How do people with brain injury understand the interaction between mind, brain, self and injury?

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Thesis declaration form

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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Overview

This thesis explores the conceptual models adults with acquired brain injury (ABI) use to understand changes following injury, particularly those reflecting the relationships between mind, brain and self. Part one is a conceptual introduction on how philosophical perspectives impact clinical models and clinicians' understandings in this area. Research into the self was also outlined indicating how adults with ABI understand changes. Biopsychosocial models were presented to demonstrate holistic understandings before an argument for the inclusion of service user accounts in our understandings. This paper concludes that there is a dearth of research exploring the conceptualisations adults with ABI use to understand changes, particularly regarding relationships between mind, brain and self.

Part two is a qualitative empirical paper exploring the conceptual models adults with ABI use to understand changes following injury. This was conducted jointly with Alice Chesterfield, although we have separate thesis with separate populations. Semi-structured interviews were conducted with 15 participants with ABI. Grounded theory guided the analysis. Results indicated that participants generally centred their brain injury, within a more holistic understanding, to understand changes. Changes in the self and the mind were indicated following brain injury and were generally attributed to ABI. Furthermore, these understandings were sometimes incomplete or indescribable. The clinical implications are outlined regarding how we should speak with adults with ABI about changes.

Part three is a reflective paper which critically appraises the process of conducting the research with regards to my assumptions, considerations of conducting research with adults with ABI and outsider research.

Impact statement

There are implications from the findings of this study to further our academic, clinical and wider public understandings of the conceptual models adults with acquired brain injury (ABI) use to understanding changes following injury, particularly those reflecting relationships between mind, brain, self and injury.

The research highlighted that adults with ABI generally centred their ABI in understanding changes following brain injury, which included changes in the way their mind works and their sense of self. However, this was embedded within a more holistic narrative that considered other contributing factors, such as faith, mental health, and culture. Clinically, this has implications that more holistic models, such as biopsychosocial ones, are likely more appropriate to use in consultations, at least for this group of participants. It also suggests that more single-factored understandings, such as only considering the physical brain injury as the functional-organic distinction would, are less helpful for this group of participants. This is important as the findings indicated that participants often did not feel that professionals understood their difficulties well, which was sometimes influenced by the perception that they were not viewed holistically. Furthermore, it could help the wider public appreciate that the experiences of adults with ABI may be explained by a variety of factors and not only their ABI.

Findings also revealed that participants' understandings were influenced by things they had read and through conversations with others. Furthermore, they did not always have complete understandings or had difficulties finding the words at times. This is helpful for clinicians (and potentially others with ABI and their support networks) to be aware of when they are supporting people with ABI with making sense of their experiences.

There did not appear to be one dominant narrative or inferable philosophical position for the relationship between mind, brain/body, and self, mirroring the myriad of perspectives within academia and more widely. These perspectives should be incorporated into our academic debates given these are the people we are ultimately hoping to help. It is also of note that when people spoke about their brain injury, they were often referring to both the physical brain injury and the psychosocial processes involved with it. This is helpful information for people to hold in mind when conversing with adults with ABI.

This study also indicates it would be fruitful to research more specific areas of mind-brain/body relationships (for example, explicitly studying the mind-body disconnect) with adults with ABI to further understanding of the conceptual models used by those with ABI. It would also be helpful to research the conceptual models developed by other clinical populations affected by the clinical tools we use, such as those diagnosed with functional neurological disorder.

The findings of this research are anticipated to be fed back to members at the brain injury charity. We hope to further the scope of the dissemination through publication in an appropriate academic journal and dissemination in clinical settings, where appropriate.

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Part 2: Empirical paper

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Part 1: Literature Review

A review of how changes are conceptualised following acquired brain injury

Abstract

Little is known about the conceptual models that adults with acquired brain injury (ABI) use to make sense of changes following their injury. In particular, how these reflect the relationships between mind, body/brain and self. Therefore, this introduction will outline how different philosophical perspectives relevant to mind-body relationships have influenced the scientific conceptualisations of disorders, including clinicians’ views and the functional-organic distinction. I will go onto review studies exploring how those with ABI understand changes in their sense of self following injury to demonstrate research exploring conceptualisations made by those with ABI. Biopsychosocial perspectives used to understand changes will also be included to highlight holistic models in understanding those with ABI. Furthermore, the importance of including service user accounts in our conceptualisations will be explored, using psychosis as an example of how this has been done. This is as a prerequisite to our qualitative study which aims to identify how adults with ABI make sense of their experiences following injury, as well as whether this relates to key concepts clinicians currently use to inform their practice and prioritise healthcare needs.

1. Introduction

In this conceptual introduction, I will review the existing literature relevant to the conceptual models adults with acquired brain injury (ABI) may use to understand changes following their injury. This will also reference key concepts, such as the mind-brain problem and concept of the self. As there is sparse research in this area, professionals' conceptual understandings will be explored. This will serve as a prerequisite to the current qualitative study where an account of how adults with ABI understand the relationship between mind, brain/body, self, and brain injury is reported.

I will begin by defining ABI and the key considerations relevant to this condition. I will then outline how different philosophical positions underpin the scientific conceptualisations of disorders, including clinicians' views and the functional-organic distinction, which is a clinical tool/framework used to understand disorders (Bell et al., 2020). Consideration of how this applies to adults with ABI will be included as these concepts within academia may influence the conceptualisations held by those with ABI.

Furthermore, I will review research exploring how people with ABI and clinicians understand changes following injury, particularly pertaining to the relationships between mind, body/brain and self. This will include an overview of studies with adults with ABI into the concept of self and biopsychosocial models used to understand some specific difficulties adults with ABI may experience. Finally, it will consider why it is fundamental for service users' phenomenological accounts to be built into our theoretical understandings of ABI.

This introduction will conclude with what needs to happen next to further our understanding in this area and how the current study proposes to begin this process. Moreover, the current study adopts a grounded theory approach and a pragmatic epistemological stance of defining truth as something that is useful and functionally helpful (Barker et al., 2016 p. 10), meaning a more constructivist grounded theory approach was used

(Charmaz, 2014, pp. 230-241). Therefore, some of the phrasing is tentative throughout to both highlight that there has been a dearth of research in this area but also that different, varied perspectives may be adopted to understand the same phenomenon or experience.

2. Acquired brain injury (ABI)

Prior to exploring literature relevant to understanding changes following ABI, an overview of the definitions and relevant considerations related to ABI will be provided. This will help contextualise the information and outline unique factors relevant to how people with ABI may navigate their understandings of themselves (for example, how their symptoms or experiences, such as cognitive deficits, may interact with how they understand themselves).

An ABI is defined as a physical injury to the brain which has occurred following someone's birth (Sheehan et al., 2019, p. 193). ABI is a broad term as it encompasses injury sustained through trauma to the brain (such as through a fall or accident), otherwise known as traumatic brain injury (TBI), as well as injury caused by cerebrovascular events where typical blood flow to the brain is disrupted, such as stroke (Driver et al., 2021; Sheehan et al., 2019, p. 193). Worldwide, there has been estimated to be 69 million people who experience a TBI each year (Dewan et al., 2018), which represents a portion of those with ABI.

An ABI has a significant impact on the affected person's life and there is generally considered to be a period of loss, grief and adjustment following the injury (Coetzer, 2004). However, this is often accompanied by a period of reduced awareness of their difficulties and therefore meaning making and adjustment may develop over time (Coetzer, 2004). Despite this being acknowledged, it can be challenging for others, such as the individual's support system and professionals, to fully understand this phenomenon (Coetzer, 2004). It is also known that a brain injury can lead to changes in the body, behaviour, emotional experiences and cognition (Gombay & Andrews, 2021; Jones et al., 2011), although the emotional experiences have been comparatively neglected in academic literature (Coetzer, 2004). While difficulties can be seen in many areas, some examples include sensory perception (Gombay & Andrews, 2021), executive functioning (Chamberlain, 2006), occupational capabilities (Klinger, 2005), memory loss (Jones et al., 2011) and speech (Carlsson et al., 2007). These various difficulties and experiences could potentially impact the individual's development of conceptual models regarding how they understand changes.

Furthermore, people with ABI are at higher risk of developing some mental health difficulties as evidenced by Osborn et al. (2014) who calculated that 27% of people with TBI had a formal diagnosis of major depressive disorder and/or dysthymia, based upon 31 studies exploring this area (although the individual study figures ranged from 9-67%). Additionally, Osborn et al. (2016) averaged that 11% of people with TBI were diagnosed with Generalised Anxiety Disorder following their injury, based upon 22 studies that included prevalence of this comorbid diagnosis. However, the link between ABI and mental health is complex given that the potential effects of brain injury can reflect symptoms of many mental health disorders outlined in diagnostic manuals (Sheehan et al., 2019, p. 200). Therefore, oftentimes, comorbid mental health difficulties may also need to be considered when holistically understanding the experiences of someone with an ABI.

Furthermore, because some changes following brain injury are largely based upon the affected individual's subjective self-reports as opposed to objective measurement (such as in perception and mood), the extent of disability validated can be varied and this means that people with ABI can be made to feel like it is "all in their head" (Chamberlain, 2006).

In sum, an ABI is a term that encompasses a diverse group of people as the associated deficits and comorbid mental health difficulties are varied in both their presence and severity.

3. Philosophy of mind

Philosophers have considered for many years whether the mind is different to the brain (Buzan et al., 2014) to understand the relationship between mental and physical states, as well as the nature in which they influence each other, if at all (Robinson, 2016). This is an area of study that has been discussed for many years and referred to as the mind-body problem, although it has been acknowledged as a “problem” which is insolvable (Beaumont et al., 1996, p. 488).

Despite this, individuals may adopt different philosophical stances in relation to the mind-body problem. These different philosophical branches can largely be grouped into two broad churches: monism (who believe the mind and body are unified and the same in essence) and dualism (who believe mind and body are distinct and separate) (Beaumont et al., 1996, p. 489).

In this paper, each philosophical position will not be outlined but rather the significant impacts of key philosophical perspectives on clinical understandings of diagnosable disorders, as well as their related practice implications. This will also include the impact of everyday understandings of human behaviour. This is to demonstrate how the simplistic view of disorders in some of the clinical tools we use do not appreciate the complexities of diagnosable difficulties (Kendler, 2012) or reflect the complexities of philosophical debates. Furthermore, how this relates to those with ABI specifically will also be considered, with the acknowledgement that their perspectives have not yet been sought on a debate which considerably impacts them.

3.1 Philosophy of mind in scientific thinking

Scientific thinking concerning disorders was significantly influenced by substance dualism until the seventeenth and eighteenth centuries (Dempsey, 2009; Kendell, 2001). Substance dualism emerged from Plato, who suggested the body and soul are separate entities that have different properties (Robinson, 2016). Similar ideas fruited over time, with Descartes inventing cartesian dualism (a form of substance dualism) by positing that that the mind and brain are fundamentally separate and constructed of different substances, the former which does not occupy space and the latter which is made of physical material (Kendler, 2012). This meant disorders were viewed as originating from either the mind or the brain (Kendell, 2001).

It is worth noting that substance dualism has now largely been disregarded (Lycan, 2013) as it has been argued to be scientifically unacceptable for various reasons, such as the fact it not a testable theory and no positive evidence exists for the immaterial substances (Churchland, 1988). However, these stark divisions between mental and physical disorders are still prevalent in the thinking of the general population and some professionals (Kendell, 2001), and it has an ongoing impact upon society (Hamilton & Hamilton, 2015).

Other philosophical positions have since become popularised in modern scientific thinking (Kim, 1995, p. 139; Poole & Bolton, 2020, pp. 1-2). One of these is positions is property dualism, as it is generally considered a more plausible form of dualism (Lycan, 2013). This position suggests that humans are not made of immaterial substances, but rather mental states simply have mental properties that are not material, unlike our physical states (Lycan, 2013). Another position is materialism, which is a form of monism that posits that the mind is birthed from the operations of the brain (Robinson, 2016) and therefore all disorders of the mind are primarily disorders of the brain. Although these positions are respectively dualist and monist, they are not incompatible as one can be a non-reductive materialist and advocate ontological monism but adopt the tenet that mental phenomenon is irreducible to the physical (Kim, 1995, p. 139). This idea of the mind emerging from brain function is popular in scientific thinking (Kandel, 1998; Poole & Bolton, 2020, pp. 1-2), as well as the proclivity to posit that mental states are not reducible to physical states (Dempsey, 2009; Fiala et al., 2011, pp. 88-89). However, non-reductive materialism specifically has been criticised for not embracing a dedication to dualism or monism (Kim, 1995, p. 139) and materialism is largely considered the dominant position (Braddon-Mitchell & Jackson, 2007, p. 4; Poole & Bolton, 2020, p. 1-2).

Notwithstanding the above, this philosophical debate is not resolved (Beaumont et al., 1996, p. 488) and various theoretical perspectives with radically different interpretations remain present in scientific discussions (Stent, 1987). For example, eliminative materialism refutes the existence of mental states and believes that as science progresses, use of mentalistic language will become extinct and more brain-based language will replace it (Heil, 2004, p. 357).

In addition to the above, the influence of the general population can be considered through the lens of folk psychology. Folk psychology refers to how lay people make sense of and predict human behaviour, often using mentalistic language (Hutto & Ravenscroft, 2021), based upon commonly held views (Braddon-Mitchell & Jackson, 2007, p. 266). Within this, folk dualism exists, which is the idea that people without specialist philosophy knowledge intuitively find it inappropriate to suggest mental processes can be suitably explained by brain-based processes (Fiala et al., 2011, pp. 89-90). However, there are those who believe folk psychology language will eventually be replaced by neuroscientific language (Churchland, 1995, p. 155). Despite this, there are also those who believe that neuropsychology pervades folk psychology as mental states are presently being understood by lay people in terms of processes and states associated with the brain (Rodriguez, 2006). Albeit an acknowledgement that folk psychology implicitly provides principles for scientific psychology (Heil., 2004, p. 363), there is comparatively little research on the interaction between folk psychology and neuroscientific understandings and conceptualisations, other than a suggestion that the public perceive “illnesses of the mind” to be less “real” and more controllable by the affected individual (Kendell, 2001).

3.2 The impact of different philosophical perspectives on current ways of thinking

As outlined, there are different philosophical perspectives and people with ABI could endorse different views. However, dualism is ingrained into western culture and science (Hamilton & Hamilton, 2015), alongside materialism, which has a significant impact on everyday life and permeates into various systems in our society, such as our legal systems, education and healthcare (Greco, 2019). The extent to which this pervades psychiatry, psychology and neurology is complicated. The impact of dualism on the healthcare system, as well as academic and clinical views, will be outlined as this may influence how people with ABI make sense of any changes they experience following brain injury. This is because they will have had contact with these systems and professionals within them.

One way in which philosophy of mind has underscored healthcare is through the functional-organic distinction, which is utilised as a pivotal instrument in organising healthcare pathways and treatments (Bell et al., 2020). This distinction encourages diagnosable disorders to be grouped into two different types: those that identifiable biological changes can help explain from those which cannot currently be explained by identifiable biological changes (Bell et al., 2020).

3.2.1 The functional-organic distinction.

Prior to the emergence of the functional-organic distinction, cartesian dualism influenced scientific thinking regarding illness in the late eighteenth century as people began to consider insanity as originating from the mind as opposed to the body (Kendell, 2001). Indeed, it has even been argued of all philosophical concepts, cartesian dualism has had the largest influence on psychiatry (Kendler, 2005). However, less than a century later, the concept of functional disorders emerged to indicate difficulties with a proposed differential level of functional activity within one’s body (Kendell, 2001). Functional disorders were further defined as disorders which current biological investigations are unable to detect (Beer, 1996).

Additionally, over the nineteenth and twentieth century, the functional-organic distinction became solidified as advancements meant that neuropathological findings were found for certain disorders (making them “organic”) and the invention of the computer birthed the analogy that the brain could be likened to hardware and the mind to software (Kendler, 2012). However, these concepts have evolved over time leading to a concurrent suggestion that neuropsychiatric problems can be understood in terms of residing in the brain (organic disorders) or in the mind (functional disorders) (Kendler, 2012). This has led to a confused picture where dualist or monist positions could be applied to these conceptualisations. Furthermore, their definitions and use have been inconsistent over time (Bell et al., 2020). Despite these inconsistencies, these concepts are still being used to distinguish between organic and “non-organic”/functional difficulties (David, 2009, p. 4).

