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Portfolio for Professional Doctorate in Counselling Psychology (DPsych)

MOVING FORWARD: LIVING BEYOND TRAUMA – HOW DO FEMALE BRAIN INJURY SURVIVORS EXPERIENCE FORMING NEW RELATIONSHIPS POST INJURY? AN IPA STUDY

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Preface

It was not until my final year that I conceived the idea for what this portfolio would stand for. Ultimately it has come to represent the ways in which people respond to the legacy of distress caused by traumatic events beyond their control. I feel this also mirrors my journey as counselling psychologist from a naïve student towards an experienced practitioner in that in my clinical work with clients there is often much that is out of my control which at times, I have found difficult to deal with and respond to. As such my portfolio has brought together two distinct pieces of work. The first is a thesis which explores how female brain injury survivors make sense of their romantic experiences encountered post brain injury. The second piece of work is a client case study and process report which illustrates a particularly challenging piece of trauma work using Acceptance and Commitment Therapy which generated insight and learning fundamental to my development as a Counselling Psychologist. Below I explain how these pieces of work came to be and why they became important to me leading them to be included in this portfolio.

My thesis was driven by my interest in neuroscience and my research question was inspired by the life experience of brain injury survivors. I have nurtured a passion and curiosity for neuroscience ever since sitting in the lecture hall at Birkbeck University listening to Dr Simon Green talk about Sperry’s split-brain experiments and the case of H.M and memory. At the beginning of my doctorate, I volunteered at a Headway Day Centre to gain experience of working with brain injury survivors. Unfortunately, I was unable to secure a placement with this population but my time at Headway cemented my interest and commitment to producing a piece of research with people with acquired brain injury. The Headway Day Centre was accessed by local adults many of whom were not able to be in paid employment and were unable to drive. During my short time at the Headway Day Centre, I caught a glimpse of what it was like for some people to live with what is often referred to as a ‘hidden disability’, and it was this time spent engaging with brain injury survivors which inspired the inception of the research question for the thesis in this portfolio. Whilst at the centre, brain injury survivors told me about the ways in which they had sustained their injuries. But they also shared stories of loneliness, broken romantic relationships and desires to find love and have sex. It quickly became clear that this was an area I could explore as part of my doctorate research. What was particularly appealing and exciting was that the seed for this research project was sown directly as a result of listening to the needs and desires of brain injury survivors themselves.

Bowen, Yeates & Palmer (2010) describe brain injury as a sudden, one off event which is for the most part unexpected and uncontrollable, that can go on to impact a survivor's capability of attaining their hopes and goals and pursuing their dreams as a result of neuropathology which can cause changes in cognition and physical abilities. In terms of existing research, brain injury literature tends to be dominated by studies which have focused on the deleterious impact brain injuries can have on existing romantic relationships (Wood & Yurdakul, 1997; Oddy, 2001; Kreutzer, Marwitz, Hsu, Williams & Riddick, 2007; Burridge, Williams, Yates, Harris & Ward, 2007). In the UK, the age group most at risk of sustaining a traumatic brain injury are 15- to 25-year-olds (Tennant, 2005). This demographic is young and will likely want to develop romantic relationships which they will have to manage alongside their brain injury symptoms. Despite findings suggesting traumatic brain injury survivors experience difficulties forming new friendships (Salas, Casassus, Rowlands, Pimm & Flanagan, 2016), I could not find anything in the literature which looked exclusively at romantic relationships that only ever existed post injury.

The paucity of research on brain injury survivors developing new relationships post injury together with hearing first-hand that developing new romantic connections was important to survivors led me to develop the research question "*How do brain injury survivors experience forming new romantic relationships post injury?"* (I went on to refine this question in terms of gender which is explained further in the Literature Review Chapter and Methodology Chapter). The application of a phenomenological approach was best suited in order to answer this research question. Interpretative Phenomenological Analysis (IPA) has its roots in health psychology and has been used to explore existential matters such as transformative ones (Smith, Flowers and Larkin, 2009), so was therefore an appropriate method for conducting research exploring the experiences of brain injury survivors. As Yates (2003) suggests, qualitative approaches can be applied to develop our understanding of the social context, needs, desires and challenges of brain injury survivors, and it was this which I hoped to achieve through this research. Exploring how people respond to the legacy of distress caused by traumatic events beyond their control also links in with my practice as a counselling psychologist.

As a professional, I have gone on to specialise in psychological trauma. Post-Traumatic Stress Disorder* (PTSD) and Complex Post Traumatic Stress Disorder* (CPTSD) are the most common presentations at the NHS Step 4 Psychology Service where I currently work. Psychological trauma draws on neuroscience and physiology as a way understanding trauma responses (Porges, 1995; Van Der Kolk, 2015). As practitioners working with trauma we are encouraged, where appropriate, to share such information with clients in the form of an intervention known as psychoeducation (Whitworth, 2016). The aim of psychoeducation is to help normalise trauma responses and enable clients to understand them which in turn gives them a choice of how to respond to their trauma symptoms as and when they arise (Phoenix, 2007). As such my work often involves working with clients to increase the different ways in which they can choose to respond to the legacy of distress caused by traumatic events beyond their control. As much as this this work is rewarding, it is also challenging and demanding. The client case study presented in this corpus of work was selected as it has been an invaluable teacher in my journey as a trainee counselling psychologist. This is because it provided a significant amount of time and space for me to reflect on my feelings and reactions towards what I perceived to be the deterioration of a client during a session in the final stages of therapy. This is something I have struggled to deal with as a therapist because it ignites in me a fear of clients relapsing towards the end of therapy. As this is a common phenomenon when therapy is ending, it was therefore something I was keen to improve on in order to benefit my practice, the therapeutic relationship and ultimately the client. The insight I gained by producing the client case study has been instrumental in increasing my ability to recognise and respond to my emotional, cognitive and behavioural reactions towards clients exhibiting distress during sessions which has improved the way in which I work with trauma survivors and changed the way I practice in the final stages of therapy. The parallels here between myself as a therapist, the clients I work with and brain injury survivors really stands out to me; we are all responding to distress, the cause of which is beyond our control.

The theoretical approach presented in the client case study is Acceptance and Commitment Therapy (ACT). I adopted ACT as an approach due to its suitability to the particular client and because it can be an effective way of working with psychological trauma. ACT is a 'non-pathologising' intervention making it appropriate for use with trauma survivors who often suffer from guilt or shame (McLean & Follette, 2016). One of the main aims of ACT is to reduce experiential avoidance (Hofmann & Asmundson, 2008) which can be a persistent trauma symptom (Marx & Sloan, 2005; DSM 5th Edition, 2013). ACT is a particularly useful intervention to use with clients who have not responded to 2nd wave CBT interventions typically offered at lower levels of stepped care within NHS mental health services. This is due to the fact ACT is not primarily concerned with symptom reduction nor does it seek to change cognitions, instead it aims to move clients away from attempts at controlling distress by developing alternative ways of responding instead thus increasing psychological flexibility (Harris, 2009).

Interestingly ACT is increasingly being explored as an intervention for brain injury survivors to help with psychological adjustment and address psychological distress post injury (Whiting, Dean, Simpson, Ciarrochi & McCloud, 2018; Roche, 2020; Whiting, Dean, McCloud, Ciarrochi & Simpson, 2020; Sander, Clark, Arciniegas, Tran, Leon-Novelo, Ngan, Bogaards, Sherer & Walser, 2020). Although seemingly different bedfellows, ACT shares common ground with the research method selected for the thesis in this portfolio, IPA. Whilst both are underpinned by different epistemologies, IPA by phenomenology (Smith, Flowers & Larkin, 2009) and ACT by functional contextualism (Hayes, 2004), they both share an interest in unique lived experience as ACT, like IPA is not concerned with discovering what is true or real as it believes we each only know the world through our own personal interactions with it (Hayes, 2004). A final notable link between IPA and brain injury is that this phenomenological approach is being increasingly utilised to explore the lived experience of brain injury survivors (Howes, Benton & Edwards, 2005; Brunsden, Kiemle & Mullin, 2015; Townshend & Norman, 2018; O'Keeffe, Dunne, Nolan, Cogley & Davenport, 2020).

Ultimately the thesis, case study and research article are explorations of the ways in which people respond to distress caused by traumatic events beyond their control. I feel this reflects the experiences of the brain injury survivors with whom I worked to produce the research as well as the trauma survivors with whom I work in a clinical capacity. In addition to this I feel it reflects the therapeutic processes I deal with as a counselling psychologist as I continue to learn to respond to my own distress when confronted with what I perceive to be a worsening of client distress, something which is beyond my control. As such this theme brings my research and practice together.

**Definitions*

The DSM 5th Edition (2013) defines PTSD as “exposure to actual or threatened death, serious injury or sexual violence” (DSM, 2013. P. 271) with the subsequent development of intrusive symptoms which can include, but is not limited to, involuntary disturbing memories of the traumatic event, nightmares and dissociation which can in turn result in internal and external avoidance and negatively altered cognitions and mood. Further to this, PTSD can also result in hyperarousal, reactivity and hypervigilance and usually lasts for more than one month causing distress or impairment in important areas of functioning (DSM, 5th Edition, 2013).

Complex trauma does not currently exist as a diagnosis with the DSM 5th Edition. It is, however, included in the World Health Organisations (WHO) ICD 11 which states that for a diagnosis to be met, all the symptoms for PTSD must be present, but accompanied by disorders across three domains – difficulties with emotional regulation, enduring negative self-beliefs along with guilt, shame or failure and problems sustaining relationships and developing emotional closeness (World Health Organisation, 2018). Whilst developmental trauma and repeated trauma are believed to be risk factors for complex trauma, they have not been found to be predictors (Dr Cloitre, The Psychologist, 2019).

PART I

How do female brain injury survivors experience forming new romantic relationships post injury?

An IPA Study

Abstract

Acquired brain injury is a leading cause of disability in the UK and often results in ‘hidden injuries’ with enduring consequences (Menon, 2018). The age group most at risk of sustaining a traumatic brain injury in the UK is 15 to 24 years (Dombrowski, Petrick & Strauss, 2000) meaning many survivors will live with associated impairments for years to come. Information regarding the number of brain injury survivors who are single at the point of injury is scarce. Several studies have highlighted negative attitudes towards brain injury survivors in wider society (Linden & Boylan, 2010; Ralph & Derbyshire, 2013), with one study suggesting people are less willing to establish relationships with those with traumatic brain injuries (Miller et al, 2009). Brain injury has been found to negatively impact romantic relationships (Wood and Yurdakul, 1997**;** Kreutzer, Marwitz, Hsu) and has been associated with difficulties establishing new social relationships (Salas, Casassus, Rowlands, Pimm & Flanagan, 2018). Previous literature has explored the impact of brain injury upon romantic relationships extensively, but very little research has attempted to explore the challenges of being single and forming new romantic relationships whilst living with the consequences of this type of injury. The paucity of research in this area is concerning given single survivors have been found to have poorer post injury outcomes compared to those in relationships (Kaplan and Michael, 2000; Donker-Cools, Birgit, Wind & Frings-Dresen, 2016) and loneliness and isolation can be common difficulties for this population (Sander & Struchen, 2011).

This study used a qualitative approach and aimed to explore the impact living with a brain injury had on forming new romantic relationships post injury by interviewing six female brain injury survivors about their experiences. Data was collected using semi-structured interviews and analysed using Interpretative Phenomenological Analysis (IPA). Four superordinate themes emerged: (i) A Fragile Self (ii) Searching for Connection (iii) Barriers to Forming Romantic Relationships (iiii) and Navigating a Way Forward. The findings demonstrate that the prospect and reality of forming new romantic relationships post injury gives rise to a unique set of challenges and concerns indicating this a specific period of adjustment whereby the self and personal needs are re-evaluated. As the participants grappled with adjusting to their brain-injured selves, they made active and purposeful investments in their recovery which resulted in becoming protective of their brain injury and related progress. Desires to form new romantic relationships often conflicted with a need to protect a vulnerable, brain injured self. At times this tension made some participants wary of developing intimate and emotional closeness with others and as such they became avoidant of pursuing romantic opportunities. Attempting to re-establish the self in a non-brain injured world whilst wishing to form romantic connections was at times distressing and overwhelming due to concerns regarding stigma and disclosure. These findings are discussed alongside existing research and implications for practice are considered along with some specific suggestions based upon the findings which are designed around creating appropriate support for single survivors wishing to develop new romantic relationships. Implications for Counselling Psychology and ideas for further research relating to this topic are also considered.

Chapter 1: Introduction

Brain injury affects millions of people worldwide each year and, as such, research in this area is extensive. The rationale and aims of the current study are outlined in this chapter and the extant literature is explored and evaluated with its limitations and shortcomings considered. This exploration leads to the identification of a gap in the literature which the current study aims to address. The ways in which brain injury survivors may benefit from these findings is considered, alongside the implications such findings may have for the field of Counselling Psychology.

Definition of Brain Injury and Related Terms

When engaging in brain injury research, it is helpful to understand certain terms and references that describe the type and severity of the injury. These terms and references are used throughout the current piece of research.

Defining Brain Injury

Acquired brain injury (ABI) is a general term used to describe disability caused by any damage to the brain sustained after birth. Damage can be caused as a result of external force to the head such as falls, violence, sports injuries and motor vehicle accidents. These types of injuries are referred to as traumatic brain injuries (TBI). Brain damage can also occur as a result of non-traumatic causes such as cerebrovascular disorders (including strokes) anoxia and viral and bacterial infections which can result in conditions such as encephalitis and meningitis. These types of injuries are referred to as non-traumatic brain injuries accordingly. The terms brain injury and head injury are generic terms often used to describe either or both types of injury, and likewise the term ‘brain injury survivor’ is used to describe anyone who has experienced either type of injury.

Level of Severity

Brain injury is believed to have occurred when there has been some sort of disturbance to consciousness. Brain injury severity is often measured by using the Glasgow Coma Scale (GCS) to assess level of consciousness. Eye opening, verbal and motor responses are measured with the total scores from the three domains ranging from 3 to 15; scores of 3 to 7 indicate severe injury; 8 to 12 indicate moderate injury; with scores of 13 to 15 indicating mild injury (Teasdale & Jennett, 1974). The GCS is designed to measure initial severity of injury and despite being initially designed for traumatic injuries; it is also used to assess severity of non-traumatic injuries (Middleton, 2012). However, defining injury is a difficult and complex process (Bowen, Yeates & Palmer, 2018), and initial measures of severity (such as the GCS) and other indicators (such as duration of loss of consciousness and post-traumatic amnesia) can fluctuate and depend on recordings at the scene or on admission and are not necessarily predictors of long-term functional outcome. For example, survivors with severe traumatic brain injuries have been found to have high levels of independence in daily living, with 80% being completely independent of care two years post injury (Lippert-Grüner, Lefering & Svestkova, 2007), and return to work for TBI and non-traumatic brain injury survivors has not been found to relate to conscious states during post injury acute stays in emergency departments (Donker-Cools, Birgit, Wind & Frings-Dresen, 2016). Beyond functioning but no less important, some evidence suggests injury severity is not necessarily correlated with quality of life (QoL) adjustment or life satisfaction (Vickery, Gontkovsky & Caroselli, 2004; Jones, Haslam, Jetten, Williams, Morris & Saroyan, 2011) as survivors with mild severity have reported low QoL ratings compared to survivors with more severe injuries (Brown & Vandergoot, 1998). One theory posited which could explain such findings is that lower levels of awareness following severe injury may protect survivors from knowing the full extent of their injury outcomes and consequences (Wilson, 2003). Uncertainty surrounding the relationship between injury severity and outcome has led psychologists specializing in neurorehabilitation to extend their attention beyond the biological to other mediating factors, namely psychological and social dimensions (Bowen, Yeates & Palmer, 2018). This has resulted in a growing recognition of the important roles relationships can play in relation to brain injury recovery (Jetten, Haslam & Haslam, 2014).

Research Rationale

There are reported to be 1.3 million people living with the effects of traumatic brain injury in the UK with an estimated cost to the economy of £15 billion (Menon, 2018). Males are twice as likely to be affected by TBIs than females (Whitfield et al, 2009) although there is a growing indication that head injuries in females are increasing (Tennant, 2015). The age group most at risk of sustaining a traumatic brain injury in the UK is 15 to 24 years (Dombrowski, Petrick & Strauss, 2000; Tennant, 2005;) meaning many survivors will live with associated impairments for many years to come. Information regarding the number of brain injury survivors who are single at the point of injury is scarce. Functional impairments and psychological consequences of brain injury have been associated with social limitations and difficulties (Brown & Vandergoot, 1998; Draper, Ponsford & Schönberger, 2007; Bowen, Hall, Newby, Walsh, Weatherhead & Yeates, 2009) and several studies have highlighted negative attitudes towards brain injury survivors in wider society (Linden & Boylan, 2010; Ralph & Derbyshire, 2013). Yet despite certain studies revealing negative attitudes towards viewing disabled individuals as prospective romantic partners (Marini, Chen, Feist, Flores-Torres & Del Castillo, 2011; Miller, Chen, Glover-Graf & Kraz, 2009), there is a paucity of research which exclusively explores attitudes of persons without disability towards dating and establishing romantic relationships with brain injury survivors. Previous literature has explored the impact of brain injury upon marriages and romantic relationships extensively, but little research has exclusively investigated the establishment of new romantic relationships post injury. This paucity of literature is concerning due to several reasons. Firstly, relationship breakdown is not uncommon post injury (Wood & Yurdakul, 1997**;** Kreutzer, Marwitz, Hsu, Williams & Riddick, 2007). Combined with the fact many TBI survivors tend to be younger, it is reasonable to assume a substantial number of brain injury survivors are single, some of whom are likely to want to develop romantic relationships. Secondly, there is evidence to suggest poorer post injury outcomes across several domains for single brain injury survivors including increased psychological distress (Kaplan and Michael, 2000) and a reduced capacity to return to work (Donker-Cools, Birgit, Wind & Frings-Dresen, 2016). In addition to this, social isolation has been identified as both prevalent and problematic for brain injury survivors (Sander & Struchen, 2011) with some research indicating difficulty in developing new relationships such as friendships post injury (Salas, Casassus, Rowlands, Pimm & Flanagan, 2018). Whilst dating and other types of disability have been examined (Andrews & Lund, 2016, Roth & Gills, 2015, Bertilsdotter Rosqvist, 2014, Saltes, 2013, Howland & Rintala, 2001, Rintala et al, 1997) dating and forming romantic relationships remains a relatively unexplored area in terms of brain injury survivors despite evidence highlighting how important they are to this population (Jumisko, Lexell & Söderberg, 2009). There is substantial evidence demonstrating how imperative intimacy and connection are to overall wellbeing for people in wider society (Rendall, Weden, Favreault, Waldron, 2011: Braithwaite and Holt-Lunstad, 2017), as well as growing evidence highlighting the beneficial roles close relationships can play in relation to recovery and adjustment following brain injury (Yeates, 2009; Bowen, Yeates & Palmer, 2018). Therefore, it is crucial for Counselling Psychologists and other professionals working with brain injury survivors to develop a greater understanding of any problems or challenges that arise for survivors pursuing romantic attachments thus enabling the provision of appropriate therapeutic support. The helpful role psychotherapy can play in recovering from brain injury is well evidenced in the literature (Cicerone, 1991; Klonoff, 2014; Lowe, Crawley, Wilson & Waldron, 2021). Findings generated by this research could also have further clinical applications for rehabilitation professionals by highlighting any issues surrounding developing romantic relationships which could inform goal setting and early interventions. These findings could also inform educational programs and workshops for survivors in rehabilitation, focusing on interpersonal skills, assertiveness, stigma and self-esteem. They could also be used to train other professionals in non-brain injury services where survivors might present such as NHS therapy services and relational advice services such as relate. Extant literature points to a lack of research and support aimed at single brain injury survivors wanting to develop new relationships post injury compared to the support offered to couples and families. This current study could benefit single brain injury survivors by raising awareness among Counselling Psychologists of the unique challenges they face thus improving the quality of the support offered and received.

Literature review search strategy and criteria

A combination of search methods was employed to source published studies relevant to brain injury and romantic experiences and related topics. The following search terms were used to identify articles relating to brain injury and relationships; brain injury, head injury, ABI, TBI, brain injury survivors, neurorehabilitation, relationships, romantic relations, dating, marriage, divorce, romantic status, quality of life, self-esteem and stigma. These terms were used in the following online search engines; PubMed, PsychINFO, EBSCO Host, Science Direct, APA Psych Articles and Google Scholar. The same search terms were used within the following journals: Brain Injury, Neurorehabilitation and Archives of Physical Medicine and Rehabilitation. The reference sections from articles closely related to the topic of the research question were also searched for additional relevant articles and books.

Literature Review

Common Brain Injury Sequalae

It is estimated approximately 1 million people in the UK visit hospitals with head injuries each year making it the most common type of trauma presented in A&E departments (Kay & Teasdale, 2001; NICE, 2014). Traumatic and non-traumatic brain injuries are often sudden, unexpected events which can require significant adjustment resulting in global upheaval. Brain injury is a major cause of disability which can result in enduring consequences with some survivors developing chronic emotional, cognitive and behavioural difficulties which can affect every day functioning (Whitfield, Thomas, Summers, Whyte & Hutchinson, 2009). Longitudinal studies have demonstrated such consequences can have a complicated relationship with psychosocial outcomes (Draper, Ponsford & Schönberger, 2007). Initial research on brain injury focused on neurosurgical aspects, survival rates and severity of injury (Krefting, 1989). A large body of brain injury research has adopted a cognitive deficit approach using tailored batteries of neuropsychological and psychometric tests to assess levels of functioning (Kelly, Brown, Todd and Kremer, 2008; Wood & Williams, 2008; Rodriguez and Carrion, 2010; Velikonja, Warriner & Brum, 2010; Beaulieu-Bonneau, Ouellet, 2016; Leonhardt, Schmukle & Exner, 2016; McDonald, Fisher and Flanagan, 2016). In a move away from concentrating on narrowly defined functional measures, a different line of research examined psychosocial changes brought about as a result of brain injury however, much of this body of research has been garnered from third person accounts such as relatives and caregivers (Ergh, Rapport, Coleman & Hanks, 2002; Collings, 2008; Lefebvre, Cloutier & Levert, 2008; Jackson, Turner-Stokes, Murray, Leese & McPherson, 2009; Braine, 2011; Kieffer-Kristensen, Teasdale & Bilenberg, 2011; Kieffer-Kristensen & Gaardsvig Johansen, 2013; Hayas, Lopez de Arroyabe & Calvete, Jarrett & Hutchinson, 2014; Whiffin, Bailey, Ellis-Hill 2015; Riley & Balloo, 2016). As research into brain injury has developed, a generation of studies have begun to adopt the views of people living with brain injury and as such there is a growing body of literature reflecting the subjective accounts of brain injury survivors (Howes, Benton & Edwards, 2005a; Howes, Benton & Edwards, 2005b; Howes, Benton & Edwards, 2005c; Erikson, Karlsson, Borell & Tham, 2007; Browns, Lyon & Rose, 2006; Lorenz, 2010; Edwards, Daisley & Newby, 2014; Salas, Casassus, Rowlands, Pimm & Flanagan, 2016). The impact that brain injury has on survivors is multifaceted, complex and diverse.

Brain injury can result in a range of sequalae such as physical impairments which can include loss of sight, motor difficulties, ataxia, and disruption to fine motor skills and gross motor skills (Walker & Pickett, 2007), cognitive impairments such as difficulties with memory, attention and executive dysfunction (Arciniegas, Held & Wagner, 2002), psychiatric disorders with depression, generalised anxiety disorder, post-traumatic stress disorder (PTSD) and agoraphobia being the four most common (Bryant et al, 2010). Further to this, TBI survivors have been found to be at greater risk for suicide than the general population with comorbidity of depression and PTSD cited as risk factors (McIntire et al, 2021). Such devastating psychological impacts are unsurprising as to experience a brain injury means suffering a trauma (Bowen, Yeates & Palmer, 2018). The comorbidity of TBI and PTSD has received particular attention (Harvey & Bryant, 2000; Rogers & Read, 2007; Bryant et al, 2009; Zatzick et al, 2010; Vasterling et al, 2021; Alosco, Supelana & Vasterling, 2017; Howlett, Nelson & Stein, 2021), leading some researchers to explore whether there is a relationship between the type of traumatic brain injury cause (such as violent versus non-violent) and associated psychological trauma (Mathias, Harman-Smith, Bowden, Rosenfeld & Bigler, 2014; Sullivan & Wade, 2017; Bown et al, 2019). However, psychological trauma has been identified across all major ABI subgroups including non-physical trauma forms of ABI such as brain tumours (Bruce, Gumley, Isham, Fearon & Phipps, 2011; Goebel, von Harscher & Mehdorn, 2011; Kangas, Williams & Smee, 2012; Fehrenbach, Brock, Mehnert-Theuekauf & Meixenberger, 2021), various types of strokes including brain haemorrhages (Edmonson et al, 2013; Goldfinger et al, 2014; Hedlund, Zetterling, Ronne-Engström, Carlsson & Ekselius, 2011; Visser-Meily et al, 2013; Hütter & Kreitschann-Andermahr, 2014), meningitis (Vermunt et al, 2008; Garralda et al, 2009) and anoxic/ hypoxic injury (Layton, Krikorian, Dori, Martin & Wardi, 2006; Wilson, Staniforth, Till, Das Nair & Vessey, 2014). Further to this, it is important to bear in mind that diagnoses such as anxiety, depression and substance use following brain injury could also be indicative of psychological trauma as they are considered as trauma related disorders when present in individuals who have sustained their injuries in psychologically traumatic contexts (Alosco, Supelana & Vasterling, 2017) therefore it is possible that rates of psychological trauma are underestimated within this population. Social impairments such as disinhibition and poor social judgement are also common following brain injury (Milders, Fuchs & Crawford, 2003) as are disruptions to social cognitions such as emotion perception, empathy and theory of mind (McDonald, 2013) with research exploring links between the two (Milders, Fuchs & Crawford, 2003). Most research relating to brain injury sequalae focuses on traumatic brain injuries as opposed to non-traumatic injuries meaning the latter are under-represented in the literature (Menon, 2018). Psychosocial, emotional and relationship outcomes post injury are hugely diverse ranging from post-traumatic growth to social isolation to chronic depression to relationship breakdown which has led some experts to suggest that the individual experiences regarding the wellbeing of survivors is not exclusively determined by injury (Jones, Jetten, Haslam & Williams, 2014) thus indicating the importance of psycho-social factors.

Romantic Relationships

Although psychology did not begin to study marriage and romantic relationships until the 1970s (Gottman, 1998), the role they play in relation to overall wellbeing is well evidenced and a highly replicable finding. For example, Rendall, Weden, Favreault, Waldron (2011) found unmarried US men and women had significantly higher mortality rates compared to their married counterparts. In reviewing the literature on romantic relationships and mental health, Braithwaite and Holt-Lunstad (2017) found that individuals who are more mentally healthy are more likely to develop romantic relationships, but relationships themselves are also associated with mental health. In addition to this there is evidence to support the notion that improving relationships can have a beneficial effect on mental health, which supports the theory that healthy relationships can act as a universal protective factor, however mental health improvements were not necessarily related to improvements in relationships (Braithwaite and Holt-Lunstad, 2017). However, the quality of relationships is also important as Robles (2014) emphasises it is happy marriages that are associated with overall wellbeing. Given the potential benefits romantic relationships may offer, it is understandable that a large corpus of existing brain injury research has focused on how this disability impacts these types of relationships. Recognising protective factors associated with relationships enables professionals to provide appropriate systemic support post injury aimed at facilitating the adjustment of survivors as they begin to re-establish their social identity and re-integrate into a society which may at times be difficult due to the lack of awareness surrounding brain injury as well as the existence of brain injury related stigma and discrimination (Simpson, Mohr & Redman, 2000; Ralph & Derbyshire, 2013)

Many studies within the literature have assessed the impact brain injuries can have on different types of relationships such as platonic ones, those between parents and brain injured children and children and their brain injured parents, as well as those concerning survivors and care givers. But by far, most relationship research in this area has tended to focus on the changes brain injuries have made to romantic relationships that existed prior to brain injuries being sustained. As such, some studies have found spousal relationships can become vulnerable to breakdown following brain injury as well as result in reduced satisfaction (Wood and Yurdakul, 1997**;** Kreutzer, Marwitz, Hsu, Williams and Riddick, 2007; Burridge, Williams, Yates, Harris & Ward, 2007). Wood and Yurdakul (1997) led the way in investigating the impact of traumatic brain injury upon marriage and close relationships finding 49% of UK participants became divorced or separated between 5 and 8 years after injury. Kreutzer, Marwitz, Hsu, Williams and Riddick (2007) aimed to build on the findings of Wood and Yurdakul (1997) by assessing relationship status from between thirty to ninety months post injury with an American sample of 120 adults (74% Caucasian and approximately 20% African American), finding 17% of the couples had divorced and 8% had become separated. These are much lower levels of separation than those found in Wood & Yurdakul's (1997) study. This same study went on to identify certain risk factors associated with relationship breakdown and found older couples were more likely to remain married, as were couples who had been together longer prior to injury (Kreutzer, Marwitz, Hsu, Williams and Riddick, 2007). In addition to this, longer periods of unconsciousness and violent cause of injury were associated with higher rates of divorce and separation. The authors openly acknowledge that an investigation at a time point further away from injury might portray a more accurate reflection of long-term marriage stability (Kreutzer et al, 2007). Whilst Kreutzer et al (2007) helped identify 'at risk' couples, the quality of the relationships from both survivor and spouse perspectives was not explored, and instead the focus was on post injury relationship status, either married, divorced or separated.

Educational level, ethnicity, employment status post injury and time since injury were not found to relate to divorce or separation rates. In terms of gender, men were no more likely to divorce or separate from brain injured partners than women (Kreutzer et al, 2007). This study largely comprised of survivors with severe brain injury and thus the overall data may not reflect the relationships of survivors with mild or moderate injuries which may account for differences in separation rates compared to previous findings. It is important to note that the research sample only included married couples and as such may or may not reflect relationships issues and outcomes pertaining to those who choose to co-habit rather than marry.

Arango-Lasprilla et al (2008) looked at predictors of continuous marriage stability across the first two years immediately following TBI and found 85% of survivors who were married at admission for their TBI remained married, whereas 15% reported being separated or divorced. This divorce and separation rate is lower than the one of 25% previously reported by Kreutzer et al (2007). However, there were similar findings. Like Kreutzer et al (2007) this study found predictors of marriage instability included age and violently sustained traumatic injuries. In contrast to Kreutzer et al (2007), Arango-Lasprilla et al (2008) found ethnicity and gender (specifically male) to be predictors of marital instability. A unique finding was how ethnicity related to the Disability Rating Scale (DRS) as for Caucasians increases in DRS results correlated with a rise in the number of divorce and separations, whereas an increase in DRS results in ethnic minorities resulted in a significantly lower number of separations and divorces. This study had a large sample size of 977, two hundred and twenty-six of whom were ethnic minorities therefore it is probably more reflective of racial diversity in the American population. However, this study’s main disadvantage is that by only using information from the TBI Model Systems National Database, they were limited to data already gathered and as such findings were not informed by length of relationship prior to injury, which has shown to be an important determinant in marriage stability (Wood and Yurdakul, 1997, Kreutzer et al, 2007). Additionally, the description of stable meaning still married and unstable meaning separated, divorced or single was unhelpful and misleading as it is of course possible remain in a marriage that is unstable.

Rather than focus on divorce and separation rates, Hammond, Davis, Whiteside, Philbrick & Hirsch (2011) used a qualitative approach to explore how TBI affects marital relationships which gathered data from two focus groups of spouses, one female and one male. Findings revealed potential gender differences but as the authors acknowledged, gender may have influenced what participants chose to disclose. This study revealed reactions and perceptions of spouses towards TBI related changes may well affect whether couples pull together or pull apart which will go on to affect martial satisfaction and stability (Philbrick & Hirsch, 2011). The attitudes of spousal resistance or acceptance to their new roles and post injury life are likely to be useful for practitioners as they could help inform interventions, but as each control group only contained five people, a larger study would be needed in order to extrapolate these findings to the wider TBI spousal population. This study also only takes the spouse's perspective into consideration therefore little remains known about the interpersonal aspects of couples living with TBI. This is an important aspect to consider as some married survivors have been found to exhibit poor levels of psychosocial functioning compared those who were unmarried (Bay, Blow and Yan, 2012). Such findings illustrate that marriage cannot always be considered as a protective factor for TBI survivors.

Forslund, Arango-Lasprilla, Roe, Perrin & Andelic (2014) employed a longitudinal design and examined relationship trajectories and stability in the same survivors at one, two and five years after traumatic brain injury in Norway. The authors extended their investigation to co-habiting couples as well as those who were married. Both relationship and employment status at the time of the injury were found to be significant predictors of relationship outcomes. In addition, Forslund et al (2014) discovered having dependent children at the time of injury, higher levels of education and having a blue-collar job at the time of injury to be significant predictors of relationship stability. However, the number of stable relationships reported in this study could be overinflated as the way data was coded and collected meant the ending of old relationships and the beginnings of new ones may not have been adequately recorded. More recent research lends support for the deleterious impact brain injuries can have on romantic relationships as a longitudinal study exploring psychosocial outcomes at discharge, one year and five years post injury reported reductions in the frequency of being married or in a relationship (Glintborg & Hanson, 2021). Interestingly this was alongside unchanged rates of depression but reported improvements in both physical function and autonomy (Glintborg & Hanson, 2021).

Godwin, Chappell & Kreutzer (2014) used a qualitative approach to understand experiences of couples' post TBI by analysing existing personal narratives written by survivors and their caregivers. Four prevalent themes emerged – ambiguous losses, reforming identities, tenuous stability and 'not all of us has died'. The authors also identified healing strategies reported by couples who felt they had found resolutions to their circumstances, such as a renewed sense of purpose, new connections to one another, developing tolerance for ambiguity and refined commitment (Godwin, Chappell & Kreutzer, 2014). Kreutzer, Sima, Marwitz and Lukow (2016) used the Marital Status Inventory and the Revised Dyadic Adjustment Scale to assess relationship stability and relationship quality respectively and applied both to survivors and their spouses. Forty-two couples were included in the study, 74% of whom were married with the remaining participants cohabiting. In terms of stability, 24% of survivors perceived their marriage as unstable compared to 29% of partners. Further to this, agreement was high regarding stability as 72% agreed with their partner about whether their relationship was stable or not. Approximately 50% of both survivors and partners conveyed clinically significant levels of marital dissatisfaction. Perhaps the most interesting finding here was even though high levels of marital stress were reported, so too were high levels of marital stability. Some relationship research has focused exclusively on relationship satisfaction post injury finding relationship satisfaction to be lower in acquired brain injury couples compared to healthy controls (Burridge, Williams, Yates, Harris & Ward, 2007) which supports previous findings.

Interestingly Johnson et al (2010) found stable marital status not to be significantly related to life satisfaction but instead found higher family satisfaction correlated with rises in life satisfaction for survivors who suffered from less functional impairment over the first five years since traumatic brain injury. This illustrates how personal appraisals unique to each individual can determine quality of life post injury and is a salient reminder that factors considered important to researchers and rehabilitation professionals may not always matter to those living with brain injury. As such this highlights the importance of listening to survivors and tailoring rehabilitation programs and interventions to meet individual needs and desires.

In a move away from a focus on deficit and loss, Gould & Ponsford (2015) examined positive changes in quality of life after traumatic brain injury. Survivors who reported positive changes were found to associate family relatives with improvements to quality of life and attached less significance to the importance and involvement of romantic relationships in the first two years post injury. Survivors who did not report post injury positive changes were more likely to have been in a relationship prior to injury and for several years afterwards. Whilst the quality and stability of these relationships was not explored, the authors suggested remaining in the same relationships prior to injury might serve as a constant reminder of what life used to be like thus emphasizing the brain injury related differences for the survivors. In fact, this suggestion could account for differences found between married and single survivors in a study by Moore, Stambrook, Gill & Lubusko (1992). Here, married TBI survivors reported higher levels of depression, anxiety, hostility, confusion as well as problems in recreational activities compared to single TBI survivors, however, this study had an exclusively male sample so these findings cannot be extrapolated to female survivors.

In findings which echo how imperative intimacy and connection are to wellbeing in wider society, partner support and relationship satisfaction along with attachment security have been found to correlate positively with health-related quality of life for traumatic brain injury survivors (Hess & McGovern, 2016). This finding led the authors to recognize and emphasize the important role romantic partners can play post brain injury as well as recommend the involvement of romantic partners in rehabilitation with a focus on dyadic support to compensate for any role changes as a result of the TBI and subsequent consequences this may bring about (Hess & McGovern, 2016). Interestingly this study included relationships that existed prior to injury as well as after injury. This may indicate relationships formed post injury help facilitate survivor wellbeing, although additional research specifically investigating relationships developed post injury is needed in order to substantiate this finding. Given the evidence demonstrating the beneficial effects romantic relationships can have, it is surprising to note that there is a paucity of research exclusively focusing on relationships that have been formed post injury.

In a trial of multiple family group work experience, Charles, Butera-Prinzi & Perlesz (2007) captured aspects of the relationship quality in couples who got together some years after the brain injury had been sustained. Charles et al (2007) found that these couples were the only ones to report an increase in marriage satisfaction at follow up compared to couples whose relationship existed prior to injury. Further to this Charles et al (2007) discovered distinct differences regarding outlook and challenges between the two types of couples whereby couples who had formed post injury demonstrated a united front and strong sense of togetherness when approaching challenges such as parenting or dealing with the consequences of the brain injury. In contrast couples who had formed their relationships prior to injury were found to focus on the shock of the brain injury and injury related change and subsequent discord. However, as this study was piloting the effectiveness of multiple family group work in relation to brain injury adjustment, samples size was small, and the study only included two couples who got together some years after their injury. As such these findings cannot be extrapolated to the wider population. Nevertheless, this study demonstrates that relationships formed post injury differ in nature and quality from those that existed before brain injury was sustained. Further to this it suggests that the type challenges faced by couples are largely determined by when such relationships were established in relation to the existence of the brain injury. There are other findings which point towards potential benefits of romantic relationships which have only ever existed post injury as the development of new, stable relationships post injury have been found to be strongly associated with post traumatic growth (Powell, Gilson & Collin, 2012) as well as facilitating the establishment of post injury identity due to the non-reliance on past identities (Gelech & Desjardins, 2011). However, neither of these studies focused exclusively on relationships developed post injury meaning once again further research is needed in this area in order to substantiate such findings.

Overall, it is surprising that the focus of romantic relationships within the brain injury literature has concentrated on relationships that existed prior to injury. This is despite some evidence suggesting both the quality of relationships and the nature of challenges faced by couples who have only ever existed post injury are substantially different from those who share a pre-injury history. Indeed, elsewhere in the disability literature romantic relationships formed after spinal cord injury have been found to be more successful that those formed prior to injury (Crewe & Krause, 1988). This highlights the importance of bearing in mind the needs and desires of those living with brain injuries. Romantic relationships are valued by some single TBI brain injury survivors as Mackenzie, Fountain, Alfred and Combs (2015) identified a desire to fulfil intimacy as one of the most important unmet needs. Further to this, younger brain injury survivors have been found to feel left behind as non-brain-injured peers have gone on to develop romantic relationships, a factor which contributed to a sense of loneliness and disconnection (Lowe et al, 2021). Also, survivors who have established romantic relationships post injury have described them as a great source of happiness which has been associated with overall wellbeing (Jumisko, Lexell &, 2009). Despite the fact that Price (1985) identified that single brain injury survivors are more likely to need support with dating as opposed to help with sexual function almost 40 years ago, there does not seem to be any research exclusively dedicated to exploring romantic relationships that have only ever existed post injury meaning little is known about the processes, experiences and adjustment involved in developing one of life’s most significant types of relationships.

