4 - Every two weeks you'd have a clinic where you'd see the consultant bloke I remember he was a group captain quite senior, it's equivalent of a brigadier and quite a lot of power and importance “what what what” (*both laugh*) but he was a senior man and we used to see him once a fortnight for about two minutes, this is how the clinic would go in the early stages of rehab, “yeah yeah yeah, see you in a fortnight” and that was it! I mean I've waited four hours for you to say “see you in a fortnight” why are we doing this? “What what what what?” Now answer my question why am I doing this for about 13 seconds every two weeks and you just show me out the door what's the point?

P4 - I won't accept people's negative responses of condition. You will never you know, if anyone ever tells me I will never do something ever again, well how dare you because you don't know me and you're not me and you're not living this day to day. I find that not only is it rude, it's intrusive.

The importance of both social and professional support for those living with ABI cannot be overstated, it was a major theme discussed at length by all four participants and its role and importance in facilitating recovery and acting as a protective factor is also well established within the ABI literature (Brenner at al., 2009; Clark-Wilson & Holloway, 2015; Knight et al. 2020; Rauch & Ferry, 2001). In keeping with the data found in this study there is existing literature around the challenges of maintaining relationships post-injury which can be due to the long-term effects of ABI including physical, and psychosocial difficulties which often result in caregiver burden (Kersel, Marsh, Havill & Sleigh, 2001; Wood & Yurdakul, 1997).

***Experiences of low mood or suicidality*** was another theme that emerged during the analysis was which captured discussion around depression, anxiety, anger, aggression, frustration, emotional distress,, suicidal ideation and suicidal actions, nihilism, self-blame, patient burden, regret, and thinking about time lost.

P3 - I've basically had every kind of emotion you could think of. Gone through, gone through it all! [ ] So like depression, anxiety, suicidal thoughts, uhh low self-esteem, no motivation, uhh sensitivity, uhh confusion, psychosis, uhhh ummm anger, frustration umm I've covered most of it there

I2 to P3 - because in you know different times in the past it's been really really up and down hasn't it? And really tricky!"

P3 - Yeah, it's been terrible, it's been, people would say to me you know I envy you but I don't envy you and all that you've been through!"

P4 shared that although they had experienced feeling low and at times despondent that they had never experienced suicidality. The secondary data source aligned with this as the case manager of P4 suggested that despite him sometimes experiencing low moods, anxiety, and frustration they believed that his preinjury personality, career and faith "*stopped him from going there with his thoughts*". Which links in with the maintenance of sense of self subtheme as well as the protective factors and coping strategies theme.

P4 - No, never any thoughts of taking my own life never, that's selfish and I wouldn't do it! Umm (*briefly sings*) "*if you feel love and everyone*" I mean I'm not gonna sit here and say it's all sunshine and rainbows because there's no way it is, it is what is, you have certain days where you're going to feel "grrrr grrrr grrr why is it such a gray day" but you overcome it

P2 spoke about an ever-present sense of patient burden and guilt that was always simmering under the surface even when things were going positively and a sense of regret and sadness over time stolen by the injury.

P2 –Yes, sometimes when things when things are bad, and you know there are days when things are challenging, I just kind of have to sort of step out and try and switch off from everything if if things allow me because because I'm aware of the burden and the years lost I know that I have caused my family [ ] So you know, even even though it's a case of going, oh, yeah, you know, I've got all these strategies in place, I'm doing all this good stuff, got a family, we've got a house, everything's nice. There is still all this background crap of the destruction it's caused. You know and it doesn't matter how good things are for me, that stuff will always be there. Along with the lost years, along with the fact that umm you start having these thoughts, "oh my daughter's amazing", umm and you start thinking, well, maybe she could have had a dad who was 10 years younger or 15 years younger, if I hadn't been fanning around and having a head injury (*laugh*) And think of all the energy that dad could have given her. Yeah, and the time and stuff the extra time that she could have had with a parent.

P1 remembered having experienced low moods, feeling nihilistic but did not recall any suicidality post-injury, when prompted by his interviewer (case manager) and instead attributed his risky behaviours to making up for lost youth. The case manager perspective data suggested a different version of events that included suicidal thoughts and statements and a suicide attempt via overdose.

I1 - And there was definite there was a definite time when I think that you were expressing wanting to harm yourself. Can you recall any of that?

P1 - No. But it was also like I remember feeling that cause I'd missed out on a lot of that growing up so I just thought ahh I'll do loads of drugs and that'll make up for it. But it didn't (*laugh*)

There is fairly extensive literature on the association between ABI and subsequent psychiatric disturbances, emotional distress and suicidality (Bahraini et al., 2013; Brenner et al., 2009; Chan et al, 2022, Knight et al., 2020; Norman, 2020; Madsen et al., 2018; Waltzman et al., 2021). This association was in fact the rationale behind the present study so this theme emerging was not unexpected however what was surprising was the scarcity of references to suicidality by the participants.



Considering that there was more reference to it from case managers both during the interviews and in the case manager perspectives suggests it could possibly be due to a lack of insight or deficits in memory from the participants (Maas et al., 2017; Owen et al., 2017).