3.2.2 Criticisms of the functional-organic distinction.

Although the functional-organic distinction is widely used, it has been criticised for various reasons. Firstly, debates around mind-body relationships do not necessarily imply that experiences can be understood as either emanating from the brain or mind, nor suggesting the brain and mind do not influence one another. However, the way the functional-organic distinction has been adopted can imply disorders have solely organic or functional aetiological origins (Bell et al., 2020).

Furthermore, this simplistic dichotomy, encouraging the categorisation of disorders into a binary system, has been criticised for perpetuating an unsophisticated level of scientific understanding that does not reflect research findings and diminishes the complexities of the multiple factors involved in understanding disorders (Kendler, 2012). For example, it has been acknowledged that there are varied factors that can contribute to understanding mental health difficulties in people with ABI, such as the individual's premorbid personality, the quality of support following injury, lesion site and severity, illness beliefs and psychiatric history (Agrawal, 2020, p. 4). This example illustrates the potential importance of social, psychological, and biological factors, all of which cannot be fully appreciated through the lens of the functional-organic dichotomy. Despite this, it is currently unclear to the extent to which these conceptualisations are adopted or understood by those who are diagnosed with some of these organic or functional disorders, such as ABI.

A further criticism of the functional-organic distinction is that some disorders which have been regarded as "functional" in nature, such as major depressive disorder, are addressed through treatments at a psychological and biological level, such as psychological therapy in addition to psychiatric medication (Bourgeois et al., 2020). Similarly, people with ABI will initially be under the care of neurologists but then may seek psychological therapy to manage their adjustment and distress, which would traditionally not be considered an intervention designed to treat an organic disorder. This demonstrates how organic disorders do not exist in a vacuum removed from other influences and that these influences may interact and intersect, requiring a more holistic understanding that includes factors one may consider 'non-organic'.

Furthermore, in the case of dysphonia, Millar et al. (1999) cautioned against using the functional/organic distinction to dictate whether someone is eligible for voice therapy, which questions the extent to which the distinction can always be relied upon to guide and prioritise treatment. Moreover, Fraguas et al. (2017) raised the question as to whether a psychiatric disorder would be reallocated to an organic one if an organic aetiological origin were to be discovered. This would have apparent implications for the acceptability of established psychiatric treatments (Fraguas et al., 2017) which may have proven to be effective, and this further emphasises the restrictive scope of dichotomous functional-organic classification.

In sum, the functional-organic distinction appears to create a perplexing picture, which does not reflect some of our scientific understandings and ways of treating an array of disorders. It is unclear how much these inconsistencies are mirrored in the understandings of those with ABI, or indeed whether people with ABI seem to be aware of these tensions within the healthcare systems and ways difficulties are understood.

3.2.3 The influence of the functional-organic distinction on clinicians' understandings.

Beyond the scientific understandings within academia, there has been research exploring how the functional-organic distinction influences clinicians' understandings of difficulties. This will likely have an impact on those with ABI regarding what conceptual understandings are conveyed to them in consultations, as well as which clinicians they will have contact with.

Firstly, the functional-organic distinction is embedded into the manuals clinicians use to diagnose mental illness, although its influence is more covert in more recent editions due to the language adopted (Bell et al., 2020). It should be noted that the first two editions of the Diagnostic and Statistical Manual of Mental Disorders (DSM) explicitly made a distinction between disorders of attributed organic or functional aetiology, the latter sometimes being indicated by psychological origin (Tsou, 2011). Although this was removed in the third edition, it appears the remnants of this thinking is still present in current diagnostic manuals as disorders which would typically be thought of as functional are now clustered into different categories, such as "secondary" (Bell et al., 2020), which thinly guises the implication that they are somehow different from disorders with an identifiable pathology within the brain.

There have also been some empirical studies which demonstrate how the functional-organic distinction pervades the ways clinicians think. Firstly, there has been shown to be some disparity in terms of the definitions of functional disorders used in practice. Kanaan et al. (2012) established this when exploring how neurologists in the UK use the term functional. They found that there was ambiguity around what they believed the term encompasses, as well as an acknowledgement that the term was sometimes used differently depending on the context (Kanaan et al., 2012). Specifically, they found neurologists sometimes understood the term to mean four things: a physical disability, a brain disorder, not organic and a psychiatric problem (Kanaan et al., 2012). This inconsistency between the definitions and use likely impacts upon how people diagnosed with functional disorders understand their own experiences, arguably because they may either receive different explanations from different clinicians or have a limited view of what a functional disorder encompasses.

Exploring how the distinction and philosophical standpoints influence clinicians' thinking more broadly, it appears that clinicians view disorders in a dichotomous fashion regarding their biological and psychological bases. Illustrating this, Ahn et al. (2009) asked professionals (social workers, psychiatrists and psychologists) to rate the biological, psychological and environmental basis for a series of disorders within the DSM-IV-TR and found that there was a strong negative correlation between biological and psychological factors. This effect was seen despite the participants being explicitly reminded that the aetiological basis options may not be mutually exclusive in the study.

Some further implications of this can be seen in Miresco and Kirmayer's (2006) study where they asked clinicians, such as psychologists and psychiatrists, to conceptualise some difficulties patients experience. In their study, clinicians reviewed vignettes of patients with disconcerting behaviours in the context of different disorders. They found that for cases where psychological aetiology was perceived, patients were seen as more responsible for their condition than those with an indicated neurobiological aetiology, with a higher degree of controllability and blameworthiness in the former. These views likely influence how patients' difficulties are understood and explained to them by clinicians.

Moreover, Ungar and Knaak (2013) posited that as the nature of an organic disorder is defined as something observably originating from the physical body (sometimes using technological means), it may be perceived as more real and palpable for a clinician. As such, the disorder may be seen as more treatable, more amenable to change, and more predictable (Ungar & Knaak, 2013). Additionally, it has been suggested that, in the context of ABI, anything reported outside of symptoms that can be objectively measured or seen through technological equipment are disregarded or deemphasised (Gombay & Andrews, 2021). Therefore, by implication, this could mean that aspects of someone's presentation which could be deemed functional or involved with the operations of the mind are not attended to. However, it may also imply that professional conceptualisations may be missing core aspects of the lived experience of ABI.

It has also been suggested that clinicians find it more difficult to conceptualise functional disorders and therefore do not view them as legitimate, even if they are not conscious of this and consider the mind-brain dichotomy as inaccurate (Ungar & Knaak, 2013). This is paramount as it would be reasonable to surmise that a clinician's beliefs and attitudes around the aetiology of disorders would impact upon the person they are caring for, particularly as they may be seen as a trusted individual to explain their difficulties.

Furthermore, Thomas (2013) underscored that given mind-body dualism is integrated into the way clinicians think, the current focus to identify biological correlates for mental health illness is not working outside of this paradigm but rather within it because mental health disorders are only being granted legitimacy and sympathy when they are found to have an organic origin. Instead, he advocates for a more holistic view of difficulties, which appreciates a variety of interacting factors: environmental, biological, emotional, behavioural and cognitive.

These debates also convey how the understanding of illnesses are inherently embedded within wider a social context, including societal narratives. It does not seem unreasonable to suggest this would impact upon the understandings of those with ABI and how they experience living with a diagnosis that exists with the functional-organic distinction.

3.2.4 The impact on those with ABI.

Dualism has been suggested to be problematic for people with brain injury as, typically, “problems of the brain” are allocated to neurologists and “problems of the mind” to psychiatrists, and therefore the interface between these two realms does not become wholly appreciated by those providing care (Sheehan et al., 2019, p. 200). Furthermore, it has been argued that neurologists should further their understanding of psychosocial factors to appreciate a fuller picture of a person’s presentation and that labelling neuropsychiatry as the realm where organic-functional interface uncomfortably meets is unsatisfactory (Reynolds, 1990).

Regarding how this may influence individuals with ABIs understandings of changes, it could be that they adopt more psychological or neurological explanations based upon which clinicians they have contact with. However, to our knowledge, there are no studies that reveal whether people with ABI adopt more neurological, psychological or holistic conceptual understandings based upon their interactions with clinicians. Furthermore, we found little research which generally enquires into the explanations people with ABI offer to explain changes following their injury and, importantly, are more active participants in the conceptualisation of their difficulties as opposed to passive recipients of an explanations. Although it is unlikely that people with ABI adopt academic conceptual terms, such as functional or organic, they may use less technical references to the operations of the mind, brain and self.

The dominant discourse in academic literature surrounding the functional-organic distinction is informed by professionals’ views, with the comparative absence of the priorities and thoughts of people these concepts are applied to (Bell et al., 2020). Indeed, we did not find any research which explicitly explores whether people with ABI tend to adopt a monist or dualist perspective to the relationship between mind and brain. This is significant as it has been suggested that people with disabilities may not share the same priorities and perspectives on difficulties as professionals who support them (Hammell, 2006, p. 137). Furthermore, it has been suggested that people with ABI can feel their voices are excluded from a system that supports them due to a lack of appreciation the system, and practitioners within it, has for the experiences of those affected by brain injury (Gombay & Andrews, 2021). Moreover, there is a wider movement within the disability community which promotes the inclusion of service users in various domains affecting them, such as research and policy making (Levack et al., 2010).

4. Research into the self

Despite there being sparse literature into the philosophical perspectives those with ABI may hold, there has been some research which explores how individuals with ABI understand themselves and changes they have experienced following injury, with reference to mind-body relationships. Research into this area appears to typically explore changes in the sense of self and identity, which there has been an increased interest in since the 1980s (Ownsworth, 2014, p. 1).

The concept of self can be defined as the integral and continual qualities that an individual may identify as defining themselves (Ownsworth, 2014, p. 1). Additionally, self-identity includes the values, goals and attitudes of the person (Bryson-Campbell et al., 2013).

In ABI, the concept of the self serves the function of interrelating the mind and body as it encourages a holistic view towards disability (Chamberlain, 2006). However, it is important to note that one’s functional abilities post-injury are not seen as directly responsible for changes in one’s sense of self but rather it is the personal meaning of their experiences that impacts this change (Ownsworth, 2014, p. 1).

Levack et al. (2010) conducted a meta synthesis on research regarding the lived experience of those with TBI and found themes of disconnect: from their pre-injury selves, socially and from their bodies. The last theme highlights that people with TBI experienced themselves as having less control over their bodies than before the injury (Levack et al., 2010). Although this disconnect between their mental and physical states were significant enough to constitute a theme, the participants’ explanatory models of how this disconnect was understood was not fully reported. However, for some other themes their explanatory hypotheses were cited. For example, in the theme of disconnect with pre-injury self, perceived contributing factors to this disconnect were cited as: memory impairments resulting from the injury, reduced autonomy resulting from post-injury living arrangements and the loss of socially desired achievements (such as marriage) (Levack et al., 2010). This research highlights that people with TBI amalgamated a variety of factors to make sense of their experiences, although it was not the primary intention of the research.

Furthermore, Nochi (1998) interviewed 10 people with TBI on the topic of sense of self using a grounded theory approach. He found a theme around a loss of self-knowledge as most people reported difficulties in understanding themselves after their injury. It was indicated that this may be due to some memories being lost, both pre- and post-injury. Furthermore, the findings indicated that participants struggled to comprehend how and why difficulties, like those with emotions and cognition, were a part of them now (Nochi, 1998). This suggests some people may struggle to fully comprehend the relationship between mind and body whilst questioning the way in which difficulties are part of them now. Alternatively, participants were seen to talk in metaphors (such as comparing their brain to a computer system) or adopt neurological terms to describe their experiences (Nochi, 1998).

Related to sense of self, Klinger (2005) researched occupational identity in people with TBI. Themes described that people attributed the injury as fundamentally changing who they were as a person and felt that what they were able to do informed how they saw themselves (Klinger, 2005). Therefore, in aetiological terms, the injury seemed to be identified as the catalyst but psychological processes, such as adjustment, were also fundamental to the process.

Similarly, Bryson-Campbell et al.’s (2013) scoping review into self and occupational identities following ABI found that people reported a change to their identity as a direct result of the impairments from their injury (such as a change in physical abilities), but that this identity was also influenced by stigma that was imposed upon them by society. Participants described subsequently rejecting or internalising this imposed aspect of identity, which consequently affected the self in different ways (Bryson-Campbell et al., 2013). Therefore, this study conveys that factors outside of the individual, such as the wider cultural context, may be integral to understanding changes following ABI. It also may implicitly suggest that the damage to the body/brain influenced a change in self, but this was mediated by influences of the mind (being the perceived imposed identity given by society).

In addition, it should be noted that there has been at least one quantitative study in this area. Jones et al. (2011) wanted to explore the relationship between injury severity, levels of life satisfaction, social changes (such as changes in support networks) and identity changes for people with ABI. They hypothesised that social and identity changes would be related to the person’s life satisfaction and they used a dataset of 630 people to investigate this. Through analysing correlations, and use of bootstrapping, they found that people with more severe injuries reported a greater quality of life. As the relationship was mediated by social and identity changes, it was surmised that those with more severe injuries had needed to engage to a greater extent with these changes and therefore had better life satisfaction. This research implies that a greater degree of introspection and understanding of oneself could impact the emotional wellbeing of individuals. It also suggests that identity changes and changes in social relationships are prominent in understanding someone's difficulties post-injury.

Despite some of the research into sense of self incorporating aspects of the conceptual understandings of those with ABI, the research is still scant when compared to philosophical debates and models proposed by academics. Furthermore, the mental models people used to understand their difficulties sometimes appeared to be peripheral to the main aims of the research. It is also noteworthy that many of the studies exploring these complex processes and concepts adopted qualitative approaches. These approaches likely best fit research topics that aim to convey the voices of those studied with in-depth accounts (Barker et al., 2016, pp. 73-75).

5. Holistic models exploring changes following ABI

It is necessary to explore the factors that are seen as relevant in understanding the causes and maintenance of specific difficulties associated with ABI. Some of these factors can be seen in models devised by professionals, although they may also include factors prioritised by people with ABI.

These holistic models adopt biopsychosocial perspectives, which incorporate the biological, psychological and social factors relevant to understanding disorders (Engel, 1977). Therefore, the following models imply inclusivity of factors considered relevant to the function of the brain, mind and self. This is because biological factors tend to implicate the brain and psychological factors implicate concepts and processes typically associated with the mind. Therefore, these models are more holistic than those that explain difficulties purely by one factor, such as biological factors (Engel, 1977).

Three examples will be presented, although it should be noted that this does not represent the full range of biopsychosocial models exploring specific difficulties in ABI as there are further biopsychosocial perspectives available, such as those exploring aggression (Johansson et al., 2008) and persistent post-concussion symptoms (Wäljas et al., 2015).

Furthermore, a reflection upon the clinical application of the biopsychosocial model will be outlined, as well as an acknowledgement of the limitations of this and the potential solutions.

5.1 Personality change

Yeates et al. (2008) developed a holistic understanding of personality change following ABI to counteract the traditional belief that a lesion or change at neurological level directly alters one's personality and this explains changes in personality. The authors named that the traditional perspective offered little hope of improvement and positions clinicians as bystanders, tasked with facilitating adjustment for those involved with little other functionality. Therefore, the authors deconstructed the biological, psychosocial and psychological causal components evidenced through research to contribute to personality change following ABI before integrating them into a comprehensive model.

Yeates et al. (2008) proposed that changes in personality can be understood through different interacting casual factors: biological factors (such as changes in emotion systems at a neurobiological level), psychological factors (such as a person's perception of difference to others and mental health status) and social factors (such as changes in social roles).

Their proposed model privileges psychological aspects, although includes the biological and social, and this enables psychological therapy as a treatment option. They further acknowledged that change in personality is a subjective experience between how one experiences themselves both generally and in the context of social interactions, as well as how others experience them (Yeates et al., 2008).

However, Yeates et al. (2008) acknowledged that the combination of these various factors into a single model create “some theoretical and epistemological tensions” but advocate for its usefulness clinically. The implication of the model is that dichotomous thinking is inadequate to fully appreciate the complex interaction between various contributors to personality change following ABI. Despite this, it is worth noting that the model is grounded in the voices of researchers, as opposed to those who have ABI.

5.2 Fatigue

A biopsychosocial perspective of fatigue in adults with ABI has also been presented, which is a difficulty that people with ABI do not feel is frequently prioritised and acknowledged in rehabilitation programmes (Malley, 2017, p. 391). There are varied definitions of fatigue, although generally reduced energy, motivation and tiredness inform a picture of fatigue (Malley, 2017, pp. 392-393).