Sex, Intimacy and ABI

It has been estimated that between 50% and 60% percent of brain injury survivors experience changes to libido and sexual functioning post injury (Kreuter, Dahloff, Gudjonsson, Sullivan & Siosteen, 1998; Simpson, 2001; O'carroll, Woodrow & Maroun, 1991) with evidence suggesting the frequency of such occurrences is higher compared to those without disability (Hibbard, Gordon, Flanagan, Haddad & Labinsky, 2000; Ponsford, 2003; Downing, Stolwyk & Ponsford, 2013). Regarding sex and intimacy in romantic relationships, Kreuter, et al (1998) found TBI affected both sexual desire as well as sexual functioning. Further to this, the authors reported a lack of relationship between location of brain injury and sexual function which led them to suggest that sexual problems were either related to low mood or a worsening of the intimate relationship (Kreuter et al, 1998). In his review on studies of brain injury and sexual function, Oddy (2001) also noted that sexual dysfunction was common after brain injury, and that enhancing intimacy by applying interventions involving both partners such as providing information, encouraging discussions about intimacy and offering support regarding grief reactions and behavioural management may well instigate positive changes in relationships. Together the work of Kreuter et al (1998) and Oddy (2001) highlight the interactions between ABI and sex and intimacy and the quality of romantic relationships. Ponsford, (2003) explored changes in sexual behaviour following traumatic brain injury in more detail and found that approximately 50% of both male and female participants reported difficulties with fatigue, reduced sex drive, a decline in the importance of sexuality as well as opportunities and frequency of engagement, reduced ability to satisfy their partner as well as a reduction in their own ability to enjoy sex and remain aroused and to climax. Interestingly in the same study, Ponsford (2003) also identified a number of key factors associated with changes in sexual behaviour post injury such as reductions in self-confidence and sex appeal, difficulties with depression, decreased levels of communication as well as relationship quality with sexual partners. In a later study, Ponsford Downing & Stolwyk (2013) elaborated on factors associated with sexuality, and in addition to depression found being older, having less independence in terms activities of daily living, and there being a shorter time since injury all related to compromised sexuality. Further to this the authors identified that poorer relationship quality and self-esteem were associated with older age at injury as well as higher levels of depression (Ponsford et al, 2013). These studies highlight that changes in sexual behaviour post injury are just as likely be influenced by individual and relational factors related to the TBI as well as by physiological and physical ones. Gill, Sander, Robins, Mazzei & Struchen (2011) employed a qualitative, dyadic approach to investigate how couples who were together prior to injury experienced intimacy post injury and found barriers to intimacy included injury related changes, emotional responses to such changes, sexual difficulties, conflict surrounding roles as well as social isolation and communication issues. Again, this study highlights how relational factors can impact sexual functioning post-injury. Interestingly links have also been made between low levels of income and unemployment and low levels of sexual functioning (Bellamkonda & Zollman, 2014) leading the authors to urge rehabilitation professionals to also consider how financial stress can affect sexual functioning and satisfaction.

In addition to a decrease in sexual functioning and satisfaction, hyposexuality and inappropriate sexual behaviour post injury has been documented among a minority of brain injury survivors. Behaviours such as inappropriate sexual talk, non-consensual touching, exhibitionism and overt sexual aggression, considered as sexual offences in many western countries, have been found to exist in approximately 6.5% of male TBI survivors (Simpson, Blaszczynski & Hodgkinson, 1999) and 8.9% of male and female severe TBI survivors (Simpson, Sabaz & Daher, 2013). These types of behaviours have been linked to injured frontal and/ or temporal regions (Simpson, Tate, Ferry, Hodgkinson & Blaszczynski, 2001) although other psychosocial aspects are considered to be influencing factors for some individuals with limited functioning, (Aloni, Keren & Katz, 2007). However, there is general agreement that such behaviour is related to etiological factors relating to the brain injury due to the absence of alcohol and histories of sexual offences pre-dating brain injury (Simpson, Blaszczynski & Hodgkinson, 1999).

To date, research in this area has identified some of the challenges faced by brain injury survivors in terms of how sex and intimacy can be impacted by brain injury and key related factors, as well as the interactions between ABI, sex and intimacy and the quality of romantic relationships. Such studies have helped raise awareness of how important this is as a health outcome which in turn has encouraged rehabilitation and health care professionals to discuss this topic with survivors, ensuring it does not go unaddressed. However, in a pattern reminiscent of the brain injury and relationship literature, sex and intimacy in the context of new romantic relationships post injury has not been explored to date.

Brain injury, Self-Concept and Self-Esteem

Self-concept relates to cognitive assessments regarding the self which can include evaluative judgements across a wide variety of domains (Fitts & Warren, 1997) whereas self-esteem embodies perceived self-worth or value (Rosenberg, 1965) and is often considered as a personal appraisal of the self. Both are likely to impacted by negative attitudes in wider society towards brain injury survivors as well as influence whether and to what degree a brain injury survivor socializes with non-brain-injured others. Self-concept and self-esteem have been explored mainly by the application of quantitative methods which have used various questionnaires and scales to assess numerous aspects pertaining to this type of self-to-self relating. Research in this area has only begun relatively recently reflecting a move beyond measuring loss, deficits and dysfunction to investigating psychological factors related to wellbeing by recognizing that subjective self-appraisals can impact psychological adjustment. Howes, Edwards and Benton (2005) compared concerns regarding body image and psycho-emotional health in female brain injury survivors with matched with non-brain-injured controls. Female brain injury survivors were found to have significantly lower self-esteem and higher levels of depression with the latter correlating with social functioning as well as anxiety and psychological wellbeing (Howes, Edwards and Benton, 2005). In addition to this female ABI survivors were found to have become more bothered about physical health and less concerned with facial and sexual attractiveness (Howes, Edwards and Benton, 2005). The same authors applied the same method to examine how male body image was affected following acquired brain injury and discovered male survivors also had lower levels of self-esteem, but also were less content with their bodies and sexual functioning than controls (Howes, Edwards and Benton, 2005). It is interesting to note the gender differences produced by these studies in that concerns regarding sexual attractiveness decreased for female survivors, whereas male survivors expressed dissatisfaction regarding sexual functioning, although such findings do support extant literature regarding gender differences in non-brain-injured populations (Franzoi & Herzog, 1987). Cooper-Evans, Alderman, Knight and Oddy (2008) found self-esteem to be reduced in ABI survivors post injury but stressed this was the case in an exclusively severely affected survivor sample. Again, links have been made in later studies between self-esteem and psychological distress (Cooper-Evans et al, 2008). And lower levels of both self-concept and self-esteem have been found in TBI survivors when compared to age and gender matched non-brain-injured controls (Ponsford, Kelly & Couchman, 2014). This study found lower self-concept spanned several areas of life domains including family, social and academic for brain-injured survivors (Ponsford, Kelly & Couchman, 2014) indicating its global and pervasive nature. Interestingly, this research did not find any significant differences between TBI survivors and healthy controls regarding physical self-concept (Ponsford, Kelly & Couchman, 2014). This led the authors to suggest perhaps due to the lack of impact of the brain injury upon the physical self, survivors may not regard themselves as being physically different from non-brain-injured others (Ponsford, Kelly & Couchman, 2014). Links between low levels of self-esteem and self-concept and psychological functioning are consistent findings as Ponsford, Kelly & Couchman (2014) also indicated a strong relationship between low self-concept and lower mood, and low self-esteem has been found to be linked to both anxiety and depression (Curran, Ponsford & Crowe, 2000; Longworth, Deakins, Rose & Gracey, 2018). Self-esteem in acquired brain injury survivors has been found to be multidimensional and differ in structure which could suggest brain injury survivors hold distinctive concerns relating to their self-concept compared to non-brain-injured others (Longworth, Deakins, Rose & Gracey, 2018). Longworth et al (2018) also found links between low-esteem and concerns regarding perceived stigma. The link between perceived stigma and low self-esteem is likely to influence personal interactions and this is considered in more detail below. Perhaps unsurprisingly, negative self-concepts have been associated with lower levels of perceived quality of life in acquired brain injury survivors (Vickery, Gontkovsky & Caroselli, 2004). The same study found greater perceived quality of life was related with positive views of the self in terms of social functioning (Vickery, Gontkovsky & Caroselli, 2004). Together these findings highlight how prevalent low self-esteem and negative self-concept are in this particular population and illustrate how they link with wellbeing and influence social functioning amongst other important life domains. As such self-concept and self-esteem are likely to influence the romantic experiences of single brain injury survivors and as such are likely to play a meaningful part in the current study.

Stigma, Disclosure, Loneliness and Social Isolation

Psychological research on brain injury adjustment has been criticized for its narrow focus upon emotion and cognition at the expense of social context (Yates, 2003). Understanding the experiences of brain injury survivors within the context of wider society is crucial from a relational perspective due to the related impact upon social identity and establishing and maintaining relationships. Stigma can exist at a societal level and is described by Goffman (2009) as the application of demeaning labels to people considered to deviate from the norm. Existing research has attempted to explore majority attitudes towards brain injury survivors to assess public knowledge regarding brain injury and determine the presence of stigma and discrimination. For the most part, brain injury has been found to be poorly understood by the general population with myths surrounding the disability remaining persistent (Simpson, Mohr & Redman, 2000; Guilmette & Paglia, 2004; Hux, Schram & Goeken, 2009; Chapman & Hudson, 2010; Ralph & Derbyshire, 2013). Whilst there is some evidence to suggest an increase in public understanding of the challenge’s survivors face, there is a lack of appreciation that brain injury can be a hidden disability, and labels with negative inferences are often used to describe survivors such as aggressive, dependent and unhappy (Linden & Boylan, 2010). The hidden nature of the disability means non-brain-injured others have been found to struggle to ascribe certain behaviours exhibited by survivors and arrive at inaccurate, negative conclusions (Linden, Rauch & Crothers, 2005; Ralph & Derbyshire, 2013). Further to this, some studies have revealed members of the public display more negative attitudes towards brain injury survivors compared to people with other injuries, and that these attitudes were exacerbated if they considered the person responsible for sustaining their brain injury (Ralph & Derbyshire, 2013). There is a lack of research which exclusively explores attitudes of persons without disability towards dating and establishing romantic relationships with brain injury survivors. However, in exploring a wide range of disabilities, Miller et al (2009) reported people in wider society were less willing to establish relationships with people who had cognitive impairments which included but was not exclusive to TBI.

Qualitative research has been used to explore the impact of stigma and public attitudes upon those with brain injuries and has highlighted concerns survivors have regarding reactions of others (perceived stigma), the associated sense of shame (sometimes referred to as internalized stigma) and illustrated how these factors can lead to non-disclosure, or concealment of the brain injury (Simpson, Mohr & Redman, 2000; Shorland & Douglas, 2010). As functional changes brought about by brain injuries are mostly invisible, this often presents survivors with a choice about whether to disclose their injury. However, due to stigma, perceived stigma and internalized stigma, it is common for such decisions to be experienced as a dilemma (Jones, Jetten, Haslam and Williams, 2014). Hidden aspects such as fatigue and impaired attention and memory can result in feelings of uncertainty in relation to interactions with non-brain-injured others as survivors are unsure whether to disclose, what to disclose and how to disclose (Hellem, Førland, Kjersti and Ytrehus, 2018). Perceived stigma and discrimination have been found to increase fear and anxiety in young adult ABI survivors (Seeto, Scruby & Greenhill, 2017) but actual experiences are also likely to inform decisions regarding disclosure too, and sadly some moderate and severe traumatic brain injury survivors have described being avoided by others post injury (Jumisko, Lexell & Söderbergh, 2007). Concerns regarding identity have also been brought to the forefront as some people with traumatic brain injuries felt that their sense of self was threatened by imposed societal labels such as ‘disability’ or ‘TBI’ (Nochi, 1998).

Non-disclosure, concealment and fear of being exposed as someone with a brain injury means social interactions are often experienced as stressful (Hagger & Riley, 2019). Ultimately this distress in addition to dealing with cognitive and neurological changes means it is difficult for survivors to create new social relationships (Jones, Jetton, Haslam & Williams, 2014; Hagger & Riley, 2019). Brain injury survivors often employ behavioural avoidance as a coping strategy in response to distress (Godrey, Knight & Partridge, 1996; Riley, Brennan & Powell, 2004; Salas, Casasuss, Rowlands, Pimm & Flanagan, 2018). Riley, Brennan & Powell (2004) linked avoidance with threat appraisals regarding concerns of being negatively evaluated by others in social situations. Further to this, not being open about a brain injury has not only been linked to social anxiety but also loneliness and reduced self-esteem (Shorland & Douglas, 2010; Hagger & Riley, 2019).

Unfortunately, social isolation, social disconnection and loneliness are not unusual among brain injury survivors (Karlovits & McColl, 1999; Martin-Gonzalez, Ortiz de Salazar, Peris-Marti, Valiente-Ibiza & Sala-Corbi, 2000; Levack, Kayes & Fadyl, 2010; Sander & Struchen, 2011; Ponsford, Kelly & Couchman, 2014; Thomas, Levack & Taylor, 2014). Many studies attribute social isolation or decreases in social interactions to either a loss of friends, family, employment or pre-injury routines and hobbies (Hoofien, Gilboa, Vakil & Donovick, 2001; Howes, Benton & Edwards, 2005; Lefebvre, Cloutier & Levert, 2008; Levack, Kayes & Fadyl, 2010) or due to sustaining impairments which impact functioning (Yates, 2003; Bogart, Togher, Power & Docking, 2012; Shorland & Douglas, 2010). More recent qualitative studies delineate between objective social isolation and a felt sense of isolation highlighting how the latter can also interfere with developing emotional closeness and cause social withdrawal leading to the conclusion that in addition to functional impairments, personal and environmental aspects combined together can also be predictors of social integration (Seeto, Scruby & Greenhill, 2017; Levack, Kayes & Fadyl, 2010; Ditchman, Sheehan, Rafajko, Haak & Kaszukauskas, 2016; Lowe, Crawley, Wilson and Waldron, 2021).

Matheson & Anisman (2014) draw on several studies to demonstrate biological responses to discrimination. For example, the authors describe how discrimination can activate the hypothalamic-pituitary-adrenal (HPA axis) and highlight how threats to social identity can either increase or blunt cortisol levels, as well as influence neurotransmitters in the brain (Matheson & Anisman, 2014). Matheson & Anisman (2014) go on to state these biological reactions have the potential to result in both psychological and physical disorders when exposure to discrimination is chronic. However, due to the fact these studies focused on neurotypical subjects, it is difficult to know the biological consequences of discrimination on brain injury survivors, but given previous research on brain injury and stigma, it is reasonable to assume that some brain injury survivors will be exposed to chronic stigma and discrimination. The authors go on to illustrate how both social support and personal coping styles have been found to play in role in mitigating the negative consequences of discrimination (Matheson & Anisman, 2014). Exploring societal attitudes towards brain injury survivors and how these impact upon survivors themselves is important because such aspects are likely to play a major role in relation to romantic experiences post injury as they will impact the personal self, the social self and potentially, social identity. Therefore, stigma and perceived stigma and related issues such as disclosure and concealment are expected to play a significant role in this current study.

Intimate Partner Violence (IPV) and Traumatic Brain Injury

Intimate Partner Violence (IPV) is defined by the World Health Organisation as “behaviour by an intimate partner or ex-partner that causes physical, sexual or psychological harm including acts of physical aggression, sexual coercion, psychological abuse and controlling behaviours”

(WHO, 2013. P. vii). Approximately 35% of women globally have faced either IPV or non-partner sexual violence across their lifetime (WHO, 2014). The link between Intimate Partner Violence and traumatic brain injury has received an increasing amount of attention over the last two decades. Suboptimal health outcomes and significant health difficulties have been identified at the intersection of TBI and IPV in women (Corrigan, Wolfe, Mysiw, Jackson & Bogner, 2003; Kwako, Glass, Campbell, Melvin, Barr & Gill, 2011; Lui, Bush, Koyutürk & Karakurt, 2020) although early detection of TBI in domestic abuse victims followed by appropriate treatment has been found to reduce adverse outcomes (Corrigan, Wolfe, Mysiw, Jackson & Bogner, 2003). St. Ivany et al (2018) conducted one of the first qualitative studies exploring how acquiring traumatic brain injury as a result of IPV impacts the lives of women and found survivors lived in fear, prioritized safety and utilized isolation as a means of protection which impacted vocations and stability. This US based study also highlighted how the intersection of IPV and TBI made accessing adequate resources difficult as services were not designed to deal with both issues (St. Ivany et al (2018). Conversely, some research indicates women with existing traumatic brain injuries could be at increased risk of IPV (Alston, Jones & Curtin, 2011; Haag et al, 2016). Whilst not exclusive to IPV, Reichard, Langlois, Sample, Wald & Pickelsimer (2007) applied qualitative research to investigate the experiences of violence, abuse and neglect among American TBI survivors. Survivors cited cognitive impairments, increased dependence and negative societal attitudes towards those with disabilities as factors which they believed contributed to their abuse (Reichard et al, 2007). Despite an increase in recognizing these links between IPV and TBI within the field of research, Haag, Sokoloff, MacGregor, Broekstra, Cullen & Colantonio (2019) discovered a lack of knowledge regarding TBI amongst IPV service providers. Although this study was based in Canada, it may reflect a wider issue indicating a silent and hidden epidemic of TBI in those who have experienced IPV. Public health concerns regarding TBI and IPV also extend to male perpetrators of domestic violence as a number of studies have identified a link between the presence of ABI in IPV offenders (Rosenbaum & Hodge, 1989; Rosenbaum et al, 1994; Banon, Salis & O'Leary, 2015). One meta-analysis found a significant over-representation of brain injury in IPV perpetrators compared with estimates of brain injury in the general population (Farrer, Frost & Hedges, 2012). In a review of research exploring structural brain abnormalities in violent perpetrators, Bannon, Salis and O'Leary (2015) concluded that there was sufficient evidence to correlate damage or reduced executive function in frontal brain areas and associated regions with violent and aggressive behaviour. As such, brain injury has been identified as a potential risk factor for IPV perpetration, however researchers specialising in this area highlight the co-existence of factors such as alcohol, substance misuse, socio-economic circumstances and mental health difficulties (Farrer, Frost and Hedges, 2012) as well as histories of child abuse and past exposure to violent traumas (Machisa, Christofides & Jewkes, 2016) and thus emphasise that brain injury by itself may not fully account for violent behaviour within intimate relationships (Bannon et al, 2015). Collectively all these studies raise important concerns regarding the complex interactions between brain injury and IPV.

Previous Literature: Limitations and Shortcomings

A large body of the literature pertaining to romantic relationships and brain injury has been conducted in the USA, UK and Europe, therefore understanding is limited regarding interactions between brain injuries, romantic relationships and culture. Initially most studies investigating this topic were quantitative and whilst such studies have been useful in highlighting prevalence rates of relationship breakdowns post injury and identifying risk factors, they reveal little about the quality, nature or nuance of these experiences. The recent growth of qualitative research in this area is redressing this balance (Godwin, Chappell & Kreutzer, 2014; Hammond et el, 2011; Hammond et al, 2012; O'Keeffe et al, 2020, Gill et al, 2011; Brunsden, Kiemle & Mullin, 2015). These types of studies are important as such findings hold clinical value for practitioners working with couples and families in rehabilitation by highlighting particular areas of difficulty as well as strengths both of which can be used to inform interventions. Relationship studies are dominated by heterosexual couples and largely focus on marriage and marriage stability thus largely precluding cohabiting couples from research findings. Marginalized groups such as lesbian, gay, bisexual, transgender, gender-nonconforming and queer or questioning-identified individuals tend to be under-represented in brain injury research including studies on stigma meaning little is known about how brain injuries impact and influence the personal and social experiences of these particular groups.

Often relationships studies have been conducted without control groups which risks exaggerating relationship difficulties and breakdowns relating to survivors as divorce rates tend to be high in wider societies in western countries such as the USA and the UK. Further to this, empirical studies have been labelled as largely unhelpful due to unclear information regarding separation rates post injury (O'Keeffe et al, 2020) as they have been found to range from 8% to 49% (Wood and Yurdakul, 1997**;** Kreutzer, Marwitz, Hsu, Williams and Riddick, 2007) leaving health professionals and survivors unsure regarding the probability of marriage breakdown after injury (Godwin, Kreutzer, Arango-Lasprilla & Lehan, 2011). As Godwin et al (2011) suggest, the reason for such disparate and unhelpful findings is likely to do with limitations of study design and methodology such as the variability of inclusion criteria in terms of injury severity, small sample sizes and outdated research whose samples do not reflect medical advances in brain injury outcomes. Kreutzer (2010) asserts that variations in social, health and legal systems across each study's country of origin may also account for the wide range in divorce and separation rates. Other reasons for the diversity of findings across such studies could be the difficulty in capturing and understanding the impact and interactions of wider societal factors upon separation such as dynamic attitudes towards divorce and disability (cultural, religious, personal beliefs), personal factors such as pre-marriage factors and contextual factors such as fluctuations regarding the availability of the provision of state care. In terms of the variations in assessing marriage quality post brain injury, Godwin et al (2011) rightly draw attention to the tendency of many studies to only focus on one partner which together with a failure to employ a systemic perspective and framework rooted in social constructionism, neglects to capture the impact of the brain injury upon whole relationships, and risks representing findings as such. Subsequently, some of the authors from this review, Marriage After Brain Injury, (Godwin, Kreutzer, Arango-Lasprilla & Lehan, 2011) have conducted further research and adopted a dyadic approach across both quantitative and qualitative studies (Godwin, Chappell & Kreutzer, 2014; Kreutzer, Sima, Marwitz & Lukow, 2016) which are bringing to light important relational components related to marital outcome which are helping to inform rehabilitation, as opposed to a continued focus on individualistic characteristics and perspectives which as Godwin et al (2011) state, limits and confuses our understanding. In addition, how relationship studies have defined relationship stability is both a crude and uninformative measure as for the most part it was determined in terms of whether couples remained together or not. Kreutzer et al (2016) suggests marriage stability needs to be moved on from being classified as married, separated or divorced. Overall, there is a lack of longitudinal studies which assess long term relationship trajectories as most of the previous research has tended to be cross-sectional in design which may influence and bias the identification of risk factors due to lack of evidence regarding temporal relationships. Increased implementation of longitudinal designs reported by Forslund et al (2014) would help elucidate further temporal associates and could investigate how factors such as self-esteem and self-concept, acceptance, stigma and post-traumatic growth in survivors interact with romantic relationships over time.

There is an over-representation of traumatic injuries in the literature regarding relationships (this is addressed in more detail later in this chapter). Whilst non-traumatic injuries are represented, they are not commonly explored exclusively. Stroke, for example, is a major cause of disability worldwide (Campbell & Khatri, 2020) and affects people across the life span thus encompassing a large and diverse demographic and age range, but little remains known about how or whether these type of brain injury survivors struggle with new romantic relationships after experiencing a stroke. Some research suggests older stroke survivors may use different criteria by which to judge themselves and their relationships (Vickery, Gontkocsky & Caroselli, 2004) but further research is needed to better understand such issues, particularly in stroke survivors of working age as an increasing number of young people are known to be affected (Rothwell et al, 2005). Young stroke survivors (aged 55 years and under) have been found to report continued impairments and disruptions in their personal lives in as well as their work lives (Kuluski, Dow, Locock, Lyons & Lasserson, 2013), but more in-depth research regarding new romantic relationships post-stroke is important as such insights may help inform rehabilitation, service provision and recovery.

Inherent in much of the previous research into relationships and brain injury is the assumption that remaining married or staying together is positive and beneficial, and that stability (often indicated as a couple merely remaining together) equals successful adjustment. These implicit assumptions are likely to be informed by the literature demonstrating how intimacy and connection are imperative to both physical and mental health (Rendall, Weden, Favreault, Waldron, 2011; Braithwaite and Holt-Lunstad, 2017). However, it is not uncommon for some people to remain in unhappy marriages with no intention to leave (Heaton & Albrecht, 1991). By the criteria set by many of the relationship studies reviewed in this chapter, such relationships would be viewed as ‘stable’. Relationship quality is imperative and being in happy marriages and relationships is related to enhanced physical and psychological health (Robles, 2014), whereas long-term, low-quality marriages have been associated with significant deleterious effects upon well-being (Hawkins & Booth, 2005).

Indeed, even within the brain injury literature there is some evidence to suggest that romantic relationships that existed prior to injury may not offer brain injury survivors the protective factors found in the general population (Bay, Blow and Yan, 2012, Gould & Ponsford, 2015). Further to this as the studies on TBI and IPV highlight, some female survivors may be at risk of becoming involved in abusive relationships. Risks pertaining to male survivors and IPV are unknown and are likely to warrant investigation as data from the 2020 Crime Survey for England and Wales shows that 1.6 million women and 757,000 men experienced domestic abuse within the past year (from January 2020 to December 2020). Whilst the importance of social interactions for brain injury survivors is becoming increasingly well recognized and growing evidence demonstrates the positive impact relationships and social interactions can have on the identity, self-esteem, sense-making and adjustment of brain injury survivors (Bowen, Yeates & Palmer, 2018), it is integral to hold in mind that not all romantic relationships are healthy, and as highlighted, some have the potential to be damaging.

It is difficult to assess how many adult brain injury survivors are single at the point of injury or at any given time due to the lack of data in this area. Single brain injury survivors seem to be neglected overall in the brain injury literature, however single people in the wider population tend to be understudied despite their growing numbers (Sharp & Ganong, 2011). One longitudinal study with TBI survivors found that at an average of 6.5 years post injury, half of the participants were single with an average age of 32 (Burton, Leahy & Volpe, 2003). This may indicate a substantial number of survivors could be looking to develop new romantic relationships. Given the broad agreement surrounding the positive contributions both social and romantic relationships have upon overall wellbeing in both neurotypical, and brain-injured populations (Rendall, Weden, Favreault, Waldron, 2011; Braithwaite and Holt-Lunstad, 2017; Jetten, Haslam & Haslam, 2014; Bowen, Yeates & Palmer, 2018) it is both surprising and concerning that existing research has overwhelming focused on romantic relationships that existed prior to brain injury. As such, understanding is limited as to what it is like for survivors to form new romantic relationships post injury. This lack of research risks doing single survivors who would like to form new romantic attachments an injustice given what we know regarding the broad range of psycho-social sequalae, romantic relationship breakdown, stigma, self-esteem and self-concept and social isolation in relation to this population. Emotional closeness and tenderness are valued by brain injury survivors who have spoken about feeling well when they felt loved and when they have had someone to love (Jumisko, Lexell & Soderberg, 2009) thus further demonstrating links between relationships and wellbeing. Research exploring subjective new romantic experiences post injury would help inform Counselling Psychologists and rehabilitation professionals on what it is like to develop these types of relationships as a brain injury survivor as their unique experiences would be brought to the forefront.

In terms of stigma and public attitudes towards brain injury, assessing how wider society perceives survivors is likely to benefit from further and more broad research. Many studies exploring public beliefs regarding brain injury are quantitative and utilize forced choice responses or directed questions which fail to capture nuance or uncertainties or explain why people arrive at particular conclusions (Hux, Schram & Goeken, 2009; Chapman & Hudson, 2010). Such studies are prone to negative bias as a result of the “stranger effect” (Wright, 1988) as brain injury is the only prominent aspect people are invited to make judgements about. This clearly does not consider the full person and reduces survivors to their injuries alone. Qualitative research in this area could capture facets which influence public opinion which could in turn inform public awareness campaigns and media representations of people with brain injuries. In addition to this there is a paucity of literature regarding how members of the public view brain injury survivors as potential romantic partners which is surprising given the negative public attitudes towards dating people with physical disabilities (Marini, Chen, Feist, Flores-Torres & Del Castillo, 2011; Miller, Chen, Glover-Graf & Kraz, 2009). Miller et al (2009) found people in wider society were less willing to develop relationships with people with cognitive impairments which included traumatic brain injuries. However, this research was not exclusive to brain injury survivors meaning understanding in this area remains limited. Most studies investigating stigma and relationships are produced by western countries. As brain injury is a global issue, it is beginning to be investigated beyond western cultures (Nochi, 1998; Cullen, Park & Bayley, 2008; Zaman, Arouj & Khan, 2019) but the impact culture may have upon survivors is largely unexplored. Using a qualitative approach to explore a number of post injury factors including stigma, Simpson, Mohr & Redman (2000) concluded that for their sample, the experience of traumatic brain injury seemed to ‘transcend cultures’. Yet findings by Arango-Lasprilla et al (2008) exploring relationship outcomes indicated ethnicity predicted marital stability as ethnic minorities had significantly lower number of separations and divorces compared to Caucasians, despite reported increases in disability rating scales. Clearly further research is needed in this area to establish potential influencing factors and psycho-social interactions between brain injury, culture and stigma.

Studies assessing self-esteem and self-concept amongst brain injury survivors tend to be quantitative using batteries of questionnaires and scales. Whilst some of the studies linked these concepts with psychological distress, self-to-self relating was not explored in relation to romantic relationships so little remains known about the existence of any bi-directional effects. Research that focuses exclusively upon forming new relationships post injury could capture relationships and interactions between self-esteem, self-concept and stigma and romantic status and factors which may act as barriers towards developing relationships despite an existing desire to have one.

Traumatic Brain Injury (TBI) versus Non-Traumatic Brain Injury

There tends to be an over representation of traumatic brain injuries in the literature meaning figures quoted in relation to brain injury often underestimate the prevalence of non-traumatic injuries (Menon, 2018). This also means the experiences of those living with non-traumatic injuries are often under-represented. The dominance of traumatic injuries in extant research is likely to reflect the fact that traumatic injuries are far more common (Teasell et al, 2007). It is common practice for studies investigating relationships, quality of life and the lived experience of brain injury to include both traumatic and non-traumatic types of injury in the same research samples (Haag et al, 2016; Ashworth, Clarke, Jones, Jennings & Longworth, 2015; Backhaus et al, 2016; Lindsay et al, 2016; Brunden, Kiemle & Mullin, 2015). However, not all studies delineate between the two types of injury meaning it is not always possible to assess which types are being explored thus making it difficult to draw comparisons and establish potential differences.

The rationale for grouping together traumatic and nontraumatic brain injuries is likely due to shared commonalties in terms of impact and subsequent need. The Glasgow Coma Scale (GCS) is often used to measure initial severity of traumatic brain injury, whereas other scales and systems such as the NIHSS are used to measure stroke severity as consciousness is often retained. Traumatic and non-traumatic brain injuries have similar clinical trajectories which often begin with brain function impairment followed by an acute recovery period focusing on functional recovery which after a time gives way to new constant levels of functioning whereby most improvements begin to plateau (Boake, Francisco, Ivanhoe & Kothari, 2000). Both traumatic and non-traumatic survivors have been found to have similar lengths of rehabilitation periods (Colatonio et al, 2011) and achieve partial functional independence between two- and six-weeks post injury (Oujamaa et al, 2017) with similarities in cognitive improvements during the first year of recovery (Tölli, Höybye, Bellander, Johansson & Borg, 2018). Both types of injury are acquired as opposed to being present since birth, they can both be chronic and experienced as hidden disabilities, and long-term sequalae can include physical impairments as well as cognitive, emotional and behavioural difficulties affecting clinical outcomes as well as quality of life and future prospects. As such, many brain injury rehabilitation centres, services, charities and information providers do not discriminate between injury type. Further to this, both types of injury are considered as a collective when assessing gaps in services, service provision, rehabilitation and economic impact (Menon, 2018). Whilst some research comparing traumatic and non-traumatic brain injuries have found no differences in aspects such as coping style (Zaman, Arouj & Khan, 2019), other studies have reported that those with traumatic injuries achieve greater functional improvements compared to survivors with non-traumatic injuries during both the acute phase of recovery (Colantonio, 2011) and the chronic phase (Cullen, Yoon-Ghil & Bayley, 2008).

Sex, Gender & Brain Injury

Females have for the most part been both exclusively under researched and underrepresented in the brain injury literature (Howes, 2005; Colantonio, 2016). Studies including male and female samples tend to be dominated by male participants (Vickery, Gontkovsy & Caroselli, 2005; Jumisko, Lexell & Soderberg, 2007; Cooper-Evans, Alderman, Knight & Oddy, 2008; Carroll & Coetzer, 2011; Jones, Haslam, Jetten, Williams, Morris & Saroyan, 2011; Turner, Fleming, Ownsworth & Cornwell, 2011; Bertisch, Long, Langenbahn, Rath, Diller & Ashman, 2013; Sigurdardottir, Andelic, Roe & Schanke, 2013; Cocks, Bulsara, O'Callahgan, Netto & Boaden, 2014; Edwards, Daisley & Newby, 2014; Walsh, Muldoon, Gallagher & Fortune, 2015; Mackenzie, Alfred, Fountain & Combs, 2015; Salas, Casassus, Rowlands, Pimm & Flanagan, 2016). This over-representation is thought to reflect the higher incident rates of brain injury in males; males are twice as likely to sustain a brain injury than females (Whitfield et al, 2009), however, there is some evidence to suggest that female head injuries are increasing (Headway, 2013). The over-representation of male participants in research is not exclusive to brain injury literature and is nothing new, as Willig highlights that the notion of 'The male as the norm' has been a feminist critique levelled at quantitative types of research since the 1960s and 1970s (Willig, 2013). However, as Caroline Criado Perez (2019) highlighted in her recent book, 'Invisible Women: Exposing Data Bias in a World Designed for Men', the male is still considered the norm in both research and design, sometimes with fatal consequences for females. Brain injury research that mainly comprises of male samples creates knowledge, predictions and expectations based on males, when recovery speed, symptom type and symptoms severity may be different for females. This male/ female imbalance in the literature risks females being measured and assessed against benchmarks and expectations informed mainly by data gathered from males and fails to consider any differences relating to biological sex and gender. This may have direct consequences for rehabilitation and recovery as professionals providing care or support for female brain injury survivors are likely to be unaware of potential sex and gender differences and as such may fail to meet the needs of female brain injury survivors. An inability to meet male-based expectations and benchmarks may be confusing, upsetting and frustrating for female survivors during what is already a distressing and challenging period. This data gap means relationships and interactions between biological sex, gender and brain injury are poorly understood. For example, little is known about whether gender influences reporting brain injuries in survivors or brain injury detection, and symptom attribution in professionals. Any differences between how female and male brain injury survivors are received and treated by society remain unknown. It is interesting to note that links between brain injury and boxing have been studied since 1928, yet brain injuries related to intimate partner violence (IPV) and women only appear to have been explored after 1990 (Casper & O'Donnell, 2020).

The lack of research into females and brain injury is beginning to be recognized and addressed whilst simultaneously highlighting that continued neglect of this area risks leaving female brain injury survivors misunderstood, mistreated and misdiagnosed. Incorporating sex and gender into brain injury research has the potential to improve outcomes for survivors, increase the generalizability of research findings and improve clinical application (Colantonio, 2016). There is growing evidence brain injury affects females differently. Sex based differences include higher mortality rates in older females as a result of severe TBIs (Ottochian et al, 2009), differences in severity (Munivenkatappa, Agrawal, Shukla, Kumaraswamy & Devi, 2016) and neurofatigue which has been found to worsen in female brain injury survivors during menstruation (Haag, Caringal, Sokoloff, Kontos, Yoshida & Colantonio, 2016). There is also a growing awareness of gender-based differences such as the relationship between women and intimate partner violence and TBI (Corrigan, Wolfe, Mysiw, Jackson & Bogner, 2003) and increased risk of TBI in female dominated vocations such as health care (Chang, Guerriero & Colantonio, 2015). Studies focusing on the lived experience of female TBI survivors remain rare (Howes, Benton & Edwards, 2005; Haag et al, 2016; St Ivany et al, 2018; Nalder et al, 2016; Fabricius, D'Souza, Amodia, Colantonio & Mollayeva, 2020) therefore focusing exclusively on female brain injury survivors embodies a departure from the dominant methodology in brain injury research. Given that gender can refer to a set of social processes (Butler, 1990) there is likely to be significant merit in exploring males and females exclusively when investigating social processes such as forming romantic relationships post injury. Further to this, there is evidence that points to existing sex differences pertaining to relational factors such as communication, social support and involvement of family in young adult brain injury survivors (Lindsay et al, 2016).

Aim of the Current Study: Addressing the gap in the literature

Whilst the impact of brain injuries upon existing romantic relationships has been explored extensively within existing research along with issues surrounding establishing new friendships and social isolation, the review of the literature has highlighted that little is known about establishing new romantic relationships after acquiring a brain injury, therefore knowledge and understanding in this area is limited. More recent qualitative studies on brain injury have concentrated on the phenomenological experience of brain injury survivors, yet few exclusively focus on those who are single. It has been suggested there is no guarantee that outcomes set by rehabilitation professionals will echo those that are valued by the people who live with the consequences of brain injury (Banja & Johnson, 1993) thus highlighting how important it is to include the voices of survivors within research, particularly those pertaining to relational goals and desires. This indicates a broader approach at this subjective level is needed given that intimacy and love have been cited as being important in life post injury by survivors (Mackenzie, Fountain, Alfred and Combs, 2015; McColl, 1998). Therefore, the aim of this current study is to build upon the recent phenomenological methods used to explore the lived experience of brain injury survivors but expand it to include the experiences of forming new romantic relationships post injury with an exclusive focus on female survivors. Further research is needed in order to understand sex and gender-based differences in brain injury and what impact these may have, particularly in a relational capacity which is influenced by gender. A continued focus on males may mean current research misrepresents female experiences. This study will follow the mainstream brain injury research paradigm of including participants with both traumatic and non-traumatic injuries as despite varying aetiologies, significant aspects such as recovery trajectories, sequalae and outcomes are similar. Therefore, this study will begin to address this gap that currently exists within the literature and generate findings to guide further related research as well as enable Counselling Psychologists and other professionals who work with brain injury survivors to gain a deeper insight into the needs of single female survivors.

Suls & Rothman (2004) suggest the biopsychosocial model is not used to its full potential within health psychology and as such encourage research which can capture interactions, feedback loops and correlations. Qualitative approaches are useful in developing our understanding of the social context, needs, desires and challenges pertaining to brain injury survivors (Yates, 2003). Therefore, research which exclusively focuses on forming new romantic relationships post injury may highlight connections and interactions between self-esteem, self-concept, stigma and romantic status. In order to capture a diverse range of experience, the degree, level and type of romantic experiences explored in this current study will be kept broad as not all romantic interactions are planned, linear or consistent such as dating, cohabitation, engagement and marriage. One-night stands, affairs, falling for a friend, sexual relationships, wanting to meet somebody but not, are all equally valid romantic experiences. A broad approach is also appropriate due to the fact this study is exploring a topic which is relatively unexplored and is therefore poorly understood. Narrowing the scope to focus exclusively on dating with a brain injury or cohabitation with a new partner post injury seems better suited to future research once a more fundamental understanding of the impact brain injury has on all types of romantic experiences has been developed and established. Therefore, the research question of the current study is as follows:

How do female brain injury survivors experience forming new romantic relationships post injury?