**Protective factors and coping strategies** was a key theme and was spoken about frequently and extensively by all four participants. It captured a range of things that participants felt both improved their functioning and general wellbeing postinjury and also helped them with their recovery, day to day struggles and difficulties, physical impairments, emotional and psycho-social difficulties (including experiences of low mood and suicidality). The theme included a diverse range of factors and strategies, some practical (e.g. exercise, music, organisation, routine, structure, breathing, meditation, various positive distractions) personal characteristics, environmental and support network factors (proximity to ocean, being in nature, having good social and professional support), or more abstract concepts like having a sense of purpose or responsibilities, proving others wrong or beating the odds, having a second chance at life, a sense of perspective/relative suffering or adversity, having faith or religion, perceived sense of others loss (in relation to suicidality).

P4 - Well, there's music! (in response to how he overcomes the low days)

P4 also used song lyrics to provide some of his answers during the interview.

P3 shared that music is an important protective factor for him and that he also uses it as a memory tool as way to reminisce about the past.

P3 - its why I go for drumming lessons

P3 - Well one of them is music, music uhh music therapy umm I like to go and listen to music because music always reminds me of periods of my life. I can usually always not all the time because I'm not that clever but I can usually track the date of when it was, the the year sorry. And uhh tell you what I was doing round about that time. You know I couldn't do that at one time but that's how far I've come you know, uhh things that support me umm so music is one

Exercise was described as helpful for dealing with the physical consequences of an ABI as well as being a protective factor in terms of their mental health.

P4 - Umm fitness, maintenance of fitness.[ ] So if I hadn't of gone to the gym, I wouldn't be mobile now, i'd be in a wheelchair and Ataxia would have won as you know, that would have defeated this all of this and I think I'd be a fat body in a wheelchair.

P1 - I need to do that exercise. Right. And if I don't I'll injure myself. My body just gives up.

P3 - Other coping strategies uhhh keeping busy, going to the gym. Getting the endorphins moving in your mind.

P2 - (*sigh*) Exercise! Exercise umm has played a strong part since 2009. Since since I was discharged from (*location removed*). So I've attended the gym normally, until COVID hit. I haven't been going to a gym since since the start of COVID. That has been more as a sort of mental health exercise rather than a he-man exercise. As you know, from my physique (*name of interviewer removed*) (*loud laugh*)

I1 (to P2) – And I think now, we're increasingly aware, aren't we of that! It also it's supporting the bizarrely its supporting the management fatigue as well?

Beating the odds, defying expectations, and proving professionals wrong seemed to be a strong protective factor and motivator.

P2 [ ] and to a certain extent uhhh prove everybody wrong, because you know, the prognosis was never really very good. Yeah, certainly after, you know, after that long, long period of several years of illness, you know, there was there's not really any expectation for me to, to do much other than just live.

P4 - But I had a doctor in the hospital that said “you'll never walk again” “if you don't go away soon you'll never breathe again, see ya!” exactly what I said to him and they put me back to sleep, yeah good night.

Acknowledging relative levels of adversity was also a protective factor.

P4 - Another saying from the past, a very good one, use this, store this one! I cried the day I lost my shoes to the poor man with no legs, realisation that everything's not quite as bad as you think is! Get over it, get on with it and crack on!

P2 - It's about you know, seeing the broad the broader picture, and appreciating what I have now, appreciating how far I've come. I think working with other people with brain injury does does facilitate that, because, you know I kind of see (*sigh*) now I'm quite open when I say, you know, this is this is, you know, I get as much benefit from this sort of work that we're doing together as you do. Umm because although I'm years down the line from it, it's still very beneficial for me. I think I've been able to appreciate what I have been through and what I have now. Yeah, it surprises me sometimes. Because, you know, people do people die from this sort of stuff, you know, people live with significant disability for the rest of their lives after this kind of thing.

Having a sense of purpose or responsibilities acted as protective factor for all four participants (e.g. employment, familial). Perception of the loss or suffering of those close to them also emerged which is similar to a theme found in Knight et al. (2020).

P3-. Occupation ummm kind of uhh working in horticulture a couple of times a week, keeping busy, keeping focused umm yeah it helps with relaxation uhh later on you know, it helps with lots! It keeps you occu it keeps you occupied

P2 - but also I have responsibilities now. You know, in terms of being the best dad that I can be given everything, and obviously those motivators weren't there when I was 21.

I1 (to P2) - you've got responsibilities to look after other people, and that's your partner and and your daughter, but you've also got responsibilities to a wider brain injured community.

I3 (to P4)- So, thinking back to your comment about you, because because I know that this study sort of touches on the things about you, you would you would never think of taking your own life because?

P4 - No, it's selfish!

P2 - And I think another part of that is it's not necessarily a positive factor. It's kind of like I have to, I have to protect these people from any further harm. Yeah, I have to be as autonomous as possible to protect them from any further harm

Exercise is well established as a protective factor for mental and physical health and wellbeing and prevention of cognitive decline (Deslandes et al., 2009). It has also been shown to be beneficial for those with ABI and other neurological conditions in reducing depression, fatigue, improving quality of life, mobility and cognitive functioning and increasing neuroplasticity (Ament & Verkerke, 2009; Pin-Barre & Laurin, 2015; Vanderbeken & Kerckhofs, 2017; Wise, Hoffman, Powell, Bombardier & Bell, 2012).