Wu et al. (2015) posited a model of post-stroke fatigue, based upon research on stroke, including the experiences of those affected by stroke. This model indicates that although biological factors preponderate as a precipitating factor (being the stroke itself and initial changes in the brain), psychological and social factors were significant in both maintenance (such as locus of control and passive coping) and predisposing factors (such as illness beliefs). They also stressed that service users have reported that available social support is a significant factor involved in the maintenance of fatigue and therefore this is included in their model.

Similarly, an amalgamation of biopsychosocial factors were seen as relevant in fatigue more broadly in ABI, such as pain, cognitive deficits, reward perception and present mental health difficulties (Malley, 2017, p. 394). Although a reduced ability to recognise fatigue when it begins has been cited by adults with ABI, their subjective experiences have still been highlighted and this reduced awareness forms a rationale to ensure sense-making is incorporated into interventions used to manage fatigue (Malley, 2017, pp. 393-395).

5.3 Obesity

Driver et al. (2021) presented a biopsychosocial perspective on individuals who become overweight or obese following ABI. They outlined the various factors contributing to obesity following ABI through a narrative review of research. They also advocate for the inclusion of a biopsychosocial perspective to ensure an encompassing and interdisciplinary approach to formulating associated treatments and policies (Driver et al., 2021). They highlight that this model is needed specifically for people with ABI due to some additional, specific factors caused by brain injury which may act as barriers to weight management (Driver et al., 2021).

Driver et al. (2021) highlighted that some of the biological factors include endocrine dysfunction, motor impairments and medication. Furthermore, an individual’s level of motivation and autonomy are cited as some of the many psychological factors. Finally, regarding social and ecological factors, social isolation, and a lack of knowledge of both local facilities and ways to exercise were indicated to increase one’s chance of obesity. It should be noted that some of these factors were based on qualitative studies exploring the narratives of people with ABI, as is the case with the factor of autonomy. Therefore, this model may include some service users’ perspectives, even though the model is not grounded in the voices of those with ABI.

5.4 Clinical application of the biopsychosocial model and its limitations

It is important to consider how the biopsychosocial model can be applied clinically, as well as the limitations and potential solutions to this.

Álvarez et al. (2012) completed a review concerning the clinical application of the biopsychosocial model within mental health settings and found that it can lead to various positive factors, such as clinicians reflecting upon the assumptions of their thinking and enabling a combination of treatments targeted at both biological and psychosocial factors (for example, psychotherapy and medication). However, Álvarez et al. (2012) also acknowledged difficulties implementing this model in mental health services as although holistic thinking may be incorporated into assessments, it can be more challenging to integrate this into subsequent treatment.

To further this point, the biopsychosocial model has been criticised as it suggests that clinicians should consider biological, psychological, and social factors but does not pragmatically provide information on the subsequent prioritisation of treatments (Ghaemi, 2009). Therefore, although it paints a more sophisticated picture, clinicians may selectively choose factors to focus on based upon individual preference (Ghaemi, 2009). However, Suls and Rothman’s (2004) paper offers a potential solution by suggesting that different clinicians, in addition to psychologists, should receive more in-depth training on the complex interactions between psychological, biological and social factors in understanding illnesses. They also encourage policymakers to be more embracing of the complexity that the biopsychosocial model outlines rather than clinging to methodologies that are less “messy” (Suls & Rothman, 2004).

Furthermore, McDaniel (1995) outlines how a biopsychosocial model can successfully be implemented when there is careful thought into how different clinicians can work, such as by fostering collaborative relationships between psychologists and physicians in medical settings where their expertise can be combined (for example, through consultation or joint sessions). However, McDaniel (1995) also acknowledged barriers to collaborative working, such as varying language being used by different practitioners and differing lengths of appointments meaning some accommodations are required to facilitate joint working.

In sum, the biopsychosocial model provides a more nuanced and holistic view of contributing factors to different disorders. However, it does not come without its own limitations and challenges to successful implementation.

6. Inclusion of service user perspectives

As noted in the previous section, there are more holistic models for understanding difficulties in ABI. However, although they incorporate views of service users, they are not explicitly grounded in their experiences. There are authors who advocate for the inclusion of service users in the construction of theoretical models, particularly when their lived experience differed from the existing understandings of their condition (Jones & Shattell, 2016). This is relevant as people with ABI could have similar or different conceptualisations of their difficulties from what the current models offer but this is unclear as it has not been well explored to our knowledge.

Using psychosis to illustrate the importance of the inclusion of service user perspectives, Jones and Shattell (2016) outlined a series of qualitative studies conducted to explore the lived experience of those with psychosis. They found that many participants were not able to articulate their experiences easily because current constructs did not facilitate this dialogue, suggesting available terminology was inadequate (Jones & Shattell, 2016). Furthermore, one study indicated that clinician’s responses sometimes directly contradicted the lived experiences of those with psychosis (Jones et al., 2016). This was because some individuals who had experienced psychosis attributed themselves as active agents in the onset of a psychotic episode. Subsequently, a clinician would attempt to reassure them they were passive in the process, inadvertently invalidating their understanding of the events and further alienating them (Jones et al., 2016). Additionally, at least one participant did not feel they could share this insight of agency with their clinician for fear of their response.

Another study which involved 80 interviews with individuals who had experienced auditory hallucinations suggested that professionals and academic literature may misguidedly normalise such experiences, not fully appreciate the heterogeneity of auditory hallucinations and fail to acknowledge the aspects of voice-hearing which are most disturbing to the individual (Jones & Luhrmann, 2016). This series of studies does not highlight misguided positions of individual practitioners but rather indicates that the current conceptualisations underpinning their practice are incomplete as they do not incorporate the views of those they are developed to understand, and they should be included.

Although there are qualitative studies where the phenomenological accounts of those with ABI are described, they do not always appear to be utilised to update current conceptualisation of ABI. Furthermore, although more holistic perspectives are cited for specific associated difficulties that include some service user perspectives, there are less studies explicitly describing mind-body relationships in relation to the broad mental models people with ABI use to understand their experiences. Lastly, the voices of those with ABI appear to be in the background as opposed to central in the construction of models.

Unfortunately, in part this may be due to writers suggesting that individuals with ABI have a reduced capacity to appraise themselves (Armstrong, 1991) or an acknowledgement that people with ABI may struggle to understand some of the changes that have happened to them (Nochi, 1998). However, as outlined, this is not always the case and this is not a valid rationale for excluding the voices of those affected. Additionally, if further research into this area were to replicate some of Nochi's (1998) findings then this offers an invaluable contribution the literature and should encourage reflection on how clinicians converse with people with ABI about their changes, particularly if they do not have a clear conceptualisation of changes years following their injury.

Despite an indication that adults with ABI may find it challenging to understand themselves in various facets of their life, Nochi (1998) suggested that it is pivotal to understand how those with ABI (TBI in the case of his study) interpret themselves as they will have their own unique accounts regarding their symptoms given that they actively interpret what happens to them as opposed to being passive in their experience of symptoms. It is also evident from this and previous sections that qualitative studies employing interviews to explore service users' experiences, grounded in their own language, helps to convey the voices of those we wish to better understand.

7. Summary

As outlined in this introduction, there appears to be varied means in which clinicians conceptualise changes following brain injury and the philosophical stances they hold towards mind-body relationships. Furthermore, much research exploring the mental models that people with ABI use to understand their own difficulties, regarding the relationship between mind and body, is often centred around changes to their sense of self and adopt qualitative approaches. Although this research is helpful at demonstrating that individuals with ABI may appreciate that multiple biological and psychological factors are pertinent to understanding their difficulties, there is less reference to broader conceptualisations held outside one's sense of self. Moreover, there is little reference to how people with ABI use or understand the relationship between the brain/body and the mind.

Furthermore, the dominant functional-organic distinction that underpins practice in the United Kingdom does not suitably reflect the multiple factors incorporated into understanding the experiences of those with ABI, which have been evidenced by biopsychosocial models for specific deficits associated with ABI. Finally, the perspectives of those with ABI are not typically centrally integrated into theoretical understandings regarding their difficulties or changes they experience. An example of how this has been done in the context of those who have experienced psychosis has also been outlined.

Therefore, the implication is that mind-body/brain and functional-organic distinctions are made all the time on behalf of people with ABI and are often imposed upon them in the healthcare system. However, very few studies have examined to what extent individual's own understandings of these distinctions matches the understandings posited by professionals.

8. The current study

Our aim was to contribute an account of the conceptual models adults with ABI use to make sense of changes following their injury, including how they understand the relationship between mind, brain and self when making sense of these changes (or indeed whether these concepts are used at all). Our research questions included:

1. What conceptual models do adults with ABI use to understand changes following brain injury? It was anticipated that within the interviews a sense of how people use (or do not use) concepts such as the self, body/brain and mind would be better understood, as well as any relationships between these concepts. It was also anticipated that the factors seen as relevant in explaining changes would also be explored.
2. What factors have contributed to the development of the conceptual models adults with ABI use to understand changes following their injury?
3. To what extent do adults with ABI reference or use similar conceptualisations as pre-existing models adopted by clinicians and in academia?

The above questions have been addressed through semi-structured interviews conducted with a group of adults with ABI, recruited through a charity. These interviews broadly explored the role brain injury plays in their lives and how they made sense of the effects of their injury. We also attempted to explore the origins and development of the participants' conceptualisations.

Importantly, when referring to participants' conceptual models, it was not implied that these models would reflect pre-existing ones used to inform clinical practice as they could have described a different way of thinking about difficulties. Furthermore, there was no assumption or prediction regarding what descriptions individuals may provide given research in this area is sparse and therefore such predictions would not be well informed.

The interviews within this study avoided explicitly referencing any pre-existing models and concepts where possible. Therefore, the study does not specifically explore how adults with ABI perceive existing models. The rationale behind this was to avoid introducing a frame of theoretical ideas into a study of exploratory nature where we wanted to portray the understandings of adults with ABI as much as possible. However, in line with the grounded theory approach, analytical sense was made of participants' words (Charmaz, 2014, p. 111) to be able to infer references to any pre-existing ideas.

A qualitative method using interviews was used for this type of study for several reasons: to enable a thorough account of participants' thoughts and experiences to be collected, to allow for flexibility in the data collection process as the interview schedule may require adaptation and refinement during the study and because they are well suited to giving a voice to participants (Barker et al., 2016, pp. 73-75). Furthermore, previous research on the similar topic of how people with ABI understood their sense of self adopted qualitative methods, such as Nochi's (1998) grounded theory study which allowed for rich descriptions of the participants' experiences. Finally, this kind of study does not suit a quantitative method given that the study is focused on deriving an in-depth understanding of a condition (Barker et al., 2016, pp. 73-75). Therefore, it was pertinent to give participants time and space to reflect on their experiences. However, it was acknowledged that as the sample size would be comparatively small in regard to the population of individuals with ABI, there would be limitations to how much the conceptual understandings explored in this study would represent the understandings used by a majority of those with ABI.

A grounded theory approach was adopted for this study because this approach is suited to inductive studies that generate theory (Charmaz, 2014, pp. 15-16). As outlined, this area of study has few prior studies and therefore the flexibility that grounded theory provided to be able to revise or shift the focus of particular questions/topics as data collection began was pertinent (Charmaz, 2014, p. 90). This is because data analysis typically occurs alongside collection in grounded theory studies (Bryant & Charmaz, 2012, pp. 39-46).

A more in-depth understanding of how people with ABI make sense of their experiences, and whether they reference relationships between the mind, body/brain and self in their conceptualisations, will help provide a fuller academic understanding and explore the extent to which their conceptualisations match the ones we already use to understand them, such as the functional-organic distinction. It may also provide insight into how clinicians may be best served to approach conversations with people with ABI about the difficulties they experience.

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Part 2: Empirical Paper

How do people with brain injury understand the interaction between mind, brain, self and injury?

Abstract

Aims: To understand how adults with acquired brain injury (ABI) conceptualise changes following their injury, particularly regarding the relationships between mind, brain/body and self. We also planned to explore what led to the development of these understandings and whether their conceptualisations related to existing ones.

Method: Remote semi-structured interviews were conducted with 15 adults with ABI, recruited through a brain injury charity. A grounded theory approach guided study design and analysis.

Results: Ten themes were generated from analysis. Some key themes revealed that participants tended to centre their brain injury, within a more multifaceted understanding, to understand changes. Changes in self and in the mind were indicated following brain injury and were often directly attributed to the injury. Themes also demonstrated that participants developed their understandings through interactions and reading, although these understandings were sometimes incomplete or indescribable.

Conclusions: Conceptual understandings adults with ABI use to make sense of changes were outlined. Implications for clinical settings were that clinicians should aim to emphasise biopsychosocial understandings of changes and appreciate that there is variability in understanding interactions between mind, brain/body and self in this context. Future research could explore our research questions with other clinical populations.

Introduction

There are various ways people understand the relationship between mind and body (Beaumont et al., 1996, pp. 488-489), and consequently the aetiology and maintenance of disorders in healthcare. Some of these clinical understandings of disorders are holistic/multifaceted (Engel, 1977) and some dichotomous (Kendler, 2012). However, these discussions often exclude the voices of people affected by key conditions in this debate (Bell et al., 2020), such as those with acquired brain injury (ABI). This is problematic as it has been suggested that people with disabilities often have different priorities and views to professionals (Hammell, 2006, p. 137) and those with brain injury (BI) hold different perspectives on mind and body changes to those without BI (Sherry, 2006, p. 169). However, there has been some research into the sense of self which touches on the formers' perspectives, which will be outlined later.

Thus, this study, guided by grounded theory (GT), aimed to include the perspectives of individuals with ABI by exploring what conceptualisations they have developed and whether these relate to existing ones. This was to improve our knowledge of the ways to understand changes following ABI and speak to people with ABI regarding the changes they experience.

Acquired brain injury

An ABI is damage to the brain which has occurred after someone's birth, which includes strokes and traumatic brain injury (TBI) (Sheehan et al., 2019, p. 193). Worldwide, it is estimated that 69 million people experience a TBI every year (Dewan et al., 2018), representing a portion of those with ABI. An ABI can lead to changes affecting emotions, behaviours, one's physical self and cognition (Gombay & Andrews 2021; Jones et al., 2011). Furthermore, individuals will likely experience a period of adjustment, including grief and altered insight into their difficulties (Coetzer, 2004). All these difficulties and processes likely contribute to how an individual makes sense of changes following BI, although there is a dearth of research exploring this.

Current clinical understandings

The functional-organic distinction (F-OD) is a conceptual tool in healthcare which aims to distinguish between disorders that can be identified as being caused primarily by biological changes (organic disorders) from those which cannot (functional disorders) (Bell et al., 2020). In psychiatry and neurology, organic disorders are frequently considered to derive from the brain and functional disorders from the mind (Kendell, 2001; Kendler, 2012). These distinctions relate to philosophical positions about the relationship between mind and body/brain function: monism (the idea that body and mind are unified and, in essence, the same) and dualism (who believe mind and body are separate and distinct) (Beaumont et al., 1996 p. 489). Both positions have been suggested to be integrated into our healthcare system (Greco, 2019), with the functional-organic distinction being cited as a dualistic approach within this (Kendler, 2012).

Although the F-OD has been criticised for advocating a simplistic explanation of difficulties that diminishes the importance of multiple factors relevant to understanding disorders (Kendler, 2012), there are more multifactorial models that incorporate a range of factors. In the context of ABI, a range of biopsychosocial models have been presented to make sense of difficulties, which includes the consideration of biological, social and psychological factors to understand the emergence and maintenance of difficulties (Driver et al., 2021; Johansson et al., 2008; Malley, 2017, pp. 391-402; Wäljas et al., 2015; Yeates et al., 2008).

However, it is unclear the extent which people with ABI may adopt more dichotomous understandings (such as the F-OD) or more multifaceted conceptualisations of changes (such as those in biopsychosocial models). We also lack an in-depth account of how they understand relationships between mind, brain/body, and self. Furthermore, the F-OD is a framework often imposed upon the individuals it aims to serve, including those with ABI, without the inclusion of their views (Bell et al., 2020) and, as previously noted, it has been suggested that they may hold different views and priorities to professionals (Hammell, 2006, p. 137; Sherry, 2006, p. 169). Therefore, an informed picture of how those with ABI view mind-body relationships and understand changes following their injury could help shed light onto the extent that their views match or differ from the conceptual framework of the F-OD (Bell et al., 2020). Furthermore, inclusion of lived experiences could inform how we can develop models of specific disorders, something that has been common in psychosis research (Jones & Shattell, 2016).