Chapter 2: Methodology

There are numerous ways in which to approach research and generate data. This chapter puts the research method selected for this present study under the microscope with the aim of justifying its selection, highlighting its limitations and considering how the research aims could have been met by the application of an alternative method of approach. The details of the research design are presented followed by ethical considerations and researcher reflexivity. A qualitative approach was chosen for this piece of research which involved interviewing a small homogenous sample using semi-structured interviews designed to elicit personal accounts and explore individual experiences. The data this generated was analysed by employing Interpretive Phenomenological Analysis (IPA), (Smith, Flowers and Larkin, 2009). IPA was selected as an approach as it was the most appropriate method by which to address the aims of the research question which was "*How do female brain injury survivors make sense of their romantic experiences encountered post injury*?". Ontological and epistemological standpoints are also considered both in relation to the position of the researcher as well as the selected method of enquiry.

Building a case for a Qualitative Approach

The field of psychology has been informed and developed by contributions from both quantitative and qualitative research, both of which aim to enlighten and inform and alleviate suffering. The National Institute for Health and Care Excellence (NICE) in the UK encourages and employs quantitative and qualitative research to improve outcomes for people using the NHS as well as inform clinical practice by producing evidence-based guidance. Quantitative and qualitative studies are built on fundamentally different epistemologies which determine certain methods of enquiry yielding different types of data, the former usually applying statistical techniques to numerical data to draw broad conclusions about large populations, the latter applying types of interpretations to descriptive data from small populations to gain insights into participants' experience (Jhangiani, Chiang & Price, 2015). Positivism, empiricism and scientific realism are regarded as the main epistemologies that have informed and influenced quantitative research in psychology with the latter considered the main stay of psychological science as we know it to date (Haig, 2013). Whilst there are variations of scientific realism, there are two common beliefs of which they all share; firstly the existence of a ‘real’ world which human beings are part of, and secondly that by employing scientific methods both observable and unobservable aspects of that world can then be identified, known and described (Haig, 2013). Hypothetico – deductivism is a type of scientific realism (Haig, 2013) and makes up most types of modern day experimental psychological research (Willig, 2013). This type of approach posits that by ascertaining what is not true it is possible to get nearer to the truth (Willig, 2013).

While existing quantitative research has contributed enormously to the field of brain injury, this type of research imposes limitations on the nature and the extent of what we know about brain injury survivors. It would be folly for this to be levelled as a criticism as extant studies have advanced knowledge in this area by substantially improving our understanding of brain injury resulting in real word applications benefitting brain injury survivors around the world. However, by acknowledging the constraints inherent in this type of research it is possible to consider alternative methods of exploration not only to continue with the progression of developing an understanding of brain injury but to widen and challenge our understanding of it. In this sense the disadvantages of quantitative research can be the advantages of qualitative research (Jhangiani, Chiang & Price, 2015) as the latter enables human experiences to be studied in a more holistic way rather than focusing on specific parts of experience (Moustakas, 1994). For example, Peter Ashworth (Smith, 2015) describes qualitative research as being concerned with uncovering people’s grasp of their world. Further to this it can be a mechanism by which to generate complicated, opaque, deep and messy findings (Finlay & Ballinger, 2006) which are arguably reflective of the experience of human existence. As such, a qualitative approach could help add richness and diversity to our understanding of what it is like for female brain injury survivors to engage in romantic relationships after sustaining their injury due to the focus on exploring the ‘how’ and the ‘what’ rather than the ‘why’ (Finlay & Ballinger, 2006).

In addition to considering the nature of data yielded by quantitative and qualitative studies, it was also useful to reflect upon the scope that both types of enquiries provide. A recognised strength of quantitative research is it can generate accurate answers in response to focused and specific research questions (Jhangiani, Chiang & Price, 2015). However, such a narrow starting position did not seem an appropriate place from which to begin to explore the topic of romantic encounters experienced post brain injury due to the paucity of research in this area. Conversely the broad and open nature of qualitative research questions produces large and rich data sets unconstrained by hypotheses which despite being generated by small sample sizes can act as a springboard for developing further research by highlighting patterns and relationships within a phenomenon suitable for exploration using quantitative methods (Jhangiani, Chiang & Price, 2015). Therefore, as qualitative research tends to generate hypotheses as opposed to test them (Finlay & Ballinger, 2006), this type of approach is more aligned with the overall research aims of this current study.

Qualitative approaches tend to involve engagement in first person accounts (Moustakas, 1994) and seek to understand how people ‘make sense of the world’ (Finlay and Ballinger, 2006. P.7) and gain insight into how particular events and conditions are experienced (Willig, 2013). Qualitative researchers usually consider things in their natural settings and recognise the role of interpretation inherent in this type of research, namely that researchers are interpreting the meanings that participants ascribe to their personal experiences (Finlay and Ballinger, 2006). Language tends to be regarded as integral in the construction of meaning (Willig & Stainton-Rogers, 2008) but there is also an appreciation of how society, culture and history affects how people make sense of their lives (Eatough & Smith, 2008). This type of research adopts the perspective of those most affected by a particular phenomenon, therefore in this current study participants are being invited to share their subjective experiences of how they construct meaning in relation to their romantic experiences encountered post brain-injury as brain injury survivors.

There are significant distinctions between how quantitative and qualitative research regard the role of the researcher which is pertinent to consider in relation to this current study. In qualitative research there is an open recognition that the researcher is involved in and connected to the research process (Willig & Stainton-Rogers, 2008), whose subjectivity is incorporated reflexively into the process which is seen as a strength (Finlay & Ballinger, 2006). There is a collective appreciation amongst qualitative researchers that others may interpret the same data in different ways (Finlay and Ballinger, 2006). This felt particularly important to consider given that I am a non-brain-injured researcher working with brain-injured participants. The reflexivity encouraged and incorporated into qualitative methodologies provided an opportunity to reflect upon the relationship I have with the participants, the data analysis and the research process as a whole, all of which appeals to me ethically. It is also congruent with my practice as Counselling Psychologist and demonstrates the equivalent roles of practitioner and researcher. As this current study is committed to taking a qualitative and reflexive stance, I will refer to myself as ‘I’ throughout this thesis as opposed to ‘the researcher’.

Finally, a more personal reason for selecting a qualitative approach was my alignment with the democratic aspirations shared by most qualitative approaches (Smith, 2004) and a social justice agenda which is aimed at promoting fairness and equity across society. Qualitative methodologies offer types of approaches that are done ‘with’ rather than done ‘to’ participants and together with their inductive nature enable the voices of the participants to be heard. In this sense it is possible for qualitative approaches to be used as part of an empowerment agenda. I considered this to be of importance when working with a brain-injured participants as brain injury survivors can be subject to prejudice, discrimination and stigma in society (Ralph & Derbyshire, 2013), and their voices are often lost in brain injury research.

Overall a qualitative approach seems most apposite for this current study which aims to gain an understanding of how female brain injury survivors make sense of their romantic experiences encountered post brain injury as they provide an appropriate means by which to explore the potential diverse range of experiences and sense-making in relation to this specific phenomenon. Qualitative research is a broad church, so although it can be a useful exercise to conceptualise these approaches as a collective, differing epistemologies underpin different approaches which shapes not only research methods and objectives but also determines what it is possible to discover (Willig, 2013). The qualitative approach chosen for this current study is Interpretative Phenomenological Analysis (IPA). Before outlining the justification for selecting this particular approach, it is important to consider my own philosophical position.

Ontological & Epistemological Position

As outlined by Willig (2013), research methodology is influenced by the epistemological position of the researcher. Defining one's own philosophical standpoint upfront is significant in that it determines the type of data gathered, how data is interpreted which in turn defines the meaning and shapes how data is conveyed. As outlined above I have identified myself with a qualitative approach and have selected IPA specifically. IPA itself is informed by a wide range of standpoints such as realism, hermeneutic informed phenomenology and researcher interpretation with a fundamental grounding in a relativist ontology (Willig, 2013). As such it is reasonable to a degree to view IPA as epistemologically flexible.

The task of identifying a personal epistemological and ontological position was a daunting one due to the absence of philosophical standpoints in published papers and that as a subject matter it is largely untaught until doctorate level. I therefore found it useful to follow the advice of both Finlay (2006) and Pitard (2017) and take time to consider my own beliefs, values and view of the world, alongside what I regard as important in my work as a counselling psychologist. After a period of reflection and some challenging reading I was able to identify with an ontological position of critical realism and an epistemological position of a 'light' form of social constructionism called symbolic interactionism. Here I outline how both of my positions align with the aims of the current research, which was to gain insight into how female brain injury survivors make sense of their romantic experiences encountered post brain injury. I also considered how my philosophical positions align with IPA.

Critical realism can be described as a standpoint which acknowledges the existence of one reality which is possible to be investigated whilst at the same time recognising different people will hold different understandings and descriptions regarding what takes places (Finlay and Ballinger, 2006). It is grounded in three core principles; ontological realism, epistemological relativism and judgemental rationalism and acknowledges the transitive and intransitive aspects of reality (Pilgrim, 2020). It would not be possible to conduct research on brain injury survivors without adopting an ontological position that was rooted in realism because as Willig (2016) points out with similar phenomena, brain injury has an ontological standing in that it would exist irrespective of whether a brain injury survivor spoke about it or not. The brain injuries of the participants and subsequent impact on functioning are simply there and not “textually generated” (Pilgrim, 2020, p. 41). In line with critical realism, I find myself occupying a space between positivism and post-modernism as both an individual and as a counselling psychologist. From this standpoint I try to remain sceptical of both of their shortcomings whilst paying heed to their legitimacy as and when deemed helpful, necessary and appropriate (Pilgrim, 2020).

Social constructionism has its roots in postmodernism and poststructuralism which represents a rejection of positivism in its relentless pursuit of universal laws, and instead emphasises the existence of multiple realities based on a fundamental notion that everything is socially constructed (Pilgrim, 2020). Symbolic interactionism, although considered a type of social constructionism, is not quite as extreme in some of its stances and is attributed to the work of George Herbert Mead (Ashworth, 2015). Symbolic interactionism is a humanist position concerned with exploring subjective and intersubjective facets of lived experience (Pilgrim, 2020). The stance symbolic interactionism assumes is that the mind and the self are both products of social interaction, that we communicate with one another through socially shared systems and that our individuality is formed within a social context (Ashworth, 2015). The social context in which the participants in this study existed in changed significantly when they went from being non-brain-injured to brain-injured, therefore is it integral that this current study takes this social context and subsequent related changes in social interactions into account. In line with symbolic interactionism, I identify as a humanist and am of the view that participants should be understood ‘within the culture in which the person is immersed’ (Ashworth, 2015, p. 17). As symbolic interactionism is regarded as being more considerate of ontology than stronger more radical forms of social constructionism (Pilgrim, 2020) it is an appropriate and respectful position from which to explore the lived experience of romantic encounters experienced by brain injury survivors post brain injury.

Both critical realism and symbolic interactionism are congruent with the philosophical stand points of IPA. Willig (2016) asserts the types of research questions IPA studies ask indicate objectives informed by realism as they seek to explore accounts of shared experiences such as chronic back pain and living with HIV. Critical realism advocates adopting constant critical reflectiveness and clarity in relation to our initial beliefs when we assume the role of a psychology researcher and emphasises that assuming such a position from the outset is fundamental to producing good, quality research, as without it our initial beliefs will endure in our work unexamined and unexplored (Pilgrim, 2020). Critical reflectiveness is a core skill for IPA researchers as it ensures we are less likely to take things for granted and fall back on assumptions thus encouraging interpretations that are grounded in the accounts of participants. IPA draws on symbolic interactionism in that it appreciates the construction of meaning can depend on and be bound up with interactions between people and social processes (Smith and Osbourne, 2014; Willig, 2013). IPA and symbolic interactionism recognise the important role language plays in sense-making by stating “reality is both contingent upon and constrained by the language of one’s culture” (Eatough & Smith, 2008, p. 184). It was therefore appropriate in this current study to be both mindful and respectful of both the language used by the participants as well as the language used in extant literature in relation to describing brain injury.

In terms of this current study, my alignment with both critical realism and symbolic interactionism allowed me to acknowledge the existence of the participants brain injuries and related symptoms (Willig, 2016) whilst appreciating that the participants are “creative agents who through their intersubjective interpretative activity construct their social worlds” (Eatough & Smith, 2008, p.184).

Interpretative Phenomenological Analyses

Interpretative Phenomenological Analyses (IPA) is a type of qualitative approach that seeks to elicit subjective accounts of specific real-life experiences from small, homogenous groups of people which through processes of interpretation are condensed into themes enabling deep and compelling descriptive insights into personal experiences.

IPA as an approach “is dedicated to the detailed exploration of personal meaning and lived experience” (Smith and Osbourne, 2015, p.25). Although IPA was developed in the 1990s, it is informed by theoretical underpinnings that are significantly older, namely phenomenology, hermeneutics and idiography.

Phenomenology is a broad philosophy which has been informed and developed by several different theorists and movements over the years (Giorgi & Giorgi, 2003). The phenomenological aspect of IPA is aimed at examining personal experiences and is interested in subjective perceptions or accounts rather than establishing objective statements (Smith & Osbourne, 2003). IPA is informed by the work of Edmund Husserl who argued that experience should be studied in the manner it happens and who advocated the detailed examination of personal experience (Smith, Flowers and Larkin, 2009). Husserl’s concepts of ‘bracketing’ taken for granted knowledge and pre-existing assumptions in order to move closer to truly understanding experiences, as well as adopting a reflective exploration of experience have become key components in the execution of IPA (Smith, Flowers and Larkin, 2009).

IPA also draws on hermeneutics, the theory of interpretation. The connection to hermeneutics is an important one as IPA recognises it is not possible to gain direct access to someone else's experience, therefore access can only be gained through the interpretations of the researcher (Smith and Osbourne, 2015). Further to this, IPA posits the existence of a double hermeneutic whereby "the participants are trying to make sense of their world; the researcher is trying to make sense of the participants trying to make sense of their world" (Smith & Osbourne, 2015, p.26). IPA encourages two types of interpretations; 'identifying or empathising with' and 'attempting to make sense of', stating the pursuit of both can generate a powerful analysis as well as help paint a picture of a person in their entirety (Smith & Osbourne, 2015, p.26). Various levels of interpretation are possible in IPA, but it is essential they remain grounded in the original account, and as such a frequent return to the parts of the text as well as a reading of the whole of text is encouraged to facilitate the development of the analysis (Smith, 2004). This relates to the notion of the 'hermeneutic circle' which recognises that in order to understand any part of an account, a look to the whole is necessary and vice versa (Smith, Flowers & Larkin, 2009). A fundamental aspect of interpretation in IPA is that the researcher is working 'from within the text' (Smith, Flowers & Larkin, 2009) as opposed to interpretations being informed by existing theories.

The idiographic element of IPA is concerned with an in-depth focus of each individual case and regarding them only in the context of themselves (Pietkiewicz & Smith, 2014). In practice this means each account is analysed in its entirety before moving on to the next account, and only when all accounts have been analysed is an analysis across the cases conducted (Smith, 2004). Thus, IPA has a strong commitment to the particular as opposed to the general (Pietkiewicz and Smith, 2014). Such is this commitment to the individual detail of each case only small samples are recommended for IPA studies, usually between five and ten (Smith, 2004). What the idiographic nature of an IPA study affords in the final write up is for the reader not only to discover general themes about the topic under investigation but also walk away having learnt something unique about each of the participants who contributed to the study (Smith, 2004).

The founder of the IPA, Jonathan Smith also encourages the researcher to adopt an inductive approach whilst working with the data and interrogative approach whilst embedding the research findings within extant psychological literature (Smith, 2004). Whilst Smith (2004) acknowledges an inductive approach is not exclusive to IPA, he emphasis it forms an integral part of the overall stance as it facilitates the discovery of the unexpected and keeps the researcher open to surprises during the analysis process. Smith (2004) is also keen to emphasise the contributions IPA can make towards psychology as the results are always considered in the context of existing research where they can be used to interrogate, challenge or illuminate extant findings and assumptions.

Justification for IPA

Suitability, strengths and limitations

As previously stated, the previous chapter reviewed extant literature on the romantic lives of brain injury survivors which highlighted a lack of research on novel romantic experiences encountered post injury thus providing an original area to explore. The next step was to consider what was it about this area that I wanted to know and what I wanted the purpose of this study to be. This process of reflection led me to recognise I was keen to gain knowledge and insight into the following: how do female survivors navigate novel romantic experiences whilst living with a brain injury? What did they consider important about these romantic experiences? What comes up for them internally and externally when pursuing love and companionship after they have sustained a brain injury? What impacts their decision-making process and influences their behaviour? What mechanisms are at play on an individual level when this population commits to finding a relationship? What did it mean to have these experiences and how did it make them feel? What, if anything, was different about romantic encounters as a result of having a brain injury compared to being without a brain injury? The nature of these questions made it clear I was interested in understanding how a particular group of people experienced and made sense of a specific phenomenon. This led to the development of the research question:

"How do female brain injury survivors experience forming new romantic relationships post injury?"

IPA was subsequently selected as the most appropriate method by which to pursue this line of enquiry and achieve the purpose of this study. Further to this there were additional reasons as to why IPA was deemed a suitable approach for this current study as well as the specific population it wished to engage with and represent.

Due to its epistemological roots, IPA gives credence to personal accounts and subjectivity which through researcher interpretation and iterative processes of data reduction generates concise insights and understandings into complex, real life experiences. IPAs alignment with symbolic interactionism means it acknowledges that how people interpret and make sense of their experiences can also be affected by social processes and interactions with others (Willig, 2013). Adopting an approach with an appreciation of interpersonal aspects seems respectful and ethical when working with brain injury survivors as they have been found to experience negative treatment from others (Hellem, Førland, Eide & Ytrehus, 2018; Jumisko, Lexell & Söderberg, 2007) and be more vulnerable to both stigma and discrimination (Ralph & Derbyshire, 2013). Therefore, this study is committed to eliciting unique and individual experiences of female brain injury survivors and contextualising them within broader social processes in which they exist. As outlined in the literature review, social context can include an increase in vulnerability, stigma, discrimination, social isolation and loneliness. In addition to this brain injury survivors can live with occupational, financial, social and recreational consequences which also impact their social context. Locating individual experiences within a social context is in line with the stance of symbolic interactionism which posits that individual meaning making stems from interactions with others, and that such meanings are created and recreated via interpretations which occur as a result of individual interactions with other people. Understanding the experiences of brain injury survivors within the context of wider society is important when seeking to explore the phenomena of forming new relationships as such processes involve a sense making of the self which may involve internalised social expectations affecting identity, as well as interactive relational processes. Embedding IPA in an epistemological position of symbolic interactionism can yield an individual's meaning, but this is not necessarily at the expense of the context in which it exists.

IPA is considered by some disciplines strongly aligned with social-constructionism and post-structuralist traditions of being guilty of naïve essentialism. Whilst it is of course true that IPA seeks to explore the experiences of homogenous groups, IPA is committed to each individual's idiographic experience but searches for divergence as well as convergence across cases and as such does not have a pre-determined agenda aimed at attributing the same characteristics to everyone in the same group, nor does it presuppose that shared characteristics are solely the result of belonging to a particular group. It is also interesting here to consider that perhaps some degree of essentialism can be helpful in terms of political and/ or social justice movements, such as Black Lives Matter and feminism. Phillips (2010) asserts that risking essence may be necessary in order for political and social advancements to exist and progress. Another interesting concept to hold in mind is that whilst essentialist constructs can be considered category errors, once they have been introduced as definitions and descriptions, they often develop a life of their own (Phillips, 2010). Whilst most people would agree that rigid essentialism is largely unhelpful and at times damaging and dangerous, continuums of essence whereby people are placed into groups according to similarity can hold utility within psychological research. For example, IPA studies have helped bring to light rich and nuanced insights into specific experiences which can challenge sweeping generalisations and assumptions (some of which can be harmful, unhelpful and misleading) which could be seen to be made at times in quantitative studies (Smith, 2009).

IPA has also been criticised for being insensitive to social contextual parameters due to its focus on the individual. This study so far has highlighted that for brain injury survivors, social context can include stigma and discrimination as well as an increase in vulnerability However, whilst IPA does focus on each individual case applying a deep, nuanced and detailed analysis exploring the meaning people ascribe to their experiences, it does recognise that these experiences are shaped by their interactions with their environment (Smith, Jarman & Osborn, 1999). This has led to IPA being recognised as a useful method particularly within Health Psychology as it contextualises findings within current biopsychosocial theories (Smith, 2004; Willig, 2013). Another reason IPA can be construed as insensitive to social contextual parameters is because its focus on the subjective perception of experience seeks only to understand as opposed to explain why such experiences may occur. This can be seen as problematic because it does not explicitly explore the conditions associated with such experiences which are born out of or impacted by previous events, histories and sociocultural factors which limits understanding (Willig, 2013). However, in defence of this Smith, Flowers and Larkin (2009) state that IPA applies hermeneutics, idiography as well as contextual analysis in order to gain an understanding and appreciation of cultural aspects which colour subjective experiences. Again, as previously mentioned, IPA analyses are not designed to stand alone, but instead be considered in the context of current psychological literature where findings can interrogate or contribute towards existing knowledge (Smith, 2004).

IPA like other qualitative approaches openly acknowledges the position and influence of the researcher (Smith, Flowers & Larkin, 2009). As a non-brain-injured researcher my understanding of the experience of brain injury is extremely limited and largely academic. The researcher's role of interpretating participants descriptions is explicitly acknowledged as an integral part of IPA data analysis (Dean, Smith & Payne, 2006) whilst appreciating the researcher can never be truly divorced from what they already know and so inevitably bring their own understandings which may in turn shape the analysis and research findings (Smith & Osbourne, 2015; Smith, 2004). This approach enabled me to reflect and consider how my interpretations of the data may have been affected by my position as a non-brain-injured researcher. This is returned to later in this chapter under the heading *Researcher Reflexivity.*

IPA tends to employ broad research questions which generate extensive data without committing to working with hypotheses (Smith, 2004). This approach lends itself to working in an open and unassuming way with data sets which can generate novel and unexpected findings as well as ones which may challenge taken for granted notions. In IPA this is facilitated by the use of semi-structured interviews which allows flexible data collection due to the real time interaction between the researcher and the participant in which the former can encourage the latter to fully explore and expand on their experiences (Eatough & Smith, 2008). This approach enabled me to focus and follow up on unique aspects of individual experiences which emerged during the interviews. This facilitates a fine grained and in-depth exploration of the research topic whist affording the participants respect by allowing them a say in where the interview goes (Eatough & Smith, 2008). This bottom-up approach makes IPA a suitable method for a population who can be exposed to stigma, prejudice and discrimination (Ralph & Derbyshire, 2013) in that it allows their voices and experiences to be heard and helps moves away from sweeping generalisations sometimes made regarding brain injury survivors in quantitative research. It is possible to view IPA as empowering as it puts participants at the centre of the research whereby knowledge is generated through their subjective experiences without the imposition of hypotheses or integration of existing theory. This aspect could go some way to address the power imbalance inherent in research.

In terms of utility, IPA provides an opportunity for specific phenomena to be brought to the forefront instead of relying on assumptions about particular groups of people. The establishment of such deep and intricate understandings can be used to inform, challenge and develop guidance, policy and interventions as well as help assess and evaluate their impact on lived experience and real-world situations. Further to this, because of IPAs idiographic commitment it can be used to reform existing guidance, policy and interventions where they are failing to be effective for particular populations that may be poorly understood or under-researched. As such, this current study could contribute towards a growing body of research aimed at improving and reforming services and support for brain injury survivors by generating insight and understanding about how romantic encounters are experienced after sustaining a brain injury.

Despite the strengths IPA offers, it is not without its limitations. A common criticism levelled at IPA is that like other qualitative approaches, its findings cannot be generalised to larger populations. At the heart of its design and related to its epistemological underpinnings, IPA encourages a detailed examination of homogenous samples which in turn necessitates small sample sizes (Smith, 2009). Therefore, making claims about informing wider contexts becomes problematic when samples are both small and distinctive. However, IPA is not designed to produce theories generalizable to whole populations (Pietkiewicz and Smith, 2014). Instead, IPA researchers are encouraged to focus on the “depth rather than breadth of the study” (Pietkiewicz and Smith, 2014. P.9).

The small sample sizes used in IPA may lead to inaccurate assumptions that the data generated lacks any validity and reliability. However, the use of large samples in IPA is discouraged due to its unfeasibility of working uniquely with each individual case in a detailed manner (Pietkiewicz & Smith, 2014). Compared to quantitative research, means by which to evaluate qualitative approaches have been slow to emerge. Indeed, a strength of quantitative research is its systematic employment of assessment criteria which asks questions about reliability, validity and generalisability thus enabling claims to be checked (McGrath & Johnson, 2003). Nonetheless more recently qualitative researchers now have several criteria at their disposal by which to assess the quality of evidence produced by their studies (McGrath & Johnson, 2003; Finlay & Ballinger, 2006; Yardley, 2015). One such approach has been adopted in this current study and can be found later in this chapter under the heading *Research Evaluation.*

The role of the researcher often comes under scrutiny in IPA in due to the subjectivity involved in the collection, selection and interpretation of data which raises concerns this contributes towards methodological weakness in terms of researcher bias. It is acknowledged within qualitative approaches that the same data could be interpretated several different ways by several different researchers which undeniably renders replicability virtually impossible. In this respect the findings generated by IPA could be construed to lack reliability and validity. Whilst it is appreciated that attaining a stance of objectivity is difficult, Smith (2011) emphasises the intention of IPA is to bring to light a reliable and sincere account, not the only reliable and sincere account. IPA along with other qualitative methods recognises its limitations and has set about ways of addressing them. For example, Smith et al (2009) suggest researcher subjectivity may be moderated by adhering to IPA procedures (Smith, Flowers and Larkin, 2009). Additionally, it is recommended that rigour in IPA studies can be attained by recruiting appropriate samples, ensuring in-depth interviewing and completing a thorough analysis (Smith, Flowers and Larkin, 2009). Good quality excerpts and quantities suitable to the sample size can also help demonstrate the thoroughness of an IPA study (Smith, 2011). IPA, like other qualitative approaches is explicit in its acknowledgement of the influential role the researcher has, but as Finlay (2002) points out, this has given rise to the existence of 'methodological self-consciousness' which has ultimately resulted in researcher reflexivity being located at the heart of qualitative approaches.

A notable restriction of IPA as an approach overall is that it serves to describe as oppose to explain which in turn inhibits a full understanding of the phenomena under investigation (Willig, 2013). Whilst this limitation is acknowledged by IPA researchers, the findings from each study are always juxtaposed with extant research in the discussion section rather being presented as stand-alone findings (Smith, Flowers & Larkin, 2009; Pietkiewicz & Smith, 2014).

Ultimately whilst criticisms of IPA are valid, they can also be considered as a trade-off for gaining in-depth, complex, nuanced and individual accounts from participants via an approach which is transparent about the integral and influential role the researcher plays in the research process. The limitations of IPA are important to hold in mind, but the strengths this methodology has to offer are suitable for the purpose of the current study as well as for the participants it wishes to engage with and represent. Collectively IPA studies have become recognised for exploring existential topics which are often “transformative, bringing change and demanding reflection and (re)interpretation for the individuals concerned” (Eatough & Smith, 2008). Therefore, the topic under investigation in this current study is an appropriate fit with the nature of IPA studies as they bring to the forefront the impact significant events can have on the sense of self and lived experience. Finally, integral aspects inherent in IPA such as phenomenology, interpretation and idiography are mirrored in the therapeutic work Counselling Psychologists conduct with their clients which may mean research findings from this study could inform clinical practice in a significant and profound way. This study hopes to build upon and contribute towards a recent body of phenomenological research that has moved away from garnering the impact of brain injury on family members, spouses, carers and clinicians and instead focus on brain injury survivors themselves.

An Alternative Qualitative Approach

An alternative way of exploring this area this current study was interested in could have been by adopting a discursive approach. IPA and discursive approaches share some integral common ground, however despite such similarities, their differences set them apart in significant ways. IPA and discursive approaches both endorse social constructionism, however there is a divergence in terms of where they fall on this continuum. IPA aligns itself more with symbolic interactionism while discursive approaches are more embedded in poststructuralist thought (Eatough & Smith, 2008). In this respect a discursive approach was not deemed an appropriate method by which to explore how female brain injury survivors made sense of romantic experiences encountered post injury because as a relativist approach it lies on the continuum of social constructionism which does not subscribe to a belief of the existence of any external reality (Finlay and Ballinger, 2006).

IPA and discursive approaches acknowledge the role and importance of language in that both recognise the action orientated aspect of talk and how conversations can shape interpersonal objectives, however IPA believes this is only a partial representation of communication.

"*seeing the individuals lifeworld merely as a linguistic and discursive construction does not speak to the empirical realities of people's lived experiences and their sense of self*".

(Eatough & Smith, 2008, p. 184).

Emotions are given as an example to highlight this point in that although it is possible to describe emotions using language, it is difficult to fully capture the extent of what emotional experiences may be purely by examining discourse (Eatough & Smith, 2008). With this in mind, it is salient to consider what is appropriate to and concordant with this current study. Living with a brain injury and experiencing romantic encounters that did not exist prior to injury are complicated, challenging and emotive experiences which would be more suited to an approach which attempts to pay heed to the entirety of lived experience.

IPA and FDA share common ground in their view of the position of the researcher and both consider researcher reflexivity as an important component of the research. Both approaches recognise the influence the researcher has on all parts of the research process and encourage researchers to reflect on such aspects in a transparent manner (Finlay and Ballinger, 2006).

A strength of FDA is that it can be used to challenge problematic assumptions and interrogate unhelpful or restrictive dominant views and as such help move towards establishing more diverse and inclusive representations (Finlay and Ballinger, 2006). There could be utility in applying this approach to the area under investigation in this current study because the participants are from a marginalised group who encounter prejudice, discrimination and stigma. However, these particular concerns were not in line with the overall purpose of this current study which instead was concerned with the detailed examination of the lived experience of romantic encounters post brain injury and how females brain injury survivors made sense of these experiences. Ultimately adopting a discursive approach would have been a move away from understanding what these experiences were like and would have involved a narrowing of focus which would have excluded salient aspects of the individuals themselves. IPA therefore was a more suitable approach in that it allowed a thorough and detailed examination of the wholeness of this specific lived experience from the brain injury survivors perspective.

Ultimately although both IPA and FDA are linguistic approaches, they are divergent in their aims; IPA seeks to understand how participants make sense of their experiences whereas FDA is concerned with how participants construct their experience (Smith, 2011). Therefore, due its exclusive attendance to language, FDA was not considered an appropriate approach by which to explore the phenomena of how female brain injury survivors have made sense of romantic experiences encountered post brain injury.

Method

Recruitment

Recruitment Procedure

Participants were recruited through two nationwide brain injury support charities, Headway and The Silverlining Brain Injury Charity, in addition to using recruitment adverts on social media. This purposive approach towards recruitment, as opposed to random sampling, forms an important part of IPA research in that a highly specific, homogenous group of people are being sought in order to generate insights into a certain type of experience (Smith, Flowers and Larkin, 2009). This purposive approach was facilitated further by the implementation of inclusion and exclusion criteria outlined below.

Headway is UK wide charity consisting of approximately 130 local groups across the United Kingdom. At a national level Headway provide a helpline, an emergency fund and a website containing information, publications, research and case studies. Regional Headway groups provide local services and support to brain injury survivors, the extent of which varies in terms of location. The Silverlining Brain Injury Charity supports UK survivors, their families and carers and aims to provide rehabilitation in community settings by running meetings, social activities and fund-raising events. Both charities were enlisted to assist with recruitment promotion as brain injury survivors utilising their content and services were likely to be in recovery from their injury and living back in the community as opposed to being in hospital, supported living or rehabilitation. As Headway and The Silverlining Charity both provide opportunities for brain injury survivors to connect with one another they are also utilised by some survivors on an exclusively social level.

Headway UK promoted the recruitment advert on their website (see Appendix II a). The Silverlining Brain Injury Charity emailed the recruitment advert internally to local group coordinators where it was disseminated at regional brain survivor group meetings. All the research adverts sign posted people to a specifically created recruitment website where potential participants could register interest and find out more about the study (see Appendix II c). When prospective participants registered interest on this site, an email was automatically generated to my city university account which included participant contact details.

Regarding social media I created and implemented the following strategy which incorporated three phases aimed at embedding the recruitment advert in content likely to be seen by female brain injury survivors. Firstly, I created Facebook, Twitter and Instagram accounts with my City University email address. I included a synopsis of the study and links to the recruitment website on each of these social media accounts. As these accounts were created for the sole purpose of recruitment, they held no personal information or content about myself other than my name. This was intentional in that it enabled me to be held and perceived in a neutral and professional light which in turn was aimed at generating accounts from participants that would be unaffected by under or over identifying with me or trying to second guess any agenda I may be working towards or specific goals I was trying to achieve.

As part of the second phase, I ‘followed’, ‘reposted’ and ‘connected’ with content, groups, services, publications and individuals which were related to brain injury, women’s issues and disabled dating across all three social media platforms. This in turn generated ‘followers’ for these accounts and helped establish an online presence.

The third and final phase was promoting the recruitment advert across these platforms (see Appendix II b). On Facebook the recruitment advert was posted in three UK based brain injury groups; UK and Ireland Brain Injury Support, Brain Injury Awareness UK and Brain Injury and Mental Health Support. For Instagram I featured various versions of the recruitment advert on my ‘insta feed’ accompanied with hashtags such as #braininjurysurvivor, #braininjury, #abi, #tbi. On Twitter the recruitment advert was posted as a ‘tweet’ in numerous different ways; firstly with the use of ‘hashtags’ such as #braininjury, #TBI, #ABI, secondly by ‘tagging’ and requesting ‘retweets’ from brain injury organisations such as Headway (national and local branches), Sameyou.org, Brain-injured Younger Adults and Pink Concussions, and exclusively female organisations, groups and services such as The Fawcett Society, Women’s Equality Party, BBC Woman’s Hour, Women’s Aid, and finally disabled groups and disabled dating services such as Disability Match, Whipsers4U and Disability Horizons. In addition to this I also heavily promoted the recruitment advert on relevant days such as Valentine’s Day and the International Day of Women and Girls in Science. A neuropsychologist and a number of allied health professionals also promoted and shared my recruitment advert on Twitter.

Two expressions of interest were passed on directly from The Silverlining Brain Injury Charity via email, two came from the Facebook adverts and the rest came through the registration of interest from the specifically designed recruitment website. Participants were screened in order of expression of interest and were subsequently recruited on a first come first serve basis. This seemed the fairest way of recruiting participants and also ensured I did not manipulate, influence or interfere with the selection process. The recruitment process was closed once a total of six participants had been recruited and interviewed as the data generated was rich and detailed and therefore appropriate and suitable for the type of analysis at which IPA is aimed.

All participants were offered £25 in cash for taking part in the study and this information was advertised on the recruitment website. This money was offered as a token of appreciation of their time and input. The ethics of paying participants to take part in qualitative research is discussed under *Ethical Considerations* later in this chapter.

Inclusion and exclusion criteria

Traumatic Brain Injury (TBI) versus Non-Traumatic Brain Injury

Traumatic and non-traumatic brain injuries tend to be chronic conditions with ‘hidden’ disabilities that result in sequalae including physical impairments as well as cognitive, emotional and behavioural difficulties all of which can affect quality of life as well as future prospects. The lifelong consequences female brain injury survivors experience is likely to be similar irrespective of how injuries have been sustained. Therefore, it is possible for female brain injury survivors to be defined as a similar group and thus suitable for an IPA study which aims at exploring similarities and differences in relation to specific phenomena within homogenous samples (Smith, Flowers & Larkin, 2009; Pietkiewicz & Smith, 2014). Subsequently participants with traumatic and non-traumatic brain injuries were recruited and the term ‘brain injury survivor’ was used in the recruitment material. The *Introduction Chapter* considers the convergent and divergent aspects between the two types of brain injury in more detail.

Level of severity of brain injury

The emotional, cognitive, behavioural and physical range of sequelae of brain injury is vast and complex and can be determined by location and severity of injury. However, severity of brain injury does not necessitate the level of difficulties a survivor may experience as even a mild brain injury can result in significant consequences. Therefore, rather than base the inclusion criteria exclusively on clinical diagnoses, levels of severity ranging from mild to moderate were specified on the recruitment adverts and were accepted as self-reported or clinically confirmed levels of injury. However, despite this being part of the original rationale, using these types of categories as an organising element for recruitment proved limiting as alternative states of consciousness were not predictive of long-term psycho-social functioning as half of the sample in this study described themselves as having a severe brain injury (please see Table 1). Nevertheless, as this current study was aimed at exploring how female brain injury survivors made sense of romantic experiences encountered post brain injury, it was imperative that participants still lived with the effects of their brain injury in their daily lives.

Male Versus Female Participants

Extant brain injury literature is comprised of predominantly male samples, but emerging data suggests head injuries in females may be increasing (Headway, 2013). More research is needed to understand sex and gender-based differences in brain injury and the subsequent impact on survivors. A continued use of predominantly male samples may mean current research misrepresents female symptoms, outcomes and experiences; therefore, this current study has focused exclusively on female brain injury survivors. A comprehensive review of the literature to date on sex, gender and brain injury is included in the *Introduction Chapter*.

Romantic Status and Experience Post Injury

As the phenomenon under investigation was how female brain injury survivors made sense of romantic experiences encountered post injury, one of the inclusion criteria was to have had any kind of romantic experiences post injury that did not exist pre-injury. All types of romantic experiences were considered equally valid, and this broad, exploratory scope is suited to the inductive nature of IPA (Smith, 2004). Further justification for this approach is detailed in the *Introduction Chapter.*

Further Sampling Criteria

The method used to gather data was one to one audio-recorded interviews, therefore a good level of English was required and females with speech impediments were excluded.

Time since injury was placed at 24 months due to findings which indicate that the vast majority of recovery brain injury survivors experience takes place within the first two years of sustaining injury (Fleminger & Ponsford, 2005). In addition to this, survivors with severe brain injuries have been found to have high levels of independence in daily living, with 80% being completely independent of care two years post injury (Lippert-Gruner, Lefering & Svestkova, 2007). Whilst many brain injury survivors will have experienced multifaceted change with various consequences, evidence suggests a ‘new normal’ level of functioning seems to have been reached after living with a brain injury for two years.

The age limit was set at 18 years or over meaning participants could provide independent consent to take part in the study. This also ensured all participants were above age of consent.

In summary, inclusion criteria for this study were as follows:

- Female
- A minimum of two years post brain injury
- Mild to moderate acquired brain injury (including traumatic and non-traumatic)
- Good level of English
- Ability to communicate verbally
- Possesses mental capacity to consent to participate and understand the right to withdraw

- Aged 18 plus
- Currently lives with symptoms of brain injury
- Has embarked on new romantic encounters post brain injury

Exclusion criteria was as follows:

- Currently in a romantic relationship which was formed prior to sustaining brain injury
- Gross language impairments
- Male

Data collection

Information sheets (Appendix IV) containing an outline of the study and what was involved were provided to all participants and informed written consent was gained prior to each interview.