Only P4 mentioned faith being a protective factor for which contrasts with previous studies that found faith to be a common protective factor (Brenner et al., 2009; Lefebvre, Cloutier & Josee Levert, 2008). However, it may be caused by cultural differences as recent statistics suggest that almost 50% of the UK identify as Atheist or non-religious which starkly contrasts with North America where the studies took place (USA approx. 23% non-religious) (van der Veen & Bleich, 2021).

Music is increasingly being acknowledged as beneficial in research and clinical settings for a variety of conditions including ABI and is thought to improve mood, and cognitive functioning. Furthermore, simply listening to music (not music therapy) has been shown to be beneficial (Hegde, 2014; Leggieri et al., 2019; Tomaino, 2009). It is being utilised as a tool to access autobiographical memories and improve mood in Alzheimer's patients and although not an ABI it is a neurological condition so some parallels can perhaps be drawn to the underlying mechanisms which aligns with P3's description of using music as a form of mental time travel (Gallego & García, 2017; Irish et al., 2006).

**Maladaptive coping** emerged as a subtheme of protective factors and coping strategies. Participants described using substances as a coping strategy to escape from negative thoughts, as self-medication for mental and physical symptoms, as means to relive lost youth, as a way to feel "normal" or fit in. It can be linked to the experiences of low mood and suicidality, and maintained and lost sense of self themes, and the social support subtheme.

P1 - Ummm well in the past yeah, I've felt like I've coped by doing drugs. So ummm just kind of trying to get my mind out of that space. Get my mind off of this planet and just black it all out, but then have double, double the issues to deal with. *(laugh)*

P1- No. But it was also like I remember feeling that cause I'd missed out on a lot of that growing up so I just thought ahh I'll do loads of drugs and that'll make up for it. But it didn't

I1 talking to P1 - And actually, what we haven't discussed today is something that could have put you really off track is I know that right now you're in back pain. And that's been an issue for you before, which has caused you to fall off the waggon, and not look after yourself.

P2 - Umm so when that relationship broke down, it was kind of almost a gift to me, it was like, well, now I can go and self-medicate.

P2 - Umm but looking back, you know, now I have insight into head injury and the process, etc, etc, I can entirely see that I was in denial over what had happened. And it was, it was that return to previous coping strategies with life anyway, you know, return to what was normal. Umm and wanting to look normal, wanting to be normal. So, going out and socialising, etc, etc, was what my peers were doing.

P3 - I worked with some of your graduates and they might say that I am an interesting bloke and I've been through one end and come out, come out the other side

P3's comment was somewhat ambiguous but the secondary data source from his case manager (I2) suggested a history with drugs and alcohol and they suggested alcohol was often involved whenever things have deteriorated during his recovery.

The results of this study aligned with the existing literature on the association between substance use and ABI as several of the participants admitted to using (or historically having used) substances as a coping strategy since their injury occurred (Adshead, Norman & Holloway, 2021; Chan et al., 2022; Corrigan, 1995; Knight et al., 2020). At least one participant mentioned that they also used substances preinjury which is in keeping with the suspected bidirectional relationship between ABI and substance use (West, 2011).

**Overcoming challenges and posttraumatic growth** is the final theme that and captured various skills and traits that participants acquired or developed post-injury, physical and cognitive achievements, ways in which they have had to adapt and grow since their injury. It has clear links to the acceptance, support network, and protective factors and coping strategies themes.

I1 (to P1)- Yeah, its improved! It's so it's it's absolutely not where it was at all. If we were to go back 15 years. So this Friday, you got an appointment that you need to travel to. You will be you planned it, you'll go on your own, you'll deal with the people, you'll come back on your own 15 years ago, you wouldn't have planned it, and someone else would have had to have gone with you. [ ] So there has been dramatic changes. That's a real considerable change!

I1 (to P1) you started to really achieve physically and you're the only person I know who's ever rung me to say "I'm supposed to renew my blue badge, should I do it?" And I said to you I said "How far can you walk?" You said "I did seven miles on Saturday". I think I think the form said 50 yards and I said well, I can remember saying this you to you "well you can defraud them and get a blue badge if you want. Or you can be one of the first people in Britain to tear yours up and not get one again.

P2 - it was, you know, is a very difficult time and I think that is one of the things that helps me manage with low mood. Yeah, its just knowing that I have succeeded as it were, in surviving

P3 - In the early days I couldn't express my feelings but I was the yeah man, a yes man so I've learned to adapt to making it easier by expressing myself

P3 - Yeah I can express myself and I wouldn't have been able to back then, I don't know if it was the, because of the industry I was in. You know the industry I was in and the culture was umm men that do manual work won't talk about their thoughts or feelings and problems and umm you know you just don't do that you know its uh if you do it you would get laughed at

P3 - I can express myself uhh which is a good coping strategy because it stops you getting abuse and other people getting abuse as well.