Research into people with ABI's conceptual models

Although there have been no studies that directly explore service users' understandings of the relationship between mind and body/brain, and their understanding of changes, some relevant evidence is apparent from research exploring the sense of self after ABI. The sense of self can be understood as overarching qualities people consider paramount to defining themselves (Ownsworth, 2014, p. 1). It has been argued that the sense of self interrelates mind and body as it encourages holistic conceptualisations (Chamberlain, 2006). Some of the key studies will be outlined.

Nochi (1998) conducted a grounded theory study with 10 individuals with TBI on how they understood their sense of self. Participants were recruited through theoretical sampling and had two or three interviews each. Within the themes, Nochi (1998) found that participants utilised neurological concepts to describe their experiences or used metaphors (such as the common likening of the brain to a computer). However, he also found that participants often did not have a clear understanding of themselves, influenced by memory loss and blanks (Nochi, 1998). Participants also reported difficulty in understanding how or why changes in thinking and feeling were part of their lives now (Nochi, 1998). Unfortunately, this study only focused on people with TBI, one form of ABI.

Furthermore, Levack et al. (2010) completed a meta synthesis of 23 studies on the lived experience of TBI and one theme indicated participants felt disconnected from their pre-injury selves, sometimes citing memory loss and their social position as reasons for this, but sometimes articulation of this process and their conceptualisations behind it were deemed inexpressible (Levack et al., 2010). Another theme described the reconstruction of their self-identity, which comprised of consciously changing how one considered themselves (Levack et al., 2010). This theme indicated agency through participants accepting the present and setting goals for the future (Levack et al., 2010). Finally, they found a theme of mind-body disconnect, which sometimes involved long-lived loss of this connection and having less (and sometimes no) control over one's body (Levack et al., 2010). Unfortunately, people's explanatory models behind this were not outlined.

Moreover, Klinger (2005) investigated occupational identity and found that people with TBI saw the BI as changing who they are as a person and that what they could do now informed how they saw themselves. Furthermore, Bryson-Campbell et al.'s (2013) scoping review indicated that people with ABI saw identity change as resulting from BI and stigma surrounding BI.

Therefore, research into the self suggests that people with BI sometimes lack an understanding into aspects of changes and mind-body/brain relationships (Nochi, 1998) or that some changes and processes are difficult to articulate (Levack et al. 2010). Furthermore, some people attributed the BI as directly causing a change in self (Bryson-Campbell et al., 2013; Klinger, 2005) and mind-body disconnection (Levack et al., 2010). However, these inferences on the relationships between mind, brain/body and self are often tangential to the main purpose of the research, such as Levack et al.'s (2010) aim of considering appropriate outcome measures for people with TBI. Thus, as can be seen from these studies, people with ABI have complex and multi-layered views on the relationship between self and BI which can be effectively explored by qualitative methods.

Furthermore, these studies highlight how service users' accounts can further our clinical and academic understandings of those we aim to help. This is relevant as it has been suggested that sometimes the subjective testimonies of service users, specifically people with ABI, are deemphasised, disregarded, or invalidated (Chamberlain, 2006; Gombay & Andrews, 2021). The implicit indication that their perspectives are less relevant is problematic as our current clinical models and tools have implications on these people and therefore, we should explore the concordance of professional and service user understandings (Bell et al., 2020).

Current study

This study aimed to contribute an account of the conceptual models people with ABI use to make sense of changes following BI. In particular, references to any relationships between mind, brain and self. This was to explore the extent these match current academic and clinical positions, namely by contrasting with extant conceptualisations. This is because a lot of the theoretical debates are made on behalf of those with ABI, meaning these concepts are imposed upon them without considering their perspectives (Bell et al., 2020). Although we were interested in exploring the extent participants' models match existing clinical models, such as the functional-organic distinction, we did not directly ask about this as the concepts may not be familiar or meaningful to participants and it could narrow the focus of conversations, missing key elements of their subjective experiences by introducing a framework of language into the interviews (Charmaz, 2014, pp. 62-65). Therefore, we explored the conceptual models they had developed more broadly to then be able to draw comparisons with extant models. The understandings individuals with ABI may posit were not predicted as this would be poorly informed due to a dearth of research in this area.

Therefore, the research questions were:

1. What conceptual models do adults with ABI use to understand changes following BI?
2. What factors have contributed to the development of the conceptual models adults with ABI use to understand changes following BI?
3. To what extent do adults with ABI reference or use similar conceptualisations as pre-existing models adopted by clinicians and in academia?

We explored these research questions through semi-structured interviews on the topic with adults with ABI, guided by a GT approach. This is because qualitative approaches are designed to "give voice" to participants (Barker et al., 2016, pp. 73-75) and GT is suited to inductive, theory-generating research (Charmaz, 2014, pp. 15-16). Furthermore, the epistemological stance of the research is pragmatic due to defining truth as something that is functionally helpful and useful (Barker et al., 2016 p. 10). Thus, this research was guided by constructivist GT, as opposed to a more objectivist GT stance, as it is more informed by this pragmatic interpretative lens (Charmaz, 2014, pp. 230-241).

Method

Ethical approval

The study's ethical approval was received from University College London Research Ethics Committee (UCL REC). Please see Appendix A for evidence of this.

Criteria for study inclusion

The formal inclusion criteria was that individuals were eligible to partake in the study if they were over 18 years old, had an ABI and current involvement with a specific BI charity.

However, staff at the BI charity were asked to identify individuals with ABI who were likely to be appropriate to engage in the research and had capacity to consent to the process. Therefore, this process would have precluded individuals who had more severe cognitive impairments that would have impeded their ability to engage in an interview which could last around an hour. Furthermore, when the researchers met with participants, they would have been able to ascertain whether participants had a suitable level of cognitive ability to be able to engage in the interview.

Although our criteria did not specify that participants had to be English speaking, it is likely that English language speakers were selected by the BI charity staff as no non-English language speakers' details were passed onto the research team. This could have been influenced by the fact that recruitment documents being written in the English language. Thus, all participants who partook in the study spoke English.

Participants

Fifteen participants partook in the study, after 23 had initially shown interest. The eight individuals who didn't partake were for different reasons: not meeting the eligibility criteria (two), no response from initial correspondence from the researchers (one), no response in later correspondence (four) or indicating they could no longer partake (one).

Participants had current involvement with a BI charity, either as members attending the day services, attending support groups or as volunteers. A range of different age groups partook: 30-39 (three), 40-49 (two), 50-59 (six), 60-69 (three) and 70-79 (one). Regarding ethnicity, one participant did not disclose this, one defined themselves as Mixed Race, one as Black Caribbean and 12 as White British. There were 13 males and two females who partook.

Participants were asked if they knew the location of their BI. Only two participants either did not know or wish to disclose the location of their BI. Four participants knew the general area of their BI: right side (two), right-side at the back (one) and at the back (one).

The remaining nine participants disclosed the location of their BI: frontal lobe (four), frontal, parietal and temporal lobes (one), brain stem (one), brain stem and spine (one), neck (one) and basal ganglia (one).

Service user consultation

During the project, an individual with ABI gave feedback on the proposed interview schedule and changes were made based upon their feedback. Additionally, they commented on the construction of some of the initial codes and added their perspective to enrichen interpretation. This was in line with a GT position of multiple individuals generating codes from their personal and professional contexts to allow fresh ideas to develop (Charmaz, 2014, pp. 117-118).

Recruitment procedure

Adults with ABI were recruited through a specific BI charity. The participant information sheet (see Appendix B) and consent form (see Appendix C) were sent through to a manager at the charity. The manager then shared this information with their team to invite people who may be interested in partaking.

The charity staff then discussed the study with potential participants. If they indicated interest in hearing more and/or taking part, their contact details were passed onto the researchers with their consent. The researchers then contacted the participant on their preferred contact method (email or telephone). Please see Appendix D for an initial email template and Appendix E for an initial phone call checklist. The researchers offered to go through the participant information sheet, consent form and answer any questions. If the participant still wished to take part, an appointment was made for a remote interview, which was conducted over Zoom (2021, version 5.9.1), Microsoft Teams (2020, version 1.0) or the telephone (on two occasions).

Topic guide

Semi-structured interviews were conducted with the participants, which was informed by a topic guide. The initial topic guide can be found in Appendix F. Two of the key papers underpinning this study were reviewed to inform the construction of the topic guide. Firstly, Bell et al.'s (2020) paper critiquing the F-OD was considered in terms of how we could pose questions which would explore the concepts that underpin this clinical tool (such as how to ask questions that explored the relationship between the mind and body/brain). Furthermore, Nochi's (1998) GT study on a similar topic ascertained information from participants on their sense of self by asking them about their current concerns and exploring written information regarding the participants' emotions, thoughts and experiences relating to themselves and their BI. Therefore, it was surmised that similar lines of inquiry would be useful in this study.

Charmaz's (2014, pp. 62-68) guidance for GT interview schedule construction also influenced the development of our topic guide because I first generated a list of potential questions and topics I wished to broadly ask with Bell et al.'s (2020) and Nochi's (1998) papers in mind. I then refined this into a structure that began with open-ended questions that eased into the interview before asking more specific questions (Charmaz, 2014, pp. 62-68) that were designed to ascertain how participants understood changes following ABI and how these conceptualisations had developed. Follow up questions that prompted further details were also included. Furthermore, interviews were approached with the knowledge that not all planned questions may need to be asked in a rigid sequential fashion as the interview could organically flow in a way that naturally answers the research questions, as Charmaz (2014, p. 65) outlines in the GT approach.

However, the topic guide was updated after the first six interviews were conducted (See Appendix G) to enable more accessible questions that were focused on the research questions as initial coding began alongside data collection. The flexibility of updating the topic guide follows GT principles as within this approach the topic guide is viewed as a refinable instrument to gather relevant data that answers the research questions (Charmaz, 2014, p. 62) by identifying gaps and revising questions to learn more about important pieces of data gathered (Charmaz, 2014, pp. 199-200). Thus, the aim was to ensure questions that provided more information on developing themes.

The update to the topic guide involved adding one main question to elicit information that answered the first research question in a more direct fashion and reduce the amount of tangential information in answers. However, the original question remained as back up in case the new question did not make sense to any of the participants, and it was still sometimes used. Furthermore, the topic guide was updated with some follow up questions to encourage a more thorough description of experiences, such as how a participant's thoughts, feelings and decisions relate to the effects of their BI. Similarly, general prompts were included, informed by Charmaz's (2014, pp. 68-69) advice on eliciting richer descriptions, such as asking what an experience felt like.

Interview procedure

Semi-structured interviews, structured with the topic guide, were conducted with the participants. The interviews were approached flexibly as questions were rephrased, if needed, and participants were free to explore areas that felt more pertinent to them. Follow up questions were also sometimes asked.

The interview length ranged from 35 to 84 minutes, with a mean length of 55 minutes. All interviews were audio recorded. Ten interviews were transcribed by the researchers and five were transcribed by an automated transcription service, Scrintal (n.d.), and checked by the researchers. During transcription, identifying information was removed from the transcript (such as the participant's names) and the original audio recording was deleted.

Participants were also given a £10 honorarium for partaking (either as a voucher or charity donation). All participants' contact details were deleted by the researchers after they partook in the research.

This project was a joint project. However, both trainees submitted separate projects with separate populations. They worked together on designing and collecting data for both studies. Please see Appendix H for a more detailed account of each trainee's contributions. The other trainee's project is Chesterfield (2022).

Analysis procedure

Analysis was guided by the GT process outlined by Charmaz (2014, pp. 109-224). Researchers used NVivo (2022, release 1.6.1) data analysis software to aid with coding. The research team also had two meetings with a qualitative research staff member at University College London who provided advice on important considerations in qualitative analysis. Initial coding began alongside data collection, partly to help refine the topic guide and what areas may be helpful to focus on during subsequent data collection, in line with a GT approach (Charmaz, 2014, pp. 199-200).

Interviews were initially coded line-by-line. However, due to the research aims and questions, there were incidents that were not heavily coded as they were tangential to the research questions. For example, participants often spoke about the lived experience and daily impacts of having an ABI and, although these experiences were important, they were not included where they were not relevant to the main research question regarding conceptual understandings participants developed to make sense of changes. Therefore, incident-by incident coding likely reflects the coding procedure better.

Initial coding involved producing a phrase (usually a gerund) to describe the meanings, actions and processes in a participant's statements (Charmaz, 2014, pp. 111-113), which were sometimes best achieved using in-vivo codes (Charmaz, 2014, p. 134). These codes tended to reflect actions, meanings and processes in participants' words, sometimes drawing forth seemingly implicit views in the data (Charmaz, 2014, pp. 111-113).

During the process of initial coding a constant comparison method was adopted, where codes were compared against each other within and between interviews (Charmaz, 2014, pp. 132-133). During this comparison process, it became apparent which codes were likely to develop into focused codes through both their frequency and significance.

Furthermore, both the researchers and the Principal Investigator separately completed initial coding for the first interview that was coded and compared their codes, to enrichen analysis with multiple perspectives and fresh discernments (Charmaz, 2014, pp. 117-118). Additionally, for the same reason, the research team met with an individual with ABI to discuss how some of the codes for this interview had been generated, based upon the interview transcript. The individual with ABI then provided verbal feedback and their perspective on the transcript and codes generated. Please see Appendix I for an excerpt of the interview coded by all three interviewers and Appendix J for an excerpt of initial coding competed by me.

Subsequently, I completed initial coding for all the remaining interviews. At several points during initial and focused coding, I met with the other researcher and the Principal Investigator to discuss the appropriateness and utility of codes (Charmaz, 2014, pp. 117-118). For example, I met with the other researcher after coding every five interviews. See Appendix K for an excerpt of initial codes generated from the first eight interviews, alongside their relevant theme/subtheme (if applicable).

Focused coding followed initial coding. Larger portions of data became accounted for using these codes as they incorporated key facets of various initial codes (Charmaz, 2014, pp. 138-147). Furthermore, some psychological concepts were incorporated into focused codes, where appropriate (such as concepts of the mind and self). This is because they appeared to fit the constructs that some participants described and therefore helped to understand and interpret the data (Charmaz, 2014, p. 159). The focused codes represent the themes outlined in the results section. Additionally, Charmaz's (2014, pp. 336-338) four-part criteria (credibility, originality, resonance, and usefulness) was reflected upon during analysis to enhance the validity of themes generated (Bryant & Charmaz, 2012, p. 52).

Sample size and saturation

The sample size of 15 participants was considered adequate for this study because, during analysis, a process of theoretical saturation was achieved in different themes, which is a principle in GT that guides when to stop recruiting participants (Charmaz, 2014, pp. 213-214). Theoretical saturation was recognised as similar codes repeated within and between interviews as the analysis progressed through the processes of coding and constant comparison. This can be seen through the number of participants that endorsed each theme. This meant that themes generated were being reinforced through further interviews (Bryant & Charmaz, 2012, p. 48) and substantial amounts of new data were not emerging in the themes (Brown et al., 2002). Furthermore, the themes created were rich in their detail of the variation within themes and the relationship between different themes were well defined, which is advised by Brown et al. (2002) and Charmaz (2014, p. 213).

Therefore, it was surmised that continued data collection would not further elucidate the themes or lead to more themes being created.

Researchers' perspectives and reflexivity

Two researchers collected the data. Both researchers completed bracketing interviews prior to data collection to assist with bringing forth any preconceptions and implicit predictions about the research process (Tufford & Newman, 2012). Memos were also kept by the researchers throughout the project to allow reflection upon assumptions (Tufford & Newman, 2012), as well as evaluate ideas gathered from the data (Bryant & Charmaz, 2012, pp. 47-48). This aided the process of reflexivity to enhance the rigor of the research (Hall & Callery, 2001).