The original plan was to conduct interviews in person at various university rooms across the country near to where participants lived in order to make locations accessible, and this is how the first interview was accomplished. However, not long after the first interview, the UK went into a national lockdown due to Covid 19, so the feasibility of using remote technology to gather the data with this particular population was explored. Email facilitated qualitative interviews have been found to be an accessible way of gathering information from traumatic brain injury survivors (Egan, Chenowith & McAuliffe, 2006), and further to this, teleinterventions have been used successfully with acquired brain injury survivors during the chronic stages of recovery (Yosef, et al 2019). Together with fact the recruitment adverts for this study were only placed online as outlined above, conducting the interviews remotely using technology was deemed feasible for this population therefore the remaining interviews were conducted via video link. Practically this enabled a flexibility suited to this population as interviews could be easily rescheduled if necessary and breaks to manage neurofatigue were tailored to each participant's needs without being constrained by room and travel bookings.

Despite the fact that many of the participants reported cognitive impairments affecting memory and concentration as well as difficulties with neurofatigue, no additional strategies were implemented during data collection as difficulties with event recollection and intolerance to stimuli were not apparent as accounts were both consistent and detailed and none of the participants appeared to struggle with free recall. Therefore, these needs were not deemed to require an adapted approach to interviewing along the lines of the mitigations as recommended by Paterson & Scott-Findlay (2002). However, all participants were asked what time of day they would prefer to be interviewed as per the author's suggestions (Paterson & Scott-Findlay, 2002) and such preferences were taken in consideration and adhered to.

The opportunity to take breaks was offered and taken up by 2 of the participants

All six participants were interviewed in depth using a semi structured interview technique that included prompts and probes as per recommended IPA protocol (Smith, Flowers & Larkin, 2009). An interview schedule was created containing questions designed to elicit in depth answers participants' lived experiences. A pilot interview with a brain injury survivor was not conducted as it did not seem ethical to gather such sensitive and personal information by the means of a potentially upsetting one-hour interview, only for the material to be used to refine and develop the interview schedule. In addition to this, as important as the interview schedule is, during data gathering interviews researchers are encouraged to follow the lead of the participant as this is how we learn more about their world (Eatough & Smith, 2008) and as such is consistent with the inductive and idiographic commitments of IPA (Smith, Flowers & Larkin, 2009). Nevertheless, pilot interviews do hold value in that they can ascertain the capacity of an interview schedule to elicit detailed responses about lived experience as well as help build confidence in the interviewer by practicing questions, pace and prompts. To this end a pilot interview on a neurotypical acquaintance was conducted about the lived experience new romantic relationships after divorce. This was deemed as an ethical substitute as this acquaintance had been divorced for over 20 years and was comfortable talking about their experiences. Verbal consent was gained after they were briefed as to the nature and purpose of the interview. I transcribed and analysed a 20-minute segment of this interview using IPA analysis guidelines (Smith, Flowers & Larkin, 2009) which provided an opportunity to see how the questions and prompts affected the nature of the answers given. I subsequently refined the interview schedule by rephrasing a couple of questions, adding additional questions and including further prompts. The final interview schedule can be viewed in the appendix (Appendix III).

Interviews were scheduled to last between sixty to ninety minutes as brain injury survivors may have taken longer to answer questions than a neurotypical sample. Longer interviews allowed time for silences, memory recollection and neurofatigue. In practice most of the interviews lasted between 90 and 120 minutes but this was because an additional question not included in the interview schedule was inserted at the beginning of the first interview pertaining to how the participant sustained their brain injury. This question elicited useful information such as the context in which the brain injury occurred, recovery trajectory and current symptoms. This question seemed to ease us both into the interview and make the participant feel comfortable. This is considered an important initial part of the interview process in that it helps establish rapport and facilitate trust and allows the participant to get used to talking, all of which helps generate good, rich data (Smith, Flowers & Larkin, 2009). This question also seemed like an appropriate place to start the interview as this was the beginning of their journey as a brain injury survivor. The utility of this question meant it was retained and it became the first question on the interview schedule for the remaining participants. I made notes during each interview to document nonverbal aspects such as body language and facial expressions not captured on the audio recording so this information could be referred back to during analysis with the aim of deepening and enriching interpretation, if, for example body language could be matched to a particularly salient passage or sentence.

All the interviews were audio recorded on two separate devices so a backup was available in the event of a technical failure. One recording was on a portable recording device and the other recording was made on a secure laptop. The recordings from the portable device were deleted once they had been uploaded to the laptop. Each interview was transcribed verbatim with the aid of a transcription pedal and software. I carried out this task myself rather than outsourcing it as it enabled me to become familiar with the data ahead of analysis. All audio recordings and transcripts were kept on a password protected laptop. Steps taken to ensure anonymity, confidentiality and data protection are outlined under *Ethical Considerations* later in this chapter.

Data Analysis

All interviews were analysed using the suggested IPA guidelines (Smith, 1996, Smith, Flowers & Larkin, 2009). Analysis involved moving through different levels, and although these are by no means prescriptive, I found it helpful to use the following process as a guide.

Level 1: Initial engagement with the data

This first level is about becoming immersed within the data and engaging with it as a whole. I read and re-read the first transcript several times. Initial readings were accompanied by listening to the interview as this helped hold the voice of the participant in mind during subsequent readings thus facilitating a more enhanced analysis (Smith et al, 2009). In particular I found listening to the interviews added a layer of understanding as to the emotional content of the participant and gauging additional sense of levels of salience they attributed to their experiences. At this point engaging with the data as a whole is important because as stated by Giorgi and Giorgi (p.251, 2003), the phenomenological point of view is “holistic”, and as such the researcher is looking to become familiar with the general sense of what is being described by the participant.

Level 2: Initial Noting

Staying with the same transcript, this next level of analysis involved a line-by-line consideration of the text and writing down anything that stood out or seemed significant. These preliminary notes were written in the right-hand margin of the transcript, and involved three different types of comments: descriptive, linguistic and conceptual. Each type of comment was colour coded to distinguish their content and help identify any patterns across the text (see Appendix VIII). This way of breaking down and coding the data and becoming aware of any connections and relationships between the comments is seen as an important step in becoming immersed in the world of the participant which in turn can facilitate analysis on a deep and profound level (Smith, Flowers & Larkin, 2009). An interrogative stance is encouraged in relation to each line of the text, constantly checking what certain aspects mean to me and what they may mean for the participant (Smith, Flowers & Larkin, 2009). IPA encourages combining 'empathic hermeneutics' which is trying to gain an understanding from the viewpoint of the participants with 'questioning hermeneutics', where more critical questions are considered to establish action, meaning and purpose as well as explore aspects which may have existed at the edge of awareness (Smith and Osbourne, 2015). To help move the analysis beyond the descriptive towards the more interpretative and psychological, Smith (2004) suggests three different levels of interpretation are possible which were held in mind during the analysis; social comparison, the use of metaphor and temporal changes or other contradictions which could indicate internal conflict or struggle. During this level analysis I began to highlight sentences, phrases and passages that stood at to me in that they communicated something strong, powerful or emotive. This level of analysis was about producing more data which informs the next level of analysis. The process outlined here was carried out for the whole of the first transcript.

Level 3: Identifying and Labelling Emerging Themes

This level involved identifying emergent themes from the preliminary notes made during level 2 and as such meant I was no longer working directly with the transcript. I created themes that captured aspects of the participants psychological and complex experiences as well as my own interpretations. Emergent themes were represented by one word or succinct phrases. This process served to reduce the size of the detail of the overall data set whilst at the same time tied together links and drew on patterns present in the preliminary notes (Smith, Flowers & Larkin, 2009). Emergent themes were written in the left-hand margin of the transcript (Appendix IX).

Level 4: Making Links and Clustering Themes

At this level I spent a significant amount of time working exclusively with the emergent themes going over them repeatedly looking for possible ways in which they related to one another on varying levels whilst holding in mind the research question to ensure their relevancy. I grouped emergent themes into meaningful clusters that I felt captured the essence of the experiences being expressed. I frequently returned to the interview in order to check my interpretations against the words of the participant. After creating a set of groups formed from the emergent themes, each group was given a title aimed at reflecting the relationship that had brought them together. All of the groups were constantly assessed as to their relevance to the research question (Willig, 2013). This process often resulted in the creation of several groups, so with the aim of reducing the data further, I repeated the process of seeing how all of the themes related to one another through their meaning, orientation or connection (Willig, 2013). To help with this consolidation and again to check that the themes developed so far were grounded in the original text, the transcript was re-read to see whether themes could be merged or condensed any further. This iterative process meant some emergent themes were disregarded and others became subsumed under themes that were closely related. The condensation of themes ended when only three or four groups remained. Each cluster was given a name, known as the superordinate theme, which collectively represented a specific or significant process or aspect of the participant’s experiences. Under each superordinate theme fell a small number of corresponding subordinate themes.

At this stage I created one document per superordinate theme which contained a series of transcript extracts (with corresponding line and page numbers) which supported each subordinate theme. This was helpful in checking the consistency among each subordinate theme (Smith, Flowers & Larkin, 2009).

The last step in this level of the analysis was the creation of a summary table reflecting the research findings and structure as a whole. Here each subordinate theme is supported by key words and phrases from the transcript with corresponding page and line numbers, enabling the original source to be located with ease. This data transparency of the analytic process demonstrates that interpretations have been grounded in the participants actual words and illustrates how themes had been constructed and organised (Smith, Flowers & Larkin, 2009).

Level 5: The Next Case

Levels one to four were then repeated for the remaining five individual transcripts. At this stage it was important to hold in mind the ‘idiographic’ element of IPA in that each time a transcript was analysed, it had to be engaged with on its own merit and uniqueness as opposed to it being interpreted in the context of previously analysed accounts (Smith, Flowers and Larkin, 2009).

Level 6: Cross Case Analysis

At this final level of analysis, the findings from all six of the cases were considered together and examined for the presence of patterns or themes as well as searching for convergence, divergence and processes. The summary tables containing the analysis of each transcript were used to inform this part of the process. Once a set of meaningful links and connections were identified a master table of themes was produced which contained superordinate and subordinate themes which were felt to reflect the whole group and capture the essence of the participants lived experience (Appendix X).

Research Evaluation

Evaluating qualitative research in terms of its validity can help ascertain whether it can be considered as trustworthy as well as assessing its usefulness (Yardley, 2015). There has been a transformation in the approach of evaluating qualitative research over the last 30 years where in the 1990s there was a general belief this type of research did not need to be evaluated through to more recently where evaluation has come to be regarded as an integral part of the research process. Quantitative research tends to be evaluated by assessing aspects such as controlled observation, reliability and validity (Girden, 2001) but these types of enquiries are based on an epistemological belief that assumes quantitative methods can capture objective knowledge largely unaffected by the humans involved in its processes, namely researchers and participants (Yardley, 2017). Conversely qualitative approaches are largely based on assumptions that all types of knowledge are unavoidably affected by personal perspectives as well as being shaped by aspects such as culture and language (Camic, Rhodes and Yardley, 2003). These differences in epistemological underpinnings between quantitative and qualitative approaches led Yardley (2000, 2015, 2017) to develop a different approach tailored towards evaluating the validity of qualitative research.

Yardley (2000, 2015) suggests a framework comprising the four following components can be applied to a diverse range of qualitative approaches: sensitivity to context; commitment and rigour; transparency and coherence; and impact and importance. I have endeavoured to employ and adhere to these guidelines in the present study.

In relation to *sensitivity to context* I carried out a comprehensive and thorough literature review (see Introduction chapter) to ensure the study was sufficiently informed by brain injury research and that it was supported by attempting to gain an understanding of and sensitivity to the perspective of brain injury survivors as well as their social and cultural context. It was important to hold in mind the stigma and stereotypes existing within wider society towards brain injury survivors and to seek to comprehend the participants accounts within these circumstances. Further to this I demonstrated sensitivity during the analysis by committing to work closely with the texts meaning interpretations and themes emerged from within the accounts. I remained mindful about the way in which data was collected in terms of minimising inconvenience to participants. I was also sensitive as to my position as a non-brain-injured researcher and what this meant in relation to the participants as well as the research process as a whole (see *Researcher Reflexivity* section later in this chapter).

In terms of *commitment and rigour* it was important to reflect on the purpose of the current study in order to assess validity (2008, 2015). This aim of this research was to gain an in-depth understanding into how female brain injury survivors made sense of romantic experiences encountered post brain injury by way of a detailed analysis of a small, homogenous sample. It is also recommended to “demonstrate competence in your analysis of the data” (Yardley, 2015.p. 267) in order to achieve rigour in a qualitative study. To address this, I worked closely with my researcher supervisor to test my interpretations and refine my themes to ensure they adequately represented the phenomena under investigation. Yardley (2015) also encourages an extensive personal commitment to the research topic either by way of accomplishing methodological skills or by connecting mindfully with the data or participants. I ensured I read widely within the brain injury literature, and I also spent one week volunteering at a local Headway Day Centre which gave me insight into the diverse impact brain injury can have and allowed me to see first-hand the type of challenges some brain injury survivors can face as a result of their injuries. I attended a series of IPA workshops which facilitated my understanding of IPA theory and provided opportunities for me to practice IPA analysis. In terms of the analysis process regarding this current study I consistently referred to the participants own accounts to ensure my interpretations were grounded in the original data (Smith, Flowers & Larkin, 2009) whilst recognising the importance of moving beyond providing mere descriptions as it was my interpretations in relation to each extract which would demonstrate their contribution to each theme they were supporting (Smith, 2011).

To demonstrate *coherence and transparency* the rational for this study and the suitability of the selected approach have been clearly outlined in this chapter. The data collection process and the levels of analysis involved in IPA have also been presented in this chapter in a detailed and open manner. Samples of original data and an example of a master table of themes have been included in the Appendices, and extracts supporting each theme are presented in the Analysis Chapter enabling the reader to see how I worked with the data. Yardley (2000, 2015) regards such transparency as integral as it clearly demonstrates what interpretations have been based on. Yardley (2000, 2015) also regards reflexivity as an essential component of qualitative research in relation to demonstrating transparency. In order to be aware of my assumptions, beliefs, fears and motivations I kept a reflexive diary throughout the research process. I also made notes after each interview to capture my initial thoughts and observations. Both processes were designed to increase my awareness of how I, as the researcher, could have influenced the study. They also served to facilitate the practice of 'bracketing' whereby I attempted to acknowledge and set aside any personal bias which may have influenced my understandings and interpretations, however there is a recognition that in practice this is difficult to accomplish (Smith, Flowers & Larkin, 2009). A section on reflexivity has been included in this chapter with the aim of highlighting my background and interests and demonstrating how I was mindful of my position in relation to this current study.

With regards to *impact and importance,* Yardley (2000, 2015) encourages researchers to reflect on why a particular piece of research is being carried out and what difference it hopes to make. Further to this Yardley (2000, 2015) reminds us that demonstrating the validity of research is necessary if we are aiming for it to have an impact. I believe that my research question has generated new information regarding the romantic experiences female brain injury survivors encountered post injury. I hope that this study may possibly stimulate further studies within this specific area. One of the main aims was to explore and expand understanding about a topic important to some female brain injury survivors which could increase awareness in relation to this area amongst Counselling Psychologists, brain injury rehabilitation services as well as the brain injury charities who provide services and support for this population. The impact of female brain injury survivors in relation to romantic relationships encountered post injury may subsequently affect mental health, welfare and benefits thus affecting funding, service provision and resources. The *importance and impact* of this current research is considered further in the Discussion chapter in terms of how its relevance to counselling psychology along with its potential links with clinical practice.

There is broad support and agreement on applying these guiding principles when evaluating qualitative research (Smith, Flowers & Larkin, 2009; Cohen & Crabtree, 2008; Cypress, 2017; NICE, 2012). Yardley (2017) encourages this guidance to be employed flexibly stating the overall aim is to encourage reflection in the researcher in relation to the research approach they have applied.

Ethical considerations

Ethical approval was granted for this study by the Psychological Research Ethical Committee at City, University of London (Ethics Reference Number: ETH1920-0718). I remained mindful at each stage of study that the wellbeing of the participants was more important than the research itself and that it was my responsibility as the researcher to ensure due diligence whilst both planning and executing this study. Ethical approval can be found in Appendix VII.

Informed written consent was obtained from each participant after they read the participant information sheet (Appendix V). At the beginning of each interview, I asked whether the participants had understood everything on the consent form and the participant information sheet and whether they had any questions and then gained verbal consent to proceed with the interview. If participants had wanted to terminate the interview or withdraw from the study at any time their decisions would have been respected and accepted with no attempts at persuading them otherwise.

Anonymity, confidentiality and data protection were all important ethical considerations in terms of adhering to research guidelines and ensuring transparency with participants (BPS, 2014). Privacy rights and confidentiality were communicated, but limits regarding confidentiality were made clear in that if anything was stated which raised concerns as to the safety of the participant or others then I would have a duty to report this appropriately. More explicitly participants were made aware I was obliged to report any current violence, abuse, harm to others and criminal activity to the police and self-inflicted harm to their GP and that I would notify them in advance in the event of any such reporting. To ensure anonymity and confidentiality, all identifiers were removed from the transcripts and each participant was allocated a pseudonym. Analysis was conducted by hand as opposed to the use of analysis software; therefore, all printed transcripts were stored in a locked filing cabinet along with the password protected laptop containing the audio recorded interviews in order to guarantee data protection and confidentiality. I was the only person who had access to both the key for the filing cabinet and the laptop. Identifiable data such as signed consent forms and demographic forms were kept separate from the transcripts and laptop to further preserve confidentiality. As per the most recent guidance according to City, University of London policy, both digital and hard copies of data will be kept for ten years after which time digital audio recordings and transcripts will be deleted and all printed data and identifiers destroyed. As City, University of London was the data controller for this research project, all data collected was subject to the current data protection legislation, General Data Protection Regulation (GDPR) which is aimed at protecting the rights of data subjects.

As part of the research planning and execution I also took steps to safeguard the psychological and physical wellbeing of the participants. Sustaining any type of brain injury could be experienced as a traumatic event therefore it was possible that Post Traumatic Stress Disorder (PTSD) may have been present for some clients. Also, as participants were invited to talk about romantic experiences encountered post brain injury, I was aware some may find this emotionally upsetting, especially if this was something they had struggled with. Therefore, I applied my clinical judgement as a trainee-counselling psychologist to identify any distress that may have emerged. One participant become a little upset at one point, whilst two others appeared to stumble across new insights during the interviews which made them pause. On each of these occasions I checked in with each participant, asked if they were ok and whether they would like to continue and gently reminded them they could withdraw at any time. All of the participants stated that they were ok and that they wanted to continue with the interview. I had a strategy in place in case any participants became highly distressed (displayed by excessive crying or shaking for example) which would have involved terminating the interview immediately and contacting my research supervisor for advice. I would not have switched into a therapeutic role and attempt to deal with any distress experienced by the participants in a psychological manner as this would not have been appropriate. The most important thing would be to help keep participants calm as this was a one-off interaction, and not part of a process of ongoing support. All participants were signposted on where they could find emotional and practical support and help should they have felt to need it after the interview. This information was included on the debrief sheet which I went through with each participant in person once the interview had finished (Appendix VI). A copy of this debrief sheet was provided to each of the participants for reference.

Interviews were conducted during the daytime which ensured buildings were occupied for face-to-face interviews as well as reducing the likelihood of participants consuming alcohol prior to interviews, thus minimising risk to participant and researcher. The first interview was conducted face to face and the remaining five interviews were conducted via video link. As previously stated, the switch in method of data collection was made in response to the implementation of a national lockdown due to the COVID 19 pandemic.

A small, private, none teaching room at City University’s Franklin Building was used for the face-to-face interview with only myself and the participant present due to the sensitive and private content being discussed. I sat close to the door to enable a swift exit in the event of any reason for it no longer being safe to remain alone with the participant. My research supervisor was informed of the interview location, date and time and was contacted via text at the beginning and the end of the interview. As the interview was conducted at City University, I assumed the building was compliant with fire safety regulations complete with fire alarms and fire escape routes that would have facilitated a quick and safe exit of the building should any emergency have arisen. As I had not used the Franklin Building before, I familiarised myself with escape routes prior to the commencement of the interview.

In terms of data collection via video links, different procedures were implemented to ensure the privacy and confidentiality of the participants during this process. Due to the pandemic both myself and all of the participants had to conduct the interviews from our own homes. I based myself in a room in a quiet part of my house where the doors were closed, and instructions given for me not to be disturbed. I felt this was not only important in order to maintain confidentiality, but that it was also respectful and helped ensure participants felt safe, at ease and comfortable enabling them to speak freely about content of a potentially sensitive and private nature. Each of the five participants were in their homes in rooms alone at the time of the video interviews and before each interview began, I asked if they were in a position to speak freely about their experiences, to which they all affirmed they were.

Interpretation

Making interpretations based on someone else’s account carries responsibility. It is something we do as Counselling Psychologists during our sessions with clients but in this instance, we can make our interpretations explicit and check them with our clients directly. The same cannot be done with the interpretations made in IPA as the participants are not present during this part of the process. The enormity of this responsibility weighed on me especially as I was keen to give brain injury survivors a voice within the brain injury literature. In order to address my concerns in this area, my interpretations were tested and developed in research supervision throughout the research process. The tension I experienced regarding interpretation is considered in the subsequent Research Reflexivity section.

Payment for Participation

As previously mentioned, participants were offered £25 in cash for taking part in the study and this was advertised on the recruitment website and in some of the recruit adverts on social media. The British Psychological Society Code of Human Research Ethics considers reasonable reward for participation acceptable in order to compensate for attendance, travel and other associated costs (BPS Code of Human Research Ethics, 2014). My motivation for offering this money was as a token of appreciation and recognition that this study would not have existed without their participation. I was mindful of the type of contributions a study of this nature involved in that the participants invested a significant amount of their time and shared deeply personal and at times upsetting accounts of their lives. Non-payment for participant involvement in qualitative research is viewed by some as unethical, therefore paying participants could be considered a benchmark of ethical practice (Head, 2009). Paying participants for their time may go some way to compensate for the power imbalance between researcher and participant in that it means the researcher is not the only one to gain from the study (Head, 2009). This transactional viewpoint was a useful reminder that the participants were helping me achieve a doctorate in counselling psychology, so whilst I was not being paid myself to conduct the research, the doctorate was in investment in my future career. As the research question and the questions in the semi-structured interview was so broad, I had no concerns that payment for participation would influence the nature of the accounts the participants shared and thus affect the quality or standard of the study (McKeganey, 2001). Regarding consent, coercion and reward I found it helpful to bear in mind the guidance of Sullivan and Cain (2004) who recommend offering an amount of money which respects the time participants have given towards the study but is not too high in that participants feel pressured to take part. There were practical considerations which affected the amount of money awarded to participants. City, University of London offers up to £250 per doctorate towards participant costs. I applied for the full amount which would have worked out at £25 per participant had I recruited ten participants (this was the largest sample size I planned to work with). As my final sample size was six, I divided the remaining £100 equally and made donations to Headway and The Silverlining Charity as a token of appreciation for their help in the recruitment process. These payments were made via their donation pages without prior notification. In terms of the participants, I was aware offering payment may act as in incentive to take part in the study, but this was not my main motivation as a researcher. Had any of the participants requested to withdraw from the study after the interview they still would have received payment to honour the investment they had made. On reflection I should have made this explicit on the participant information sheet to ensure that the payment did not prevent participants from withdrawing had they felt the wish to do so.

Researcher Reflexivity

As the influential and subjective stance of the researcher is recognised in qualitative research, researcher reflexivity is encouraged as it provides a space for reflecting upon the ways in which we have may have shaped the research and subsequent findings (Willig, 2013). I kept a reflexive journal for the duration of this study with the aim of developing my self-awareness and encouraging critical self-reflection of my role in and impact on the research I was generating. This led to the following reflections and insights outlined below.

In terms of disclosure, Pitard (2017) believes that researcher transparency in terms of how the researcher relates to the data is fundamental in gaining the trust of the reader. This affirmed how important it was to demonstrate transparency regarding my position as a non-brain-injured researcher conducting research with brain-injured participants in the methodology. This also caused me to reflect upon disclosing my non-brain-injured status to the participants and what this may mean. The issue of disclosure is often encountered in our clinical work as Counselling Psychologists. I decided to make my position as a non-brain-injured researcher explicit during the screening process which was when I first introduced myself to the participants as it seemed honest, ethical and fair. In terms of data collection and analysis I considered my position as a non-brain-injured researcher an advantage as it facilitated a closeness to each account both during the interviews and the analysis which in turn enabled an idiographic commitment to each participant which is considered an integral characteristic of IPA (Smith, 2004). In contrast to my differences, I did share some common ground with the participants in that I have spent periods of time as an adult being single and in pursuit of a romantic relationship culminating in various romantic experiences, one of which resulted in my current marriage. Personally, at times I did feel stigmatised as a result of being single as many personal enquiries only extended to my romantic status, I was often excluded from social activities as I was not part of couple and the enforcement of single persons supplements which sometimes rendered some holidays unaffordable.

I was also aware my role as researcher automatically placed me in a position of power in relation to a participant group from a population who have been found to be vulnerable to discrimination (Ralph & Derbyshire, 2013). Although I chose to disclose my non-brain-injured status, I revealed little else about myself which was in stark contrast to participants divulging their vulnerabilities. Whilst I recognised it was difficult to redress this power imbalance (Smith, 2006), it has been suggested that appropriate recourse could be to make the research available to those who have been researched (Whalley Hammel, Carpenter & Dyck, 2001). In line with this I intend to make the publishable paper available to all the participants who took part in this research, as well as offer it to Headway, The Silverlinings Charity and Pink Concussions where it can be made publicly accessible to other brain injury survivors.

My motivation for doing this research came out of a desire to work with brain injury survivors in a clinical capacity. I had hoped to secure a placement in this area but unfortunately this did not come to fruition. My interest in neuroscience remains and once the doctorate is complete, I shall once again explore potential opportunities in this area. I was however fortunate enough to spend a week volunteering at a Headway Day centre in Nottingham which is where the seed for this research project was sown as many of the brain injury survivors who were single expressed desires to have romantic relationships. I was also driven to produce a piece of research which was co-created with participants with a broad, inductive approach. I noticed a large corpus of brain injury literature tended to focus on loss, deficit and difficulty which is why the following quote really resonated with me:

“Focusing on isolated deficits and ignoring strengths, however, represents a medical model of care that is not always relevant to the lives of the persons living with chronic conditions such as brain injury”. (Lorenz, 2010, p. 872).

This reflexive space also affords the opportunity to reflect on the method of data collection which is pertinent given it became necessary to revise the original plan which could have impacted the data quality. Initially all data collection was due to take place face to face. One interview was conducted in person but due to the COVID 19 lockdown the remaining five interviews were carried out via video link. My preference would have been to conduct all interviews in person because in my experience as a Counselling Psychologist is it is easier to establish rapport, trust and ease face to face. Making the participant feel comfortable is regarded as important foundation on which to build a high-quality IPA interview (Smith, Flowers & Larkin, 2009). However, my sense was the five participants interviewed via video link seemed very relaxed and at ease from the beginning of the interviews which may suggest they felt comfortable due to the fact they were at home in familiar surroundings and in addition to this began the interviews without being affected by a commute. As previously stated, the video links enabled us to respond flexibly to neurofatigue which meant breaks from the interview were taken as and when they suited each participant. In summary I do not believe the data generated was adversely affected due to the change in method of data collection. In fact, I would go as far to recommend it as suitable, respectful and ethical way to collaborate with brain injury survivors with mild to moderate brain injuries. Whilst I do not believe it negatively affected the quality of data, there were other implications brought about by this change. Not all participants were experienced with video links and so extra time was taken talking them through this process and conducting practice runs. It also meant at times we were vulnerable to poor quality internet connection but thankfully this did not happen often. Finally, it did make the data collection process more time consuming as I had to post hard copies of the Participant Information Sheet and Consent Form and wait for the Consent Forms to be signed and returned in the post before conducting the interviews.

I have also considered whether the pace at which I have conducted the research affected it in any way. I have worked three days a week at an NHS Step 4 service which specialises in PTSD and complex trauma whilst conducting this research. Due to the COVID 19 lockdown I conducted my therapy sessions either on the phone or via video link from home which I have found exhausting. Consequently, it took me longer to achieve each research milestone which made me concerned as to a loss of momentum. However, looking back, this slower pace enabled me to spend more time with the transcripts thus immersing myself in the life experiences of the participants.

In terms of the analysis, I experienced some tension in relation to the interpretation of the data. I was aware of trying to bracket my own taken-for-granted knowledge, which Husserl believed was an essential component in enabling us to see things as they are (Smith, Flowers and Larkin, 2009; Willig, 2013), but I remained conscious of my active role as the researcher and the potential impact of subjectivity when selecting significant excerpts and identifying emergent themes. In some instances, this resulted in interpretations remaining at a descriptive level. I attributed this to a nervousness of making ‘suspicious’ interpretations instead of ‘empathic’ ones, the latter type being more attuned with the phenomenological underpinnings of IPA research (Eatough & Smith, 2008) whilst remaining conscious of the ethical responsibility that comes with the power of making any type of interpretations on behalf of another human being (Willig, 2013). In order to address this tension and concern, I worked closely with my research supervisor who encouraged a more interrogative and critical examination of the data to help move my interpretations to more abstract and conceptual levels. Repeatedly returning to the transcripts and re-reading them sometimes as a whole, more often in larger sections ensured my interpretations were grounded in the participants' actual words and facilitated substantiation for interpretations I was unsure of making (Eatough & Smith, 2008). I recognised this process as moving around the hermeneutic circle as I acknowledged the mutuality at play between the parts and the whole (Willi, 2013).

Participants

Participants in this study were aged between 25 and 50 years with a mean age of 43 years old. Level of brain injury ranged from moderate to severe and time since injury ranged from three years to 31 years, with a mean of time since injury of 14 years. All participants received in-patient rehabilitation following admission for their brain injury. Post discharge support varied greatly. Demographic information is reflected in the following table (Table I). Table II summaries each participant's ABI event in more detail and illustrates key forms of physical, cognitive, emotional and social post-injury changes which were self-reported by the participants.

Table I: Participant Information

Pseudonym	Age	Injury	Severity	Time Since Injury	Pre/ post injury Occupation	Romantic Status at point of injury/ current	Children	Living	Mobility status	Sexual Orientation
Participant 1 (P1) “Mia”	25	TBI	Moderate	10 years	Student/ 999 100 Operator	In a relationship/ long term relationship	No	Independently	Fully mobile	Heterosexual
Participant 2 (P2)“Chrissie”	47	TBI	Severe	3 years	Software engineer/ Legal consultant	Single/ Single	Yes/ Pre-injury	Independently	Fully mobile	Heterosexual
Participant 3 (P3) “Charlie”	48	TBI	Moderate to severe	31 years	Student/ Part time volunteer	Single/ Single	No	At home with support	Fully mobile Supported travel	Heterosexual
Participant 4 (P4) “Ruth”	50	TBI	Severe	10 years	Administrator/ Full time volunteer	Single/ Single	No	Independently	Fully mobile	Heterosexual
Participant 5 (P5) “Sarah”	45	TBI	Moderate	22 years	999/100 Operator Part time student	Single/ long term relationship	No	Independently with support	Limited mobility	Bisexual
Participant 6 (P6) “Bella”	41	ABI*	Severe	6 years	TV Producer/ Part time podcast producer	Single/ Dating	No	Independently	Fully mobile/ Partially sighted	Heterosexual

* *Type of encephalomyelitis caused by a virus*

Table II: Summary of ABI Event and Self-reported Post Injury Change

Pseudonym	ABI Event	Near Death Experience	Mental Health Diagnosis/Emotional Changes	Physical Change	Cognitive Change	Social Change/ Consequences
Participant 1 (P1) “Mia”	Intimate Partner Violence (IPV)	Yes	PTSD/ Depression Anxiety	Fatigue Speech aphasia Balance Constant pins and needles down RH side which affects strength and ability to grip Headaches	Concentration and short-term memory declines when tired Impatience Neurofatigue	Reported difficulties: cannot do certain social activities, cannot socialise at same rate and pace as peers, cannot travel long distances, needs regular breaks and down time, no longer drinks alcohol. Noted additional contextual factors: Spent two years post-injury in rehab, missed 2 years of being a teenager, was 2 years behind peers at university,
Participant 2 (P2) “Chrissie”	No fault fall	Yes	PTSD	Fatigue Speech aphasia Body temperature regulation	Concentration declines when tired Some evidence of lack of inhibition (saying some thoughts out loud without meaning to)	Reported difficulties: loud noises affects social decision making, no longer drinks alcohol. Noted additional contextual factors: Prefers to keep herself busy all of the time with work, hobbies and exercise
Participant 3 (P3) Charlie	Road traffic incident: pedestrian	Yes	Self-reported PTSD/ loneliness/ Sadness for what has been lost and loss of future/ Fear	Fatigue	Poor memory & concentration, Compromised executive function Neurofatigue	Reported difficulties states the need to live a slow, uncomplicated life Noted additional contextual factors: Has never had paid work or a long-term relationship, does not live independently, public transport is difficult, avoids social situations, volunteers part time
Participant 4 (P4) Ruth	Road traffic incident: cyclist	Yes	Anxiety	Fatigue, Issues with dizziness, balance & co-ordination	Poor memory and some communication and comprehension difficulties Navigation difficulties	Noted additional contextual factors: Initial loss of friends, returned to existing job then later medically retired, now volunteers full time
Participant 5 (P5) Sarah	Road traffic incident: motorbike passenger	Yes	Depression, PTSD, Anxiety	Fatigue Speech aphasia Balance Sometimes walks with aids.	Neurofatigue, Executive dysfunction - struggles with organisation	Reported difficulties: not able to sustain working full time, cannot socialise at same rate and pace as peers, needs regular breaks and down time, pacing is important, no longer drinks alcohol Noted additional contextual factors: Lives independently with domestic support, currently studying and looking to work part time
Participant 6 (P6) Bella	Encephalomyelitis caused by a virus	Yes	Anxiety	Partial sighted Alexia Fatigue Can no longer type	Neurofatigue, poor memory, unable to perform mental arithmetic, finds change difficult to deal with, especially last-minute change	Reported difficulties: Was not able to return to original job or full-time work, Noted additional contextual factors: currently volunteering and looking for part time work with assistance from support worker

Chapter 3: Analysis

The qualitative analysis section expands on the data gathered from the participant interviews and aims to answer the following research question:

How do female brain injury survivors experience forming new romantic relationships post injury?

The interviews all followed a semi-structured format (see Appendix III). This flexible and open type of interview technique is encouraged in IPA (Smith, Flowers & Larkin, 2009) and is designed to elicit in-depth answers about participants' lived experiences. The interviews generated rich, individual accounts of the impact brain injuries have had on how the self is viewed within the context of romantic relationships and wider society, and how at times, brain injuries have inhibited the development of intimate relationships. The accounts demonstrated how important maintaining post injury recovery was and that brain injuries were something to be carefully considered when making decisions regarding romantic prospects. They also illustrated the presence of vulnerability and abusive relationships thus highlighting the need for professionals to be aware of risk factors between brain injury and intimate partner violence (IPV). The analysis of the data was carried out by implementing an IPA approach which involved moving through six distinct levels as recommended by Smith, Flowers & Larkin (2009). IPA analysis provides multiple levels of interpretation (Smith, 2004) and moves between offering descriptive representations of participants experiences through to more conceptual, abstract and detailed interpretations (*Pietkiewicz & Smith, 2012).* Themes which emerged from the analysis reflect connections and conceptual similarities across the group and were determined as recurrent if they occurred for at least half of the participants (Smith, 2009). Four superordinate themes emerged from the analysis which represent how participants made sense of forming new romantic relationships post injury. Each superordinate theme incorporates subordinate themes which shared connections around a specific lived experience whilst bringing to light the participants' sense-making in relation to this. Each theme is supported by participant quotations and related researcher interpretations. Pseudonyms have been used within all the extracts which extends to all third parties, and any identifying information has been removed. Some quotes have been edited and as such [ ] means some words have been removed and …has been used to indicate long pauses. The excerpts illustrating each theme were felt to capture the essence of the participants' experiences. Further to this, the inclusion of such excerpts ensures the voices of the participants, and their experiences are heard and contextualised to allow the reader to assimilate these verbatim accounts alongside researcher interpretations (*Pietkiewicz & Smith, 2012*).

All themes are presented in Table II below. These themes are: *A Fragile Self*, which reflects how the participants made sense of their brain-injured selves as well as the relationship they had with their brain injury its enduring effects; *Searching for Connection* which refers to the ways in which participants experienced themselves in the context of wider society; *Barriers to Forming Romantic Relationships* which captures how at times their brain injury has inhibited developing intimacy and emotional closeness with others; and *Navigating a Way Forward* which refers to how the participants factor their brain injury into future romantic plans.

Table II: Table of Superordinate and Subordinate Themes

Superordinate Themes	**Subordinate Themes**
A Fragile Self	Vulnerability Making sense of a brain-injured self Investment in the Self Acceptance
Searching for Connection	Feeling disconnected Yearning for Belonging Putting on a Performance Concerns about revealing a brain-injured self
Barriers to forming romantic relationships	Self-Preservation Fear Inner conflict, confusion & uncertainty Feeling Worthless & Undesirable
Navigating a way forward	Weighing it all up: uncertainties, needs and risk Re-learning and learning Safety

Superordinate theme one: A Fragile Self

This theme explores how most of the participants felt profoundly different as a result of sustaining their brain injury and examines what this was like as they navigated new relationships with themselves, others and the enduring changes their brain injuries brought about. Four subordinate themes fall under this theme; *Vulnerability, Making Sense of a Brain-injured Self, Investment in the Self* and *Acceptance* which collectively convey an image of a self that had emerged from the brain injury as fragile.

Vulnerability

Most of the participants described experiences which communicated an existence couched in vulnerability after sustaining their brain injuries which subsequently influenced their romantic outlook and romantic interactions.

Chrissie has been living with her traumatic brain injury for three years which is the shortest time out of all of the participants. Chrissie describes how her awareness of her vulnerability affected how she approached the formative stages of a recent sexual encounter.

"I said look, I am honour bound to tell you at this point I haven't even kissed anyone in that 18 months, so I wanted to make it very clear to him that, this wasn't….you know….[ ]…..I dunno what I was making clear to him…..I think what it was, I was presenting him with what the pitfalls of this situation was, in my mind I was saying to him, I'm vulnerable, you know". (Chrissie, 75.15)

Although Chrissie expresses some uncertainty behind the reasons of her disclosure, she seems to feel a strong need to communicate her vulnerability. Her use of the word 'pitfalls' indicates that she wanted to convey that becoming involved with her may involve hidden or unsuspected difficulties.

Mia is the youngest of the participants and is ten years on from sustaining her TBI. Mia is currently in a long-term relationship but recalls her reservations about forming romantic relationships initially after her injury when she was still single.