**Community engagement** was a subtheme of overcoming challenges and posttraumatic growth and captured the drive that some of those living with an ABI feel to give something back to others often to those in the brain injured community specifically (e.g. time, knowledge, lived experience).

I1 (to P2) I think it is quite special that you're able to very genuinely use your experience

P2 - for the benefit of the recording, I'm doing a master's in in health promotion, all the modules are finished. I'm working on my dissertation at the moment, which is a critical autoethnography on return to work after brain injury [ ] Umm so I want to use my experience

as an asset. And you know this is something I hear from a lot of people that they want to put back into the system. And because I've been through the system over a long period of time on multiple occasions at this point, I thought you know, it's not just that I want to put back into the system. It's that I want to understand the system in case I'm ever in it again

P1 -Probably it's like, my brain is kind of more empathetic. Just because I've been shown so much love and kindness, and kind of understanding and stuff. I just feel I should pay it back a bit

I1 (to P1) - Interestingly, you now talk things through with other people for their benefit. And I don't think that's very common. I think that's quite a unique to you.

The concept of posttraumatic growth (PTG) has only recently been applied to ABI, as previous research about the consequences of brain injury have tended to focus on the negative implications. However, as evidenced in the present study and the available literature sometimes those who experience an ABI see positive changes or growth in themselves post-injury. It applies to various domains and can be in relation to employment, personal development, supporting others, and the acquisition of new skills or traits but having a sense of purpose has been suggested as the most powerful predictor of PTG (Powell, Gilson & Collin, 2012). Downing et al. (2021) found that social support and engagement are predictive of wellbeing and successful rehabilitation which can be similar to the community engagement subtheme and wanting to give something back and be involved with the community.

## **Conclusion**

The present study set out to explore reasons for living after an ABI, it was decided an important avenue of investigation based on previous literature around the increased rates of suicidality in those living with ABI and a lack of qualitative and recent research on that topic. The analysis found two overarching themes of *Loss and maintenance of sense of self (subtheme Long-term effects of ABI)* and *ABI is a hidden disability (subtheme of Lack of knowledge around ABI)* and five other main themes of *Acceptance, Support networks (subthemes of Social and Professional support), Experiences of low mood or suicidality, Protective factors and coping strategies (subtheme Maladaptive coping)* and *Overcoming challenges and posttraumatic growth (subtheme Community engagement)*. The deductive stage of the analysis found several themes within the data that were similar to those found by Knight et al. (2020), however since suicidality turned out to be a comparatively minor theme in the present study the underlying structure and focus of most of the themes was fundamentally different. As sometimes happens with qualitative research the focus and results of the research evolves and is guided by what emerges from the data (Silverman, 2013). Based on the data collected the themes that emerged included factors that facilitate recovery, rehabilitation, well-being and functioning rather than suicidality specifically. Learning to accept help was an important step in recovery and was also discussed in a case manager perspective as being key for their client. They also suggested that it might be something that could be pre-emptively broached with clients to improve their quality of life and recovery.

There were a few mentions of suicidality however evidence was not found for chronic suicidality. This may have been caused by sampling bias as it was a small and homogenous sample so may not be representative of those living with ABI in the UK, and data saturation was not reached (Fusch & Ness 2015). The Knight et al. (2020)

sample was purposively selected and pre-screened to only include those experiencing suicidality which is likely also a factor in the differing results.

It is also possible that it was a sample of individuals with characteristics or traits that offered them protection against suicidality (e.g. maintained sense of self). Perhaps more likely it was a combination of long-term case management, a good support network, acceptance (in various forms) and participants having a diverse and effective range of protective factors and coping strategies developed and honed over their recovery and posttraumatic growth. All four participants in the present study were 22 years or more post-injury having had very long-term case management and support in place. Whereas the mean time since injury in the Knight et al. paper was between eight and nine years possibly lending support to suicidality being ameliorated by long-term, good quality structured support being in place.

Another potential explanation is that the participants may have been lacking awareness, insight or memories around experiencing suicidality. Lacking insight or awareness around one's condition post-injury is quite common (Coelho, 2007; Douglas, 2010) and is one of the reasons that the secondary data source was sought from the case managers. There was a clear difference in recollection around experiences of suicidality between two of the participants and their case managers. One participant did briefly discuss experiencing suicidality in the past but focused more on the various other mental health and emotional difficulties that he had experienced and did not dwell on it for long. However, the case manager perspective suggested that suicidality had been a significant and ongoing issue for their client. They suggested that his tendency toward being "*future focused*" might explain the lack of discussion around it during the interview. They felt they were "*always on suicide watch*" and said his risk is determined by triggers and stress-levels in his life. Another participant had no recollection of ever being suicidal, yet his case manager remembered the past quite differently. This divergence in recollection lends some support to the idea that lacking insight, awareness, or having memory deficits or a future focus might mean that they do not conceptualise historical difficulties with suicidality the same way that a neurologically intact individual might.