I am a white, 29-year-old man studying a doctorate in clinical psychology. Both prior to and during training, I had worked in neuropsychology settings with individuals with ABI. Therefore, I had preconceptions regarding the way they may conceptualise their experiences. I suspected participants would find it challenging to articulate their mental models due to being accustomed to receiving explanations from professionals rather than providing them. I also believed that it may be difficult for myself to understand some alternative perspectives posited by those with ABI due to being accustomed to existing psychological theories and models. Therefore, I believed being unassuming and ensuring I got a detailed account of experiences would help with this process of discovery. During data collection and analysis, I was aware of these preconceptions and noted these in my memos. However, I accepted that I held prior knowledge and may have used some concepts to aid me in understanding the data but remained cognisant of these to prevent them dictating the content of codes produced (Charmaz, 2014, pp. 155-160). As noted, the other researcher engaged in a similar process. Further details of their position and perspectives can be found in Chesterfield (2022).

Results

Ten themes were generated during analysis. Themes were arranged into two sections based on the first two research questions, which included six themes for research question 1 (the conceptual models adults with ABI use to understand changes) and four for research question 2 (What factors have contributed to the development of the conceptual models). The themes have been outlined in Table 1. An account of themes, with illustrating interview excerpts, is presented below.

Section 1- research question 1 themes

Participants conceptualised changes following ABI in several ways, including some variability and paradoxes both within and between accounts. The first six themes will outline these.

1.1 The centrality of biology in explanations: "I'm sure that's the brain injury" (P1).

Participants primarily used their physical ABI to explain some of the specific changes they had experienced, such as: memory, fatigue, personality traits, and impulsivity.

> *I'm not sure which part of my brain got disconnected. Probably something in the executive functioning, as they call it, don't they? I don't know, but I didn't get depressed, I don't get depressed, I feel less inhibited* (P11).

Several participants also discussed the importance of knowing the location of their BI (or the associated effects from damage to a particular area) to make better sense of the specific difficulties they experienced. Some participants explained that their deficits made sense in the context of the location of their injury.

> *Because with frontal lobe damage, you lose the buffer zone. So, you might react in a certain way that's over the top to you, but not to me* (P2).

Participants described wider knowledge of the brain and body that provided a framework to understand changes following ABI, such as the brain interacting with the body through signals. Some participants adopted metaphors or similes, such as likening the brain to a computer, to help them understand what may be happening internally.

> *The way I think about it is my brain is like a computer and sometimes the hard drive just goes offline and then, you know, there's only so many things you can remember* (P8).

Table 1

Themes and subthemes generated during analysis

Research question 1

Theme/*subtheme*	Number of interviews where this theme featured
1.1 The centrality of biology in explanations	15
-BI largely accounting for a difficulty	*15*
-Needing to know the location of BI	*6*
-Needing knowledge of the brain and body generally	*10*
1.2 Needing to be seen as a whole person	15
-Needing to be seen holistically by professionals	*6*
-Needing to be seen as a person by others	*9*
-Identifying single factors relevant to understanding	*15*
-Considering multiple factors needed to understand	*9*
1.3 A sense of changing or remaining the same person	15
-Being a different person than before	*11*
-Identifying constant characteristics	*9*
-Starting over	*5*
1.4 Varying use of mind-body frameworks in sense-making following BI	11
-Identifying a mind-body disconnect	*9*
-Separating the brain from other concepts	*7*
-Unifying the mental and physical at times	*8*
1.5 Attributing changes in the mind to BI	15

-Mind changes due to BI	*12*
-Mind changes due to social and psychological processes	*8*
1.6 Differing degrees of control	15
-Feeling passive	*13*
-Having some control	*15*
-Recharging to counter the effects of BI	*5*

Research question 2

Theme/*subtheme*	Number of interviews where this theme featured
2.1 Learning through social interactions	11
-Advocating for the voices of those affected	*10*
-Working with others to understand	*9*
2.2 Learning through reading	8
2.3 Not reaching a complete understanding	13
-Struggling to understand generally	*10*
-Difficulties finding the right words	*9*
-Rejecting concepts and processes that are not meaningful	*4*
2.4 Asserting a lack of understanding in others	10

1.2 Needing to be seen as a whole person: "her MRI scan was very boring" (P12).

Despite the centrality of biology in explanations, some participants spoke about needing to be viewed holistically by those supporting them, such as healthcare professionals. This included the consideration of multiple influences, such as mental health, BI and personality. Sometimes, feelings of frustration emerged when they felt reduced to a single aspect of their experiences.

> *But often when you go to the doctors, the consultants, or you have had that MRI scan, they're not really interested in you, they're interested in your MRI scan. I admit it's all connected, what's going on in your brain, you can tell various things from your MRI scan that you can't tell otherwise. But the most interesting thing is about your personality and how you are* (P12).

For some, the importance of being seen as a person more generally was emphasised in making sense of themselves. This included normalising their experiences and understanding that difficulties they faced also happen for many people, as well as needing to be seen as more than a diagnosis or statistic to other people. This process of normalising their own experiences appeared to prevent over-attributing causation to BI.

> *Like if you forget something, people forget all the time. But alright, I might forget a little bit more than the average person but, because I forget that little bit more, I blame it on my brain injury. Do you know what I mean? Like, it could be related to it, but people do forget anyway* (P5).

Participants usually cited another factor that needed to be considered when making sense of changes, alongside the effects of BI. There were many factors considered, such as age, confidence, culture, mental health, diet, medication, sleep, and relationships. These factors were often interwoven into their narratives and demonstrated that, in many contexts, people did not view their injury as the sole factor relevant to understanding changes.

> *Because when we eat, it goes down into… the liver does what it does when we are asleep and then it our food goes to our brain* (P6).
>
> *I believe that I've had something behind me. I've had Jesus or God behind me, backing me and helping me* (P13).

For some, multiple factors were coherently embedded into their narratives of making sense of changes or specific situations. This sometimes increased their awareness of what things can be helpful to them in terms of factors they can control (for example, the noise in an environment). Occasionally, participants spoke about other factors interacting with their BI in a qualitative/additive way. For example, participant 1 spoke of their BI as causing limited mental resource and factors reducing this resource: stress, anxiety, and noise.

> *If I get stressed or worried that seems to drain me quicker. I suffer with anxiety pretty bad actually, so that will become overwhelming. I mean it's all sorts of things, like when I go out the noises… I could go on* (P1).

Occasionally, participants regarded multiple factors as distinct from their BI. However, they spoke about how these factors combine quantitatively to explain their experiences. For example, below is participant 9's narrative of their recovery, citing the various contributions of interpersonal conflicts between others, their recovery from BI, perceived pressure and maintaining a positive mentality.

> *There was a lot of bickering from both sides, like with my ex's family and my family and everything else. That was when I was in ICU. That was nothing to do with me, but I only found out about it when I come round and everything else. So, that put more pressure on me. And then that pressure, you know, made things a lot more difficult with the recovery side of things as well on top. So, all those factors brought me to rock bottom, if you like. But as I say, I found a way to pick myself up, in the sense of like just looking at the positives of what I was doing* (P9).

1.3 A sense of changing or remaining the same person: "they take me for me, not the person I was before" (P5).

Numerous participants believed they had either become a different person to who they were before the BI or were viewed by others as different. Participants defined being changed in different ways: not having the same capabilities, not being able to engage in the same activities as before, integrating BI as a “part of me now” or a change in their personality. Therefore, this sense of self incorporated mental and physical elements and highlighted parts of themselves that remain across different contexts. This process enlisted an array of intense emotions: grief, confusion and annoyance. Paradoxically, one participant described gratitude for this change and another felt their partner would have seen a positive change. However, even negative perceptions were intermingled with positive experiences, such as gratitude to their support network for staying by them.

> *Because I’m not the same person I used to be and I can’t do things that I used to do. Like, when I have to think of something, it takes me longer to think. People don’t seem to have the patience* (P5).

Despite participants indicating they changed as a person, several also described constant characteristics that were present before the BI and persisted afterwards. These tended to be personality traits or constructs that define personality, such as “a fighter”, strong-minded and impatient. Therefore, the nuance of identifying things that had changed, whilst also recognising constants, were presented in the narratives of many.

> *So, I had a good sense of humour before my stroke and I’ve still got it now. I haven’t lost it. There’s some things you lose and some things you keep* (P15)

Finally, some participants would describe their lives as starting over following BI, meaning they began life again or reverted to an earlier stage in life, such as being a child (either practically re-learning skills or their position within their family). See Appendix L for excerpts of interviews leading to this subtheme generation.

> *The brain injury basically sent me back to being a baby again. So, I had to learn how to walk, talk…* (P8).

1.4 Varying use of mind-body frameworks in sense-making following BI: "I think of it all as whole" (P11).

Participants had varying ways of organising concepts relevant to understanding changes. Some found it helpful to use concepts of body/brain, mind, self and spirit. Some participants described processes or concepts that appeared related to these concepts without using the terms. However, participants differed within and between interviews about the unity, collaboration and separation of these concepts. Furthermore, for a couple of participants, the concepts of mind and brain were used interchangeably suggesting a more unified understanding of internal processes. The subthemes below will describe these.

Participants described experiencing a disconnect between what they would like to do and what their body was practically capable of doing. Some participants spoke about their mind or thoughts being more ambitious than their body. This tended to lead to feelings of frustration, as well as a re-evaluation to consider how they could do the things important to them. One participant also highlighted how wellbeing improves for those who experience moments when they can physically do what they hope to.

> *You're trying to fight with a body that does not want to budge, kind of thing. But it's not the body that doesn't want to budge, it's the brain that is not sending signals to make the body budge. So, it's like you're trying to overrule and fight with that, as well as coming to terms with the fact you're not physically the same* (P9).

For several, it felt important to separate different concepts to understand changes and how these concepts operate. Namely, this was separating the brain from the self, although sometimes the brain from the mind or spirit. Sometimes, this distinction was defined by conflicting processes and outcomes. Some participants spoke about these processes and appeared to be able to observe them, indicating a third concept, as illustrated by the excerpt from participant 15 below.

> *I think it's a bit like ying and yang [emotions and effects of BI]. I think, you know, one side says "oh yeah do this" and the other side says "oh no don't do that". I just carry on and get on with it* (P15).

Participants also spoke about unifying some concepts. Paradoxically, some of these participants were included in the previous subtheme as they also separated concepts at times. Therefore, it appeared that on one level it felt helpful to think about concepts (that may map onto mind, body/brain, and self) as separate and on another level, it felt more helpful to consider processes in a unified manner.

> *Effectively everything that makes you human is related to the brain, your mind being part of it. Your feelings, your sense of touch, sense of smell, sense of everything…. Is all related to your brain* (P2).

> *I don't think of anything as separate. Yeah, I think of all of it as whole. I don't separate anything really* (P11).

However, the shift between the same person unifying and separating concepts also appeared to be due to increased clarity that developed throughout the process of the interview. A brief example of how a participant first spoke about concepts separately and later unified them is shown below.

> *My head is telling me one thing, my brain is telling me another* (P10).

> *No, your brain's in your head isn't it? I suppose that's the way it is* (P10).

1.5 Attributing changes in the mind to BI: "I was changed in the way I think" (P12).

A majority of participants spoke about the brain and BI influencing the operations of the mind, often using language of thoughts and emotion. Although this appears similar to theme 1.3, this theme focuses on more mental aspects (specifically thoughts and feelings). Several participants spoke about BI triggering or worsening mental health difficulties, such as anxiety. However, two participants spoke about a positive shift in the way they think since BI (being more assertive and seeing things clearer).

> *Well anxiety is the brain injury, well it's caused by the brain injury. Because where you were confident before, you're now not confident because the things you used to be able to do, you can't do* (P2).

However, it should be noted that, at times, it was difficult to disentangle whether it was the physical BI directly causing changes in the mind or the psychological and social processes that accompany BI, such as adjustment to BI or changing social position. This can be appreciated in participant 5's account below. However, a few participants conceptualised changes in the functioning of one's thoughts solely in terms of psychological processes associated with BI.

> *Routine is key and if something don't go right, if there's a missing link to my routine, oh my god, my day is ruined. And then I get agitated and find it hard to control my anger, so people close to me tend to get an anger outburst. Like, not physical but aggressive, do you know? Yeah, I blame that on my brain injury for definite* (P5).

1.6 Differing degrees of control: "I can't control it happening, I just have to deal with it" (P10).

Most participants spoke about feeling passive to the effects of BI, both physically and mentally. Therefore, many spoke about the process of accepting the aspects they are not able to control and managing to move forward with their life despite these.

> *I've got so many letters here. At one point, I had letters over six months that I hadn't opened, you know. And that's not me, well it wasn't me, but nowadays I have to accept that's who I am* (P14).

However, all participants spoke about ways in which they believed they had control over aspects of their lives influenced by BI. People described this in different ways: setting goals for themselves, self-evaluation and introspection to ascertain their capabilities, being able to develop ways to manage and compensate for things they found difficult and setting limits for themselves. These positions conveyed more hope and showcased the practical ways in which their own conceptualisations had enabled them to engage with meaningful activities. Below, participant 4 describes control in setting a goal and participant 3 describes a way they consciously manage their difficulties.

> *Setting achievable goals is important, of what's possible to achieve in the next 6 months, or a year or something. And you might get there. And then you might reach that goal and reassess basically* (P4).
>
> *So, I have to try and do things straight away whereas before I would store it all up in the brain and then you would just it that way. Now you can't. If I don't do it straight away, I can't do it* (P3).

Regarding ways participants manage consciously, a third of participants described the effects of their BI as having a draining effect on their capabilities or having a limited resource of energy. These individuals spoke of managing by recharging or conserving energy.

> *Well now I know when I am tired, I am tired and I need to rest. I know how to manage my energy and that's very, very, very important* (P7).

Section 2- research question 2 themes

The themes below relate to how participants developed their understanding of changes following BI, which most outlined as a process that developed over time and, for some, continues as an ongoing process of introspection. Additionally, themes describe barriers and related considerations to this process.

2.1 Learning through social interactions: "I said to my mates there, 'what's different about me?', he said…" (P2).

Many participants emphasised that the voices of those with ABI, or people with similar experiences, need to be heard to aid understandings of changes following ABI. For many in this group, it was emphasised that hearing from others was how they began to understand their difficulties. For some, they spoke about how they helped others understand changes and recovery.

> *That's why I like [BI charity]. I think I been going there, I done four sessions there so far. And I'm slowly learning about brain injuries and how other people react, and trying to find myself though other people, even though I'm an individual* (P10).

For many, their understanding was partly developed through talking with other people. Mostly, this was through conversations with services specialising in BI. However, sometimes it was through conversations with their support network. Many spoke about having increased insight into their difficulties and how to manage them following these conversations.

> *I went to something called talking therapies, which I think you will be familiar with? And they explained to me about fatigue. They said to me that you've got to chunk your jobs* (P14).

2.2 Learning through reading: "You could fill your room with printouts of this, that and the other" (P1).

Several participants spoke of learning about changes following ABI through reading relevant material: received from BI services, self-directed reading on specific difficulties or tangentially through their studies.

> *I was reading up that it does, when you've had a brain injury, it does change you, you're not the same person* (P15).

2.3 Not reaching a complete understanding: "So, I just get on with it" (P15).

Most participants spoke about struggling to understand changes following BI or conceptualise the relationship between mind, brain/body and self. It appeared that although most had a conceptualisation or framework to understand changes, these felt incomplete or difficult to describe. Some participants spoke of struggling to understand generally, in terms of predicting how they may be in a situation, why certain things were difficult or different for them and how the mental and physical relate to each other. An example of the latter is described in participant 3's account below.

> *I mean I think the brain injury definitely, it sort of nulls me or slows me down or- I don't know, I find it quite hard to sort of make that link between things. You know, what causes this? What causes that? The impacts and stuff, so I find it quite hard sometimes to work that out* (P3).

For many, there were difficulties finding the right words to convey their understandings. Sometimes, participants readily expressed this explicitly and others named this when they were asked follow-up questions about concepts they spoke of and interactions between them. The former is illustrated in the excerpt from participant 1 below when they were asked if there was anything to add towards the end of the interview.

> *No because it's so hard to explain… it really is. Probably talking, like we're talking, years ago would have been good to be honest* (P1).

Finally, a small portion of participants rejected certain processes or concepts in conceptualising changes following BI. For example, not feeling the need to formulate an understanding of some situations or rejecting concepts that do not seem helpful to them.

> *It's unnecessary concentration, which is tiring. So, if it doesn't need to looked at, delved into, separated, I don't do it. Because I know all that work in trying to think about it, that will make me….the fatigue just gets… I will be tired earlier* (P1).