"I thought to myself, well, I'm better off by myself because then I can have that, you know, I can control what happens to me if no-one else is involved". (Mia, 156. 6)

Concerns regarding becoming vulnerable by entering a romantic relationship are likely to be shared by the wider population, but Chrissie and Mia convey a sense of coming from a starting point of vulnerability as a result of their injuries, and both suggest becoming involved with other people increases this vulnerability.

Sarah has lived with her traumatic brain injury for 22 years but did not receive any support or rehabilitation for the first decade. Here Sarah describes her attitude towards romantic relationships and subsequent consequences immediately after sustaining her injury.

"I just didn't want any responsibility, erm….I didn't want any conflict, so it was like, no conflict at any cost, so I just let people walk over me". (Sarah, 35.9)

Sarah reflected on the nature of a long-term romantic relationship she become involved with not long after the accident that caused her TBI.

"..he almost re-parented me in some ways…[ ] he was looking after me, "looking after me", but he wasn't, because he was being physically and emotionally abusive, and financially abusive [ ] and coercive control as well". (Sarah, 22.4)

Sarah's description of this relationship highlights its abusive nature. Sarah makes sense of how she thinks her pre-brain-injured self would have dealt with this relationship and what role she thinks her brain injury played in relation to it.

"I, I wouldn't have stayed. I would have had more energy to do that. With the neurofatigue, and I how was feeling, I was exhausted, mentally and physically, and the thought of, it sounds bizarre, but the thought of moving back home or trying to find somewhere else to live…or…because I'd met him at work…to find a new job or…to have everyone know…the shame…whereas I truly believe because of the brain injury, all those, all that reasoning…went out the window". (Sarah, 32.3)

Sarah's accounts illustrate how she felt more vulnerable in relationships and less able to make decisions and act within her own best interest because of her brain injury. This raises important considerations in relation to safeguarding and intimate partner violence (IPV) for female brain injury survivors who enter romantic relationships after sustaining brain injuries and emphasises the need for immediate support post injury. This issue of IPV is returned to in the Discussion chapter.

Ruth is ten years on from sustaining her TBI. Ruth is currently single but has had long term romantic relationships as a brain injury survivor. Like Sarah, Ruth identifies a change within herself as well as a change in how she was treated by romantic partners post injury.

"….part of the old me was still there…well it had got worse actually, it was still there but it was worse than it was before....of letting someone use you". (Ruth, 53.8)

Ruth makes sense of her romantic experiences in relation to her brain injury.

"I don't think I thought enough of myself because I was, I was meeting any man than showed an interest….erm….and yeah….sort of letting things go their way". (Ruth, 14.15)

Ruth's suggestion of low self-esteem seems to be linked to an increase in vulnerability. Both Sarah and Ruth recall a changed sense of self as a result of their brain injury which seems to have resulted in periods when they have been vulnerable to being taken advantage of by others. Interestingly this was a departure from their pre-brain-injured romantic experiences suggesting a relationship between a change in self due to the brain injury and a difference in relationship quality. Whilst the risk of becoming involved in abusive relationships is not exclusive to brain injury survivors, it does raise questions about decision-making, risk and vulnerable adult status regarding this specific population.

"I do think you need to be on your own for a long time…well…but I do kind of think if I had been on my own for a long time I wouldn't, maybe wouldn't know now…erm…what I do…so…that's a hard once actually". (Ruth, 69.16)

Ruth seems to be torn here as although she makes it clear she believes it is important to be single for a long time, she realises it is difficult to learn in the absence of experience. Her language implies her experiences of being vulnerable and treated badly have enriched her with knowledge, suggesting she is better off as a result. However, her ending words convey these two aspects are difficult for her to reconcile and fathom.

Whilst the participants describe varying experiences, the theme of vulnerability was clear. All four participants expressed an increased sense of vulnerability as a result of their brain injury. This vulnerability made Chrissie and Mia cautious about interactions with others and may be underpinned by a fear of how they could be treated by potential partners. Unfortunately, Sarah and Ruth became involved in unhealthy relationships and there is a profound sense that this was linked to how they were affected by their brain injuries. It is important to note that one participant, Bella, is not represented in this theme as this did not reflect her experiences. The theme of *Vulnerability* relates to three other subsequent subordinate themes presented later in this chapter, namely *Fear*, *Self-Preservation, Learning and Re-learning* and *Safety*.

Making sense of a brain-injured self

This theme captures the way in which all the participants described a changed self as a result of their brain injury and how they experienced getting to know this new self. The theme title reflects that this is a continuous journey of self-discovery.

A common experience for most of the participants was a fundamental change to self.

“It’s not fine, I’m not the same person at all. It…things changed, you know, instantly the moment it happened”. (Chrissie, 82.18)

Chrissie describes how this resulted in grief.

“….it’s also the bereavement for the loss of who I was as well because it does feel…like I died that day as well, certainly who I was before died that day”. (Chrissie, 131.9)

Chrissie and Ruth spoke about the process of getting to know this new self.

“..this is where the brain injury thing kicks in because….I had to think about things like that on a very deep level. Right, who am I? And there was…a few tears shed over that”. (Chrissie, 59.7)

“I felt like I didn’t know myself……and maybe that’s why I was….going along the way I was because it was making me get to know myself better….you know cause I didn’t know how, how I felt and what was right and what was wrong…..erm…..yeah….I do feel…..sorry…that’s something that erm I’ve not thought before, but I, I yeah, I didn’t know myself, well, I don’t know if I still do really…”. (Ruth, 30.15)

Chrissie and Ruth both convey an absence of a familiar self. Chrissie recounts how the ‘death’ of her former self evoked sadness. For Ruth, the realisation of how she has become familiar with her new self only seems to dawn on her as she is talking which seems to lead her to another realisation, that she is unsure whether she knows herself now. Ruth’s unfolding stream of consciousness has a tone of surprise, and along with her admission of not having thought about this before suggests this is a significant, new insight for her. But for Ruth not all reflections provided such clarity.

"….it seems I thought less of myself after the injury but [ ] I was also more confident than I was previously, but I don't know if those two things go together or do they clash?". (Ruth, 17.8)

Sarah, Ruth and Mia spoke about this new post-injured self, evolving over time.

"..at one point I was very submissive, you know, that's not healthy, whereas I'm, you know, and then at one point I got a bit angry, which isn't, you know, so it's a bit, that in-between, that assertiveness ". (Sarah, 129.10)

"I think at first it made me very full of myself and very erm…..very different erm, to how I was, but, but that's kind of passed, it, [ ] didn't stay like that….erm……..yeah….I think I thought a lot of myself for a while, but I guess that's possibly maybe one of the things a brain injury does to you". (Ruth, 12.5)

"….I stopped seeing myself as sort of disabled and started looking at what I could do rather that what I couldn't". (Mia, 80.2)

These accounts indicate an ongoing process of re-evaluation is necessary as this new post-injured self is not static but instead shifts and changes over time.

For Ruth, this sense-making extended to her behaviour with men post brain injury.

"…..it is embarrassing to me a lot of the time to think and look back on what happened, and I think, god how on earth did it all happen and why did it happen the way it did? Erm…..I I look back and think of myself as stupid, not, not now but in the past". (Ruth, 41.11)

Bella speaks about her sense of self post injury in relation to dating.

"Ask anyone actually when you have a brain injury, for anyone, it will, it will shape your life and then you have the new normal afterwards, so I'm still learning who the new Bella is really [ ] compared to who you….yeah….and so then the dating thing is a some, is a different bit of it, which you haven't, I haven't filtered that into, together with it yet, it's still two different parts of my life and you're kind of like trying to find that equilibrium in each". (Bella, 91.11)

Conversely, unlike the other participants the brain injury did not result in a clear demarcation between an old self and a new self for Bella.

"I might be quite numb from…. [ ] it's more of a numbness err in the brain that might not be working, [ ] but like how….the brain maybe doesn't allow you to get cl close to people, erm…..and maybe I was always like that anyway". (Bella, 18.19)

For Bella there is a strong sense that aspects of her pre-injured self are still present.

"I wouldn't take any shit which is why I'm still single (laughs) [ ] I've always been like that….[ ] I didn't think it would have changed either ways because they've always been like that [ ] even though I've had this brain injury which a huge, big thing that's happened in my life, but I don't think it's changed what's happened…". (Bella, 25.6)

Bella was the only participant to refer to multiple aspects of her pre-injured self remaining. Living with familiar personality traits indicates Bella did not experience her brain injury as hugely disruptive to her sense of self which may correlate with her absence from the previous theme of *Vulnerability.*

The extracts in this theme convey a prominent sense of change as a result of the brain injury for most of the participants, giving way to a new, different and unknown self or aspects of the self. It seems important for the participants to make sense of what is going on for them, but for some this can be a struggle as well as upsetting and confusing. There is a sense of the brain injury being an interruption; it interrupted their life stories that helped them make sense of who they were and their place in the world, it interrupted their continuity, and it changed the context in which they were living. For some this new sense of self is not described as static but changing over time which may be why these participants return to re-examine themselves. This theme is related to the subordinate themes of *Learning and Re-learning* and *Considering the Self as Undesirable.*

Investment in the Self

The title of this theme conveys the purposeful and active role participants have played in their recoveries. Five of the participants were single at the point of injury and subsequently embarked on their journey of recovery as single adults. As Mia was a teenager at the time of her injury, she had the support of her family during the first few years. Three of the participants had to re-learn to walk again and all of them described a post adjustment period after leaving hospital. Initially after injury there was a focus on physical, cognitive and emotional recovery which over time moved towards focusing on the self and developing relationships with others.

Ruth describes the initial impact of her brain injury.

"*When I was in hospital and everything I did have to learn to walk and talk again*". *(Ruth, 38.16)*

Chrissie recalls how for her this period was couched in uncertainty.

“I mean initially when I was really sick, so I didn’t know whether how physical I was gonna be again, whether I could even read again for any length of time, it was more about trying to find where these boundaries were again”. (Chrissie, 61.1)

Chrissie’s words convey this was a frightening and overwhelming experience.

“I did sort of isolate myself but, with a view to, with a reason why [ ] rather than just being frightened by life, it was because I wanted to work on myself to get myself better”. (Chrissie, 9.13)

Chrissie’s language expresses a strong sense of determination and self-reliance. Chrissie suggests by excluding others this was an independent journey of recovery but her use of the word ‘isolate’ conveys this was a lonely experience. She is clear about her recovery being ‘work’ which indicates effort, focus and dedication.

Bella has lived with her non-traumatic brain injury for six years and considers her recovery ongoing. Bella is partially sighted as a result of her injury and regularly practices a rehabilitation technique aimed at improving her sight. Bella describes other techniques she employs to help her manage the effects of her brain injury.

“I’ve done a lot of mindfulness techniques, [ ] I use it erm, every day and fifteen minutes to calm my brain down to know that I can, just be able to push forwards to the next stage really”. (Bella, 38.8)

Bella highlights how fundamental her rehabilitation is to her independence.

“I guess it’s your confidence to go out and about, cause I can’t see and I’ve had to re-learn to, to see”. (Bella, 35.12)

Bella is clear about being dedicated towards her rehabilitation. Whilst her accounts have a practical focus, they may hold a deeper meaning in that these efforts are likely to be contributing towards creating a foundation which enables Bella to develop interpersonal relationships including meeting people online, going out on dates and pursuing romantic opportunities.

Not all the accounts regarding recovery related to physical aspects as four of the participants referred to the purposeful efforts they made towards their psychological recovery.

“..that took a lot of work to realise I am not going to be that person I was when I was 22, you know, erm…. And that took long. Hard. Work. (Sarah, 117.7)

Although acceptance is a theme within itself in this section, it felt important to include this excerpt here as Sarah is clear that acceptance did not come about as a result of the passage of time but instead involved a long and difficult process requiring dedication and commitment. That this was far from easy for Sarah is conveyed by her emotive emphasis and separation of her last three words ‘long. Hard. Work’. Sarah’s tone of voice dropped, and her speech slowed down when she imparted these last three words as if they were being pressed upon the listener which on a deeper level indicates this experience has left an indelible mark upon her.

“…those first ten years were sheer hell, and I came through a lot, and I realise that…[ ]….I’m very protective of it….and if someone rejected me because of that, that would be……devastating”. (Sarah, 119.6)

Sarah's use of the metaphor 'sheer hell' emphasises her struggle and demonstrates her emotional pain. Sarah is explicit about being protective of the gains she has made post injury, and the fear she felt at potentially being romantically rejected is clear. Mia recalls having a similar outlook with regards to the gains she had made post recovery.

"It was just safe. I, you know, I knew I was able to cope, I was able to, to, to live as I was, and fair enough I might…..looking back I wasn't the happiest but I was the happiest I'd been at that point….And you know, I didn't want anything jeopardising that. I felt like I'd worked so hard to get myself to that point". (Mia, 124.1)

The language both participants use conveys a sense that their recovery is fragile, and as such they are protective of it, their progress is something to be guarded. There are strong links here with the themes of *Self-Preservation* and *Safety* but it felt salient to include them here as they highlight the active role the participants have played in their recovery.

These extracts capture the levels of recovery the participants have worked through from more initial physical and practical levels to more psychological and emotional ones. The participants' descriptions convey these efforts have been a struggle which have been experienced as emotionally overwhelming and exhausting at times. The enormous efforts they have made towards improving the quality of their lives really stood out. On a deeper level this investment in the self may represent a process of adjustment which enabled the participants to re-establish a connection with a new or different brain-injured self. This theme relates strongly to the themes of *Self Preservation,* and *Safety* and *Learning and Re-learning.*

Acceptance

Four of the participants spoke explicitly about the role acceptance has played in their lives post injury.

"…it took a fair few years but I was like, do you know what? There's just no point like gazing through the window, I might as well, you know, look at the nice cosy fire I've made here". (Mia, 30.14)

Mia's use of the metaphor, 'gazing through the window', indicates recognising the futility of merely being an observer. Her use of the word 'window' also implies feelings of isolation and a sense of separateness. Mia follows this with another metaphor of 'the nice cosy fire' she has created which suggests she has moved on and found comfort and ease in her own way of living, and that this may be enough for her. Mia expands on what acceptance meant for her.

"once I sort of had to come terms with it, [ ] it feels, yeah, I feel a lot more sort of…..normal….a lot more neurotypcial I think the word is, isn't it?" (Mia, 76.4)

Bella also spoke about acceptance.

"...with brain injuries it's different because it isn't again like it's, it's just acceptance now isn't it rather than anything else?". (Bella, 98.12)

Bella is clear that she considers self-acceptance as an important and powerful focus and means by which to move forward in life as a brain injury survivor.

Conversely, acceptance means something quite different to Charlie.

“..if I accept it feels like I’ve given up, I’m giving up, if I accept, and I think that I have, because I’ve worked so hard, and I just don’t feel I can do anymore, so…I’ve given up…I really feel that I’ve given up. [ ] On life getting better and improving and moving forward and getting over this and leaving this behind…”. (Charlie, 71.8)

Charlie’s account reflects despair as well as frustration at working hard without anything changing. Charlie’s language indicates a strong desire to be without her brain injury and for life to be very different from how it is. There is profound sadness conveyed here as well a sense of hopelessness. It is interesting to note that Charlie is the participant who has lived with her brain injury for the longest time, but out of all the participants she is the least accepting of her injury and everything it entails.

For two of the participants the notion of acceptance extended beyond the self and instead was about being accepted by others.

“Here was someone that was accepting of me…erm…even after I’d had this accident”. (Sarah, 37.18)

Sarah is referring to the first serious romantic relationship she developed after sustaining her injury which occurred before she received any kind of brain injury support. This relationship became abusive over time. Here Sarah is making sense of how powerful and meaningful it was to be accepted by one person when no-one else around her seemed to understand her. Her use of the words ‘even after I’d had this accident’ conveys a sense of understanding the enormity of the injury she has suffered and as such it was a struggle to comprehend that someone else could be accepting of this brain-injured self.

"He just had to compliment me for about half an hour and I'd be like no, you're lying [ ]…it took quite a long time for me to sort of accept….accept that he thinks something different about me than I think about myself". *(Mia, 161.7)*

Here Mia is talking about the formative stages of her five-year relationship and is clear it was a struggle to comprehend that her partner viewed her in a positive light. This suggests low-self-esteem was present for Mia which has been found to be common amongst female brain injury survivors. Low self-worth was a common theme in this current study and is represented under the theme *Feeling Worthless and Undesirable.*

The theme of *Acceptance* captures the significant role self-acceptance can play in terms of coming to terms with a brain injury and moving forwards. It also illustrates the importance of being accepted by others in a romantic capacity but indicates this is in turn may have been difficult to accept for some of the participants. It also highlights that self-acceptance is not something that happens naturally as a result of the passage of time emphasising it is not a passive process but rather an active one. Achieving self-acceptance seems to be dependent on the participants themselves in that some of them made an active choice to become more accepting of their brain injury and the way in which it has impacted their life as opposed to being rejecting of their disability, limitations and differences.

Superordinate theme two: Searching for Connection

This theme collates the ways in which the brain injury has impacted how the participants feel in relation to other people, how they orientate themselves within society and explores how the concerns they have about being judged by others affects their sense of self. Four themes represent these various experiences; *Feeling Disconnected, Yearning For Belonging*, *Putting on a Performance* and *Concerns About Revealing a Brain-injured Self*.

Feeling disconnected

Four of the participants described feeling an amplified sense of separateness from other people after sustaining their injuries which had a profound impact on their sense of self as well as how they felt in relation to social interactions.

"I don't feel like I can join in". (Charlie, 3.11)

"I was still feeling again, still adrift, still so adrift". (Sarah, 54.3)

"I feel like a stranger". (Charlie, 3.11)

The language Charlie and Sarah use alludes to feeling distant from other people. It is interesting to note that Sarah seems to be talking about a period of time in the past suggesting she no longer feels like this whereas Charlie uses the present tense indicating this is ongoing for her. Charlie is clear that interacting with others is something she struggles with.

Two of the participants used powerful and haunting metaphors of physical separation to depict how alienated they felt as a result of their brain injuries.

"It was sort of like looking through a window…..where like everyone else was on the outside and it was just me sort of by myself". (Mia, 20.16).

This is a powerful image which conveys sadness at not being able to join in with others and communicates a deep feeling of loneliness. Mia's use of the word 'window' implies a sense of being cut off from other people whilst still being able to see them. On a deeper level this could reflect frustration and envy at not being able to join in due to the limitations imposed by her injury such as neurofatigue. In this metaphor other people are ‘on the outside’ suggesting she herself is inside which could demonstrate a sense of feeling limited or restrained. Mia uses the metaphor of a window twice in her interview when relating to others indicating a profound and enduring sense of difference between herself and other people.

“I described it before as being like a brick wall, trying to move a brick wall, trying to get through…that…nothing will…you push harder, nothing happens, nothing”. (Charlie, 3.12)

Here Charlie is talking about her efforts to return to her pre-injured state. Charlie’s description of failing to move the brick wall sounds emotionally painful, difficult and exhausting. The repetition of the words ‘trying’ and ‘nothing’ convey a sense of frustration and hopelessness in relation to her futile efforts at making a difference. It is clear Charlie feels stuck behind this wall and her tone of voice at this point was wistful implying a longing for escape. There is also a sense that this metaphor represents how she feels in relation to other people as the words ‘brick wall’ imply a sense of separation and being cut off, and that anything or anyone beyond the wall is inaccessible.

Both metaphors illustrate how the participants feel separate from others. However, windows can be seen through, and opened connecting the inside to the outside, whereas brick walls are more permanent and difficult to break. The difference between these two metaphors may reflect differences in outlook between Mia and Charlie perhaps with Mia being more hopeful and Charlie less so.

Charlie and Mia go on to talk about how they feel different from non-brain-injured people.

"To not feel normal makes me feel guarded, it makes me feel I want to withdraw from society. I don't want people to know". (Charlie, 59.10)

"It was getting to grips with the idea that I wasn't like everybody else as well". (Mia, 26.16)

Charlie and Mia's descriptions both convey a strong sense of not feeling the same as other people, however the way this has affected them is different. Charlie describes how this makes her want to withdraw, and her wishes of not wanting others to know about her brain injury could indicate shame or wariness. The language Mia uses highlights her struggle to come to terms with her differences, but that this was a process she dealt with rather than avoided.

"I do get tired really easily, I do get really bad headaches you know, I do lose my balance if I get drunk you know….and all of those things lead…to a feeling of sort of…sort of us, and, us and like them and me. Where you know it was like everyone else was able to do everything that I wanted to do…." (Mia, 28.13)

Mia's account highlights how her brain injury symptoms made her feel different from others and how they have made some activities inaccessible making these disparities apparent to both herself and others. Mia's use of words of 'them and me' portrays the difference between herself and others as gulf which emphasises her loneliness and isolation. Towards the end Mia expresses sorrow, loss and grief in relation to the things she can no longer do due to limitations her brain injury imposes.

"I got a lot of misunderstanding and I didn't know how to express…. how I felt". (Sarah, 15.5)

Sarah indicates feeling cut off from other people here. This conveys a sense of complete isolation which speaks of devastation and loneliness. This also highlights the interpersonal challenges Sarah faced at times since sustaining her injury in relation to communicating her experiences.

In contrast, Bella's experiences were qualitatively different in respect of who it was she did not feel connected with.

"I like being able to communicate quite frequently [ ], whereas a lot of people who have brain injuries will be unable to do that so, which is why I'm very lucky". (Bella, 112.6)

Bella frequently compared herself to other brain injury survivors as opposed to non-brain-injured people. These comparisons contrasted the difference in severity of symptoms indicating Bella felt very different from other brain injury survivors. This direction of social comparison was unique amongst the participants and is returned to in the Discussion chapter.

"I've only got little bits really that are still struggling, at least I can smile and chat and I go to all the Silver Lining Meetings and stuff, and the people there are just so, so much more brain damaged", (Bella, 82.7)

For Bella this seemed to enable a sense of gratitude.

"I find it quite therapeutic to go to those meetings and feel very lucky [ ] to be alive really and yeah not more brain damaged really", (Bella, 82.11)

These extracts imply Bella feels disconnected from other brain injury survivors. The process of repeatedly comparing herself with individuals with more severe brain injuries seems to provide Bella with a point of reference whereby she re-evaluates herself in a positive light. Bella's use of the word '*therapeutic'* in the last extract implies she finds these experiences positive and beneficial. Bella's description of feeling 'very lucky to be alive' is something she touched on earlier in the interview when she said of the cause of her non-traumatic brain injury "*It's around 20% chance of survival" (Bella, 82.1).* This near-death experience may also contribute towards her sense of gratitude. This also serves as a reminder that ABIs acquired in what are considered 'non traumatic' circumstances (the result of a viral infection in Bella's case) can still be experienced as traumatic.

In addition to this, unlike other participants, Bella expressed a connection with non-brain-injured people.

"..dating is a nightmare for anyone, anyway so….it doesn't matter if you've got a brain injury or not….I don't think it's changed in the, in the time that I've been dating", (Bella, 59.6)

Bella is clear that the quality of dating was the same for her both pre and post injury, namely difficult and uncertain. This continuity of experience may help enable a sense of normality, consistency and familiarity for Bella within a context otherwise dominated by transformative change brought about by sustaining a brain injury.

This theme highlights the sense of alienation some of the participants felt after sustaining their brain injury which not only impinged on their sense of self in terms of feeling different from others, but also affected interpersonal interactions.

Yearning for Belonging

This theme explores what romantic relationships represented to four of the participants and why they longed for them.

"I didn't want people to think that I was so desperate cause I'd always been single or something like that…erm….I felt like I had to say…look I have been with someone for a while [ ] but I expect that probably made me feel better". (Ruth, 23.19)

Ruth recalls her concern as to how others may have regarded her because she was single, alluding towards the stigma in wider society towards people not in relationships. Ruth seems to struggle with being viewed as single but goes on to reflect that communicating the existence of a past long term relationship served to improve the way she felt about herself. Ruth's language suggests a belief that the existence of a romantic relationship communicates a certain message to society. This aspect is something Sarah touched on as she recalls how she felt after sustaining her injury.

"I became obsessed with having another relationship. Erm, again fitting in, and all these things, erm, my esteem was low". (Sarah, 52.14)

Sarah expands on this further.

"I thought that's what I needed. I needed a relationship cause my esteem was low….and I just wanted to be like everyone else…..because obviously something was going on, and I just wanted to get back to the way I was before the accident". (Sarah, 48.3)

Sarah is clear about wanting a relationship to help make her feel better and to fit in. Both of Sarah's accounts convey she viewed a romantic relationship as synonymous with a ‘normal’ existence which included her own pre-injury existence. Sarah’s language and emphatic tone of voice also imply she experienced this desire for a romantic relationship as an intense longing, particularly with her use of the word ‘obsessed’.

Charlie has had various romantic experiences since sustaining her brain injury but has never had a serious long-term relationship despite wanting one. Here Charlie speaks about what it meant for her to have had a close platonic relationship instead.

“….when I was with Miles…. [ ] I felt fine then, I felt alright because I had a friend, so I could say to people, but well my friend, I have a friend, and that was alright…just having a friend, it didn’t matter [ ] that it wasn’t a romantic…..he was there…..and he was my friend, so it was alright because people can take [ ] from that what they will”. (Charlie, 57.2)

Charlie describes how she liked being able to communicate that she had a friend to other people and is clear about this making her feel better. Charlie’s language suggests having a close relationship was experienced as validating on two levels; firstly, that someone wanted to be close to her, and secondly because this could be made apparent to others. This highlights the positive effects of personal validation and illustrates the importance of external perception and judgement as Charlie’s focus is on how this friendship may look from the outside. Here she seems pleased this relationship is open to interpretation and hopeful it is perceived as a romantic one. Together Ruth, Sarah and Charlies’ experiences highlight an intersection of a double stigma in the co-existence of being both brain-injured and single and illustrates the profound impact this has on them. This is a topic which is returned to in the Discussion.

Mia also expressed a desire for ‘normality’ and equated this with having a romantic relationship. Mia has been in a long-term romantic relationship for five years. Here she recalls what it was like in the formative stages.

“I needed Aiden to be able to like show me…that…a normal relationship is possible for someone like me. [ ] You know. Someone that, that has been through emotional and physical trauma and come out with a brain injury and I’m still able to live like a normal life with a normal relationship”. (Mia, 55.8)

Mia’s use of the word ‘normal’ implies she does not consider herself this way. She conveys a sense of disbelief that she was capable of having a romantic relationship. Mia’s language suggests a deep longing for her relationship to bring her a sense of normality. Mia’s description highlights her sense of feeling different but alludes to how she hoped the relationship would help her feel less different.

Being in a relationship appears to be considered as a benchmark of ‘normality’ by all four of the participants and part of ‘fitting in’ with society. The theme of *Yearning for Belonging* seemingly works on two levels; firstly, a longing to be part of a romantic relationship, and secondly a yearning to belong and be accepted as part of society which can be reached by achieving the former. Concerns about being judged due to being single are likely to be felt by the wider population, but the accounts here suggest an intersection of a double stigma; being both brain-injured and single. Notably this may exacerbate any sense of feeling different from others, and as such this theme has a powerful connection with the previous theme of *Feeling Disconnected*, as well as with the subsequent themes, *Putting on a Performance and Concerns about Revealing a Brain-injured Self.*

Putting on a Performance

ABI is commonly referred to as a 'hidden injury' or an 'invisible disability' in that for some survivors symptoms are not obvious to others. This theme captures a common experience in brain injury literature known as concealment of injury and referred to by brain injury survivors colloquially as 'masking'. These are attempts at behaving in ways which seek to keep the hidden injury a secret. Four of the participants spoke about their experiences in relation to this and described the impact it had on them.

Charlie talked frankly about how at times she has pretended to have been in a romantic relationship.

"I have lied about that in the past, that I have got someone". (Charlie, 56.11)

Charlies expands on her reasons for doing so.

"*to seem ordinary, so I seem ordinary and normal, because I don't feel like I am…..and I don't want people to judge me because of not having a job…….of not having a relationship you know*? *(Charlie, 54.14)*

" it makes me feel ordinary and…that kind of just like everyone else". (Charlie, 56.16)

Charlie's longing to be like 'everyone else' is clear here and emphasised by her repetition of the word 'ordinary'. Charlie's accounts suggest she considers being in a relationship, along with having a job, as benchmarks of 'normality', and that the absence of either may invite negative judgement from others. The way Charlie talks about her experiences in these two extracts illustrates the external and internal benefits of her pretence; it makes her *seem* ordinary and *feel* ordinary. This illustrates how external behaviours can affect internal states, and highlights the ameliorating effects the former can have on the latter.

“I think it’s a really big…there’s a stigma attached to people who don’t work, society values work I think and so if I don’t work, I’ve really felt that…….erm……that I haven’t worked and…..that I’ve been disabled and that’s been difficult”. (Charlie, 33.5)

This feels like it has been an incredibly painful experience for Charlie which she has had to live with for a long time. Charlie sustained her injury when she was 17 years old and has been living with her injury for 31 years. Collectively Charlie’s experiences highlight the intersection of disability stigma and social stigmas such as not working and being single, and her language conveys a sense of this being deeply internalised, which seems to reflect the hurt she feels and the fear of judgement from others that she constantly lives with.

Sarah and Mia also described ways in which they hid their injuries.

“I was masking as well, so I was all yay let’s go for a drink, yay let’s do this, oh yeah that’s my favourite film too, desperate to fit it”. (Sarah, 37.20)

“I was in first year of uni at 20 so he was like oh, couple of years out and I was like yeah yeah I did like a gap year, did I fuck I was in a neuro rehab place for 2 years..” (Mia, 32.1)

Despite the absence of negative judgement their masking behaviour afforded and the subsequent lack of distress it enabled; it was not without its own negative consequences.

“I was fighting against a lot of people’s...impressions…of what they thought….of how I was, and then I was also…..trying to go on as normal myself…erm….so my self-esteem was, I’m passing here and, and it’s killing me”. (Sarah, 19.13)

"….I had this façade up and it was so stressful cause I was trying to keep up this façade for these like first 6 months….and I was just making myself ill, and I was stressing myself out". (Mia, 123.1)

"That [ ] proper over, over compensating that I do is, is all the physical stuff… [ ] it's…it's exhausting when I think…do I really think like this all the time? That I'm, that, that's…flamin' full on convincing every…and convincing who? That I'm…normal? You know, it's…no I, I have got a plastic skull, you know? I've got, I've got all sorts of PTSD issues around…oh…death". (Chrissie, 84.2)

These descriptions highlight the toll masking and concealment took on the participants. Chrissie's account illustrates the dual function masking can have as she begins to question who she is trying to convince with her behaviour; herself or others, which highlights the ongoing dilemma she struggles with. Chrissie goes on to question whether she is trying to prove that she is 'normal' but she follows this with descriptions of the legacy of her brain injury which suggests she is aware she is different as a result of what has happened to her. Chrissie's language seems to convey a conflicting attitude towards her overcompensation which could suggest this is something she is still figuring out, which would make sense as she has only lived with her injury for three years. This is the shortest time period out of all the participants.

The accounts here demonstrate how at times the participants controlled how they presented themselves in social situations in order to manage how they came across to others which ties in strongly with stigma, perceived stigma and discrimination. The phenomena of not feeling 'normal' and 'masking' are well documented within brain injury literature and are returned to in the Discussion chapter. This theme is strongly related to *Concerns about Revealing a Brain-injured Self* as well as to the theme of *Fear.*

Concerns about Revealing a Brain-injured self

The decision to disclose the presence of a brain injury is a dilemma and challenge that many individuals have to carefully consider. This theme explores how all the participants experienced the multifaceted aspects surrounding the disclosure of a hidden injury.

Charlie and Sarah both described their reluctance to disclose their injury.

"I didn't want to mention it, didn't want nobody to know about it, just wanted to forget about it and...move forward". (Charlie, 76.14).

"I went through a point of not bringing it up at all you know, just thinking, if I try harder, I will be back to who I was…" (Sarah, 48.19)

Both accounts convey a sense of denial and perhaps reflect a struggle to accept the new, brain-injured self. On a deeper level it poses the question, what does it mean to the self to disclose the injury to others? Sarah's words indicate a longing for her old pre injured self which she believed she could return to by making more effort.

Mia and Ruth both described a temporal change in their attitudes towards disclosure since sustaining their injuries.

"it did feel big at the time, it felt like a real big issue. And I probably should have just told him 'cause I don't think it was a massive issue, I think the issue was, was that I hid it from him and that he couldn't understand why.[ ] I think at the time I saw it as much bigger issue than it actually is". (Mia, 55.3)

Mia is referring to the disclosure of her brain injury to her partner in the initial phase of their five-year relationship. Mia's language is reflective and hints at regret. Her account also highlights how partners can be impacted by delayed disclosure which Mia describes as being an issue within itself. Mia's description of her current view of disclosure may suggest her attitude has been affected by the positive way in which her injury was received and that it did not inhibit the development of her romantic relationship. This highlights the complexity of disclosure in relation to a potential romantic partner as the implications can be huge for the self and others involved. Mia's repetition of the word 'big' conveys that this was an overwhelming decision for her at this point in time suggesting this required a lot of thought and reflection.

Conversely Ruth's approach towards disclosure took a different direction over time.

"I did at first mention the brain injury and what it did to me, but, but then I got to the stage where I felt like I shouldn't just, just say you know you had a big accident or whatever, but don't, don't describe, don't go into any detail". (Ruth, 23.2)

Ruth expands on why she changed her approach.

"…there are a lot of different issues for people who are brain-injured [ ] cause I experienced it, from losing friends and even from people I don't know, they, they can't, they don't like it and they can't handle it, they think there'll be something odd about you or off with you". (Ruth, 23.7)

Ruth's descriptions highlight disclosure can be about both revealing the brain injury as well as the related symptoms. The accounts of how others have reacted towards Ruth highlight how real-life experiences have informed her current attitude and decisions regarding disclosure. Ruth's tone of voice is impassioned as she recalls these events suggesting although they are in the past, they have left an indelible mark of emotional hurt.

For three of the participants the prospect of disclosure brought about a fear of being negatively judged and concerns regarding the potential reactions of others upon revealing their brain injury.

"…there's a lot of fear of being like stigmatised by it". (Mia, 118.3)

"I didn't want to scare people off, cause as soon as you say brain injury to anyone, they're like "brain injury" (says brain injury in a funny voice) it's like even that guy that I'm sort of seeing at the moment…… I don't even know if I've told him exactly, what's wrong with me". (Bella, 32.1)

"I need to show him that you know I'm not…….not some like lunatic with you know sort of a, a……massive like brain bit, like you know….brain issue". (Mia, 54.3)

The language Mia and Bella use here to describe their brain-injured selves indicates an element of internalised stigma through using words such as 'lunatic' and phrases such as 'what's wrong with me'.

Chrissie reflected on how her concerns regarding disclosure depended on social context.

"it's being around clever people that…I get, I get this overarching feeling inside, are they secretly thinking I'm thick? And I know that's stupid but, it's, it's…isn't it…wanting to prove myself in some way that I'm…just as capable as them, or I'm as capable as I've ever been". (Chrissie, 82.11)

Chrissie's questioning of herself seems to lead to the realisation that her overcompensation is about proving her capability to herself as well as to others.

A further challenge for two of the participants regarding disclosure was *how* to communicate their brain injury and related symptoms to romantic partners.

"I was going through the brain injury rehab and then my thyroid went, and I had this really bad thyroid erm, thing and it was just like I can't, you know...how am I going to explain all this to someone?". (Sarah, 58.12)

"….the aphasia bit I almost had to show, I had, like I had to show him …what….what could happen". (Mia,134.5)

Mia expands on what this process of revealing her brain injury to her partner was like.

"… it was exhausting emotionally because I was so up and down because I didn't, he, he wouldn't, because I wasn't explicitly saying are you ok with my tiredness, he then wouldn't explicitly say "Yes I am ok with your tiredness"". (Mia, 137.1)

Bella was the only participant using dating websites and apps. Here she describes the dilemma this presented in terms of disclosure.

"..it felt like I, if I didn't tell them, I felt like I was lying, that I, you know, and I'm meeting someone who I should, should just be honest with them, but you don't wanna scare them off". (Bella, 31.1)

“you don’t really, don’t wanna tell them before you meet them……oh my name’s Bella and I’ve got a brain injury, you try not to tell them, and I don’t have to necessarily tell them”. (Bella, 27.9)

The excerpts presented in this theme demonstrate the challenging dilemmas participants encountered in relation to disclosing their hidden disability. The accounts reflect a fear of how others may react as well as concerns they themselves will be judged and defined by their injury. The reluctance, hesitancy and apprehension evident in most of the accounts suggests the role of stigma was an influencing factor. Stigma and disclosure are clearly important issues and as such shall be returned to in the Discussion chapter.

Feeling Disconnected and *Yearning for Belonging* represent isolation, feeling different and the desire to fit in with non-brain-injured others, whereas *Putting on a Performance* and *Concerns About Revealing a Brain-injured Self* centre around *concerns* about fitting in and being accepted by others as well as dealing with stigma, perceived stigma and discrimination. Collectively these themes highlight how feelings of alienation and difference alongside fears of being judged due to being brain-injured can impact social and romantic interactions as well as social identity. This illustrates the complex interactions between the self, the brain injury and others as well as emphasises how important it is to consider the experiences of brain injury survivors in a relational context as well as wider society. The participants words indicate they have experienced various difficulties with interpersonal relationships. This could suggest developing closeness with others is particularly challenging. This is discussed further in the Discussion chapter.

Superordinate Theme Three: Barriers to forming romantic relationships

Despite strong desires to form new romantic relationships, many of the participants referred to specific aspects of their injuries and internal emotional and psychological states which, at times, prevented them from seeking, initiating or developing intimacy and emotional closeness with others. Such barriers to forming romantic relationships are represented in the following themes: *Self-preservation*, *Fear, Inner conflict, confusion & uncertainty* and *Feeling worthless & undesirable.*

Self-Preservation

Three participants spoke about how important it was to protect and maintain their post injury recovery as well as concerns they had about their recovery being threatened or disrupted by becoming involved in a romantic relationship.

Chrissie highlighted the need to consider a range of potential risks….

“I feel like I’ve got to protect myself a lot more”. (Chrissie, 130.7)

For Chrissie this was in stark contrast to her pre-injured self.

“before the brain injury I didn’t give a shit about risk, [ ] I was far more free and easy”. (Chrissie, 129.1)

Contemplating risk was also something Sarah expressed concerns about.

“It was fear of…having to open up…about my brain injury…let someone in, for this thing that I’d worked so hard to be able to manage, and it was like I can’t let anyone interfere with that [ ] I wanted to protect myself I think, so that was a big thing”. (Sarah, 108.4)

These powerful descriptions embody several themes in addition to the current one, namely the earlier themes of *Vulnerability* and *Investment in the Self,* the subsequent themes of *Fear* and *Safety.* Chrissie is clear about her need to protect herself and manage risk. In the context of romantic relationships this indicates Chrissie perceives them to be a threat to her sense of self and as such this is something she must guard against. Again, Chrissie is clear this way of existing is in stark contrast to her pre-injured self. Sarah's words communicate fear that her post injury recovery could be compromised by a potential romantic partner. Her language conveys a sense that the prospect of becoming romantically involved with someone was experienced as risky, uncertain, frightening and contending with the unknown, which could echo Sarah's experience of recovering from her brain injury. This sense of protection is something Sarah returned to later in the interview.