### **Strengths and limitations**

Downing et al. (2021) suggests that research on positive factors and influences on rehabilitation is lacking, so hopefully despite the somewhat unexpected results the present study will still add to a critical area of research. Based on the depth and richness of the collected data case managers conducting the interviews was a sound decision. They were able to prompt and scaffold their clients to get much richer responses than someone who lacked that level of familiarity, they were also well placed to monitor for psychological distress. Conversely, the case managers conducting the interviews could also be seen as a limitation as the scaffolding did mean some leading questions were used, and due to their profession they undoubtedly had assumptions about ABI and its relationship to suicidality.

There is an obvious but important limitation of a very small sample size and data saturation not being reached (Fusch & Ness 2015) and there were also no females, and even considering the uneven gender distribution among those living with ABI it was not representative. Due to the nature of undergraduate research, the data were coded and themes identified by the student researcher only, (although the analysis

was discussed with the research supervisor). Interrater reliability was therefore lacking as was the diversity of opinion and knowledge that having multiple perspectives from people with diverse backgrounds and expertise achieves.

An unfortunate further limitation of this study was the exclusion of individuals living with the most severe ABI as the inclusion criteria of the study specified cognitively able and psychologically stable enough to participate which in effect meant that those with particularly severe injuries or enduring cognitive or psychological difficulties were not able to take part. The theme of ABI is a hidden disability specifically references those most severely affected by ABI not having a voice or input, so it is a shame that the present study has perpetuated this problem. Linked into user voice being lacking a further limitation was not completing “member checks” where one speaks to the participants post (or during) analysis and verifies that the data has been accurately interpreted (Cutcliffe & McKenna, 2002).

### **Future research and implications**

Future research could use a larger sample and perhaps also use a qualitative survey to further expand the data collected. Involving other researchers and case managers in the analysis process would also be helpful, developing themes through discussions and ideally including at least some consultation with the participants themselves (Locock et al., 2019). It would be interesting to do a follow up study to Knight et al. (2020) using their original sample to see if the additional time spent being supported under case management was a factor in ameliorating suicidality.

The data from the present study suggests that those living with ABI who have long-term case management, a good support network, various protective factors and coping strategies, and practice acceptance may experience reduced levels of suicidality and emotional distress as well as improved wellbeing, functionality, and posttraumatic growth. However, the level of transferability from the present study is limited due to sample size and data saturation not being reached so further research is needed to draw any firm conclusions.

### **Acknowledgements**

I would like to say a massive thank you to my research supervisor Dr Alyson Norman who has also been my mentor during most of my time at Plymouth University. Her support, kindness, and guidance have been invaluable and life changing, and I feel very lucky to have met her! I would also like to say thanks to the participants who were kind enough to take part in this research and share some of their lived experience and valuable knowledge. A special thanks also to Dr Mark Holloway and the case managers who took part, as well as the BABICM research committee, as this research would not have been possible without their assistance. I would also like to thank Dr Sue Jackson for her kind assistance. Last but by no means least I would like to thank my husband Don and my late but beloved rescue dog Blue for their patience and loving support while I worked on this research and my late parents who in their own ways both inspired me to pursue psychology and a career in mental health.

## References

- Adshead, C. D., Norman, A., & Holloway, M. (2021). The inter-relationship between acquired brain injury, substance use and homelessness; the impact of adverse childhood experiences: An interpretative phenomenological analysis study. *Disability and rehabilitation*, 43(17), 2411-2423.
- Alexander, B. K., Beyerstein, B. L., Hadaway, P. F., & Coombs, R. B. (1981). Effect of early and later colony housing on oral ingestion of morphine in rats. *Pharmacology Biochemistry and Behavior*, 15(4), 571-576.
- Ament, W., & Verkerke, G. J. (2009). Exercise and fatigue. *Sports medicine*, 39(5), 389-422.
- Bahraini, N. H., Simpson, G. K., Brenner, L. A., Hoffberg, A. S., & Schneider, A. L. (2013). Suicidal ideation and behaviours after traumatic brain injury: a systematic review. *Brain Impairment*, 14(1), 92-112.
- Barco, P. P., Crosson, B., Bolesta, M. M., Werts, D., & Stout, R. (1991). Training awareness and compensation in postacute head injury rehabilitation. In J. S. Kreutzer & P. H. Wehman (Eds.), *Cognitive rehabilitation for persons with traumatic brain*
- Barnes, M., Bennet, E., & Etherington, J. (2018). Acquired brain injury and neurorehabilitation time for change: All party parliamentary group on acquired brain injury report. *UKABIF: UK*.
- Batty, R. A., Rossell, S. L., Francis, A. J., & Ponsford, J. (2013). Psychosis following traumatic brain injury. *Brain Impairment*, 14(1), 21-41.
- Beck, A. T., Brown, G., & Steer, R. A. (1989). Prediction of eventual suicide in psychiatric inpatients by clinical ratings of hopelessness. *Journal of consulting and clinical psychology*, 57(2), 309.
- Beck, A. T., Steer, R. A., Kovacs, M., & Garrison, B. (1985). Hopelessness and eventual suicide: A 10-year prospective study of patients hospitalized with suicidal ideation. *American journal of Psychiatry*, 1(42), 559-563.
- Belmont, A., Agar, N., Hugeron, C., Gallais, B., & Azouvi, P. (2006). Fatigue and traumatic brain injury. In *Annales de réadaptation et de médecine physique* (Vol. 49, No. 6, pp. 370-374). Elsevier Masson.
- Bessell, A. L., Watkins, E. R., & Williams, W. H. (2008). Depressive rumination reduces specificity of autobiographical memory recall in acquired brain injury. *Journal of the International Neuropsychological Society*, 14(1), 63-70.
- Bjork, J. M., & Grant, S. J. (2009). Does traumatic brain injury increase risk for substance abuse?. *Journal of neurotrauma*, 26(7), 1077-1082.



- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2), 77-101.
- Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*. Sage.
- Braun, V., & Clarke, V. (2022). *Thematic Analysis: A practical guide*. Sage
- Bredewold, F., Verplanke, L., Kampen, T., Tonkens, E., & Duyvendak, J. W. (2020). The care receivers perspective: How care-dependent people struggle with accepting help from family members, friends and neighbours. *Health & Social Care in the Community*, 28(3), 762-770.
- Brenner, L. A., Homaifar, B. Y., Adler, L. E., Wolfman, J. H., & Kemp, J. (2009). Suicidality and veterans with a history of traumatic brain injury: Precipitating events, protective factors, and prevention strategies. *Rehabilitation Psychology*, 54(4), 390.
- British Psychological Society. (2018). Code of Ethics and Conduct (2018). <https://bps.org.uk/newsand-policy/bps-code-ethics-and-conduct>
- Cantor, J. B., Ashman, T., Gordon, W., Ginsberg, A., Engmann, C., Egan, M., ... & Flanagan, S. (2008). Fatigue after traumatic brain injury and its impact on participation and quality of life. *The Journal of head trauma rehabilitation*, 23(1), 41-51.
- Carroll, E., & Coetzer, R. (2011). Identity, grief and self-awareness after traumatic brain injury. *Neuropsychological rehabilitation*, 21(3), 289-305.
- Chan, V., Toccalino, D., Omar, S., Shah, R., & Colantonio, A. (2022). A systematic review on integrated care for traumatic brain injury, mental health, and substance use. *PLoS one*, 17(3), e0264116.
- Christie, N. C. (2021). The role of social isolation in opioid addiction. *Social Cognitive and Affective Neuroscience*, 16(7), 645-656.
- Clark-Wilson, J., & Holloway, M. (2015). Life care planning and long-term care for individuals with brain injury in the UK. *NeuroRehabilitation*, 36(3), 289-300.
- Coelho, C. A. (2007). Management of discourse deficits following traumatic brain injury: Progress, caveats, and needs. In *Seminars in Speech and Language* (Vol. 28, No. 02, pp. 122-135). Copyright© 2007 by Thieme Medical Publishers, Inc., 333 Seventh Avenue, New York, NY 10001, USA..
- Corrigan, J. D. (1995). Substance abuse as a mediating factor in outcome from traumatic brain injury. *Archives of physical medicine and rehabilitation*, 76(4), 302-309.
- Cutcliffe, J. R., & McKenna, H. P. (2002). When do we know that we know? Considering the truth of research findings and the craft of qualitative research. *International journal of nursing studies*, 39(6), 611-618.

- Deaton, A. V. (1986). Denial in the aftermath of traumatic head injury: Its manifestations, measurement, and treatment. *Rehabilitation Psychology*, 31(4), 231.
- Deslandes, A., Moraes, H., Ferreira, C., Veiga, H., Silveira, H., Mouta, R., ... & Laks, J. (2009). Exercise and mental health: many reasons to move. *Neuropsychobiology*, 59(4), 191-198.
- Douglas, J. M. (2010). Relation of executive functioning to pragmatic outcome following severe traumatic brain injury.
- Downing, M., Hicks, A., Braaf, S., Myles, D., Gabbe, B., Cameron, P., ... & Ponsford, J. (2021). Factors facilitating recovery following severe traumatic brain injury: A qualitative study. *Neuropsychological rehabilitation*, 31(6), 889-913.
- Fereday, J., & Muir-Cochrane, E. (2006). Demonstrating rigor using thematic analysis: A hybrid approach of inductive and deductive coding and theme development. *International journal of qualitative methods*, 5(1), 80-92.
- Festinger, L. (1957). *A theory of cognitive dissonance*. Evanston, IL: Row, Peterson.
- Fleming, J. M., Strong, J., & Ashton, R. (1996). Self-awareness of deficits in adults with traumatic brain injury: how best to measure?. *Brain injury*, 10(1), 1-16.
- Fusch, P. I., & Ness, L. R. (2015). Are we there yet? Data saturation in qualitative research. *The qualitative report*, 20(9), 1408.
- Gallego, M. G., & García, J. G. (2017). Music therapy and Alzheimer's disease: Cognitive, psychological, and behavioural effects. *Neurología (English Edition)*, 32(5), 300-308.
- Graham, D. P., & Cardon, A. L. (2008). An update on substance use and treatment following traumatic brain injury. *Annals of the New York Academy of Sciences*, 1141(1), 148-162.
- Headway (2018). Retrieved from <https://www.headway.org.uk/about-brain-injury/further-information/statistics/>
- Hickley, A. (2018). Verbatim, intelligent verbatim or edited transcription.
- Holloway, M., & Norman, A. (2022). Just a little bit of history repeating: the recurring and fatal consequences of lacking professional knowledge of acquired brain injury. *The Journal of Adult Protection*.
- Irish, M., Cunningham, C. J., Walsh, J. B., Coakley, D., Lawlor, B. A., Robertson, I. H., & Coen, R. F. (2006). Investigating the enhancing effect of music on autobiographical memory in mild Alzheimer's disease. *Dementia and geriatric cognitive disorders*, 22(1), 108-120.