2.4 Asserting a lack of understanding in others: "I don't think they knew what they were talking about" (P7).

Generally, participants felt people without BI did not fully understand changes following BI and how to conceptualise them. Although some examples were directed towards the general public, many were also regarding professionals they had worked with in the context of ABI. This theme is closely linked to being needing to be seen holistically as a person (such as thinking about culture) as this breathed into many of the narratives of those who asserted this lack of understanding. However, some also noted that, over time, peoples' understandings of BI had improved.

> *It comes down to the doctors i.e., you can go a psychiatrist or whatever you want, a traumist or whatever, any specialist you want, you know? But none of them understand what goes on with the brain* (P10).

Discussion

This study aimed to explore the conceptual models people with ABI use to understand changes following BI (research question 1). We also attempted to explore what led to the development of these models (research question 2). Therefore, this discussion will begin with a summary of findings, including its relation to previous research. Reference to how this relates to pre-existing conceptualisations of changes following ABI will integrated into this as this was research question 3, which was not directly explored in the interviews as it would reduce the inductive frame of the interviews. The implications of this research for clinical practice will then be discussed before a consideration of the limitations of the study and areas for further research.

Summary of key findings in relation to existing research

I will begin with a summary that amalgamates some of the themes to highlight the key findings. Overall, it appears that participants considered biological explanations strongly in their conceptualisations, but between interviews, participants described a range of relationships involving different factors. Additionally, within interviews, some participants seemed to have incomplete or multiple models that they employed to understand changes (some of which were not completely consistent but made sense in each context). This suggests that, as a group, participants did not have one particular way of understanding mind-brain experiences, or that some may not have an internally coherent model about the relationship between mind and brain that they applied consistently to their experiences. This is evident in several themes: 1.2, 1.4, 1.6 and 2.3.

I will now summarise the findings specifically in relation to research questions 1 and 3, regarding the conceptual models participants used to understand changes and whether these relate to current clinical conceptualisations, such as F-OD and the biopsychosocial models.

Results from the analysis found that participants tended to centralise the brain and physical BI in their conceptualisations of changes (theme 1.1), sometimes adopting key concepts from neuroscience, such as the brain-computer analogy (Kendler, 2012). The use of language likening the brain to a computer has been found to be used by people with ABI in previous research (Nochi, 1998). BI being cited as the central cause of difficulties is perhaps unsurprising given there is a wealth of existing literature on the cognitive, social, emotional and physical effects of BI (Gombay & Andrews 2021; Jones et al., 2011), and participants cited reading (theme 2.2) and learning from professionals (theme 2.1) as aiding them develop their understandings.

Despite the above, participants generally considered multiple factors, rather than solely focusing on their physical BI, to understand changes (theme 1.2). They largely called upon multiple contributing factors in their conceptualisations and considered themselves in the context of being a person beyond their injury (such as normalising their difficulties as something people without BI may experience). This is in keeping with biopsychosocial models that consider a range of biological, social and psychological factors in understanding difficulties (Driver et al., 2021; Engel, 1977; Johansson et al., 2008; Malley, 2017, pp. 391-402; Yeates et al., 2008). These findings generally refute the simplistic F-OD distinction for these participants because its dichotomous nature calls for conceptualising difficulties from the mind or the body (Kendell, 2001), not both, which does not mirror how many participants spoke about their understanding of changes.

Additionally, findings suggested that people with ABI implicitly or explicitly considered changes in their mind (theme 1.5) and self (theme 1.3) as being due to their BI. It should be noted that the self often incorporated aspects of the mind and physical self so there is arguably overlap between them. As opposed to inferring that this means participants were more likely to adopt a materialistic view of mind-brain/body relationships, in keeping with most scientific thinking (Poole & Bolton, 2020, p. 1-2), it appeared they also encompassed the psychological and social processes known to be involved in ABI and recovery (Chamberlain, 2006; Coetzer, 2004) when they referred to BI. Therefore, for some, a materialist view may have been adopted but for others they appeared to have been considering the psychosocial factors of BI as influencing changes in the mind. Additionally, it is of note that not all participants felt this way and the variability in separating and unifying concepts (theme 1.4) within and between interviews may reflect the myriad of different philosophical positions that are present in broader philosophical debates (Beaumont et al., 1996, pp. 488-489). Despite this, a couple of participants used the concepts of mind and brain interchangeably, similar to the manner that lay people sometimes use these concepts as having related and overlapping meanings (Rodriguez, 2006). Therefore, for some, direct comparisons with scientific models may be flawed.

This research also found that some participants had conceptualised a mind-body disconnect (within theme 1.4), mirroring findings from Levack et al.'s (2010) meta synthesis into the lived experience of TBI. Theme 1.3 also mirrored previous studies as generally the self was viewed as changed following BI (Bryson-Campbell et al., 2013; Freeman et al., 2015; Klinger, 2005). Despite this, many participants also identified aspects of themselves unchanged or affected by BI.

The results additionally suggested that participants felt they had varying degrees of control in different aspects of their life, which was influenced by their conceptualisation of what causes difficulties they experience. This concept of being active in recovery and sense-making echoes previous research in this area, as does the process of being more powerless to the effects of BI (Levack et al., 2010).

Regarding research question 2, results demonstrated that participants developed their understanding through interactions with others, often professionals, and related reading on ABI. The clinical implications of this will be discussed later.

Despite participants finding some professionals helpful at developing their understandings, many also appeared to find some professionals as lacking an understanding regarding their experiences or this was not evident during their conversations (theme 2.4). This could reflect the restrictive nature of our systems meaning that people's difficulties are sometimes discussed in a reductionistic fashion by different professionals. This inference is illustrated in Ahn et al.'s (2009) study where professionals were seen to view psychological and biological basis of disorders as mutually exclusive, which is likely influenced by the F-OD. However, it also likely reflects that people with ABI hold different priorities and views to professionals, which has been highlighted previously (Hammell, 2006, p. 137; Sherry, 2006, p. 169).

As previously outlined, the results suggest that some participants did not have a fully coherent account developed to understand changes following ABI in several places, which is particularly highlighted in theme 2.3. This mirrors previous research indicating that some understandings of processes and understandings appear to be indescribable (Levack et al., 2010). However, what our findings also revealed was that some participants did not feel they needed to have a clear conceptual understanding in every context.

Alternative explanations

It is possible that participants centralised the physical BI in their explanations because clinicians have previously emphasised to them that this is most pertinent factor they should consider in understanding their difficulties. It would be naïve to not acknowledge that participants may have been influenced by the context of the interviews, knowing they are being interviewed by individuals studying clinical psychology and this shaped their responses. This is important to consider given the research was approached from a constructivist frame and therefore data is situational (Charmaz, 2014, pg. 236). In essence, there may have been an unspoken belief that the researchers did not hold the same priorities as participants, which has been highlighted in other contexts (Hammell, 2006, p. 137; Sherry, 2006, p. 169), and therefore they felt inclined to say what they believed the researchers were expecting to hear.

Similarly, in theme 2.3, where participants indicated they did not have a complete understanding, it could have been that they did have an internal model to understand their difficulties, but our current language does not allow for those explanations to be readily expressed. This has been found previously in the context of psychosis (Jones & Shattell, 2016).

Implications for clinical practice

As outlined, participants generally had holistic understandings of changes following injury, incorporating multiple factors in understanding changes following ABI. Although this is a small portion of a wider heterogenous population, it is suggestive that biopsychosocial models are likely more appropriate than restrictive models in understanding difficulties. Therefore, the former is likely more suitable to use clinically. Although it would be far-reaching to completely refute the F-OD from this study, particularly as our findings are not widely generalisable outside of the specific context it was conducted (Leung, 2015), it at least implies that those with organic disorders still consider the psychological and social processes involved in their disorders. Furthermore, some may view difficulties that are typically deemed as functional, such as anxiety, as emanating from an organic difficulty (ABI).

To further this point, participants sometimes felt professionals lacked a full understanding, which often appeared to be linked to a perceived sense of not being considered holistically by professionals. We have not necessarily concluded that clinicians do not hold multifactorial understandings, as biopsychosocial perspectives were suggested many years ago (Engel, 1977), but it may be helpful for clinicians to be more explicit in their multifaceted understandings in conversations with people they provide care for. We envisage this will help strengthen the conceptualisations people with ABI have constructed and help them feel more considered and understood. It may also help some people have more complete conceptualisations of changes following BI, as the study revealed they can appear incomplete or difficult to articulate at times.

Another implication for clinical practice would simply be for clinicians to signpost clients to appropriate reading material as this appeared to be a key method which helped participants develop a more complete conceptualisation of their difficulties and understanding changes following ABI.

It appeared participants largely believed their BI influenced changes in mind and self. Therefore, clinicians could highlight this materialistic perspective in conversations to help clients become aware that this is how some people with ABI make sense of the interactions between mind, brain and self. Furthermore, to be inclusive of all perspectives and not just the dominant one, they could explain that some do not see things this way.

Study limitations and implications for future research

As with much research, this study has its limitations. Hopefully, some of these limitations will encourage future research to be conducted in this area.

One limitation was that all participants were recruited through one BI charity. This could be problematic as they exist within a share community and culture. Therefore, they may have developed shared understandings through social interactions with each other (which was suggested in theme 2.1). Therefore, although this study does not aim for generalising to other contexts and focused on the experiences of a particular population within a specific context, like much qualitative research (Leung, 2015), it does represent a very specific group within a heterogenous group. It would be fruitful to explore whether individuals with ABI, from different contexts who may have less access or contact with others with ABI, would have held similar views.

Additionally, from those that chose to disclose the location of their injury, there were some that did not appear to have injuries in particular areas, such as an occipital lobe injury or a pure parietal lobe injury. However, research exploring some of these different groups of people would be helpful future pieces of research.

Another limitation of the research was that as the intention of the research was to understand participant’s conceptual models, the interview questions were broad in their scope. This could be seen as a limitation as a more detailed interview, pertaining to specific elements of their conceptualisations (for example, purely focusing on the disconnect between body and mind) would have developed a more detailed account of their conceptualisations. As this concept of a mind-body disconnect has been highlighted before (Levack et al., 2010), future research could explore this area more specifically and explicitly.

Finally, this research presents the suggestion, albeit small in scale, that some clinical conceptualisations of disorders and ways of organising care in medical settings related to neurological problems may be insufficient (namely the F-OD). However, ABI represent only one group of individuals within this system. Further research with another group affected by the F-OD, such as those diagnosed with functional neurological disorders, could further our understanding in this area.

Conclusions

This project outlines aspects of people with ABI’s conceptual understandings of changes following injury, with some reference to interactions between mind, body/brain, and self. Although many of these conceptualisations may not have been complete or fully describable, they indicated that participants understand changes though a multifactorial lens that centres the biological, psychological and social aspects of BI in understanding changes in their physical selves, thinking and social identity (which encompasses the mind and self). This research indicates a perceived lack of knowledge of those without ABI and this has clinical implications on how to speak with those with ABI about changes they have experienced.

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Part 3. Critical Appraisal

Introduction

This paper will critically appraise the process of designing and conducting the study outlined in Part 2 of this volume. The paper will begin with an acknowledgement of the assumptions I held at the beginning of the study and how my position changed over its course. I then explore specific considerations regarding conducting research with adults with acquired brain injury (ABI) and how these were present and accounted for in the current study. Finally, I will reflect upon the experience of conducting research with a group of people which I did not share the same broad experience with, in this case the experience of living with an ABI.

Preconceptions and assumptions

Within the paradigm of qualitative research, it is acknowledged that researchers will hold pre-existing ideas and assumptions that could influence the research at every stage (Barker et al., 2016, pp. 74-75; Charmaz, 2014, pp. 155-160; Fischer, 2009). Indeed, good practice in qualitative research promotes the declaration of the researcher's biases to aid the reader in further understanding the study's findings and interpretations (Barker et al., 2016, p. 91). There are processes to help researchers become aware of their preconceptions and I will outline those employed in the current project.

Bracketing interviews are one method of researchers becoming aware of their assumptions to help decrease their influence on the research process (Fischer, 2009; Tufford & Newman, 2012). I completed a bracketing interview around the time of topic guide construction which aided reflection upon my assumptions.

I believe that my assumptions developed through my pre-training experiences of working in both acute and rehabilitation neuropsychology settings with individuals with acquired brain injury (ABI), in addition to academic learning about psychological theories. Regarding the latter, I completed a modest amount of reading to aid study design, although attempted to minimise embedding pre-existing ideas into study design and analysis by delaying a full literature review until later in the study (Charmaz, 2014, p. 306). However, a review of some literature was required for the project proposal and sensible construction of the topic guide (Charmaz, 2014, p. 307). Indeed, when literature was reviewed, I remained appropriately critical of it (Charmaz, 2014, p. 307) and reflected regularly on its impact upon my thinking. There is disagreement between when the relevant literature should be read in studies informed by grounded theory (GT) (Charmaz, 2014, p. 306), but I chose to read literature when pragmatically needed (considering the processes required by my training). Finally, it is of note I had relatively little personal experience of ABI outside of distant family members and I did not presume to have insight into their conceptualisation of changes.

During bracketing, I reflected upon the functional-organic distinction and presumed that individuals with ABI would not solely consider organic factors as accounting for changes following ABI. However, I also believed there would be a multitude of idiosyncratic conceptualisations between participants and thus there would not be one dominant narrative or process which allowed for straightforward summarisation of experiences into a comprehensible account of themes. Therefore, I anticipated that I may need to look for broader implicit meanings and purposes (Charmaz, 2014, pp. 111-113) in conceptualisations to help coherently make sense of participants' accounts. The latter assumption was challenged and shifted throughout the research as I realised there were commonalities in how participants made sense of themselves and navigated changes following brain injury, such as use of goal setting and asserting parts of themselves that were unchanged following ABI.

Furthermore, I believed that participants would find it challenging to express internal models they used to understand changes as current language may not lend itself well to explaining these in lay people's language. Therefore, I was confident that a GT approach was well suited due to its preference for data analysis alongside collection (Bryant & Charmaz, 2012, pp. 39-46) as it would assist early revision of the topic guide based upon data gathered. However, I found that during the process of conducting interviews, participants had varied accounts that meant it was not a simplistic task of utilising discussions from earlier interviews to further develop the frame of language in later interviews. However, I was able to appraise interview questions that usually encouraged lengthy answers that were tangential to the research questions and change them accordingly.

Finally, the bracketing interview highlighted my belief that if participants had undiscovered conceptualisations, far removed from current clinical understandings of changes following ABI, that I may struggle to easily comprehend these. Therefore, the process of being unassuming with language that participants used (Charmaz, 2014, pp. 83-84) aided me in ensuring I was interpreting the meaning and processes implicated in their words when analysing data as opposed to assuming I understood what was meant by their language. The conduction of semi-structured interviews was paramount to this aim due to the flexibility for follow-up questions to build upon core questions (Samuel et al., 2020, pp. 47-48).

The process of bracketing was particularly useful at aiding the construction of the initial topic guide. Although the process of GT topic guide construction already promotes open questions (Charmaz, 2014, p. 65), I was mindful that this would also protect the research from being too influenced by my assumptions at the earliest stage. I was also careful to not have too many questions, which would obstruct the ability to use individualised follow up questions that would help elaborate upon a participant's conceptualisation of changes (which would further safeguard against filling in any gaps with assumptions).

Despite this, I grappled with uncertainty regarding the use of existing concepts embedded into the interview guide throughout data collection. This is because broad questions without these concepts sometimes encouraged participants to discuss the effects of ABI, perhaps a more familiar conversation, as opposed to describing how they made sense of these changes. However, I also appreciated that a participant's account of changes inevitably needed to precede their conceptual understandings of these changes given the variability of difficulties (whether cognitive, emotional, physical or otherwise) within the heterogenous ABI population (Barman et al., 2016; Covington & Duff, 2021), meaning participants would need to specify their specific changes first.

GT also suggests preconceptions can be elucidated during memo writing and coding (Charmaz, 2014, pp. 156-159). Indeed, I was cautious in utilising extant concepts and understandings within academia in coding phases and ensured that when they were used, they were appropriate to the implicit meanings in the data (Charmaz, 2014, p. 159). I did this by questioning how these concepts would help me or readers understand the data and whether their omission either occluded anything or aided articulation of certain processes (Charmaz, 2014, p. 159). An example of this was applying the concept of the mind when participants discussed internal thought processes. A way in which I guarded the application of my pre-existing knowledge as a frame to coding was to minimise their use in initial coding (unless participants explicitly used the concepts) to make sure the codes remained close to the data/participants' voices.