"I think in terms of your brain injury, it's something to protect. [ ] Something to nurture and no-one can mess with that". (Sarah, 126.12)

Sarah's account suggests her brain injury is not merely something to be lived with and tolerated, but instead something to be looked after and cared for. Her words imply she is fiercely protective of her recovery which indicates she considers it to be fragile. Together both excerpts highlight Sarah's fear that emotional upset or instability that entering a new romantic relationship could bring about could cause her to regress to a place she does not wish to return to.

Mia also recalls being reticent about developing romantic relationships in the period after sustaining her injury.

"I found solace in the fact that people found me like physically attractive…….and I, I think I thought to myself you know, you could let them in, but why would you? [ ] I think I just

felt like I was better off alone. Because at least then, if anything went wrong, I only had myself to blame. And I could control that. (Mia, 155.11)

Mia's language conveys a belief that to develop emotional closeness with someone would increase her vulnerability. Mia explains this reticence was still present in the formative stages of her now five-year romantic relationship.

"I was living a, a mostly normal life. Fair enough the bits that weren't normal really got to me, but I was living mostly normal life erm…. that I didn't want anything to jeopardise it. And I wasn't you know, I wasn't willing to let friends, family or indeed Aiden jeopardise that". (Mia, 124.17)

Here Mia is clear she had reached a level of functioning she did not want to risk losing. Mia's repetition of '*living a mostly normal life'* followed by the repeated use of the word '*jeopardise*' imply that reaching this level of recovery was important to Mia, and that other people, including her partner, may threaten her progress and achievements. Mia's account portrays a sense of caution, hesitancy and uncertainty which persisted into the beginning phases of her romantic relationship. The use of the word 'indeed' before her partners name represents an inner conflict in relation to developing a relationship, as on one hand Mia was attempting to balance her need to protect her brain-injured self, with desires, however unwelcome, for emotional closeness. The concerns expressed by the participants here regarding the increased risk, threat to functioning and being protective of their gains may relate to the traumatic circumstances during which their injuries were sustained as they were all near death experiences and relate to psychological trauma. This is considered in the Discussion.

Fear

Another theme to emerge was that of fear, as four of the participants described experiences which relayed a sense of trepidation at the prospect of developing romantic relationships.

Chrissie spoke about her justification for remaining single…..

"So I won't get hurt again. That's all. That, that somebody won't have the power to hurt me". (Chrissie, 128.13)

Here Chrissie is clear about protecting herself from the potential hurt a romantic relationship may bring about. This was something Sarah and Mia were also concerned about. Here they describe their dread about being rejected as a result of their brain injury.

"I thought I mightn't be good enough in that respect [ ]. I thought I would let someone in and then have the disappointment and the rejection of being told, you're not enough because of your brain injury, cause they can't handle it". (Sarah, 113.18)

"…I was worried that he, you know, he'd just be like nah, it's too much baggage, because it is, it is quite a lot of baggage". (Mia, 34.17)

These accounts succinctly convey real fears about being judged as 'unwanted' and subsequently rejected based on their brain injuries. Sarah's use of the words '*cause they can't handle it*' and Mia's metaphor of '*quite a lot of baggage'* imply they considered themselves as something to be coped with and reflect concerns about being perceived as a burden to others. Both accounts highlight the emotionally painful dread of being romantically rejected because of having a brain injury which are likely to be underpinned by concerns regarding stigma.

Sarah elaborated on why she would have found romantic rejection difficult to deal with.

"I think the rejection alone would have been devastating [ ]. Just the actual rejection itself, and then the rejection of being a person with a brain injury. I'd worked so hard to accept it myself. It took a long time, a lot of hours. I still struggle with it, now and again …erm...but [ ] a high percentage of me, 97 per cent of me accepts I have a brain injury". (Sarah, 117.4)

Sarah's language emphasises how important her self-acceptance is and suggests this could have been threatened or compromised as a result of being rejected by someone else because of her brain injury. Sarah's words suggest a rejection would have been devastating partly due to the purposeful efforts she has made towards achieving self-acceptance, although she is clear this is something she still struggles with at times. Sarah's tone of voice here is imploring underscoring how imperative maintaining self-acceptance is. On a deeper level a romantic rejection by someone else could mirror the initial self-rejection of the brain-injured self before acceptance was reached. Overall, this highlights the complexity of the interface where the personal meets the interpersonal and illustrates the psychological challenges brain injury survivors may face when contemplating developing romantic relationships. This also demonstrates the complex interactions between the current theme of *Fear* and the themes of *Acceptance* and *Investment in the Self.*

However, as Sarah and Mia explain, fear extended beyond concerns of being emotionally hurt and rejected because of having a brain injury.

"I was very, very scared. I was scared for someone to see me as vulnerable...when I had neurofatigue, erm, or when my speech goes, erm, or you know, when I have to rest. [ ] I felt that that was erm, in a romantic relationship, I felt that that was showing all my cards as such". (Sarah, 109.10)

"I didn't want to show him everything….like you know, strip myself bear as it were…….and for him to go woah, you know, if…..I think I almost had like a hierarchy of like things about me that were scary". (Mia, 131.18)

Here both Sarah and Mia are making references to their current brain injury symptoms. These accounts indicate their fear about being *seen* as brain-injured by a romantic partner. Sarah is explicit in her worry of someone else seeing her as vulnerable but her use of the metaphor "*showing all my cards"* indicates a feeling of vulnerability on her part. Mia also alluded to feeling vulnerable with the use of the metaphor "*strip myself bear*". Both descriptions give insight into the consternation Sarah and Mia felt about the prospect of feeling fully exposed in a relationship and how this evoked caution and hesitancy about being in that position.

Charlie expressed a significant level of unease about the reactions of others in relation to her brain injury.

"I think I, I felt…reluctant to start a relationship because of people not…. of a man not understanding…not being able to understand. I don't work, and that's one, been one of the <u>biggest</u> things for me, not being in paid work, paid employment, so, if someone didn't understand that because, there's absolutely nothing to see that, it's completely hidden, you know?". (Charlie, 31.1)

There is a clear sense here of Charlie being held back due to concerns about the consequences of her injury not being understood. Charlie's emphasis on the word *'biggest'* suggests this is the legacy of her injury that she has struggled with the most. Charlie's language reflects a fear of being unrelatable which conveys a sense of isolation. Overall, this seems like a deeply emotionally painful experience for Charlie.

The accounts here give an indication of the depth and the range of specific fears evoked in anticipation of forming new romantic relationships post injury. They highlight certain cognitive processes and behavioural reactions such as self-doubt, low-self-esteem and avoidance, all of which sound emotionally painful for the participants and demonstrate the struggle involved in moving forwards romantically. Elements in this theme link strongly to the previous theme of *Self-Preservation* as some of the accounts here highlight how protective the participants are of their post injury recovery. There is also a relationship with the theme *Concerns about Revealing a Brain-injured Self* as some of the participants expressed fears about being seen with their brain injury symptoms present by potential romantic partners.

Inner Conflict, Confusion & Uncertainty

This theme represents the overwhelming ambivalence that the prospect of forming new romantic relationships evoked in many of the participants and the subsequent doubt this cast over their decisions regarding which directions were best to take in terms of their brain-injured selves.

"I woke up at 3am one morning and I sat bolt upright and I went oh no. Like, I, I felt sick at the idea of being in a relationship. I felt absolutely sick at the idea". (Mia, 126.3)

Mia recalls how she felt when what she had initially perceived to be a casual sexual relationship seemed to be developing into something more serious. Mia's repetition of the word sick suggests she was physically fearful of letting someone in. But as Mia elaborates, the prospect of becoming involved with someone also evoked feelings and thoughts of self-doubt.

"……I was having this complete existential crisis about the fact that someone might actually like me". (Mia, 173.3)

Sarah also expressed self-doubt at becoming romantically involved with someone.

"Part of me was like, yes I'd be very happy being single if that's my choice, but then it was starting to be no, I'm not happy, I think I need to, try again, but I was feeling oh, well what [ ] can I bring?….you know…..I'm not working, I have this brain injury". (Sarah, 107.1)

Sarah highlights the conflict she felt between remaining single or being in a relationship, but the prospect of becoming involved with someone clearly caused her to evaluate herself in the context of being a romantic partner with a brain injury.

"To me relationships, romantic relationships, I didn't have a template, and I was concerned about that, so it began, then the fear started to come in, it's just like, I, I don't know if I want to bring that into my life". (Sarah, 104.17)

Sarah is explicit about feeling frightened at the prospect of entering a romantic relationship. Her uncertainty about this is also clear here and suggests her dilemma is about balancing her desire to look after herself with the desire to have a romantic relationship.

For Charlie, confusion and uncertainty centred around past personal decisions resulting in unexplored romantic opportunities

“I know that there has been times that I have got a little further when I haven’t felt attracted to them but I think, I perhaps take it too seriously that…. why not? Why couldn’t I just try with someone? Why couldn’t I just take it further? Why couldn’t I just have a date with someone or…?”. (Charlie, 62.10)

Charlie’s recollections lead to a self- interrogation and her use of questioning suggests regret and frustration at herself. There is also a sadness conveyed in this account, and a sense of grief and mourning for missed opportunities lost in time.

“I don’t know what I want, that’s the thing and I…but all the time I’m not doing this, I’ve got no way of knowing…. what it is that I do want”. (Chrissie, 77.6)

Chrissie expresses uncertainty and confusion in relation to a potential romantic opportunity. This description suggests she feels stuck, perhaps paralysed by indecision. Her words convey she feels conflicted, because meeting someone she is attracted to has evoked fear and reservations about developing a relationship.

“…it’s an odd one this case it…. I mean this, this could be the most important relationship I’ve ever had in my life, or it could be a big, fat dud”. (Chrissie, 78.9)

Chrissie emphasises her uncertainty of not knowing how this potential relationship may turn out. She elaborates on this further.

“…this is what confuses me about relationships now because, what it feels like I’ve lost is that ability to take a risk, that ability to, to trust in the universe a bit and think…..yeah

they might be alright for me, [ ], they might be a mistake, but you're not gonna get it right first time, there's gonna be plenty of duffs". (Chrissie, 55.1)

This is a powerful statement as it conveys a strong sense of Chrissie emerging from her brain injury as more vulnerable and cautious and subsequently more risk averse towards developing romantic relationships. On a deeper level, the vulnerability, risks and uncertainty brought about by surviving a brain injury seem to be mirrored and magnified by the prospect of entering a romantic relationship.

The fact that all the participants expressed desire to be in a romantic relationship, whilst feeling deeply conflicted about it happening is indicative of just one of the many dilemmas they are faced with. Many of the excerpts convey they are feeling held back with the sense that this was related to becoming more vulnerable, relinquishing control and entering the unknown. As such the prospect of entering a relationship was intimidating and overwhelming especially after experiencing and recovering from a brain injury. It is notable that this theme is strongly related to the two previous themes of *Fear* and *Self-Preservation* as well as to *Vulnerability* and *Safety.*

Feeling Worthless & Undesirable

This theme emerged as an indication of complex feelings relating to low self-worth and, or negative evaluations of the self, or multiple selves after their brain injury. Viewing the self in a negative light as a result of comparisons with the pre-injured self and non-brain-injured others is well documented in brain injury literature. Five participants spoke about experiencing low self-esteem and negative self-concept post brain injury.

"I think I must have thought more of myself before…then maybe I did afterwards". (Ruth, 16.13)

Ruth contemplates the impact her brain injury has had on her self-concept indicating she considers it to be more negative post injury. This negative evaluation of the self was something Charlie also expressed.

"It's been massive, how I've felt about myself. [ ] Low confidence, low self-esteem, low self-worth…all them... You know so that's not going to make me feel good about myself. [ ]. I've not felt good enough for anyone else. You know, the kind of person that I wanted, you know, I've looked for, I felt wouldn't want me, because I don't work"
(Charlie, 67.6)

Charlie describes how her low self-esteem and negative self-concept led her to believe she was not good enough for others. Charlie's tone of voice becomes strained at this point suggesting viewing herself as undesirable by others is emotionally painful.

Interestingly for Mia, low self-esteem and negative self-concept persisted despite becoming romantically involved with someone.

"I couldn't work out why he wanted to be with me. [ ]. And I think my self-esteem was so low [ ] …because you know I didn't, I didn't particularly like you know, I didn't like the fact that I, I felt disabled. I didn't like the fact that you know…. I did get irritable, I didn't have much patience, I didn't like any of that...I think I couldn't, I couldn't see the good in me, as it were". (Mia, 104.13)

Mia's language indicates developing a romantic relationship invoked internal conflict as her negative self-appraisal was now being confronted and challenged by someone else regarding her in a positive light. This struggle is highlighted by her repetition of the word 'couldn't' and listing what she considers to be her undesirable qualities suggests they were deeply internalised.

However, for two of the participants, negative self-appraisal brought about by the brain injury went beyond internal reflections and concerns and had a direct impact on their decision-making process and behaviour when it came to pursuing romantic opportunities.

“Since the brain injury the one thing that I thought stopped me, prevented me was low self-esteem, low self-worth, low self-confidence”. (Charlie, 44.11)

“When someone was actually expressing an interest and seemed like a nice person, I ran a mile…. cause I don’t know…...deep down I thought maybe I didn’t deserve it, or [ ] they would find out that I was damaged in some way”. (Sarah, 54.9)

These extracts clearly demonstrate how Charlie and Sarah were held back from exploring romantic opportunities by their low self-worth. Sarah’s words indicate she felt unworthy of romantic attention and imply she was afraid of others learning of her brain injury and seeing and judging her as “damaged”.

Low self-worth also extended to concerns about failing to meet the expectations of potential romantic partners.

“I have someone in mind [ ] I think for certain that they would have to be confident, and self-assured [ ] you know, so…if I’m not so confident… [ ] why would someone confident want someone who isn’t confident?”. (Charlie, 68.11)

Here Charlie is describing the kind of romantic partner she would like to be with. Charlie is clear she considers her lack of confidence to be an undesirable quality. Charlie’s language indicates an imagined rejection, which on a deeper level may represent a rejection of herself as she has struggled to accept herself as brain injured.

Sarah’s concerns about the expectations of others were more practical.

“I wouldn’t be able to do all the things that maybe are expected in a relationship….in terms of social activities…. which I am very sociable, but at the same time I need to rest, I’d need to manage that, I need to rest before and after the frequency of social interaction”. (Sarah, 113.9)

Sarah’s focus on the everyday type of social expectations partners may have of one another indicate she considers these shared activities to be an integral part of being a couple. Sarah’s concern about not being able to meet these expectations due to the limitations of her brain injury is clear and may feed into her low opinion of herself. Sarah’s description of herself as ‘very sociable’ suggests a disparity between her desire to be social and her ability which could indicate frustration. The types of concerns Charlie and Sarah have described here may also contribute to feeling different to and separate from others and as such relate to the earlier theme of *Feeling Disconnected.*

However, low self-esteem and negative self-concept did not seem to be fixed as three of the participants went on to describe an improvement in how they viewed themselves suggesting post injury self-concept is fluid and subject to change. As such this ties in with the theme of *Making sense of a brain-injured self.*

“I do feel like I’ve become more positive about myself”. (Ruth, 56.11)

Ruth reflects on what she thinks has contributed to this change.

"I do volunteering now because I don't do paid work anymore…[ ] and I'm working in great shops with great people…[ ] I feel…I feel that's kind of made me…(sighs) I don't know if it's more confident…or… [ ] yeah I think that's been making me see myself and my life differently". (Ruth, 56.19).

Ruth's description highlights the important role vocational factors and social relationships can play in relation to post injury adjustment illustrating the positive effects enjoyable charity work and new friendships has had on her self-esteem, self-concept and outlook in general.

Mia describes what she found helpful in changing the way she viewed herself.

"I went you know, managed to get some sort of therapy for it and self-esteem sort of shot up slightly so I was able to be like, ok, I might be irritable, I might not have much patience BUT I'm actually quite a nice person (laughs)". (Mia, 105.6)

Sarah also singles out therapy along with other professional support in helping her change her low self-worth and negative self-concept.

"I've had some more therapy at this point and then, the, you know, I had the self-esteem work, which had helped, and then obviously got into the brain injury rehab". (Sarah, 57.9)

Mia and Sarah's accounts illustrate the important roles psychotherapy and rehabilitation can play post injury in helping brain injury survivors move towards establishing a more positive self-concept and increased self-esteem.

Low self-esteem has been found to exist prominently in the female brain injury population. The mechanisms and the implications of these findings will be addressed in the Discussion. Interestingly there was a notable absence of concerns regarding physical attractiveness. Perhaps this is because the brain injury largely did not affect physical appearance. Instead, low self-esteem was linked to not feeling good enough because of their brain injury, and like the brain injury, these feelings were private and hidden. At times the presence of a negative self-concept prevented some of the participants from exploring romantic opportunities. However, some participants expressed an improvement in how they viewed themselves suggesting negative self-concept and low-self-esteem is neither or fixed or determined by the presence of brain injury.

Self-Preservation, Fear, Inner Conflict, Confusion and Uncertainty and *Feeling Worthless and Undesirable* have all at times acted as barriers to forming new romantic relationships post injury. It seems important for the participants to maintain their post injury recovery which for some is considered as fragile and as such needs protecting from the instability a potential rejection or romantic relationship may bring. The prospect of developing a romantic relationship evokes fear which could be about entering the unknown as well as intentionally opening the self up to being vulnerable. On a deeper level this could echo the path the participants have already trodden in recovering from their brain injuries and as such may explain their unease at becoming involved in relationships which they fear may replicate these emotionally painful experiences. Overall, these themes reflect the complexity which exists at the interface of where the personal meets the interpersonal. Together the shared accounts of the participants highlight the complicated and dynamic interplay between all the subordinate themes presented here which illustrates how incredibly difficult it is to adjust to the idea or reality of a romantic relationship irrespective of how strong a desire there may be to have one.

It is important to note that Bella is not represented in any of the themes under *Barriers to Forming Romantic Relationships* because she did not refer to anything that was holding her back romantically, and she began actively dating as soon as she could do so.

Superordinate Theme Four: Navigating a way forward

This theme brings together the various ways in which the participants are orientating themselves towards their future from their current positions whilst taking with them their experiences and learnings from their recent brain-injured past. Facets of this theme are *Weighing it all up: Uncertainties, Needs and Risk, Re-learning and Learning,* and *Safety.* Woven throughout each theme is the impact the brain injury has had on how they have got to where they are now, and what this means for their plans, hopes and wishes. In many ways this reflects the pervasive and enduring ways in which a brain injury affects the life course of survivors and the continued adaptions and adjustments that are still necessary long after the acute phase of recovery has ended. Collectively these themes highlight how significant life decisions such as those pertaining to romantic relationships prompted the participants to assess potential impacts both upon themselves as well as upon their injuries and recoveries.

Weighing it all up: Uncertainties, Needs and Risk

This theme explores how the participants weigh up what is important in relation to their love lives as well as their lives in general, and illustrates the differences having a brain injury makes when contemplating relationship options. Having lived through near death experiences is likely to give rise to components related to generic ‘survivor’ identity whereby notions of safety are shattered thus making maintaining stability crucial, which is something most of the participants were striving for. The weight that considerations regarding romantic relationships carried for the participants demonstrates how significant and distressing these types of decisions can be for survivors and illustrates how brain injuries and the recovered self are priorities when contemplating present and future opportunities.

Remaining single is something both Ruth and Chrissie considered but motivations for doing so were different. Ruth had recently emerged from an unhealthy romantic relationship where upon reflection she realised she had been taken advantage of. Since medically retiring from her full-time job to which she had returned after sustaining her injury, she was dividing her time between volunteering roles which time wise were akin to working full time hours but bought her an immense sense of enjoyment and purpose.

“I’m really happy living on my own and being able to do my own thing [ ] whenever I want and…or if…if you start living with someone again that all changes..” (Ruth, 47.1)

Whilst Ruth sounds impassioned and invigorated when she is talking indicating genuine happiness regarding the freedom she now has, her slight pause and hesitation mid-sentence reflects uncertainty as to how her current happiness may be affected by future romantic relationships thus indicating a conflict between balancing the fulfilment she currently enjoys with the compromises she feels a relationship would inevitably bring.

“I’d rather be able to get comfortable with the idea of, of being on my own for the rest of my life…..it’s because I can…..whether that’s something too control freaky about it”. (Chrissie, 97.2)

Chrissie’s language here conveys a sense that to commit to being alone is a struggle which suggests she may be considering remaining by herself because she believes it would be better for her as opposed to something she genuinely desires. Chrissie’s reference to control allude to her belief that relationships come with risk and pose a risk to stability. By choosing to be by herself enables an ensured sense of safety and stability. It is choosing the known over the unknown.

"I could quite comfortably settle into a life of one-night stands and no real formative attachments to anyone, which might actually be healthier for me in the long run. Is it right? I mean there's no wrong and right with anything, but, that would serve my purposes". (Chrissie, 16.20)

The way in which Chrissie positions herself in relation to having exclusively sexual relationships suggests a preference to separate the emotional elements of relationships from the physical ones. Chrissie's questioning reflects her uncertainty here, but her language conveys a sense of weighing up what would be best for her overall. On a deeper level this may be about protecting herself from emotional pain and keeping herself safe by remaining single.

Mia also expressed concerns as to her wellbeing in the context of relationships, although unlike Chrissie, it was being without her current relationship that caused her consternation, yet the underlying concerns were the same; the need to protect oneself and maintain a sense of stability and safety.

"…I almost don't want to let, let that sort of mutual growth go...because...what if that sort of, you know if I'm up here now and I started off down here……what's to say that you know…if, if we weren't together anymore, I wouldn't then drop back down to here". (Mia, 86.7)

Mia's language conveys she is mindful of the role her relationship has played in her recovery, but her questioning here suggests concerns she considers her recovery to be dependent upon the relationship itself. Mia's words suggest a fear that the ending of this relationship may cause regression in terms of her recovery, indicating she considers her recovery to be fragile and easily threatened. This highlights how protective Mia perceives her relationship to be as well as indicating her recovery is something to be protected. Overtime the brain injury, her recovery and her relationship have become enmeshed, and now it seems almost impossible to consider one without considering the other.

Three of the participants reflected on their current motivations in relation to developing romantic relationships.

"… it has (laughs) made me less bothered about blokes". (Ruth, 58.6).

"looking after myself seems more important now". (Ruth, 60.8)

Ruth expands on this change in her motivation to be with someone else.

"…it's become lower in the list…..yeah… I've got a, a, I've got a new list now….and there's some things I do and the, the friends I have and the things I do at the shop and the school, the friends I have because of it and the things I do with them….erm……they're kind of…..higher on the list". (Ruth, 59.19)

"I do like to feel like I'm needed [ ] and I like doing things for people [ ] but yeah I've I've been able to do that [ ] just, just for friends, you know, it doesn't have to be just for a bloke". (Ruth, 45.4)

The shop and the school Ruth refer to relate to her volunteering roles. It is clear these roles bring Ruth a great sense of purpose and fulfilment and have yielded a new group of friends. Ruth's accounts indicate how all kinds of relationships can bring about a sense of joy and wellbeing, and they do not necessarily have to be romantic in nature for them to be meaningful and bring about a sense of purpose.

Chrissie reflects on the shift in her motivation towards relationships since sustaining her brain injury.

“..that’s one of the things that drives you towards finding a relationship isn’t it? It’s like I want someone to look after me, I want someone to share my life with, I want someone to take the, the weight off my shoulders now and again and to be two of you pulling on a rope and stuff….I don’t feel that”. (Chrissie, 139.16)

Conversely Charlie remains motivated towards finding a romantic relationship as for her they represent a benchmark of normality. Whilst this was something expressed by many of the participants, it perhaps held even more importance to Charlie in terms of social identity as she had never been able to be in paid employment since sustaining her injury, and this was something she was painfully aware of as marking her out as different from others. Being in a romantic relationship would be an external indication of sameness.

“I want someone else to show me a different life… [ ]..something else to take me away from it”. (Charlie, 82.8)

Charlie’s language here conveys a deep longing to leave her brain injury behind and a sense that she would like to escape her life through someone else. This feels quite evocative to me as it implies a deep unhappiness with her life as it is. Charlie was only 17 years old when she sustained her injury, and it has had a profound impact upon her life. In addition to not ever being in paid employment, she does not live independently and although fully mobile, often needs assistance when travelling. In wishing for someone for someone to take her away from her life, Charlie implies she is neither accepting of her injury or the associated consequences.

Another consideration for two of the participants when weighing up their romantic futures was the issue of cohabitation and what the consequences would be of living with or without a romantic partner. However, these were not simply decisions regarding weighing up the pros and cons but instead were couched in uncertainty and inner conflict.

"I don't like to think of me spending the rest of my life on me own but, [ ]…I do feel like (laughs) I'd never be able to live with someone again". (Ruth, 46.8)

The ambivalence Ruth feels in relation to her romantic future is clear here and represents an inner conflict regarding competing desires. The way Ruth laughs here indicates bemusement as she realises the paradox she is halfway through expressing. In many ways it seems this pithy contradiction of competing desires represents the experiences of many of the participants in this particular theme. On the one hand there is an innate desire for romantic connection, but it is constantly competing with the need for certainty, familiarity, stability and safety.

Living with a partner is also something Sarah expressed uncertainty about.

"I've been on my own a long time. I've lived on my own a long time. I'm used to a certain amount of space and erm, you know, I'm not sure any, you know [ ] I think I would find it hard to live with anyone again". (Sarah, 99.13)

Sarah has been with her romantic partner for two and a half years. Here she explains why the issue of cohabitation is far from straight forward for someone in her position.

“If he moved into my house, I, we’d lose of lot of legacy benefits, so you know, there’s that to consider, you know, that’s what a brain injury’s brought to our relationship as well, will I ever be able to move in with him?”. (Sarah, 93.17)

“I realise, well hold on a minute, you know yes, it’s lovely being in love but it doesn’t conquer all and I’m not going to give up certain safety nets for it. I have a council house which I waited a very long time to get [ ], I wouldn’t give up this house for anybody”. (Sarah, 94.5)

Sarah clearly articulates what she would lose out on by moving in with her partner whilst also illustrating the restrictions this imposes on their relationship. Sarah’s language is emphatic in relation to not losing the practical and financial support she currently receives which conveys her determination to maintain it and indicates how important these things are to her in the face of an uncertain future. Here Sarah highlights how these circumstances are unique to certain groups of people with disabilities thus bringing to light a difficult and harsh reality likely to be experienced by many people in similar positions who are forced to choose between what should be a normal relationship trajectory or maintaining financial support and stability. Again, this indicates the enormity behind decisions regarding romantic relationships illustrating how stressful they can be as well as the losses they involve which ironically run parallel to being with someone, namely the loss of not being able to live together despite a mutual desire to do so.

“someone without a brain injury…isn’t necessarily not gonna be working again, [ ] people can move in with each other and people [ ] with certain disabilities can’t because they, they have to think about this sort of thing”. (Sarah, 95.11)

Finally, Bella was the only participant to talk about the prospect of having children post brain injury.

"I think there's so many kids in the world that maybe I can just be someone's step mum (laughs), I think that that might just work (laughs) better. Particularly with a brain injury and noise and kids, the kids things an issue I think, for for meeee...at my age and all that sort of thing but I'm not really that arsed". (Bella, 16.14)

The accounts in this theme highlight the additional considerations brain injury survivors have to make when starting, developing or ending romantic relationships. Many of the participants factored in how their brain injury and recovery may be affected by changes to their romantic status highlighting how much they valued their wellbeing and recovery. Decisions were about mitigating risk and maintaining stability and safety which is understandable given the traumatic circumstances under which they had all sustained their injuries. There were no bold statements of being happy every after with someone or having blind faith in love. Perhaps then the brain injury had shattered assumptions regarding the certainties of relationships, and these too were now viewed as fragile and transient in nature.

Re-learning and learning

All the participants experienced initial objective negative functional impairments as a result of their injuries which included not being able to walk or talk, as well as experienced enduring objective negative life changes which included impaired mobility, loss of partial sight, neurofatigue and anxiety as well as a loss of future and expected life directions. This inevitably resulted in periods of re-learning and learning as they adjusted to living life with a brain injury. Interestingly this process was also spoken about in the context of developing romantic relationships although for one participant it was in relation to continued recovery.

Firstly, three of the participants spoke about how they felt they had had to re-learn about men and relationships after sustaining their injuries.

"...it felt like I had to learn how to love or learn how to open up myself to love or at least to an intimate relationship. And it almost brought back a lot of me having to like re-learn how to walk, how to talk, how to do all of these things…even though they were very physical and this is very emotional but it felt like, you know...sort of difficult in that manner". (Mia, 139.19)

Mia expresses how her experience of re-learning how to be in a relationship evoked memories of her physical recovery. These comparisons indicate that developing a romantic relationship for the first time as a brain injury survivor represented a period of significant adjustment, which, like recovering from the brain injury, was also challenging, albeit in different ways. Mia expands on what this process was like in the context of her romantic relationship.

"I remember how frustrated I was at not being able to talk…and...I remember how frustrated I was having to do these tiny little baby steps with him and show him, like show Aiden these tiny little bits of me and there was sort of real parallels between sort of physical recovery and this emotional sort of recovery into a relationship. And you know it was just really frustrated, frustrated and drained". (Mia, 140.8)

This process of re-learning romantically was similarly evocative for Ruth.

"when I was in hospital and everything, I did have to learn to walk and talk again…..and they did….you know, the doctor did say you, you'll be growing up again, you'll be, you'll be learning things again and so I think I have been learning erm…the relationship, romance whatever thing again". (Ruth, 38.16)

This led Ruth to make comparisons with past experiences from when she was much younger, before the brain injury.

"…it's like when I was a kid before I had my first boyfriend, I I feel like I've gone through all that again differently to how I did before the accident….[ ] I feel like I've had to go through this kind of process and to teach myself [ ] what to deal with, how to be, with men and myself". (Ruth, 39.10)

Ruth's descriptions are a reminder of how alienating and isolating it can be to survive a near death experience and then embark on a journey of recovery alone without a significant partner or family for support or continuity. Ruth's references to not knowing, re-learning and teaching herself indicate a sense of being lost and alone during what must have been a distressing experience. Ruth's language also suggests that for her, developing new romantic relationships for the first time as a brain injury survivor represented a significant period of adjustment.

For Chrissie the process of re-learning in the context of men and relationships was a more conscious decision.

"I've literally taken myself back to the point when I was 15, and that's how I felt about…. what a boyfriend would be, cause that's the only time that it started to make…that, that it made sense to me, cause everything subsequent to that has, has been a nightmare" (Chrissie, 51.8)

Another facet of this theme related to managing the brain injury and related symptoms in the context of being a couple. All the participants had learnt how to manage their injuries in the absence of a significant other. Becoming part of a couple post injury brought about a process of re-learning how to manage the brain injury as they now had to manage the expectations of significant others who were also impacted by the enduring life changing consequences the injury had brought about.

“so one thing going out for a date for dinner, and then, you know, going home and then going to sleep and stuff but [ ]..when we started spending days together, you know, he would, you know, well, well…..do you wanna do this? And then I’m thinking, oh god, we’re doing this later, I can’t do both”. (Sarah, 83.10)

Sarah had learnt how to manage her neurofatigue effectively by herself prior to being in a relationship, but her account about the formative stages of dating suggests it was something she had to re-learn in response to the demands of being with someone else. Her words towards the end convey a sense of panic at not being able to meet the expectations of her partner.

“the neurofatigue’s been a big thing, and talking about it was a big thing…erm…and just setting out boundaries [ ] in terms of what…we...expect of each other”. (Sarah, 89.1)

Sarah indicates this has been a learning curve for both her and her partner and that it is something they have navigated together as a couple. Sarah’s repetition of the word ‘big’ indicates her neurofatigue has been a significant issue for her in her relationship. In addition to this her language conveys that *talking* about her neurofatigue has also been an important part of their communication as a couple, as well as highlighting this was extremely difficult for her to address.

Mia also spoke about learning that has taken place within her relationship.

"…anxiety for instance, I think they, Aiden and I are still trying to navigate our way round that and try to find out, you know, he's trying to work out what helps me and I'm trying to work out what I need from him and what he needs from me in relation to that. Like after I've had a big old panic does he need time? Do I need time? I, you know, there are still bits that we're still trying to navigate [ ] our way round [ ] but we try and navigate those together…but sometimes it feels like the after effects of the brain injury can [ ] drive a bit of a wedge between us because…he doesn't understand why I'm anxious". (Mia, 110.6)

The language Mia uses suggests her and her partner are on a joint journey of discovery together. Her use of the word 'still' implies it is current, and her questioning suggests there are still things they are unsure of, again emphasising this is a continuous joint process of learning about and responding to what the brain injury brings up. Mia also indicates that dealing with the effects of a brain injury as a couple is not without its difficulties. Nevertheless, overall, Mia seems to regard this aspect of their relationship in a positive light.

"….he's had to learn a lot with me and I've had to learn a lot with him and I think there's been a mass…..like sort of mutual growth". (Mia, 86.4)

Sarah's and Mia's descriptions suggest they, as survivors, were relearning about their brain injury in response to the challenges brought about by being part of a couple which signifies how becoming involved in new romantic relationships post injury represents a period of adjustment. Their partners were learning about the brain injury and its effects for the first time, and together they were learning how to respond to everything as a couple. Their accounts convey a sense that the brain injury existed in the space in-between themselves and their partners which was novel to both parties and as such became part of the process of getting to know one another. These accounts recall the concept of a ‘shared disability’ in the way the brain injury impacts both partners, and both play a role in managing it.

Conversely, Ruth’s learning stemmed from a different kind of relationship experience post injury.

“I let him pick me up and drop me many times…erm…and yeah he could, he could be really nasty too sometimes [ ]. I mean… usually… what happened was after, after every time he dumped me, after a couple of weeks he’d tr’ try and pick me up again, but after the last time he dumped me in August last year, he, he hasn’t tried to pick me up again, which has been good because it’s given me a lot of time to really think about it and erm…you know…think …what it was, what it was doing to me…erm…and yeah…it, it has made me feel really differently about it all and think I, I won’t let that happen again and be like that again”. (Ruth, 36. 19)

For Ruth, being treated like this was something she had attributed to her brain injury which again highlights how vulnerable some survivors can be post injury. It is also a reminder that not all relationships are healthy or supportive. Ruth’s tone was reflective here as she recounted the patterns of her past relationship, and she seems to realise as she is speaking that her time alone has been instrumental in yet another process of re-learning regarding looking after and prioritising herself, a realisation she seems to value highly.

“it’s made me tougher….and it would have to be on my terms if anything happened with anyone again”. (Ruth, 44.4)

Finally for Bella her experiences of re-learning and learning were in relation to her recovery.

“I can’t see and I’ve had to re-learn to, to see [ ] soooo….those kind of things, cause it’s linked to your brain and your eyes, so I had to re-learn how to get those things to work, and [ ], when I get overwhelmed or if I get too many, too many people or things going in your brain or your eyes, it doesn’t work, so again that’s quite, that’s quite hindering and, and stressful…”. (Bella, 35.12)

Here Bella expands on a technique she was taught whilst in hospital.

“you have to use mindfulness techniques and chill out and trying to do that to function properly, otherwise you lose your eyesight and you have to chill out and you know, and do my fifteen minutes mindfulness to calm it all down, and then I, I can get through my day basically so, I do that three times a day to try to….to……function, to be able to function normally”. (Bella, 36.2)

Overall, these extracts portray that for brain injury survivors relearning and learning is a dynamic and constant process which contributes to their wellbeing. The accounts of re-learning and learning in terms of partners and relationships suggest that entering, or preparing to enter, into a romantic relationship is a significant period of emotional regulation and readjustment for brain injury survivors. The fact the participants are dealing with neurofatigue as a result of their hidden disability makes this process for more difficult, challenging and stressful.

Safety

The circumstances in which all the participants in this study sustained their injuries were as a result of near-death experiences. Therefore, they have all lived through extreme, traumatic life events which are known to have the potential to shatter our every day, taken for granted assumptions about ourselves, the world, and others. Psychological trauma has been found to be associated with all types of ABI (see Literature Review). Perhaps then unsurprisingly many of the participants spoke about a sense of safety and described why this was so important to them in their post injury lives.

Mia sustained her brain injury as a result of intimate partner violence (IPV) when she was a teenager. Now, aged 25, she reflects on what her current partner of five years has come to mean to her.

"I worry about my ability to cope with life without having Aiden as a safety net, 'cause he is my safety net". (Mia, 86.19)

It is clear Mia has concerns about what the absence of this relationship may mean for her which indicates a sense of vulnerability. Mia's use of the metaphor 'safety net' is powerful and implies her partner and their relationship hold protective properties for her which she fears being without. This highlights the dual nature of things we hold dear, whilst we may value and treasure them, we also live with the knowledge of how transient they are. It seems this is even more pertinent for Mia which is perhaps reflective of the trauma she has lived through.

"I feel like there's more, it's almost like more risk associated with not having him". (Mia, 88.16)

Mia conveys a strong sense that being without this relationship would leave her feeling exposed which again conveys a strong sense of vulnerability. Mia's reference to risk highlights how important it is for her to maintain a sense of safety, stability and certainty. Clearly for Mia this romantic relationship has become an important aspect of her post injury life.

Sarah sustained her injury whilst on holiday riding pillion on a motorbike when she was involved in a road traffic accident. Her last-minute decision to wear a helmet which was prompted by someone else doing so is something she cites as saving her life. Her near death experience has left an indelible mark and as such maintaining a sense of safety became an important part of her post injury life.

“I’d met friends, and they were so understanding of everything, erm, and, you know, they knew I was having brain injury [ ] rehab[ ], they still included me, you know, and if I couldn’t come out, that was ok, you know, I’d see them next time, you know, erm, when my thyroid went, they were so supportive, you know, erm, erm, in lots of different ways, you know, and everything felt safe…and fun. And…so that was great for a while…but part of, you know, part of me didn’t want to leave that bubble…because I had the rehab going on, so I felt safe there”. (Sarah, 102.11).

Sarah’s description of this time in her life post injury suggests feeling supported, accepted and understood both socially and professionally facilitated a sense of safety. The protective and stabilising benefits Sarah gleaned from these relationships are clear here thus demonstrating how instrumental healing relationships can be for brain injury survivors. Sarah felt her basic needs were being met which enabled her to live her life more fully and experience joy and fun. Sarah’s repetition of the word safe emphasises how important this was to her. Her use of the metaphor of a ‘bubble’ suggests she felt protected, but also implies there was a sense of knowing this period was transient and fragile and not taken for granted.

Sarah went on to describe how she sought to maintain a sense of safety when she was single.

"I've read a lot around weight and stuff and erm…someone said, you know, it makes you feel invisible, and that suited me, that actually suited me [ ]. Because I…it was keeping me safe. It meant erm I didn't have to deal with potential suitors". (Sarah, 122.13)

This powerful account from Sarah expresses how she did not want to be seen, and like her injury she wanted to remain hidden. Her description highlights the paradox that becoming bigger and taking up more space in the world is exactly what made her disappear and seem invisible to others. By associating her sense of safety with the purposeful absence of romantic and sexual attention, Sarah illustrates how, at times, these types of attention were perceived to be a threat to her sense of self and sense of safety.