- Kangas, M., & McDonald, S. (2011). Is it time to act? The potential of acceptance and commitment therapy for psychological problems following acquired brain injury. *Neuropsychological rehabilitation*, 21(2), 250-276.
- Kersel, D. A., Marsh, N. V., Havill, J. H., & Sleigh, J. W. (2001). Psychosocial functioning during the year following severe traumatic brain injury. *Brain injury*, 15(8), 683-696.
- Knight, E., Norman, A., & Simpson, G. K. (2020). Living with suicidality following traumatic brain injury: A qualitative study. *Brain injury*, 34(8), 1010-1019.
- Lefebvre, H., Cloutier, G., & Josee Levert, M. (2008). Perspectives of survivors of traumatic brain injury and their caregivers on long-term social integration. *Brain Injury*, 22(7-8), 535–543. <https://doi.org/10.1080/02699050802158243>
- Leggieri, M., Thaut, M. H., Fornazzari, L., Schweizer, T. A., Barfett, J., Munoz, D. G., & Fischer, C. E. (2019). Music intervention approaches for Alzheimer's disease: A review of the literature. *Frontiers in Neuroscience*, 13, 132.
- Liang, S. (2016). Otter Ai [Web based software]. [www.otter.ai](http://www.otter.ai)
- Locock, L., Kirkpatrick, S., Brading, L., Sturmeay, G., Cornwell, J., Churchill, N., & Robert, G. (2019). Involving service users in the qualitative analysis of patient narratives to support healthcare quality improvement. *Research involvement and engagement*, 5(1), 1-11.
- Maas, A. I., Menon, D. K., Adelson, P. D., Andelic, N., Bell, M. J., Belli, A., ... & Francony, G. (2017). Traumatic brain injury: integrated approaches to improve prevention, clinical care, and research. *The Lancet Neurology*, 16(12), 987-1048.
- Madsen, T., Erlangsen, A., Orlovska, S., Mofaddy, R., Nordentoft, M., & Benros, M. E. (2018). Association between traumatic brain injury and risk of suicide. *Jama*, 320(6), 580-588.
- Menon, D. K., Schwab, K., Wright, D. W., & Maas, A. I. (2010). Position statement: definition of traumatic brain injury. *Archives of physical medicine and rehabilitation*, 91(11), 1637-1640.
- Myles, S. M. (2004). Understanding and treating loss of sense of self following brain injury: A behavior analytic approach. *International journal of psychology and psychological therapy*, 4(3), 487-504.
- Nochi, M. (1998). "Loss of self" in the narratives of people with traumatic brain injuries: A qualitative analysis. *Social science & medicine*, 46(7), 869-878.
- Norman, A. (2016). A preventable death? A family's perspective on an adult safeguarding review regarding an adult with traumatic brain injury. *The Journal of Adult Protection*.

- Norman, A. (2020). *Life and Suicide Following Brain Injury: A Personal and Professional Account*. Routledge.
- Norman, A., Holloway, M., Odumuyiwa, T., Kennedy, M., Forrest, H., Suffield, F., & Dicks, H. (2020). Accepting what we do not know: A need to improve professional understanding of brain Injury in the UK. *Health & Social Care in the Community*, 28(6), 2037-2049.
- O'callaghan, C., Powell, T., & Oyebode, J. (2006). An exploration of the experience of gaining awareness of deficit in people who have suffered a traumatic brain injury. *Neuropsychological Rehabilitation*, 16(5), 579-593.
- Odumuyiwa, T., Kennedy, M., Norman, A., Holloway, M., Suffield, F., Forrest, H., & Dicks, H. (2019). Improving access to social care services following acquired brain injury: a needs analysis. *Journal of Long-Term Care*, 2019, 164-175.
- Olsen, C. M., & Corrigan, J. D. (2021). Does traumatic brain injury cause risky substance use or substance use disorder?. *Biological psychiatry*.
- Owen, G. S., Freyenhagen, F., Martin, W., & David, A. S. (2017). Clinical assessment of decision-making capacity in acquired brain injury with personality change. *Neuropsychological rehabilitation*, 27(1), 133-148.
- Oyesanya, T. O., & Ward, E. C. (2016). Mental health in women with traumatic brain injury: a systematic review on depression and hope. *Health care for women international*, 37(1), 45-74.
- Perry, D. C., Sturm, V. E., Peterson, M. J., Pieper, C. F., Bullock, T., Boeve, B. F., ... & Welsh-Bohmer, K. A. (2016). Association of traumatic brain injury with subsequent neurological and psychiatric disease: a meta-analysis. *Journal of neurosurgery*, 124(2), 511-526.
- Pin-Barre, C., & Laurin, J. (2015). Physical exercise as a diagnostic, rehabilitation, and preventive tool: influence on neuroplasticity and motor recovery after stroke. *Neural plasticity*, 2015.
- Ponsford, J., Alway, Y., & Gould, K. R. (2018). Epidemiology and natural history of psychiatric disorders after TBI. *The Journal of neuropsychiatry and clinical neurosciences*, 30(4), 262-270.
- Ponsford, J., Kelly, A., & Couchman, G. (2014). Self-concept and self-esteem after acquired brain injury: A control group comparison. *Brain Injury*, 28(2), 146-154.
- Powell, T., Gilson, R., & Collin, C. (2012). TBI 13 years on: Factors associated with post-traumatic growth. *Disability and rehabilitation*, 34(17), 1461-1467.
- Rauch, R. J., & Ferry, S. M. (2001). Social networks as support interventions following traumatic brain injury. *NeuroRehabilitation*, 16(1), 11-16.