There was also an ongoing tension between the use of academic language and everyday language in the consideration of topic guide review as the study aimed to be inductive in approach (Charmaz, 2014, p. 15). Yet, people already use certain concepts, such as those of the mind, in everyday language and there has been an argument that neuropsychology language has already pervaded lay people's language (Rodriguez, 2006). However, I leaned towards excluding these concepts as it would assume shared understanding of these phrases and could have reduced the possibility of participants introducing language that fitted better for them. This felt appropriate given the results revealed that a couple of participants sometimes used terms, such as the mind and brain, interchangeably.

I remained cognisant of some of the preconceptions and assumptions I held during coding and memo writing (Charmaz, 2014, pp. 156-159). For example, I found this particularly helpful for the theme which described participants ascribing different degrees of control in their lives. I initially believed that participants attributing much of their difficulties to the brain injury indicated that they felt passive within their conceptualisation of changes following injury, perhaps partly influenced by my own assumptions about biological factors. However, when I thoroughly examined other initial codes and explored their meaning, I found participants indicated having control over changes in varying ways, such as goal setting and strategies to reduce or compensate for difficulties.

It was also pertinent to examine certain findings when my preconceptions seemed to mirror them. For example, the subtheme that described participants having difficulties finding the words to describe their conceptualisations was aligned to my preconception that models may be difficult for participants to articulate. Therefore, I scrutinised the excerpts that were under this subtheme, in the wider context of their interviews, to ensure my interpretations were not far removed from the context of the interviews or their meanings. However, I questioned whether this would then increase the possibility of coding to summarise as opposed to analyse, which can also be problematic (Charmaz, 2014, p. 159). At these times, I found it helpful to ask myself what the participant meant or what the process revealed to ensure I was making sense of the data beyond their actual words (Charmaz, 2014, p. 111).

Completing research with adults with ABI

Conducting research with adults with ABI has specific considerations, which I will outline and describe their relevance to the current study.

Having prior experience working with adults with ABI when I began the project meant that I was aware of various factors that may affect their ability to engage in the interviews, such as potential physical and cognitive impairments (Nestvold & Stavem, 2009). I considered some of the skills I had gained in clinical settings that could transfer to research in aiding interview conduction, such as offering a reminder of the interview appointment to increase attendance rates and considering shorter appointments due to cognitive deficits (Ownsworth & Gracey, 2017, pg. 318). Another factor that assisted with interviews was that the brain injury charity would share aspects of a participant's risk assessment, with their consent, if there was a specific difficulty that a participant had that would be relevant to the interview. For example, difficulties regulating certain emotions. This was invaluable at preparing for interviews and considering etiquette (Charmaz, 2014, pp. 68-71). For example, tentatively asking a participant's permission to explore certain topic and giving them as much power as possible to decline this (Charmaz, 2014, p. 68), particularly if they are known to experience intense emotions when talking about certain experiences. To this end, it also generally helped to inform participants that we would only discuss topics they felt comfortable to.

Another consideration specific to adults with ABI is the suggestion that they are not reliable informants of their own experiences due to cognitive changes, such as a reduced capacity to self-evaluate (Armstrong, 1991) or a lack of insight (Egan et al., 2006). Additionally, it has been highlighted that people with ABI may have distorted perceptions of their experiences due to deficits, such as believing someone has abandoned them as their memory deficits means that interactions are forgotten (McGrath & King, 2004, pp. 333-334). However, research has suggested that interviews with people with ABI can still be meaningful, but the interviewer may need to utilise creative skills to facilitate interactions (Paterson & Scott-Findlay, 2002). Moreover, I discovered that participants often named when they were unsure about an aspect of their experiences or had difficulties understanding. Additionally, even if cognitive impairments influenced their narratives, I reflected that this is the nature of brain injury and therefore their conceptualisations of changes are being accurately reported from their subjective experiences. It should be noted that none of the participants had cognitive deficits to the degree that they were unable to engage in semi-structured interviews for at least 30 minutes. Finally, my supervisor helped me reflect that participants citing incomplete conceptualisations is a finding within itself, as opposed to necessarily reflecting a methodological issue within the study to capture data.

It has also been suggested that people with ABI may experience difficulties with communication, distractibility, reduced insight and other cognitive difficulties that may impede their ability to engage in an interview (Paterson & Scott-Findlay, 2002; Sherry, 2006, p. 94). For example, people with ABI have been demonstrated to show a reduced ability to maintain topics in conversations (Snow et al., 1997). I developed skills to respond to these difficulties and make the interviews accessible. For example, if a participant appeared to be talking tangentially to the topic, I would ask a prompt question that guided them back to the topic. Furthermore, the ability to speak with participants over the phone before the interview (to explain the study) allowed me to develop a sense of how they communicate as communication difficulties are common in ABI (Carlsson et al., 2007). Illustrating this, I recall one situation where the participant named their speech clarity difficulties, and we agreed respectful means in which I could interrupt them if their speech was unclear. Similarly, with other participants we agreed that they could interrupt me or ask me to rephrase if my communications or questions were unclear.

I also considered cognitive and communication difficulties when a participant would make false starts, have extended periods of silence or there was a pause after I asked a question. I was mindful not to infer that this meant the participants could not answer the question or did not have the words to describe their experience but that they may need more time to consider their answer (Sherry, 2006, p. 95). Again, I would also offer to reframe questions where needed.

There was also a tension between wanting to have an open, inductive frame to interviews and being aware that some people with ABI struggle with more open-ended questions if they have frontal lobe injuries due to difficulties with generating spontaneous thought without structure or prompts (McGrath & King, 2004, p. 345). Although this could have influenced the interviews, participants did not generally seem to be perturbed by open-ended questions and the interviewer could narrow the scope of conversations through follow-up questions if their responses were broad in scope. However, there were instances when questions were reworded but it appeared that the question did not make clear sense to the participant and it did not appear to be answered directly. On reflection, it may have been fruitful to have formulated less open-ended alternatives beforehand should the need arise in interviews.

To maximise the accessibility of the research, a brain injury survivor assisted with topic guide revision, which is a recommended means to overcome cognitive-linguistic barriers in research, alongside usually discussing the study with participants to set up the interview, to assist with rapport building and understanding their communication (Egan et al., 2006).

Additionally, the coronavirus pandemic required interviews to be conducted remotely, which led to specific considerations for participants as cognitive impairments could impact their ability to engage optimally with this (Topping et al., 2021). I was able to anticipate some of these aspects beforehand, such as the environment the participant may be joining from, their technological competence and difficulties with internet connectivity (Topping et al., 2021). During the initial phone call, the checklist we used (see Appendix E) ensured that we discussed with participants to make sure they had a private space with stable internet, as well as planning in case this was not possible. We also offered to use the same video platform that was routinely used by the brain injury charity at the time, meaning there was likely familiarity with this platform. However, after data collection began, it became clear that there was also a necessity to agree contingency plans in case participants were unable to join the meeting or there were technological difficulties (Topping et al., 2021), such as agreeing to call the participant if they were not in the virtual meeting five minutes after its start time.

However, the use of remote interviews did not capture observable aspects of the participants that would otherwise be available in-person, such as some non-verbal cues and gestures (Khalil & Cowie, 2020). However, a benefit for remote interviews was that some participants would have been able to engage in the research more easily as the appointments may have been seen as more convenient and less costly in terms of time and money as travel was omitted (Egan et al., 2006; Ownsworth et al., 2020).

However, an alternative methodology that could have been employed is the use of email interviews, which would have allowed for greater time for participants to reflect and formulate their answers (Egan et al., 2006). This is a method which could be employed for future research in this area, particularly for the areas participants appeared to find difficult to articulate. Despite this, email interviews would miss the nuance of interaction and non-verbal communications (Egan et al., 2006). Alternatively, it may have been useful to consider multiple interviews with participants to help manage fatigue and encourage reflection between interviews (Paterson & Scott-Findlay, 2002). Furthermore, multiple interviews with the same participant are sometimes recommended in theoretical sampling within GT (Charmaz, 2014, pp. 103-104).

A brief reflection on the process of conducting outsider research

During study design, but particularly during data collection and analysis, I was acutely aware of my position as someone who did not share the same core characteristics as the participants I was researching, in this case an ABI. Although an individual with ABI assisted by providing some feedback on the topic guide and some initial codes, the rest of the research team were outsiders to the experience of ABI. Therefore, this research would broadly be considered outsider research (Bridges, 2001) and I will outline my experience of this in this section.

It should be noted that there is an emphasis on service user involvement within the disability community, including involvement in research (Levack et al., 2010), of which I was aware going into the study. Although I already saw the importance of populations being involved in debates that concerned them (Bell et al., 2020), I found myself becoming more aligned to this view throughout the research as I read more literature and during data collection. Although I believed I was helping further academic knowledge by understanding participants through research, I was also aware I was actively interpreting data, in line with the GT approach (Charmaz, 2014, pg. 111), but interpreting inherently through the lens of an outsider. This led to a sense of discomfort at times during the research process due to my outsider position. Furthermore, I found myself feeling inspired and humbled by Sherry's (2006) book, "If I Only Had a Brain", which details the experiences of people with ABI that he had researched as a person with ABI himself. The discomfort I felt regarding my research at times appeared to be emanating from my belief that the voices of these individuals needed to be shared but this was through the interpretative vessel of myself, someone without a brain injury who may not readily understand the nuances of this experience through their language expression and interactions (Berger, 2015).

However, I also reflected that a benefit of conducting outsider research was the empowerment and expertise that was placed upon the participants as I was coming from a stance of not knowing, particularly as the participants may feel marginalised and unheard typically (Berger, 2015). Although I acknowledged that the outcome of the research would be impacted by my influence as an outsider, there are arguments that outsider research can still be beneficial in enhancing the understandings of both the researcher and the wider public (Bridges, 2001).

Conclusion

In sum, this paper offers a reflection regarding the conduction of this piece of research, particularly the assumptions I held going into the research and where they may have developed from. I outline my attempts to safeguard the processes of study design, data collection and analysis from these assumptions, whilst appreciating that I am an outsider to the community I was studying and inherently I would have had an undeniable influence on the research as I interpreted data. A reflective discussion was also presented regarding the considerations that are unique to conducting qualitative research with adults with ABI and how the research could have been otherwise conducted. I hope these reflections will be valuable to other researchers considering a study in a related topic.

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Appendices

Appendix A. Evidence of ethical approval

UCL RESEARCH ETHICS COMMITTEE
OFFICE FOR THE VICE PROVOST RESEARCH

16th February 2021

Dr Vaughan Bell
Department of Clinical, Educational and Health Psychology
UCL

Cc: Jordan Harvey & Alice Chesterfield, Clinical Psychology Doctorate Students, Department of Clinical, Educational and Health Psychology

Dear Dr Bell

Notification of Ethics Approval with Provisos

Project ID/Title: 19001/001: How do people with brain injury understand the interaction between mind, brain, self and injury?

Further to your satisfactory responses to the Committee's comments, I am pleased to confirm in my capacity as Chair of the UCL Research Ethics Committee (REC) that your study has been ethically approved by the REC until **20th May 2022.**

Approval is subject to the following conditions:

Notification of Amendments to the Research
You must seek Chair's approval for proposed amendments (to include extensions to the duration of the project) to the research for which this approval has been given. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing an 'Amendment Approval Request Form' http://ethics.grad.ucl.ac.uk/responsibilities.php

Adverse Event Reporting – Serious and Non-Serious
It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator (ethics@ucl.ac.uk) immediately the incident occurs. Where the adverse incident is unexpected and serious, the Joint Chairs will decide whether the study should be terminated pending the opinion of an independent expert. For non-serious adverse events the Joint Chairs of the Ethics Committee should again be notified via the Ethics Committee Administrator within ten days of the incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Joint Chairs will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

Final Report
At the end of the data collection element of your research we ask that you submit a very brief report (1-2 paragraphs will suffice) which includes in particular issues relating to the ethical implications of the research i.e. issues obtaining consent, participants withdrawing from the research, confidentiality, protection of participants from physical and mental harm etc.

In addition, please:

- ensure that you follow all relevant guidance as laid out in UCL's Code of Conduct for Research: https://www.ucl.ac.uk/srs/file/579
- note that you are required to adhere to all research data/records management and storage procedures agreed as part of your application. This will be expected even after completion of the study.

With best wishes for the research.

Yours sincerely

[redacted]

Professor Michael Heinrich
Joint Chair, UCL Research Ethics Committee

Appendix B. Final participant information sheet

Participant Information Sheet

This study has been approved by University College London (UCL) Research Ethics Committee.

Ethics ID Number: 19001/001

How do people with brain injury understand the interaction between mind, brain, self and injury?

Centre for Clinical Psychology, University College London

Contact details of Researchers:

Jordan Harvey ([redacted])

Alice Chesterfield ([redacted])

Contact Details of Principal Investigator:

Dr Vaughan Bell ([redacted]) [redacted]

We are inviting you to participate in a research project conducted in partnership with [redacted] This document will describe the project and will help you decide whether you would like to take part. Please carefully read this document. You can also contact the researchers using the contact details above with any questions you may have. This research is being funded by University College London.

Aims of this research
The aim of this project is to help understand how people with brain injury understand any relationships between their injury and their experiences (such as their feelings, thoughts, behaviours and difficulties).

Who can take part?
We are inviting members of [redacted] to take part, who are over the age of 18 and have an acquired brain injury.
This study is completely voluntary and you don’t have to take part or give a reason for not doing so.

To consent you need to sign a consent form or allow your verbal consent to be audio-recorded. However, you may withdraw from the study at any time, without giving a reason.

What does participation look like?
Participation would involve taking part in an interview, which would take around an hour of your time. The interview will focus on how you make sense of your brain injury and other aspects of your life. We will ask questions around which factors you see as relevant in understanding any challenges you experience in life. These interviews will take place on Microsoft Teams or Zoom, which participants will be able to access through a hyperlink.

We will also collect some demographic information by asking your age, ethnicity and gender to help us understand the diversity of the people we interview. We will also ask the location of your brain injury, if known, as this may be relevant to understanding your specific experiences. However, this information is not essential.

You will be able to withdraw from the study during the interview or up to two weeks following the interview, without providing a reason. In this event, all of the data you have provided will be deleted (all of your details and the interview recording). Unfortunately, we would be unable to withdraw your data after this two-week period as all of your data will be anonymised.

We will be offering a £10 Amazon voucher to those participating, as a token of acknowledgement to the time you will be spending with us (around an hour). However, you will still receive this token if you choose to withdraw from the study partway through or completely.

The interviews will be recorded and will later be transcribed (typed out) by the researcher or an approved transcription service called Scrintal, which is a UCL approved automated transcription service. Following transcription, we will remove personal details from the text, and store them securely. No one outside of the original research team and approved transcription service will have access to the original recordings.

What are the potential benefits and disadvantages of taking part?
Given the interview topic, there is a chance that discussing certain aspects of your life could cause some emotional distress or discomfort. Therefore, we would like to invite participants to only disclose what they feel comfortable with.

Whilst there are no immediate benefits for those taking part, we hope that the project will further our understanding of how people make sense of their brain injury.

Complaints
If at any point, you have any concerns, complaints or would like to discuss further support after engaging in this research, please email the Principal researcher at [redacted]

If any complaints are not addressed satisfactorily, you may contact the Chair of UCL Research Ethics Committee at ethics@ucl.ac.uk.

Confidentiality
All of the information we collect about you during the course of the interview would be kept confidential. You will not be identified in any reports or publications that may arise from this work. However, anonymised quotes may be used in the write up of the research to highlight some of the themes from the interviews.

The exception to maintaining confidentiality would be in the exceptional event that something arises in our conversations which indicates yourself or others may be in danger of harm. In this case, the researcher would need to inform the relevant agencies of this. However, we would aim to discuss this with you first and would only share information that is pertinent to keeping yourself or others safe.

What will happen to the results?
The information collected in the interviews, along with the results, will be written up as scientific papers and a thesis for a clinical psychology doctorate programme at UCL.

We hope to also have an event at [redacted] to share with members a summary of the study and how this has been helpful (this would, of course, be anonymised). We hope that this will happen in-person but it may need to be online (via Microsoft Teams or Zoom) if coronavirus governmental advice dictates.