Here Sarah and Mia explain why safety was important to them.

"If I feel safe, I'm more mentally healthy, erm, maybe because of experiences growing up, but also the brain injury, I've felt unsafe, and I didn't have what I was meant to have [ ] in a way, in terms of care [ ]. So now safety, mentally and physically, and emotionally, was paramount to me". (Sarah, 127.16)

"having something which I, I know or at least perceive to be normal, stable, happy, content, ok, everything is [ ] safe, that when things don't feel safe I feel more able to deal with them than I was able". (Mia, 83.10)

Sarah's language suggests maintaining a sense of safety is good for her overall well-being and as such it is a way of looking after herself whereas Mia's description conveys a sense that feeling safe enables her to function more effectively.

Chrissie sustained her injury as the result of a fall, and if she had not have been found by someone immediately it is highly likely she would have died. Here Chrissie reflects on how her attitude towards relationships has changed as a result of her brain injury.

"I was a lot more playful before I think...you know…it's thinking about consequences…and serious things…" (Chrissie, 106.14)

This different approach suggests Chrissie has re-developed her personal theory of reality and her post-injured self is much more mindful of risk and potential threat to self.

"the safety is, when you're, when you're a loner and you like being a loner, your safety is being alone …..isn't it……it's…it's……that's your safety, that's your…..and untethering from that and leaving that to be in a relationship again is……terrifying (whispers)….really terrifying……so.. but we'll see………"
143.19

The fear that Chrissie describes here is made potent with her repetition of the word 'terrifying' which is whispered the second time. Chrissie also repeats the word 'safety' implying this is highly significant to her post injury life. The way Chrissie refers to safety as something to untether from and leave behind in order to be in a relationship suggests she considers safety and relationships to be mutually exclusive. Her language suggests trepidation about leaving the familiar and opening up to the uncertainty that a relationship would bring. However, her last words imply she remains open minded yet cautious about developing a relationship in the future.

For Ruth and Bella their concerns about safety related to more physical and practical aspects.

"I think I felt odd on my own then [ ]. I mean I don't now. But erm, I did earlier, a few years ago and yeah I felt, I felt it wasn't good to be on my own because of what happened and how I was…..I felt like I really needed someone for those reasons…" (Ruth, 21.10)

Ruth sustained her injury from road traffic accident and was not expected survive the first night. Here, Ruth is referring to the period of time after initially after sustaining her TBI and comparing this to how she feels now, ten years on. Her reflective language highlights her change in need and implies that she no longer requires a relationship in order to feel safe.

For Bella, safety was about being able to keep herself safe when going out on dates.

"Those skills haven't changed and I'm able to know that I'm in safe situations or, in bad situations I know that, I've gotta get out of here (laughs) right! How am I gonna get out of here (laughs) and not have a drink with this man (laughs)". (Bella, 61.40)

All the participants in this theme are clear that maintaining a sense of safety post injury is crucial in their lives as brain injury survivors, yet how they cultivate and manage this sense of safety varies. For most of the participants a sense of safety relates to relationships, but these associations are complex; relationships with others either provide a sense of safety or pose a threat to a sense of safety. As such this theme is strongly linked to *Self-Preservation* and *Vulnerability*. Safety is considered alongside the concept of psychological trauma in the Discussion.

In closing, four superordinate themes encapsulate the various ways in which these six female brain injury survivors have made sense of their romantic experiences post injury. The impact of the brain injury upon the self is captured in the first theme of ***A Fragile Self.*** The felt sense of difference from others the participants reported is explored in

Searching for Connection along with how they were affected by and responded to social expectation and stigma in relation to developing romantic relationships as a brain injury survivor. ***Barriers to Forming Romantic Relationships*** highlights various aspects which have at times prevented some of the participants from becoming involved in romantic relationships. ***Navigating a Way Forward*** provides insight into how the participants orientate themselves towards their romantic futures whilst factoring in the presence of their brain injuries. As mentioned throughout this chapter, there are connections and overlaps between some of the subordinate themes which will be looked at further in the Discussion.

Chapter 4: Discussion

Relationships have been cited as an ‘important vehicle for change’ in relation to positive outcomes after sustaining a brain injury (Bowen, Yeates & Palmer, 2010. p.1). However, brain injuries can often have deleterious impacts upon existing romantic relationships (Wood & Yurdakul, 1997; Oddy, 2001; Kreutzer, Marwitz, Hsu, Williams & Riddick, 2007; Burridge, Williams, Yates, Harris & Ward, 2007). Despite findings suggesting traumatic brain injury survivors experience difficulties forming new friendships (Salas, Casassus, Rowlands, Pimm & Flanagan, 2016), no research to date had exclusively focused on the development of new romantic relationships post injury. Therefore, the current study sought to address this gap in the literature by aiming to answer the following question,

How do female brain injury survivors experience forming new romantic relationships post injury?

This chapter highlights the main findings that emerged from the data analysis which was carried out by implementing interpretative phenomenological analysis (Smith et al, 2009). These findings regarding the romantic experiences of female brain injury survivors are discussed in relation to the existing literature enabling potential connections and differences to be explored. The main themes in this current study have been considered in the context of the biopsychosocial framework (Englel, 1977) which conceptualises adjustment across three domains which Gracey & Ownsworth (2014) describe as; (i) neuropathology and effects on function, (ii) social and environmental context and (iii) personal appraisals and reactions. This is consistent with the ontological and epistemological positions of this current study and its application is used to inform formulations when working in health settings with brain injury survivors (Yates, 2003; Suls & Rothman, 2004). A critique of the present study is also provided which explores its limitations and drawbacks. Recommendations for further research are suggested and the implications this current study holds for counselling psychology are considered. Researcher reflexivity is also revisited given the study has now drawn to a close.

Overview of Findings

The aim of this research was to explore and understand the meaning female brain injury survivors ascribe to new romantic experiences encountered post brain injury. The semi-structured interviews provided space for participants to reflect upon and make sense of their experiences. The analysis revealed the prospect or reality of developing a romantic relationship was characterised by cognitive appraisals of the brain-injured self, concerns regarding perceived stigma and some psychological adjustment. For some of the participants, experiences of re-learning about romantic relationships mirrored their journey of recovery and re-learning how to walk and talk.

The participants reflected on their sense of self after emerging from their brain injury with some describing a sense of vulnerability which they feared would increase by becoming involved with someone else. Unfortunately, two participants disclosed unhealthy relationships (one was abusive) which the participants made sense of due to a changed sense of self as a result of their brain injury. Making sense of the self was portrayed as a continuous journey of self-discovery of getting to know this new or different or sometimes evolving self. All the participants spoke about how much they invested in their recovery. Initially post injury there was a focus on physical and practical recovery but after time this gave way to working towards psychological and emotional recovery. Some of the participants indicated this recovery was fragile and felt it could be threatened by developing a romantic relationship. The role acceptance played in life post injury was discussed but was complex and multifaceted. Acceptance of the brain injury and its enduring effects was not automatically reached due to the passage of time but instead involved an active investment of the self. Adjusting to a brain-injured self brought about a sense of fragility for many of the participants which impacted romantic outlook as well as romantic interactions.

Most of the participants described feeling different from non-brain-injured others resulting in feelings of isolation and loneliness. Many harboured strong desires to be in romantic relationship as they felt it would improve self-esteem and make them appear ‘normal’ to others. Concerns about societal attitudes towards brain injury survivors meant at times some of the participants changed their public behaviour or discourse to keep their injury a secret. These same apprehensions together with the nature of brain injury often being a hidden disability meant the issue of disclosure was experienced as a dilemma.

Five of the participants spoke about how at certain times specific factors had held them back from pursuing romantic opportunities. Protecting themselves from emotional hurt as well as protecting their post injury recovery was important. Participants also described fear that developing a romantic relationship would increase vulnerability and bring about uncertainty. Many of the participants portrayed experiencing internal conflict as they struggled to reconcile their desire for a relationship with a sense of caution. Participants indicated low self-esteem and negative self-concept at times held them back from exploring romantic opportunities. Self-concept was not static as some of the participants reported an improvement in how they felt about and viewed themselves over time. Notably barriers towards developing romantic relationships were not permanent as five of the participants have experienced romantic involvement since sustaining their injuries.

Participants orientated themselves towards their romantic futures and considered what it may mean to either stay single or remain in current relationships as well as contemplated the impact their brain injuries may have upon cohabitation and having children. Future orientations seemed couched in uncertainty as the participants weighed up their needs and risks. Half of the participants reflected upon how re-learning about romantic relationships echoed the re-learning involved in their physical recovery post injury. Finally, some of the participants spoke about the importance of maintaining a sense of safety going forward, indicating the complicated relationship that safety has with social and romantic relationships. A lack of a sense of safety was associated with increased vulnerability whereas its presence was associated with increased self-efficacy.

All of the findings from the participant interviews were condensed into several different themes as displayed in the analysis chapter. Significant themes were organised across four superordinate themes which represented the overarching experiences of the subordinate themes: *A Fragile Self, Searching for Connection, Barriers to Forming Romantic Relationships* and *Navigating a Way Forward*. The fundamental findings which emerged from these themes are considered in detail below and placed within the context of extant brain injury literature.

Consideration of findings in the context of extant literature

The brain injury along with its enduring effects had a profound impact upon most of the participants in the current study as it gave way to new, different or unfamiliar aspects of the self. Experiencing a changed sense of self is common after sustaining a brain injury (Nochi, 1998; Howes, Benton & Edwards, 2005; Levack, Kayes & Fadyl, 2010; Carroll & Coetzer, 2011; Thomas, Levack & Taylor, 2014; Martin, Levack & Sinnott, 2015). Not surprisingly brain injury survivors have been found to engage in sense-making in the period following injury which can be understood as a process of adjustment as survivors come to terms with the differences their brain injuries have brought about (Nochi, 2000; Gelech & Desjardins, 2011; Levack, Kayes & Fadyl, 2010; Douglas, 2013; Seeto, Scruby & Greenhill, 2017). As life continued for the participants in the current study, the prospect or reality of developing a romantic relationship seemed to evoke another phase of adjustment whereby the brain-injured self was re-evaluated in the context of an intimate relationship, and relationships were evaluated in terms of what they might mean for the brain-injured self. Many of the participants emerged from their injuries as more cautious and risk averse which is understandable given the traumatic circumstances within which they were sustained. Romantic relationships became part of determining their place within the world but provoked uncertainty and distress as well as provided challenges and tension as the participants sought to balance their desires for romantic relationships in the face of perceived stigma with the need to take care of the brain-injured self and manage the potential threat they feared an intimate relationship may pose.

What was synonymous for all participants was the relationship they developed with their brain injury and recovery which began with an active and purposeful approach towards recuperation in the acute stage of recovery continuing into the chronic phase. For many of the participants this developed into a lifelong partnership where the brain injury was nurtured and given priority when considering important life decisions, particularly those regarding romantic relationships. The active role all the participants played in their recovery was captured under the theme of *Investment in the Self.* It is not unusual for brain injury survivors to be action orientated in terms of their recovery (Nochi, 2000; Chamberlain, 2005; Fadyl, Theadom, Channon & McPhearson, 2019) with some researchers suggesting it can relate to the reconstruction of the self-post injury (Levack, Kayes & Fadyle, 2010). For most of the participants in the current study, assuming a proactive approach towards their recovery facilitated the development of positive post injury narratives which were couched in affirmative action resulting in positive outcomes and improved functioning and quality of life. The subordinate themes of *Investment in the Self*, *Self-Preservation* and *Safety* capture how recovery had become an intrinsic, yet fragile part of the brain-injured self which was regarded as the product of active self-investment. This fragile nature of recovery was highlighted by the strong desires expressed by half of the participants to protect post injury improvements from the threat romantic relationships may pose and the potential instability they may bring. The importance participants attached to recovery and concerns regarding its threat may be the product of living with daily reminders of neuroplasticity and its benefits and as well as memories of initial fundamental impairments sustained at the point of injury. Having first-hand experience of how responsive brain injuries can be to active and sustained efforts may have contributed towards participants fearing the reverse could also be true. Perhaps progress related recovery attributed to the self leaves in its wake a legacy of concerns that human endeavours from others could be just as instrumental in its destruction. Therefore, the theme of *Self-preservation* could be understood in the context of threat appraisal (Folkman, 1984). In the current study desires to form new romantic relationships conflicted with a need to protect a vulnerable, brain-injured self. At times this tension made some participants wary of developing intimate and emotional closeness with others and as such they became avoidant of pursuing romantic opportunities. Riley (2004) found threat appraisals and subsequent avoidance were common in TBI survivors in relation to social situations and personal physical safety. This current study could be seen to add to these findings by illustrating threat appraisal and subsequent avoidance can also extend to the development of romantic relationships. The avoidance of and attempts to manage threat is closely linked to the theme of *Safety*. It may also be helpful to consider safety and self-preservation in the context of psychological trauma as all the participants described the events surrounding their injury as life threatening and all reported the presence of either PTSD, anxiety or depression which are considered as trauma related disorders when accompanied by traumatic experiences (Alosco, Supelana & Vasterlin, 2017). Self-preservation and the importance of safety could be the result of hypervigilance which is a common symptom of PTSD (APA, 2013). The function of self-preservation which served to protect the post-injured self may relate to and provide further support for previous research that relates the active role survivors play in their recovery to the reconstruction of the self in the aftermath of a brain injury (Levack, Kayes & Fadyle, 2010). In this same vein it is also useful to consider the findings of Gelech & Desjardins (2011) who reported that discontinuity caused by brain injuries posed a threat to survivor’s sense of self. Gelech & Desjardins (2011) suggested that maintaining a continued and stable inner sense of self following injury helped some participants avoid being overcome with chaos. Perhaps then for the participants in the current study self-preservation post injury serves a similar function in that reconstructing one’s world around recovery and related achievement helps stabilise self-identity. Recovery and improved functioning become familiar and constant providing a sense of continuity, thus suggesting self-preservation serves to maintain post injury order and help keeps participants from becoming overwhelmed. This may be particularly important for survivors who have sustained their injuries in traumatic circumstances, which was the case for all the participants in the current study, as this is likely to help to balance their emotional regulation system which has found to help those who have suffered psychological traumas and TBIs as the same parts of the brain are believed to be affected, namely the pre-frontal cortex and medial temporal lobe (Kühn & Galliant, 2012; Shenton et al, 2012). However, at times self-preservation came at the cost of developing intimate and potentially supportive romantic relationships. As such, the current study may add depth to previous research regarding recovery by highlighting the relationship survivors have with their recovery and by illustrating the ways in which this can impact the development of romantic relationships. The subordinate theme of *Investment in the Self* may at an initial glance seem like a clinical, medical based theme unrelated to romantic experiences, however it is a lynch pin drawing together many of the themes such as *A Fragile Self, Vulnerability, Self-Preservation, Fear* and *Safety.* Together, these themes represent a fundamental part of the post injury romantic experience for half of the female brain injury survivors in this current study.

However, active investment in the self did not provoke the need for self-preservation in all participants. Charlie described despite working hard on her recovery post injury, her efforts had not brought about the changes she had wanted. For Charlie the development of a romantic relationship was not perceived as a potential threat to recovery but instead viewed as an opportunity to leave the brain injury and all that it entailed behind. This reflects that Charlie did not consider herself to have anything to lose but instead everything to gain from meeting someone new. For Ruth and Bella, a sense of self-preservation was also absent as they did not consider that becoming romantically involved with someone would compromise their recovery in any way. In fact, Bella's post injury experiences were divergent from many of those shared by the other participants. Bella was the only participant in the current study to have a non-traumatic brain injury, however her brain injury was a near death experience. Bella was the only participant who felt a connection with non-brain-injured others and did not report feeling lonely or isolated. In addition to this Bella was accepting of her injury, she dated with ease and as such was completely absent from the theme of *Barriers to forming romantic relationships*. For Bella, much of her pre-injured self remained indicating a preserved sense of self. Bella's overall experiences lend support to research that has found that continuity of self is associated with sustained wellbeing (Jones, Jetten, Haslam & Williams, 2014) as well as personal growth post injury (Gelech & Desjardins, 2011).

Acceptance of brain injuries has been associated with adapting to life post injury, finding new meaning, self-efficacy and improved quality of life (Curran, Ponsford & Crowe, 2000; Snead and David, 2002; Howes, Benton and Edwards, 2005; Yehene, Lichtenstern, Harel, Druckman & Sacher, 2020). Brain injury survivors have also spoken about the importance of being accepted by others (McColl, 1998; Freeman, Adams & Ashworth, 2015). Acceptance of the brain injury did not automatically occur for the participants in the current study. For half of the participants acceptance was the result of an active and purposeful approach that formed part of their recovery thus linking with the theme of *Investment in the Self*. Interestingly, the participant who had lived with their brain injury the longest was the least accepting thus lending support for previous research which has found that time since injury is not a predictor of achieving certain milestones for TBI or of health-related quality of life (Hess & McGovern, 2016). This particular participant also interpreted acceptance as giving up on the quality of life improving, a belief which has been found amongst other survivors (Jumisko, Lexell & Söderberg, 2009). Of the three participants in the current study who spoke explicitly about accepting their injury, two were in long term romantic relationships and one had been dating someone exclusively for six months. The participant who remained unaccepting of her injury had never experienced a long-term romantic relationship despite wanting one. Although a fourth participant, Ruth, did not mention acceptance, she was clear about being happy and content with her life and had decided to remain single for the time being. As such, the current findings lend support for perspectives in health literature which suggest individual outlooks and personal coping mechanisms can affect adjustment after the onset of physical illness or a health crisis (Moos & Schaefer, 1984) as well as after sustaining traumatic brain injury (Moore & Stamford, 1995). However, acceptance and adjustment for survivors is far from straightforward as individual aspects such as coping may be affected by ABI related neuropathology (Godfrey, Knight & Partridge, 1996; Krpan, Levine, Stuss & Dawson, 2007). Social factors may play a part too as Seeto, Scruby and Greenhill (2017) reported that barriers towards acceptance included concerns of being judged by others and a retreatment from socialisation.

Following the distressing and life changing experience of sustaining a brain injury, it can be expected that survivors experience an innate sense of vulnerability. This is likely to reflect the unavoidable confrontation of a situation whereby a formidable external event exerted a powerful control over their whole being with life-changing consequences (Howes, Benton & Edwards, 2005). All the participants in the current study sustained their injuries under traumatic circumstances and all were described as near-death experiences. For some of the participants in the current study, this innate sense of vulnerability extended to their romantic encounters as it affected decision-making and behaviour. Some participants described concerns that developing romantic relationships may increase an already existing sense of vulnerability, which at times held them back from developing romantic relationships. Two of the participants in the current study related their post injury vulnerability to the development of unhealthy romantic relationships, one of which was abusive. Both participants were clear about not having had these types of relationship experiences prior to their brain injury and how their pre-injury selves would not have tolerated being taken advantage of or abused. As such this demonstrates how the presence of vulnerability in female brain injury survivors may increase the risk of becoming involved in unhealthy relationships. Feelings of vulnerability are not uncommon after sustaining a brain injury, especially TBIs (Howes, Benton & Edwards, 2005). Haag et al (2016) discovered concerns about sexual behaviour being affected by an increased libido or decreased inhibitions. In addition to this, female brain injury survivors were aware of an increase in their vulnerability which led them to discuss risk and lack of safety in relation to the potential abuse of others (Haag et al, 2016). This current study strengthens these findings whilst also highlighting the complex way in which vulnerability can impact upon romantic interactions.

The issue of Intimate Partner Violence (IPV) was only raised by two participants in the current study; however, it would be unethical not to include it due to the significant implications it holds for clinical practice in relation to duty of care, safeguarding and brain injury survivor wellbeing. IPV has been recognised as a cause of TBI in women, and in addition to this concerns have been raised in extant literature that female brain injury survivors may be at an increased risk of IPV (see Introduction chapter). This current study included examples of both types of IPV; one participant sustained their brain injury as a result of IPV and another participant became involved in a physically abusive relationship post injury and prior to receiving brain injury support. This demonstrates the dynamic interplay between IPV and brain injuries thus supporting extant findings that IPV can be a risk factor for TBI, and TBI can be a risk factor for IPV. Interestingly, the World Health Organisation does not identify brain injury as a risk factor for IPV (WHO, 2014) which could indicate further research is needed in order to establish the degree of risk. Whilst IPV is not exclusive to brain injury survivors or women, this study further emphasises the importance of screening those known to have experienced IPV for brain injuries (Kwako et al, 2011) as well as the importance of educating health care professionals about these risks (Haag et al, 2019). The findings in the current study also exemplify how integral it is for health care professionals to engage female brain injury survivors in conversations about the potential and complex impact brain injuries can have upon intimacy and romantic relationships (Haag, 2016).

Maintaining a sense of safety became an important hallmark of post injury existence for many of the participants in the current study and was intrinsically linked to relationships. The importance of safety is likely to relate to the way in which the participants sustained their injuries. All participants experienced a type 1 trauma which is described as a single, one off event that is extreme or life threatening (Bonanno & Diminich, 2013). Such experiences can lead to the development of Post-Traumatic Stress Disorder (PTSD) and there is growing evidence to suggest that PTSD is a potential outcome following traumatic brain injury (Roche, 2020). However, not all single event traumas result in PTSD which has led some experts to suggest that the capacity for turning adversity into a trauma is when the mind is experienced as being alone (Fonagy, Luyten, Campbell & Allison, 2018; Luyten and Fonagy, 2019). Most of the participants in the current study were single at the point of injury and all the participants proceeded through the acute recovery phase without a romantic partner. For these participants, maintaining a sense of safety become an important part of moving forwards. Howes, Benton & Edwards (2005) found safety emerged as a theme in their study with female TBI survivors. The authors reported their participants' worldview seemed to be impacted by sustaining an injury which profoundly changed their lives leaving them feeling vulnerable and insecure (Howes, Benton & Edwards, 2005). The importance of a sense of safety is recognised in brain injury rehabilitation as working towards achieving a non-threatened safe sense of self is the aim of certain rehabilitation models such as 'The Y-shaped Model' (Gracey, Evans & Malley, 2009). Notwithstanding the salience a sense of safety holds for brain injury survivors specifically, feeling safe with other people is believed to define mental health for everyone as safe relationships are necessary in order to live meaningful and full lives (Van Der Kolk, 2015). In terms of the current study, for some of the participants a sense of safety was generated from relationships, both romantic and platonic, which provided support, acceptance and understanding which contributed towards developing resilience and self-efficacy. In mapping out neuropsychological processes that may be implicated in post injury social and psychological adjustment, Gracey and Ownsworth (2014) suggest that when a survivor is feeling safe and understood and there is an absence of social judgement, they are better able to access both temporal and frontal parts of the brain, areas which would be inaccessible when the threat system is activated. This helps explains why maintaining a sense of safety is important to brain injury survivors, and the experiences of the participants in the current study lend support to this way of understanding safety and the benefits it brings. Contrary to this, two participants described garnering their sense of safety by remaining single. Furthermore, the forming of romantic relationships was perceived to be a threat to this sense of safety due to the fear they evoked regarding potential rejection, judgement, uncertainty and instability they may involve. The link between maintaining a sense of safety and the avoidance of relationships is likely to be linked to threat reactions posed by external, uncontrollable aspects such as negative social judgements that are associated with the automatic neural basis of fear (LeDoux, 1995). The current study together with these existing findings highlights the complex and dynamic interpersonal interactions that have the potential to both provide a sense of safety as well as threaten its existence.

Romantic relationships were seen to be a way of re-establishing the self in the social world. Having a romantic relationship was viewed as ‘fitting in’ with others and considered as a benchmark of ‘normality’. As such the current findings support previous literature which acknowledges a human tendency to pursue social acceptance by conforming to similar experiences shared by others (Marinelli & del Orto, 1984). Romantic relationships in the current study also served as a mechanism of external validation by providing a sense of value, thus emphasising links to self-esteem. Low self-esteem and negative self-concept in brain injury survivors are well documented within brain injury literature (see Introduction chapter). This study brings to light their impact within the context of romantic relationships as the theme *Yearning for belonging* emphasised how important romantic status was in terms of social value. Low self-esteem and negative self-concept were captured under the theme of *Feeling Worthless and Undesirable* whereby participants expressed thinking less of themselves as a direct result of sustaining their brain injury. Low self-esteem and negative self-concept appeared to have divergent effects on the participants in the current study. On the one hand they increased vulnerability as some participants sought sex and romantic relationships as a way of feeling better about themselves which for some resulted in the development of unhealthy relationships. On the other hand, the presence of low self-esteem and negative self-concept held some participants back from exploring romantic opportunities at times as due to their brain injury they struggled to see themselves as desirable, romantic partners. For some this persisted even after they became romantically involved and felt loved. However negative self-evaluations were not permanent as half of the participants described an improvement in how they viewed and felt about themselves which they attributed to therapy as well as a result of engaging in meaningful activities. These evolutions within the self explain the constant sense-making many of the participants engaged in which was represented in the theme *Making sense of a brain-injured self.* This current study highlights the complex effect low self-esteem and negative self-concept can have on upon brain injury survivors and their decision making and behaviour in relation to developing romantic relationships.

The degree to which social acceptance was linked to romantic status was further emphasised by the concerns and distress some participants described in relation to being judged negatively due to being both brain-injured and single. Intersectionality offers an understanding of how different categories (such as gender and disability) can intersect, combine and interact to influence individual experiences (Hills, Collins & Bills, 2020). Participants in the current study were female, brain-injured, and at times single. Stigma, perceived stigma and discrimination regarding brain injury survivors is well documented within the extant literature (see Introduction chapter). Stigma related to being single is not exclusive to brain injury survivors and is not unusual within the wider population where it has been found to result in ostracism (Williams & Nida, 2005). Case & Williams (2004) describe ostracism as having the effect of separating people from a shared connection with others and carrying an implicit message of transgression which can result in low self-esteem. This description echoes the experiences of most of the participants in the current study represented in the themes of *Feeling Disconnected* and *Feeling Worthless and Undesirable.* Further to this, previous research has found women have reported having their social world dominated by expectations to be in relationships, marry and have children (Sharp & Ganong, 2011). For some of the participants in the current study, being both single and brain-injured was at times a source of unhappiness and exacerbated low self-worth. These participants believed the acquisition of a romantic relationship would mitigate against stigma, further emphasising the important role external validation plays in terms of self-worth. This current study together with previous findings suggests some single, brain-injured women may be at risk of experiencing a treble stigma.

However, the desire to have a romantic relationship as a means of ‘fitting in’ was not necessarily fixed or constant as two of the participants, Ruth and Chrissie, began to prioritise activities that aligned with their core values above developing romantic relationships. For Ruth this brought about a new sense of purpose and joy and this new way of living meant relationships were now ‘lower in the list’ as she had developed a preference for being single. Although Chrissie remained conflicted about the prospect of developing a romantic relationship, she too was investing her time in meaningful activities and found the prospect of living alone appealing. For these participants, the purposeful engagement in meaningful activities and hobbies provided a sense of personal value and expanded their view of life beyond the scope of romantic status thus lessening the need for external validation.

Concerns regarding stigma reflected the importance of social identity in this current study and reflect the existing work of Martin et al (2015) who highlighted survivors make sense of themselves in terms of their social environments. Stigma can represent a threat to the self and is often underscored by a fear of being invalidated by others, and as such came to influence how many of the participants in the current study chose to interact with non-brain-injured others. All the participants lived with functional impairments as a result of their injuries, most of which were invisible leaving them with a choice of whether to disclose their injury to others, including prospective or actual romantic partners. The themes of *Putting on a performance* and *Concerns about revealing a brain-injured self* relate to non-disclosure and disclosure respectively. Most of the participants described how at times they changed their public behaviour to conceal their injuries in order to avoid the labels and stereotypes associated with brain injury. Survivors refer to this colloquially as ‘masking’. Within the literature Hagger & Riley (2019) refer to such behaviours as ‘stigma-related self-concealment’. Non-disclosure included not telling others about the brain injury, attempting to socialise at the frequency and pace of non-brain-injured others and pretending to have romantic relationships. It was clear non-disclosure provided certain benefits as participants reported how ‘masking’ helped them both *seem* ‘normal’ and *feel* ‘normal’ which was motivated by a desire to fit in with others. This lends support for previous research which has found the avoidance of being known as a brain injury survivor can facilitate well-being (Jones et al, 2014) as well as protect the survivor from stigma and discrimination (Bos, Kanner, Murris, Janssen & Mayer, 2009). Despite its benefits, not being open about a brain injury can pose certain drawbacks which Jones et al (2014) describe as living with fear of exposure, reluctance at seeking professional support as well as inhibiting the development of social support. Non-disclosure did not prevent any of the participants in the current study from seeking professional support but their accounts around changing their behaviour contained implicit fear of becoming known as someone with a brain injury. Many of the participants spoke about how masking made them less open and honest with people, which supports the finding that non-disclosure can inhibit the development of social support (Jones et al, 2014). Three of the participants in the current study spoke of the stress and exhaustion they felt at changing their behaviours to fit in with others which reflects the research of Salas, et al (2018). This highlighted how unstainable masking was, further emphasising the personal cost of maintaining a façade. This is particularly pertinent to brain injury survivors given that fatigue is well documented among this population and has been found to impact lifestyle (Ziino & Ponsford, 2005). Interestingly, keeping brain injuries hidden has been connected to social anxiety, low self-esteem, social avoidance as well as loneliness (Hagger & Riley, 2019). This may help explain why non-disclosure was distressing and difficult for the participants in the current study as well as highlight how non-disclosure may relate to other themes, namely *Feelings of Disconnection* and *Feeling Worthless and Undesirable.* However, non-disclosure-based behaviour was by no means permanent for all the participants, neither did it seem to follow a linear trajectory in terms of lessening over time, but instead seemed context and experience dependent.

Disclosure was experienced as a dilemma by the participants in the current study as well as challenging as it involved decision making on who to tell, how much to disclose and when to tell them and as such lends support to extant research (Jones et al, 2014; Hellem et al, 2018). Being open about having a brain injury has been found to facilitate acceptance which in turn can increase openness to effective support thus enabling post traumatic growth, all of which can act as a buffer when encountering discrimination

(Jones et al, 2014). Sarah and Mia went on to develop romantic relationships and disclosed their injuries to their partners. They spoke specifically about how accepting, helpful, considerate and mindful their partners were of their injuries. Sarah and Mia were also both accepting of their injuries and their subsequent changed sense of self, but both articulated disclosing and explaining their brain injuries to their partners was far from easy. However, disclosure of injury can also carry risks. Ruth described losing friends due to disclosure and went on to say of wider society and brain injury "*they don't like it and they can't handle it, they think there'll be something odd about you or off with you*" (Ruth, 23.7). This emphasises the link between disclosure, stigma and discrimination. These experiences shaped Ruth's subsequent disclosures in terms of what she decided to reveal, and now she tells people she had a 'big accident' without going into any further detail. Delayed disclosure to significant others carries the risk of harming relationships as it involves a lack of genuineness and signifies concerns regarding trust (Jones, Jetten, Haslam & Williams, 2014). This was reflective of one of the participants in the current study, Mia, who kept her injury a secret from her partner in the formative stages of their now five-year relationship. Mia described how her partner found it difficult to understand why she had kept her injury a secret and how it was the secrecy he struggled to come to terms with rather than the brain injury. Disclosure becomes part of a how a survivor manages their relationships with others (Jones et al, 2014) and the distress caused by stigma in addition to dealing with cognitive and neurological changes means it is difficult for survivors to create new social relationships (Jones, Jetton, Haslam & Williams, 2014). This current study supports these views and lends support to findings which have highlighted how the opinions and behaviours of non-brain-injured others impacts the social participation of survivors (Gelech & Desjardins, 2011). New but perhaps expected findings generated by the current study highlight how issues surrounding disclosure may contribute towards difficulties in developing closeness with prospective romantic partners due to concerns regarding stigma and revealing a brain-injured self.

Decisions related to romantic relationships elicited conflict, confusion and uncertainty in many of the participants which related to self-doubt as well as caution and hesitancy at the prospect of becoming a romantic partner. This reflects how risk averse some of the participants had become since sustaining their brain injury as well as demonstrating their need to re-evaluate what it may mean to have a relationship as a brain injury survivor. There was an inherent tension for some of the participants who wanted a relationship yet feared the uncertainty developing one may bring. This was experienced as a dilemma as the participants attempted to balance their need to look after themselves as brain injury survivors, with their desire to be with someone romantically. This led some participants to weigh up the benefits of remaining single compared to the risks of becoming romantically involved. Many of the participants in the current study experienced both the prospect of and the actual transition into a romantic relationship as a stressful event and for some this seemed to impact their decision-making ability. Interestingly, Krpan et al. (2007) discovered that negative assessments in relation to stressful circumstances made by traumatic brain injury survivors correlated with an increase in executive dysfunction. This led Krpan et al. (2007) to suggest that the same neural substrate was involved in both coping and executive functioning. It is therefore unsurprising that the prospect or actual transition into romantic relationships was couched in uncertainty and inner conflict for the participants in this current study.

Given the relational focus of this current research and the challenges participants faced in relation to developing romantic relationships, it is useful to consider the nature of rehabilitation for brain injury survivors who are single at the point of injury and its potential impact. Brain injury rehabilitation tends to be based on the empowerment agenda, a concept often applied in mental health and disability (Fenton & Hughes, 1989). Neath and Shriner (1998) describe the ‘personal power’ aspect of the empowerment agenda as being heavily informed by the medical model and highly individualised, whereby people are encouraged to use therapy and access other types of support with the aim of enabling individuals to influence their own personal situations. It is interesting to note that in the current study, recovery during the acute period started as an individual journey. Individualistic approaches towards rehabilitation are both common, and in part necessary (such as physiotherapy, speech therapy and occupational therapy) and are considered as an integral part of rehabilitation (Bowen, Yeates & Palmer, 2018). However, perhaps being single at the point of injury and the absence of family means the journey of recovery beyond the acute phase remains one couched in solitude. It could be that the exclusive application of individualistic rehabilitation may have the unintended consequence of exacerbating feelings of difference and isolation. The absence of relational and community rehabilitation may mean single brain injury survivors do not learn how to be in relation to others, at a time when they most need to develop interpersonal skills to help reconcile painful feelings of difference and isolation and establish supportive relationships, including those of an intimate and romantic nature.

Nearly all the brain injury survivors in the current study were single at the point of injury and all of them, at some point in their post injury life, had wanted a romantic relationship. Having a brain injury was by no means a prohibitive factor in establishing such relationships but being a brain injury survivor made developing these relationships more challenging and distressing as participants sought to navigate desire alongside protecting their more vulnerable selves whilst maintaining a sense of safety. Participants were clear that their approaches and outlooks towards romantic relationships post injury were a demarcation from their pre-injured selves thus attributing all associated differences to the acquisition of their brain injury. Whilst those conversant with brain injury literature may not be surprised at the discovery of such findings, they are novel in that no other research to date has exclusively explored what it is like for survivors to form new romantic relationships after sustaining a brain injury. Whilst establishing new romantic relationships is not likely to be a priority for survivors in the acute recovery phase, the findings in the current study highlight it could become important at later stages. The current study also lend support for calls for relational approaches to be adopted as central part of rehabilitation even when working at an individual level (Bowen, Yeates & Palmer, 2018; Jetten, Haslam & Haslam, 2014; Martin et al, 2015). The current study placed within the context of existing research provides a broad framework from which to begin to consider and explore the complex interactions between the psychological and social processes as survivors attempt to establish meaningful romantic relationships after sustaining their injuries. Working with single brain injury survivors in relational ways may facilitate the development of supportive romantic relationships post injury which in turn could lead to further positive psychosocial outcomes.

Study Limitations & Critical Reflections

In order to ensure quality and rigour and uphold ethical standards, this research followed a number of procedures and guidelines. Firstly, this study adhered to the BPS Code of Human Research Ethics Guidelines (2014) and was conducted after receiving ethical approval from the Psychological Research Ethical Committee at City, University of London (see Appendix VII). Secondly, Yardley's (2000, 2015) framework was adhered to (see Methodology chapter) with the aim of achieving validity by demonstrating data collection and analysis was conducted in a trustworthy and transparent manner. The final part of Yardely's (2000, 2015) framework, impact and importance which helps assess a study's usefulness, is considered later in this chapter underneath *Implications for Counselling Psychology*. This current study has certain limitations which merit consideration due to the impact they may have had on the findings. They are also important to highlight as they may hold implications for future research in this area.

Methodological Issues

Sample sizes in IPA are often small and this study was no exception. Small sample sizes in IPA enable an in-depth, case by case analysis aimed at generating detailed examination of specific phenomenon rather than developing theories that can be generalised to large populations (Pietkiewicz & Smith, 2014). Therefore, the findings in this current study may not be representative of female brain injury survivors and their post injury romantic experiences and as such generalisations should not be made to all brain-injured women. IPA aims to connect with existing literature within the discussion section by supporting, challenging or deepening existing understandings and theories (Smith et al, 2009). There are also hopes for corpuses of IPA studies to converge around particular areas with the aim of more integrative IPA research emerging collectively (Smith, 2011). Nevertheless, it remains the case that the focus of the present study was on detailed analysis as opposed to gathering a breadth of findings, with the aim of providing in-depth accounts of a particular experience rather than generating theories regarding large populations (Pietkiewicz & Smith, 2014).

Another limitation of IPA asserted by Willig (2013) is that IPA is too dependent upon language requiring highly articulate participants. This may result in an over representation of middle-class groups in this type of research. However, Smith (2004) contends in his own experience he has found no connection between social economic status and the reflexive, articulate accounts gathered. Smith (2004) goes on to state he believes the richness that accounts hold is more to do with the meaning and importance that the participants attribute to the experiences they are discussing. Willig (2013) also highlights spoken accounts unable to generate rich data are often excluded in IPA. This is true for the current study as gross language impairments were part of the exclusion criteria as spoken accounts were being sought. This is a particularly important point to consider for IPA related brain injury research as aphasia can occur as a result of injury (Kavanagh, Lynam, Düerk, Casey & Eustace, 2010). On reflection the current study could have been supplemented by including measures such as drawings or journal entries. This would also have made the study more accessible to survivors who experience challenges with memory recall and concentration (Paterson & Scott-Findlay, 2002).

The type of data this current study generated could be viewed as restrictive as it is limited to describing a particular phenomenon as opposed to offering explanations. Willig (2013) suggests this serves to inhibit a full understanding of the topic being explored. Whilst the capturing of such data was not the aim of this current study and lies beyond the scope of its methodology, the current research findings highlight the complexity of the phenomenon under investigation by illustrating how psychological and social factors overlap and interact with one another thus providing insight on romantic behavioural outcomes.

Research Design Issues

The aim of this research was to explore how female brain injury survivors made sense of new romantic experiences encountered post injury therefore one of the inclusion criteria was to have had any romantic experiences post injury that did not exist pre-injury. This study's exclusive focus on all types of romantic experiences was deemed appropriate due to the paucity of research in this area. However, it is possible this approach was too broad. Whilst the current study elicited insight into the various experiences related to becoming involved in new romantic relationships as a brain injury survivor, it was also restrictive in that there were less opportunities to explore specific experiences in detail. A more focused stance may have produced more detailed descriptions and understandings of these.