- Rogers, J. M., & Read, C. A. (2007). Psychiatric comorbidity following traumatic brain injury. *Brain injury*, 21(13-14), 1321-1333.
- Rosenfeld, J. V., Maas, A. I., Bragge, P., Morganti-Kossmann, M. C., Manley, G. T., & Gruen, R. L. (2012). Early management of severe traumatic brain injury. *The Lancet*, 380(9847), 1088-1098.
- Silverman, D. (2013). *Doing qualitative research: A practical handbook*. Sage.
- Simpson, G. K., Tate, R. L., Whiting, D. L., & Cotter, R. E. (2011). Suicide prevention after traumatic brain injury: A randomized controlled trial of a program for the psychological treatment of hopelessness. *The Journal of head trauma rehabilitation*, 26(4), 290-300.
- Simpson, G., & Tate, R. (2002). Suicidality after traumatic brain injury: demographic, injury and clinical correlates. *Psychological medicine*, 32(4), 687-697.
- Simpson, G., Simons, M., & McFadyen, M. (2002). The challenges of a hidden disability: Social work practice in the field of traumatic brain injury. *Australian Social Work*, 55(1), 24-37.
- Soo, C., Tate, R. L., & Lane-Brown, A. (2011). A systematic review of acceptance and commitment therapy (ACT) for managing anxiety: Applicability for people with acquired brain injury?. *Brain Impairment*, 12(1), 54-70.
- Stein, M. B., Jain, S., Giacino, J. T., Levin, H., Dikmen, S., Nelson, L. D., ... & TRACK-TBI Investigators. (2019). Risk of posttraumatic stress disorder and major depression in civilian patients after mild traumatic brain injury: a TRACK-TBI study. *JAMA psychiatry*, 76(3), 249-258.
- Stroke Association (2020). Retrieved from <https://www.stroke.org.uk/what-is-stroke/stroke-statistics-sources-and-definitions>
- Teasdale, T. W., & Engberg, A. W. (2001). Suicide after traumatic brain injury: a population study. *Journal of Neurology, Neurosurgery & Psychiatry*, 71(4), 436-440.
- Tomaino, C. M. (2009). Clinical applications of music therapy in neurologic rehabilitation. In *Music that works* (pp. 211-220). Springer, Vienna.
- van der Veen, A. M., & Bleich, E. (2021). Atheism in US and UK Newspapers: Negativity about Non-Belief and Non-Believers. *Religions*, 12(5), 291.
- Vanderbeken, I., & Kerckhofs, E. (2017). A systematic review of the effect of physical exercise on cognition in stroke and traumatic brain injury patients *NeuroRehabilitation*, 40(1), 33-48.

Waltzman, D., Daugherty, J., Sarmiento, K., & Proescholdbell, S. (2021). Lifetime history of traumatic brain injury with loss of consciousness and the likelihood for lifetime depression and risk behaviors: 2017 BRFSS North Carolina. *The Journal of head trauma rehabilitation*, 36(1), E40.

West, S. L. (2011). Substance use among persons with traumatic brain injury: A review. *NeuroRehabilitation*, 29(1), 1-8.

Whiting, D. L., Deane, F. P., Simpson, G. K., McLeod, H. J., & Ciarrochi, J. (2017). Cognitive and psychological flexibility after a traumatic brain injury and the implications for treatment in acceptance-based therapies: A conceptual review. *Neuropsychological rehabilitation*, 27(2), 263-299.

Wise, E. K., Hoffman, J. M., Powell, J. M., Bombardier, C. H., & Bell, K. R. (2012). Benefits of exercise maintenance after traumatic brain injury. *Archives of physical medicine and rehabilitation*, 93(8), 1319-1323.

**Appendices are provided separately as supplementary files (please see additional downloads for this paper).**