We will aim to publish the results of this study to enable the results to be helpful to others who may have, or be supporting those with, an acquired brain injury. We would aim to publish results in 2022/2023.

Local Data Protection Privacy Notice
The controller for this piece of research is University College London (UCL). The specific overseer of UCL activities regarding the processing of personal information is the UCL Data Protection Officer. They are contactable on data-protection@ucl.ac.uk

This local privacy notice details the specific information that is relevant to this project. Additional information on how UCL uses participant information is available within our general privacy notice.

For participants in health and care research studies, click here

The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the ‘local’ and ‘general’ privacy notices.

The categories of personal data collected will include: name, age, gender and contact information (telephone number or email). We will collect two pieces of special category personal data, if possible, which is the location of your brain injury and ethnicity.

The lawful basis that will be used to process your personal data are: ‘Public task’ for personal data and’ Research purposes’ for special category data.

Your personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible. We will store any identifiable information (your name and contact details) and interview recordings electronically. Only the research team, listed on the first page of this document, will have access to this data. This data will be deleted when it is no longer required (once transcripts have been provided and by the end of the project in 2022).

We will store anonymised transcripts of the interviews and demographic data (on age, gender, ethnicity and location of brain injury) indefinitely. Only the research team will have access to this data during and after the study. Furthermore, your contact details would not be stored together with transcripts as they will be deleted following interviews. Any records of consent will be stored on secure UCL systems that only the researchers will have access too.

If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at data-protection@ucl.ac.uk

If you would like further information on the study before agreeing to take part then please contact Vaughan Bell on: [redacted] or [redacted]

Thank you for taking the time to read this information sheet and considering to take part in the research study.

Appendix C. Final participant consent form

Consent Form for Participation in the Study:

How do people with brain injury understand the interaction between mind, brain, self and injury?

Please complete this form after reading the participant information sheet and discussing any questions you have with one of the research team.

Department: University College London, Faculty of Brain Sciences, Centre for Clinical Psychology.

Contact details of Researcher(s): [redacted], [redacted]

Contact Details of Principal Researcher: Dr Vaughan Bell ([redacted] Tel: [redacted]

Contact details of the UCL Data Protection Officer: [redacted]

This study has been approved by the UCL Research Ethics Committee. Project ID Number: 19001/001

Thank you for the time you have already spent considering whether to partake in this study. Please note this study must have been explained to you before you agree to be involved. If you have any questions from the information sheet, please ask the researcher before completing this form. You will be given a copy of this consent form to keep for your records.

I understand that if I do not give consent for any element of the below, I will not be able to take part in the study. I understand that by ticking/checking each box that I will be indicating consent for this aspect of the study. I understand that unchecked boxes will indicate that consent is not given.

		Initial/tick/check
1	I confirm that I have read and understood the Participant Information Sheet and understand the expectations of the study. I confirm I have had the opportunity to ask any questions before the study begins and these questions have been answered satisfactorily	
2	I understand that I will be able to withdraw my data for up to two weeks after the interview. After this time, the transcript will be anonymised and withdrawal is not possible. I understand my personal data will be deleted if I do withdraw	
3	I consent to participate in this study. I understand some personal data will be collected. I understand that demographic data will be collected for age, gender, ethnicity, and location of brain injury (if known). I understand the purposes of the collection for such data. I understand that the lawful processing of this data will be for public interest, and 'research purposes' will be the lawful basis for processing special category data.	

4	I understand that all of my personal data will be kept confidential and efforts will be taken to ensure I am not identifiable in any reports. I understand that the data I provide will be stored anonymously after it is transcribed. I understand that I will not be identifiable in any publications from this study	
5	I understand the risks and benefits of taking part. I understand I can receive support should I become distressed from the interviews by discussing with Dr Vaughan Bell or [redacted]	
6	I understand I will not benefit financially from this study or any possible outcome from it in the future	
7	I understand that I will be compensated for the time I spend in the interview with a £10 Amazon voucher. I understand I will still receive this if I choose to withdraw	
8	I understand that the information I provide will be part of a published report	
9	I consent to my interview being audio recorded and that the recording will either be transcribed by the researcher or Scrintal, an approved transcription service. I understand my data will be used for specific research purposes. I understand I cannot take part in this study if I do not wish to be audio recorded.	
10	I understand the inclusion criteria for this study	
11	I understand who I can contact should I wish to make a complaint	
12	I voluntarily agree to take part in this study	

For remote interviews, the contents of this consent form may be completed verbally and a recording kept of the process.

Name of Participant:

Date:

Signature:

Name of Researcher:

Date:

Signature:

Appendix D. Initial contact email to participants

Dear X,

Thank you for your interest in the research study.

I have attached the study information sheet and consent form for you in case you have not seen these yet.

I could call you if you have any questions before deciding whether you would like to take part or if it would be easier to discuss these forms. If this would be preferred, please can you provide a phone number (preferably mobile) and a suitable time on a weekday to call you.

If you have no questions and would like to take part, would a Wednesday or Friday suit you for an interview? Please note that I can try to be flexible if neither of these days work for you.

Best wishes,
Jordan Harvey
Research Department of Clinical, Educational and Health Psychology
University College London
1-19 Torrington Place, London, WC1E 7HB

Appendix E. Initial participant phone call checklist

Introduce self and confirm study details	
Check whether the potential participant has received the information sheet and consent form- if not, offer to send by email and go through it with them.	
If they have not had chance to look through it, offer to call back after at least 24 hours if they would like time to review it.	
Check they meet inclusion criteria – over 18 years old, have an acquired brain injury and current involvement with the BI charity	
Check if they have any questions at this stage about the study.	
Ask their preference for a Zoom call or Microsoft Teams call. Check they have stable internet and access to a computer in private space. Verbally get consent to send invite over email or write down details of the invite.	
Explain they can email if they have any questions and would like to talk, rearrange interview or decide they do not wish to partake.	

Appendix F. Initial interview topic guide

Topic guide (April 2021)

Initial questions

- Can I ask how you define your gender?
- And ethnicity?
- And age?
- This next question you do not have to answer if you do not feel comfortable or wish to. Can I ask the location of your brain injury?

Main questions *(Italics- possible follow-up questions, if needed)*

As we discussed, I hope to be able to understand more about how you see the relationship between your brain injury and the rest of your life.

1. Can I start by asking what interested you in taking part in this study?
2. Could you tell me what role your brain injury plays in your life? [emotional life / social life / mental life]

   -*As we talk about your (social, emotional etc) life, are there any events that come to mind that you can describe?*

   -*Are there any other factors that influence this aspect of your life? Could you tell me more about the relationship between these aspects?*
3. How does this compare to other influences in your life?

   -*Has your understanding changed over time?*

   -*If so, how (and/or why) has it changed?*
4. Can you tell me whether it makes sense to distinguish your thoughts, feelings and decisions from the effects of your brain injury? *(Elaborate, if needed).*

   -*What are your thoughts and feelings about this?*

   -*Has anything or anyone been important in influencing your understanding of the relationship between your brain injury and your thoughts, feelings and decisions?*

5. Does your understanding of the relationship between your brain injury and the rest of your life differ from other people's?

   -*Could I ask where these ideas come from?*

6. Is there anything I have not asked which feels important to add or talk about?

Appendix G. Final interview topic guide

Final topic guide (May 2021)

Initial questions

- Can I ask how you define your gender?
- And ethnicity?
- And age?
- This next question you do not have to answer if you do not feel comfortable or wish to. Can I ask the location of your brain injury?

Main questions *(Italics- possible follow-up questions, if needed)*

As we discussed, I hope to be able to understand more about how you see the relationship between your brain injury and the rest of your life.

Remind of topic throughout: how you understand any relationships between your injury and your experiences (such as your feelings, thoughts, behaviours and difficulties).

1. Can I start by asking what interested you in taking part in this study?
2. *How has [your experience of/*how you relate to*] your thoughts, feelings and behaviours changed since the time of your brain injury?

   How do you understand these changes?
3. *Could you tell me what role your brain injury plays in your life? [emotional life / social life / mental life]
    - *As we talk about your (social, emotional etc) life, are there any events that come to mind that you can describe?*
    - *How do you understand these changes since the time of your brain injury?*
    - *Are there any other factors that influence this aspect of your life? Could you tell me more about the relationship between these aspects?*
    - *How does this compare to other influences in your life?*
    - *Has your understanding changed over time?*

- *If so, how (and/or why) has it changed?*

4. Can you tell me whether it makes sense to distinguish your thoughts, feelings and decisions from the effects of your brain injury? *(Elaborate, if required)*
    - *How do they relate to each other?*
    - *What are your thoughts and feelings about this?*
    - *Has anything or anyone been important in influencing your understanding of the relationship between your brain injury and your thoughts, feelings and decisions?*
5. Does your understanding of the relationship between your brain injury and the rest of your life differ from other people's?
    - *Could I ask where these ideas come from?*
6. Is there something I have not asked which feels important to add or talk about?

General follow-up questions:

- *Is it...?* (Repeating their statement/own question/descriptive word)
- *Can you describe...?*
- *When you thought of x, what did that feel like/mean?*
- *Tell me what x is like for you.*
- *What does/did x mean to you?*
- *How did/do you make sense of that?*
- *What's behind that, in your mind?*
- *Tell me more about your understanding of/how you make sense of that.*
- *Can you describe your thought process at that time/in that example?*
- *What does x look like to you?*

Please note that usually only question 2 was asked but question 3 was posed if participants did not understand question 2.

Appendix H. Trainee's contributions to each other's projects

Please see below for contributions Alice Chesterfield (another Trainee Clinical Psychologist at UCL) and I made to each other's projects.

During study design, we discussed ideas for topic guide construction in joint supervision, although the guides were written for each project independently.

During data collection, Alice conducted seven out of 15 of the interviews for my project and I conducted 10 out of 20 interviews for her project. Alice transcribed five interviews for my project and I transcribed eight for hers.

During analysis, Alice Chesterfield coded one of the interviews she conducted for my project. I independently coded this interview and we discussed codes that were generated.

Furthermore, during analysis, I met with Alice at regular intervals (after sets of five interviews) to discuss codes generated.

Appendix I. Initial coding excerpt from three researchers

Transcript- P3	Coder 1 (AC)	Coder 2 (JH)	Coder 3 (VB)
P3: I would say quite a big part now because I can't... it's the lack of independence and I suffer from fatigue now, which I never used to. So, I used to work really hard, I'd start early in the morning, work right through 'til late at night and I can't do that now because, what I found was I would get- by about lun- by about 1 o'clock, I'd start getting grumpy, which wasn't me. And then I'd st- my wife would say something to me and then in the end I would just like shout at her. And I've never done that, and that really upsets me 'cause I'm not that sort of person. So, I realise now what I have to do is have a sleep for an hour and then that recharges the batteries a bit. So, fatigue is a big impact on my life, I think at the moment. And the whole lockdown's been really hard as well because not seeing people, 'cause I love seeing people. So, and that drives her mad as well 'cause when we go out everywhere I like to talk to everybody. 'Cause I just find it, I don't know, it just stimulates me, I think.	-New suffering -Comparing what can do now with before injury -Disowning grumpiness as not part of self -Finding increase in aggression upsetting -Learning how to manage fatigue -Finding it hard not seeing people -Being stimulated by talking to others	-Asserting big impact on life -Labelling change in pace -Noticing changes in mood following brain injury -Struggling to accept mood changes as part of self -Naming need for recharging -Noticing a quantitative effect of demands on mood -Identifying a love for seeing people	-BI reduces independence -BI causes fatigue -BI curtails daily activities -Hard worker was a previous characteristic… …impacted by BI -BI alters emotions / causes negative emotions, causes verbal hostility to wife -BI acts outside the 'real me' -BI causes limited mental resources that need to be replenished -Lockdown is emotionally difficult -Seeing people affects me positively -Social interaction stimulates me

Appendix J. Excerpt of initial coding completed by Jordan Harvey

Transcript	Initial codes
P: I suffer with fatigue pretty badly, even after nine years. So, waking up it’s like so how do I feel? I wake up every day feeling pretty awful but within fifteen minutes I’ll know whether I’m going to have a good day or bad day. So, I never, always know… so each day as it comes. Fortunately, a lot of the time it's good days at the moment. Erm and then that’s okay. If it’s a bad day, I literally can’t do anything. And then if you’re on a good day, I’m conscious all the time that I mustn’t overdo things, do too much, take too much on board. And then if I’ve done something, I’m meant to rest in between doing things to sort of conserve some energy and recharge a bit. Erm yeah I’m conscious that you should have routines and sleep hygiene ideally when you go to bed. And when you go to bed. And then it’s in bed ‘am I going to sleep tonight or am I going to be lying here for four hours?’ Erm and then it starts all over again.	- Believing brain injury causes fatigue - Questioning self to ascertain impacts -Struggling to predict impacts -Feeling passive -Needing to develop new ways to manage- not doing too much -Recharging/conserving energy to counter effects -Questioning self to ascertain impacts
Interviewer: Okay and you mentioned about knowing within the first kind of fifteen minutes in the day. Could I just ask a little bit more about that?	
P1: Yeah, I wake up every day feeling like I’m getting up with an… the only way I can describe it is a hangover. This is without the drinking. So, every morning I feel like I’ve got a hangover, which fortunately, will hopefully disappear within up to fifteen minutes these days… so I’m doing this as it is now rather than how it has been. So, this is nine years down the line. Erm yeah and it goes very quickly if it’s going to go. If I’ve overdone things within the last couple of days, I’ve still got that hangover feeling erm it means basically I need to go back to bed and sleep.	-Believing brain injury causes hangover feeling -Comparing experiences with other difficulties or something more relatable -Noticing patterns following injury
Interviewer: Okay.	
P1: So, I think the effect is caused by the sleep process. So, my brain isn’t ready to kick into play, so I have to go and have some more sleep and then it generally okay. Erm yeah so that then governs what I do that day. Whether I make appointments that I’ve booked or erm not basically. Or what I can do. Is that okay?	-Identifying sleep as a factor/cause -Feeling passive to biological processes
Interviewer: yeah, that’s really helpful, thank you.	

Appendix K. Excerpt of initial codes from the first five coded interviews

Table K1

Excerpt of initial codes from first eight interviews and themes/subthemes, if applicable

Name of initial code	Number of interviews code occurred	Theme/*subtheme* it later became integrated into (if appropriate)
Difficulties finding the words	2	Not reaching a complete understanding/ *Difficulties finding the right words*
Dissonance between the physical and mental	2	Varying use of mind-body frameworks in sense-making following BI/*Identifying a mind-body disconnect*
Experiencing difficulties being ascribed to PTSD	1	N/A
Experiencing others attributing difficulties to BI	2	N/A
Explaining the brain as filtering spirit	1	Varying use of mind-body frameworks in sense-making following BI/*Separating the brain from other concepts*
Feeling BI acts outside the real me	2	Differing degrees of control/*Feeling passive*
Feeling professionals do not have all the answers	1	Asserting a lack of understanding in others
Finding it hard to separate brain injury from me	1	Not reaching a complete understanding/*Struggling to understand things*

Appendix L. Interview quotes included in subtheme of starting over

Table L1

Excerpts from interviews included in theme 1.4 within the subtheme of starting over

Participant number	Excerpt from interview
P4	"But it's just like… what I found was it was like a complete factory reset. So, you have a phone, and you just erase it and you start getting- and there are certain things you can do and certain things that you physically can't do". "Yeah, that's why I think it's like a total reset. You know, it's just like... [bleach brand name], just destroys everything and you eventually, you know, get back to normal, good or bad really".
P6	"Where it's like some of it is like when you were a kid again, do you know what I mean? Like, like you understand, you hear things so much more clearer, do you know what I mean? But when we get older, we forget them things because we're too busy working and everything".
P8	"Yeah, I think it definitely is, definitely changed the speaking and being determined because I mean I could of-. The brain injury basically sent me back to being a baby again. So, I had to learn how to walk, talk, talk badly obviously my speech is terrible, a bit unclear um, but I had to learn how to eat food and, for a while, I had to inject myself with liquid because I wasn't allowed to eat food".

	“As I said, it made me start again as a kind of baby learning how to walk and talk and do everything, yeah. How do you use the internet? Find everything? It’s like, although I was old enough and it’s never going to be impossible, it’s been interesting trying learning, to learn everything again.”
P12	“But after your stroke, your relationship reverses, you’re the child and your children are telling you what to do”.