A potential issue in the current study is the type of brain injuries that were included in the sample. A decision was made to combine both traumatic brain injury and non-traumatic brain injury survivors (see Introduction chapter for a detailed rationale). It is common practice in brain injury research for samples to include both types of injury. Five of the participants in the current study had traumatic brain injuries and one participant, Bella, had a non-traumatic brain injury. The reason this merits reflection is due to the differences in the quality of experiences of Bella, compared to the TBI survivors alongside the pattern of absences of Bella from particular themes. Unlike the other participants Bella retained a strong familiar sense of self post injury, felt connected to non-brain-injured others and explored romantic opportunities with ease. In addition to this, Bella was absent from many of the themes which seemed particularly salient to most of the other participants experiences such as *Vulnerability, Yearning for Belonging, Putting on a Performance, Self-Preservation, Fear, Inner Conflict, Confusion & Uncertainty* and *Feeling Worthless & Undesirable*. It is difficult to know whether such differences are a result of how Bella's injury was sustained and experienced. Unlike the other participants, Bella's injury was not a result of an external force to the head, however this does not mean the experience of acquisition or subsequent impairment and recovery was not traumatic. Likewise, it is difficult to know whether the quality of Bella's experiences differed due to injury related neuropathology or whether they are reflective of pre-morbid psychosocial coping. Nevertheless, the degree to which the experiences were divergent between Bella and the other participants may build a case for future qualitative studies to explore the experiences of traumatic and non-traumatic brain injury survivors separately to further explore any differences between the two groups.

In terms of brain injury severity (mild, moderate and severe), this study calls into question the utility of using these categories as an organising element for recruitment criteria in qualitative, psychosocial research as not only are they are not always predictive of long-term functioning, their continued use and application risks excluding important and valuable voices from studies exploring first person accounts. Half of the participants in this current study described themselves as having severe brain injuries, all of whom contributed rich accounts and experiences to this topic which has largely been neglected within the brain injury literature to date. Whilst the Glasgow Coma Scale (GCS) is useful in initial prognosis and chronic clinical management, this study would challenge the continued use of its categories regarding the recruitment of brain injury survivors in future qualitative studies with a psychosocial focus. An alternative approach could be to move away from recruiting participants based on categories of severity and instead utilise the guidance provided by Paterson and Scott-Findlay (2002) and assess suitability and employ any necessary adaptations by conducting preliminary meetings with brain injury survivors interested in taking part .

Procedural Issues

This study focused exclusively on female brain injury survivors (see Introduction chapter for rationale). This ensured the homogeneity of the participant group which is concordant with the aims of IPA research (Smith, et al, 2009). The exclusion of males means nothing is known about how men experience new romantic encounters post brain injury and as such this could be an area for future research.

No exclusions were made based on sexual orientation, race or nationality. A minimum age of 18 was required for the study (see Methodology chapter for rational). Recruitment adverts were placed mainly online, and participants were selected on a first come first serve basis. The impact the recruitment campaign had on the final participant group is considered below along with how this may have influenced the current study's findings.

The participants that responded to the recruitment adverts were self-selecting as they themselves choose to participate. Most of the participants stated they were motivated to take part as they felt this current study was exploring an important area. Any additional motivations to take part in this study remain unknown and as such it is difficult to know how representative the experiences captured in this current study are of other female brain injury survivors.

The fact the study was mainly advertised online may have influenced the type of participants recruited. The main source of recruitment was intended to be through local Headway centres. Three centres were contacted via email across a period of six months but were unresponsive and so an online recruitment strategy was employed instead, however this meant any survivors not online were precluded from taking part. As such, there was an over-reliance on participants who use the internet and have social media accounts. However, there is some evidence to suggest there has been a growth in online presence and social media accounts across all age ranges and all types of social economic status which may mean the recruitment adverts were accessible to a large and diverse brain-injured population (Statista, 2020).

The final sample included females who were all of Caucasian descent and all British. It is important for this to be held in mind when considering the research findings as the experiences described are only reflective of white British Caucasian women. Other races, ethnicities and cultures tend to be underrepresented in brain injury literature. Some research suggests those from minority backgrounds are at risk of poorer outcomes post injury (Gary, Arango-Lasprilla & Stevens, 2009), therefore the way that race, ethnicity and culture influences attitudes towards brain injury is an important area to be explored given the crucial roles relationships can play post injury (Bowen, Yeates & Palmer, 2018).

In terms of sexual orientation five of the female brain injury survivors in this current study were heterosexual and one was bisexual. Sexuality seems to be under-researched in terms of brain injury literature but there is a growing recognition of the need for rehabilitations services to address sexual and gender diversity amongst survivors with calls being made for further research in this area and for programs to focus more strongly on LGBTIQA+ survivors rather than exclusively on heteronormative couples and families (Moreno, Laoch & Zasler, 2017; O’Shea, Frawley, Leahy, James & Nguyen, 2020).

Further Research

The broad approach adopted by the current research has highlighted several ways in which it could be extended. Firstly, the same question and approach could be applied to explore the experiences of male survivors, LGBTIQA+ survivors as well as survivors from varying and diverse cultures. This could ascertain any potential gender similarities and differences as well as explore any impact of intersectionality and stigma. Such studies may concur with the existing findings in the current study or diverge thus revealing further areas for exploration.

Additionally, the current study could have been extended by conducting IPA interviews with the partners of some of the survivors to explore the phenomenon of post injury romantic relationships from their perspective. Larkin, Shaw & Flowers (2018) suggests adopting this type of conceptual framework could encapsulate complex and extrinsic phenomena by exploring multiple perspectives. There is some evidence to suggest that relationships established post injury differ in quality from those established before injury (Powell, Gilson & Collin, 2012), therefore the application of a multi-perspective IPA approach in this area could explore the relational dimension of this phenomenon.

Another way of extending the current research would have been by incorporating this IPA study into a mixed methods design to better understand the area being researched. The added quantitative measures could explore any potential correlations and relationships between variables identified from the IPA analysis. For example, the incorporation of questionnaires distributed to a larger sample size could capture data on romantic status, relationship goals, previous psychological therapy as well as measure self-esteem, perceived stigma, perceived threat and acceptance of injury and ascertain the importance of safety and maintaining post injury recovery. Information regarding the romantic status of survivors' post injury could help inform service need, provision and funding. A larger sample size could include a wider age range, capture a diverse range of time since injury and include both traumatic and non-traumatic brain injuries to explore any differences which might exist within or between any of these groups. This type of mixed methods design where the details of the quantitative component have been informed by qualitative component would have the added benefit of being underpinned by the experiences of brain injury survivors meaning the whole project is centred around their needs and concerns.

Finally, there were particular themes which emerged in the current study which may benefit from being studied more closely thus providing another way in which this current study could have been extended. For example, concentrating on specific aspects such as sense of safety, self-preservation or fear could facilitate a more detailed and nuanced analysis perhaps shedding more light on what these meanings held for participants. These three themes in particular seemed to be quite unique within the brain injury literature and further exploration could elucidate how they relate to developing intimacy with others and increase our understanding of the challenges involved in moving from being a single brain injury survivor to becoming part of a couple.

How this current study could inform counselling psychology

This current study has provided an opportunity for the voices of female brain injury survivors to be heard and bring their experiences of new romantic encounters and relationships post injury to the forefront. As such it has added to the existing corpus of IPA research on the lived experiences of brain injury. More crucially it has made an original contribution to brain injury research and to the field of counselling psychology by addressing a knowledge gap within the existing literature. As demonstrated in the Introduction chapter, the impact brain injuries have upon existing relationships is well documented and understood. However, until this current study nothing was known about what it was like to form new romantic relationships post injury. As such this study has provided fresh insights which have highlighted the challenges that exist at the intersection of being single, female and brain-injured and in pursuit of a romantic relationship. It has also illustrated that becoming a romantic partner post injury gives rise to particular difficulties and concerns which may indicate this is a specific period of adjustment.

An appropriate starting point when reflecting on how this current study may inform counselling psychology is to reflect on whether psychological support is necessary or beneficial to those survivors looking for relationships. There was evidence in the current study to suggest the role of psychological therapy had benefitted half of the participants in terms of self-esteem, acceptance and boundary management which in turn helped them develop romantic relationships. This suggests therapeutic support may well be helpful for this population, especially given that most of the participants described difficulties and concerns in this area. Psychological support may not be necessary for everyone in this position, but some types of clinical interventions could be designed and introduced to ensure those in need can access relevant and beneficial support.

In order for this research to inform clinical work it is essential to consider when, how and where interventions informed by issues identified in this current study could be applied. In terms of appropriateness of timing, given that most of the participants in this current study spent significant periods of time in hospital receiving rehabilitation to address physical impairments, support regarding prospective romantic relationships would not be a priority during the acute phase of recovery. However, towards the end of this phase it might be possible for rehabilitation professionals to ask survivors about their future wishes regarding relationships and signpost them to sources of information and support which they could access at a later date. Overall, findings in the current study suggest that accessing support would be more likely during the chronic phase of recovery and as such may not be sought exclusively from rehabilitation or brain injury services.

Single brain injury survivors seeking support in developing romantic relationships may access help from services not conversant in the specific challenges faced by brain injury survivors. As such there may be merit in developing specialised training for professionals working in the following services to which people can self-refer: Improved Access to Psychological Therapies (IAPT) and Relate, who provide support for single people experiencing difficulties starting relationships. Professionals from charities that support women who have experienced Intimate Partner Violence (IPV), such as Woman's Trust and Solace Women's Aid may also benefit from specialised training, particularly given the links between female brain injury and IPV as outlined earlier in this chapter. Interventions could involve providing psycho-education on the risks of IPV and include work on developing assertiveness skills to help safeguard survivors who may be vulnerable to abuse. Such charities and mental health services also need to be alert to the possibility of undiagnosed head injuries as a result of IPV so that appropriate referrals can be made in order to maximise support and increase optimal outcomes. Providing specialist training to staff is also appropriate given that single brain injury survivors may present at mental health services articulating difficulties with loneliness and low self-esteem, issues not obviously related to brain injury.

Some rehabilitation does extend beyond the acute phase of recovery meaning some survivors receive more long-term rehabilitation. This current study highlights the importance of rehabilitation professionals incorporating the romantic desires of single brain injury survivors into formulations as this may help incorporate more relational and systemic ways of working. Rehabilitation professionals could help identify barriers to developing relationships as well as highlight maintenance factors which may be keeping unhelpful attitudes and behaviours in place. There is some evidence to suggest that survivors would like their life goals to be taken into consideration during rehabilitation rather than just focusing on physical recovery (Martin et al, 2015).

Not all brain injury survivors may feel comfortable accessing psychological therapy due to the stigma surrounding mental ill health in the UK. This type of support may be avoided by a population who already harbour concerns regarding perceived stigma pertaining to their injury. In addition to this, NHS waiting times can be lengthy thus therapy can be difficult to access at the moment of need. Therefore, brain injury charities such as Headway and Silverlinings UK could provide and disseminate information that is easily accessible in a non-stigmatising environment at both local and national levels either through face to face or online workshops or by producing leaflets and literature available online and through the post.

There are a number of ways in which the potential needs highlighted in the themes produced by the analysis could provide direction for interventions which could help survivors develop romantic attachments post injury. Table 3 (below) presents some key interventions which are considered to be particularly beneficial to the specific and complex biopsychosocial challenges faced by brain injury survivors. Brief explanations and rationales for matching the following themes with these particular interventions are provided below.

Table III: Themes from analysis matched with Psychological Interventions

Themes from analysis	***Psychological Interventions***
Safety Self-preservation	*Eye Movement Desensitisation and Reprocessing Therapy (EMDR)* *Trauma Focused CBT*
Safety Vulnerability Self-preservation Fear	*Compassion Focused Therapy* *Trauma Focused CBT*

Concerns about revealing a brain injured self Putting on a performance Feeling worthless and undesirable Feeling disconnected	
Making sense of a brain injured self Feeling disconnected Yearning for Belonging Fear Self-preservation Acceptance Inner conflict, confusion and uncertainty	*Acceptance and Commitment Therapy* *Mindfulness Based Stress Reduction*
Re-learning and Learning Investment in the self Self-preservation Making sense of a brain injured self	*Opportunity for specialised course*
Vulnerability (in terms of IPV/ abuse)	*The Freedom Programme* *https://www.freedomprogramme.co.uk/*
Inner conflict, confusion and uncertainty Weighing it all up: uncertainties, needs & risk	*Motivational Interviewing*

Eye Movement Desensitisation and Reprocessing Therapy (EMDR) along with trauma focused CBT is a NICE recommended treatment approach for PTSD (NICE, 2018). It involves specific methods aimed at reducing the power of traumatic memories via bilateral stimulation (Shapiro, 2002) and its effectiveness is thought to relate to processes which integrate the emotional, somatosensory, cognitive and temporal systems (Bergmann, 2020). EMDR also employs techniques specifically aimed at engaging affiliative systems such as compassionate, safe and calm place imagery. EMDR could help brain injury survivors begin to feel safer and less vulnerable as their brain injured self but it essential this is delivered by a trained professional with an understanding of neuropsychology and couched within a compassionate approach. A number of studies have demonstrated that Trauma Focused CBT is effective at treating PTSD (Lewis, Roberts, Andrew, Starling & Bisson, 2020), therefore it may be a helpful intervention to apply to the themes of *Safety* and *Self-Preservation* as they seemed to be based around hypervigilance and risk aversion. All the participants described their brain injury event as a near death experience, and all of the participants reported the existence of at least one trauma related psychiatric disorder, namely PTSD, anxiety and depression. Trauma-Focused CBT could help survivors develop a non-threatened safe sense of self which could free them up to explore romantic attachments by reducing the activation of the threat system and freeing up temporal and frontal parts of the brain (Gracy & Ownsworth, 2014).

Compassion Focused Therapy (CFT) was developed by Professor Paul Gilbert to specifically address shame and self-criticism and promote the ability to self-soothe which in turn can facilitate feelings of safety (Gilbert, 2009). Such an approach could help survivors address issues such as self-criticism and shame which may underpin the themes of ‘concerns about revealing a brain injured self’, ‘putting on a performance’ and ‘feeling worthless and undesirable’. Compassionate mind training taught as part of CFT involves learning skills specifically designed to influence affect regulation by purposeful attempts to engage the soothing system (Gilbert, 2009). Developing such skills enables people to feel safe, content and trusting both within themselves and with others which could help survivors manage their concerns and anxiety surrounding the themes of ‘fear’, ‘safety’, ‘vulnerability’, ‘self-preservation’ and ‘feeling disconnected’ all of which have been identified as prohibitive factors in developing romantic relationships in this current study. The neuroscientific basis on which CFT is built is concordant with recent research on the neural profiles of the impacts of both TBI and PTSD which led the authors to recommend targeting emotional regulation for treatment and early intervention with the aim of mitigating potential adverse psychological and emotional impacts of TBI (Weiss, Webb, deRoon & Larson, 2022). Using Trauma Focused CBT across this set of themes could help identify the associated cognitions, emotions, bodily sensations, urges and behaviours and highlight maintenance cycles thus discovering opportunities for change. All of this information could further inform psychoeducation with the aim of increasing the self-awareness of survivors.

Acceptance and Commitment Therapy (ACT) could be utilised to address a number of difficulties associated with the following themes: ‘Making sense of a brain injured self’, ‘Feeling disconnected’, ‘Yearning for Belonging’, ‘Fear’, ‘Self-preservation’, ‘Acceptance’ and ‘Inner conflict, confusion and uncertainty’. ACT recognises the importance of context (i.e. social stigma and discrimination) and understands how it can impact choices and behaviour, thoughts regarding the self and influence avoidance. (Harris, 2009). One of the main aims of ACT in is to help people understand how their behaviour interacts with consequences so that ultimately behaviour becomes shaped by consequences rather than thoughts and emotions thus increasing psychological flexibility (Hayes, Levin, Plum-Vilardaga, Villatte & Pistorello, 2013). This intervention could help those brain injury survivors wishing to form romantic attachments become more action orientated with the overall aim of improving their quality of life and mental health outcomes instead of being held back by their thoughts and beliefs. Identifying values and values-based committed actions could help with ‘making sense of a brain injured self’, ‘feeling disconnected’ and ‘yearning for belonging’ and thus facilitate post traumatic growth. ACT could also facilitate acceptance of having a brain injury and living with the consequences, and its focus on ‘experiential avoidance’ and notion of ‘workability’, i.e., is what you are doing helping you lead the life you want to be living? (Harris, 2009) could help survivors work through the difficulties associated with ‘Yearning for Belonging’, ‘Fear’, ‘Self-preservation' by helping them develop different ways of responding to their emotional distress thus freeing them up to live more rich, full and meaningful lives. Applying ACT as an intervention to develop heath related behaviour change is encouraged within Health Psychology (Zhang, Leeming, Smith, Chung, Hagger & Hayes, 2018). ACT has also recently been adapted for work with psychological trauma (Harris, 2021). Mindfulness Based Stress Reduction could also help brain injury survivors deal with the difficulties associated with the aforementioned themes due to its focus on developing awareness of moment-to-moment experiences aimed at increasing awareness of mental processes. The benefits of adopting such skills are linked to reduced negative affect, reduced anxiety as well as improvements in coping and this intervention is used to support both physical and mental health in a range of community and clinical settings (Fjorback, Arendt, Øbøl, Fink & Walach, 2011; Grossman, Niemann, Schmidt & Walach, 2004).

The co-existence of the themes of 'Re-learning and Learning', 'Investment in the self', 'Self-preservation', 'Making sense of a brain injured self' and 'Safety' seem quite unique to brain injury survivors so perhaps there is scope to develop some tailored and bespoke support programmes to address these challenges within the context of developing new romantic relationships post injury. Interventions could help normalise the challenges and difficulties faced by single brain injury survivors that are captured in these themes. Dating support could be provided and informed by the model proposed by Wiseman-Hakes, et al (2020) which was designed specifically for adolescent girls and women with TBIs to maintain and develop intimate relationships and enhance positive social outcomes. Given the individualistic focus in the acute recovery phase perhaps some aspects of this type of support could involve group work with the aim of developing interpersonal skills. This is concordant with recommendations for rehabilitation to adopt more relational approaches (Bowen, Yeates & Palmer, 2018; Jetten, Haslam & Haslam, 2014; Martin et al, 2015). This highly specialised type of support may help alleviate the distress and uncertainty triggered by both the prospect and the reality of becoming romantically involved with someone and remove barriers to developing emotional closeness and intimacy and facilitate adjustment. This type of support could form part of a holistic and bespoke approach such as those offered at the Oliver Zangwill Centre in Ely, Cambridgeshire. A unique course centred around these particular issues unique to survivors could be a useful addition to the pluralistic and integrative approaches towards brain injury employed at places such as the Oliver Zangwill Centre and compliment the range of topics already on offer such as vocational rehabilitation, family and systemic therapy, fatigue management and participation in meaningful activities.

The Freedom Programme is an online and in-person series of courses providing information on domestic abuse. Although it was designed for victims of domestic abuse, it is often recommended for people who are also considered at risk of abuse. Although this is not therapy and designed for educational purposes only, it could be a helpful resource for brain injury survivors in addressing vulnerabilities and raising awareness of intimate partner violence. The programme is free, and people can join by signing up themselves.

Motivational Interviewing may help brain injury survivors who are highly ambivalent regarding developing new romantic relationships by working through romantic decisions and choices as captured in the themes of ‘Inner conflict, confusion and uncertainty’ and ‘Weighing it all up: uncertainties, needs & risk’. Motivational Interviewing can be beneficial when ambivalence is high, and mixed feelings and conflicting thoughts keep people stuck and is often used within healthcare settings to help promote behaviour change (Rollnick, Bulter, Kinnersley, Gregory & Mash, 2010) although further research is needed in terms of overall efficacy as a technique in terms of brain injury survivors (Holloway, 2012).

Ultimately the neurobiology of traumatic brain injuries and psychological trauma (along with other psychiatric conditions) share many similarities (Alosco, Supelana & Vasterling, 2017). As psychological trauma has been found to exist across all major subgroups of acquired brain injury (see Literature Review) approaches which incorporate a trauma-informed approach and target the neural alterations thought to exist in traumatic brain injury are likely to be of benefit to brain injury survivors who struggle adjusting to the prospect of new romantic relationships post injury. For example, there is evidence to suggest that TBI may disrupt frontal subcortical neural circuitry, which is involved in emotional regulation, which in turn increases emotional distress resulting from exposure to psychological trauma (Eckhart et al, 2011; Williamson, Heilman, Porges, Lamb & Porges, 2013). Interventions which focus on developing more adaptive coping styles can facilitate emotional adjustment post injury (Anson & Ponsford, 2006). Also helping survivors manage distress can help improve executive function which helps with decision making (Krpan et al, 2007). Therefore, approaches which seek to actively engage affiliative systems and teach people how to be with their distress (such as EMDR, CFT and ACT) as opposed to controlling it, could help brain injury survivors manage the psychological distress and unhelpful cognitions associated with the adjustment involved in developing romantic relationships whilst living with a brain injury.

In terms of Counselling Psychology, a recent development means all Professional Doctorates in Counselling Psychology programmes are now required to teach neuropsychology. This in turn has led to a new training route for the Qualification in Clinical Neuropsychology (QICN) enabling Counselling Psychologists to qualify as clinical neuropsychologists (a route previously only available to Clinical and Educational Psychologists). However, even without this additional training, all Counselling Psychologists are expected to have an understanding of neuropsychology. This grounding in neuropsychology could be expanded upon within Counselling Psychology Doctorates to incorporate information on how work with brain injury survivors may differ from work with more neurotypical populations and build upon the work of Ward, Delrue & Plagnol (2017). For example, general psychological interventions tend not to be designed specifically around the treatment of co-morbid psychological disorders and brain injury, therefore therapies may need to be modified accordingly in order to maximise benefit to survivors. Cognitive demands of interventions should be held in mind alongside brain injury related cognitive deficits and other difficulties. Modification of session length, online provision, repetition to help with consolidation, physical handouts, written summaries of sessions and manageable homework tasks could all help with post-injury symptoms such as physical fatigue, neurofatigue, executive dysfunction, compromised attention and memory problems (Wolf, Strom, Kehle & Eftekhari, 2012; Ashman, Cantor, Tsaousides, Spielman & Gordon, 2014). It may be helpful to emphasise the role of psychological trauma across all types of acquired brain injury and emphasise that although the event during which the injury was sustained may not be remembered, this does not necessarily mean survivors are not traumatised or negatively impacted by the event, even if it was not sustained in what the literature considers to be "traumatic circumstances". It would also be important to convey that some symptoms displayed by survivors can be misunderstood by professionals who do not have a grounding in neuropsychology. Additional training on working with people with brain injuries could ensure such behaviours and responses are not misinterpreted. Although some responses during therapy will be psychological, others will be the result of brain injury such as inattentiveness, forgetfulness and confabulation. Such nuances and contextual factors become important when working with people with brain injuries and failure to be aware of them during therapy could negatively affect the therapeutic relationship and limit the effectiveness of therapy for survivors and compromise the ability of survivors to maintain therapeutic gains (Alosca, Supelana & Vaterlling, 2017). Brain injury needs specialist understanding and Counselling Psychology Doctorates could incorporate this into neuropsychology modules to ensure Counselling Psychologists are aware of such needs as the common occurrence of depression, anxiety and trauma is likely to mean survivors present at services beyond brain injury rehabilitation.

Final Considerations of Reflexivity

As this research draws to a close it too brings my own reflexivity to an end, the beginning of which was introduced in the Methodology chapter. In keeping a reflexive diary throughout this research, I have attempted to bracket my personal preconceptions which has enabled me to take a more grounded stance when considering the influence I may have had upon the research I have been so closely involved with (Smith, Flowers and Larkin, 2009; Finlay, 2002).

My journey with this research and the participants I have worked with has at many times echoed my clinical practice where I work with clients diagnosed with complex trauma. The indelible marks left in the wake of the traumatic experiences of the participants mirrors the lives of the clients with whom I work. My clinical experience of using Acceptance and Commitment Therapy (ACT) with trauma survivors together with my Acceptance and Commitment Therapy training has highlighted to me as a professional that actively working towards acceptance can be a powerful vehicle for change in moving forward and developing a meaningful life in the face of powerful past events which have left behind a legacy of distress.

These parallels between the research and my clinical practice have caused me to reflect on whether my professional stance and experiences influenced my analysis of the data in terms of knowing the role acceptance can play in the aftermath of traumatic events. However, both IPA and qualitative researchers in general acknowledge that it is not possible for researchers to be fully separate from the research process (Smith et al, 2009) and that researchers play a central role in the process as they produce the data and are active in its interpretation (Finlay, 2002). I found it useful to bracket my preconceptions regarding acceptance in my reflexive diary throughout the research project and as such believe that findings generated in the study capture the lived experiences of the participants.

One of my concerns throughout conducting this research was how my position as a non-brain-injured researcher would impact the research findings. I was nervous about influencing the findings with my own personal values and world view which I was afraid would undermine the experiences of the participants. I was also concerned that my position as a female researcher without an ABI may inhibit disclosure and influence the exchanges that took place between myself and the participants due to complexities surrounding self-disclosure and presentation of the self, both of which were salient themes in this current study. Indeed, Paterson and Scott-Findlay (2002) refer to ‘Image Management’ as one of the challenges when working with traumatic brain injury survivors in qualitative research, where participants may be keen to present an ‘image of normalcy’ and one of wellness and seek to minimise their difficulties. Whilst I believe the broad scope of the research question together with the semi-structured interview schedule created a space in which the participants were able to express and explore their experiences, it is likely that this was limited due to the fact I did not have an ABI myself. For example, I think my ableism made me naïve regarding the importance and experiences of sex and intimacy for survivors, because considering this study’s research question, there was only one question in my interview schedule regarding sex and intimacy, but the content of this was question related to sexual confidence (see Appendix III). To me this highlights the importance of conducting a pilot interview followed by a detailed debrief with a brain injury survivor, whereas my pilot interview was conducted on a similar topic, but with someone who did not have a brain injury. Further to this, I have reflected on what it might have been like for the participants to open up to someone without a brain injury regarding sex and intimacy. Only two of the participants spoke explicitly about sex and a third participant spoke briefly about the topic, but two out of these three seemed to become embarrassed and explicitly asked if we could move on and not discuss the subject any further. In particular, one of the participants discussed post injury experiences of sexual intercourse and described that orgasms either did not happen during sex or took longer and that this has caused some issues within her romantic relationship and then quickly changed the subject, and the same happened again when discussing vaginal dryness, and I wonder whether my position as a woman without ABI made this a more uncomfortable subject or an unapproachable one because it was something I had no direct experience of, and what might it have meant to the participants to reveal such things? Upon reflection I felt quite uncomfortable myself discussing sexual intimacy with the participants because I felt out of my comfort zone with regards to addressing this particular topic with strangers as it felt rude and invasive. Sex is discussed in my therapeutic work, but as I specialise in psychological trauma, sex is usually discussed in relation to rape and childhood sexual abuse within the context of the therapeutic relationship. As such perhaps I have become un-used to discussing sex and intimacy in the context of consent, desire and love. Another noticeable absence from the exchanges between myself and the participants was that of the prospect of motherhood and starting a family post injury. Once again this was something that I had not covered in my interview schedule, and on reflection this was an oversight again influenced by my ableism as I have not personally had to weigh up the prospect of having children whilst living with a disability. Ultimately the parameter set by me being a non-brain injured researcher may well have constrained important content regarding sex, intimacy and motherhood in a study whose focus was solely about romantic relationships post injury. The role and impact of ableism in non-disabled researchers is quite rightly recognised and debated within academia and politics (Stone & Priestley, 1996; Oliver, 1990; Morris, 1991), but given my concerns about being a non-brain injured researcher, this is something I could have better prepared for by seeking the involvement of those with lived experiences of brain injury and new romantic relationships post injury at the outset of this study. Nevertheless, despite the constraints my position imposed, I believe this study generated rich and illuminating data in a novel area which I hope may benefit other survivors who wish to pursue romantic relationships post injury.

Conclusion

The aim of this piece of work was to explore what it was like for female brain injury survivors encountering new romantic experiences post injury as well as demonstrate the importance of research in this area. I have attempted to provide insight into the social and emotional worlds of survivors as they adjust to the prospect or reality of developing emotional closeness and intimacy with a significant other and illustrate the unique stressors their brain injuries bring about as they navigate this stage in their lives. I have endeavoured to highlight the gap in existing brain injury literature and illustrate a potential unmet need in this specific population which could be addressed by the provision of specialist information and support. A qualitative approach was adopted to give single brain injury survivors a voice from within research whereby their experiences could be shared with rehabilitation professionals and health care staff who may not fully understand the unique set of challenges they face.

I have endeavoured to highlight how important and relevant this research is to Counselling Psychology, particularly by demonstrating how clinical interventions may benefit single brain injury survivors in the future. It is my wish that this piece of research will raise awareness of how the romantic decisions of single brain injury survivors are influenced by factors distinctive to this population, as well as offer valuable information and insight on how best to support such individuals who are in this particular situation. Given the paucity of research in this area this current study also hopes to ignite interest in this topic and inspire fellow researchers and doctorate students to pick up the mantle to continue to explore the experiences of brain injury survivors who are forming new romantic relationships post injury.

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Appendices

Appendix I: Recruitment Advert

Department of Psychology,
City, University of London

PARTICIPANTS NEEDED FOR RESEARCH IN FORMING NEW ROMANTIC RELATIONSHIPS AFTER BRAIN INJURY

We are looking for female volunteers aged 18 plus with mild to moderate acquired brain injury to take part in a study exploring the experiences of forming new romantic relationships after brain injury.

You would be asked to take part in an interview, which will be audio recorded.

Your participation would involve one interview, which is approximately 60 - 90 minutes.

In appreciation for your time, you will receive £25.

For more information about this study, or to take part, please contact:

Researcher: Joanne Ball - *joanne.ball@city.ac.uk*

Or

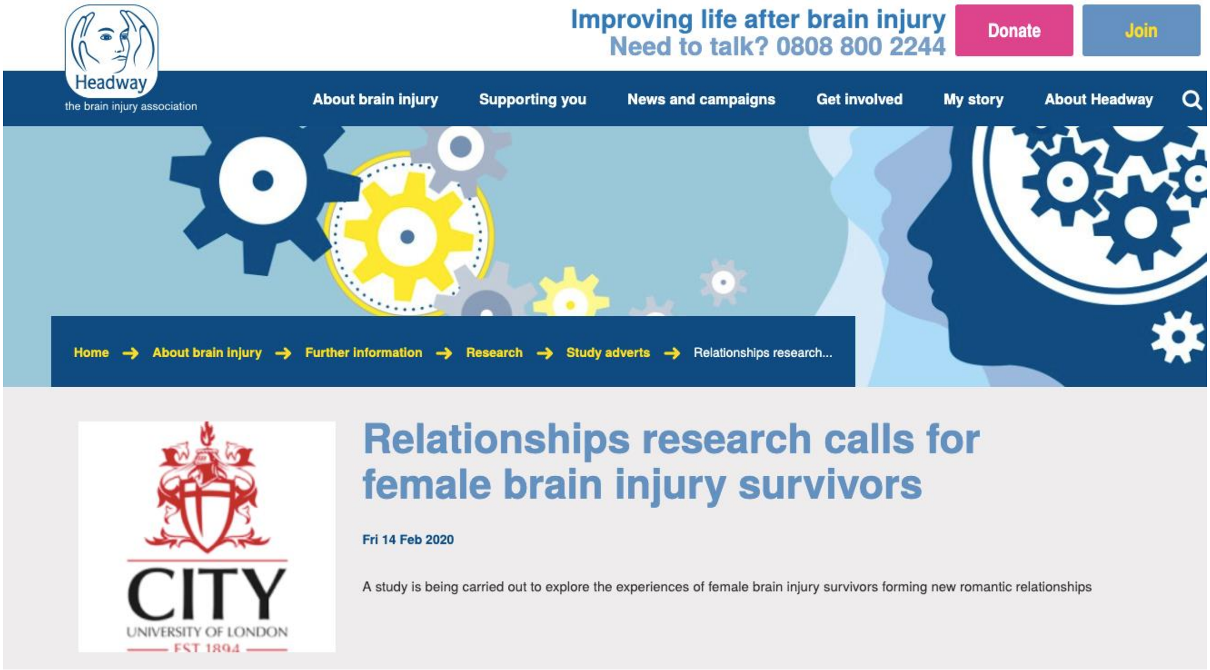
Research Supervisor: Dr Trudi Edgington - *Trudi.edginton@city.ac.uk*

This study has been reviewed by, and received ethics clearance through the Psychology Department's Research Ethics Committee, City University London [ETH1819-0345]

If you would like to complain about any aspect of the study, please contact the Secretary to the University's Senate Research Ethics Committee on 020 7040 3040.

Appendix II: Online Recruitment Adverts

(a) Headway UK website recruitment advert



Relationships research calls for female brain injury survivors

Fri 14 Feb 2020

A study is being carried out to explore the experiences of female brain injury survivors forming new romantic relationships

(b) Twitter recruitment advert

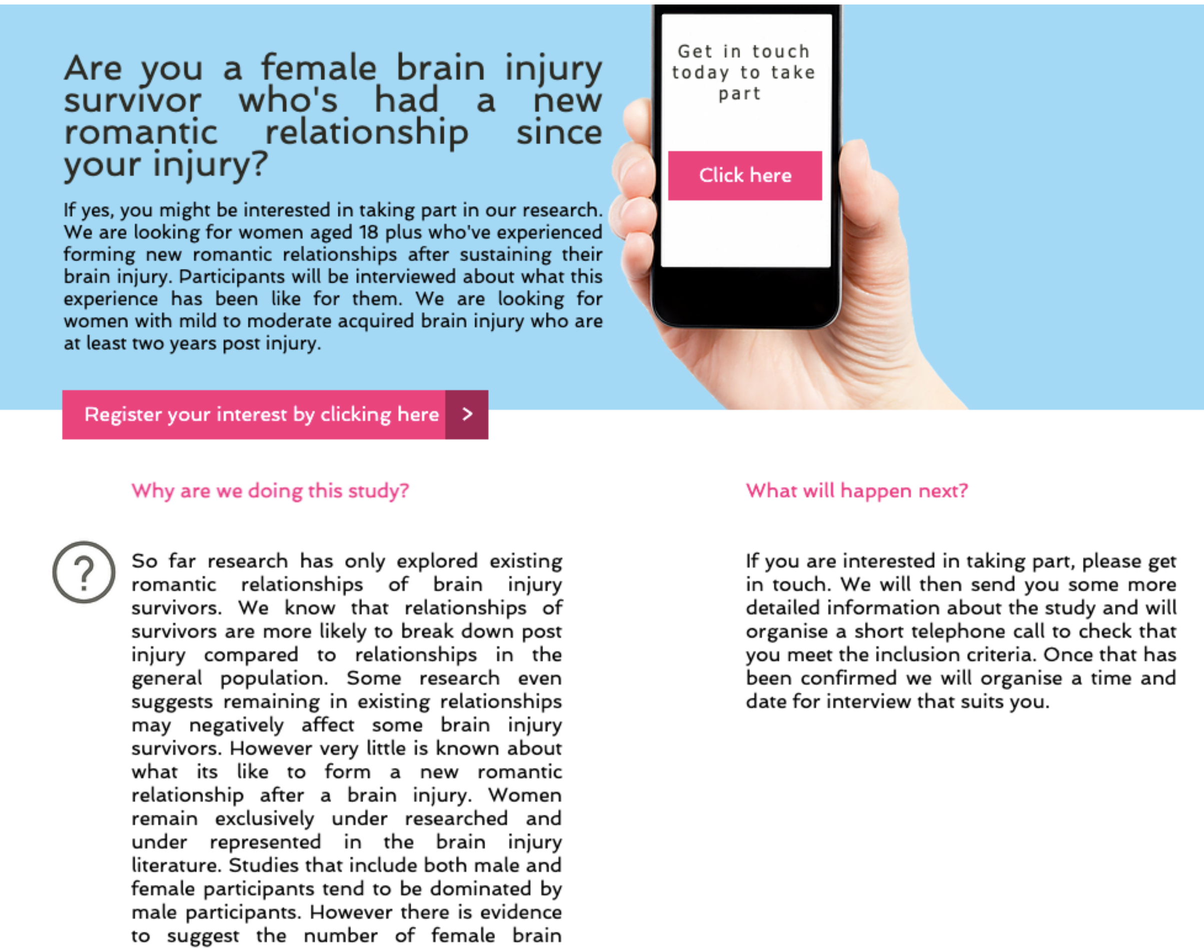
Joanne Ball @JoanneB55690574 · Feb 14, 2020

Are you a female brain injury survivor from the UK who's started a new romantic relationship after your brain injury? If so a new study would love to hear from you. You'll get £25 for taking part. Click here for more info:

joanneball.wixsite.com/mysite

#valentinesday2020 #braininjury

(c) Purpose built recruitment website



Are you a female brain injury survivor who's had a new romantic relationship since your injury?

If yes, you might be interested in taking part in our research. We are looking for women aged 18 plus who've experienced forming new romantic relationships after sustaining their brain injury. Participants will be interviewed about what this experience has been like for them. We are looking for women with mild to moderate acquired brain injury who are at least two years post injury.

Why are we doing this study?

So far research has only explored existing romantic relationships of brain injury survivors. We know that relationships of survivors are more likely to break down post injury compared to relationships in the general population. Some research even suggests remaining in existing relationships may negatively affect some brain injury survivors. However very little is known about what its like to form a new romantic relationship after a brain injury. Women remain exclusively under researched and under represented in the brain injury literature. Studies that include both male and female participants tend to be dominated by male participants. However there is evidence to suggest the number of female brain

What will happen next?

If you are interested in taking part, please get in touch. We will then send you some more detailed information about the study and will organise a short telephone call to check that you meet the inclusion criteria. Once that has been confirmed we will organise a time and date for interview that suits you.

Appendix III: Interview Schedule

1. Can you start by telling me about your brain injury?
2. What does a romantic relationship mean to you?
3. Could you tell me a bit about your romantic/ love life before your brain injury?
4. How do you/ did you feel about forming new romantic relationships after your brain injury?
5. Since your brain injury how do you feel in terms of sexual confidence?
6. Can you describe how your love life has been since your brain injury?
7. What did you want relationship wise?
8. What it’s like forming new romantic relationships?
9. Is there anything else that has impacted your ability or outlook on relationships?
10. How did what you experience fit in with your expectations?
11. How did new relationships compare to ones you’d had before your brain injury?
12. How did you experience forming new relationships post brain injury?
13. Has what’s happened to you shaped the way you think others may view you?
14. Does your romantic status affect your every day life? If so how?
15. How does your romantic relationship affect your everyday life?
16. How do you think your relationship with yourself has impacted/ affected your experiences of forming new romantic relationships?

Appendix IV: Participant Information Sheet

Title of study: How do female brain injury survivors experience forming new romantic relationships post injury?

We would like to invite you to take part in a research study. Before you decide whether you would like to take part it is important that you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

So far research has only explored existing romantic relationships of brain injury survivors. We know that relationships that existed before brain injury are more likely to break down after brain injury compared to relationships in the general population. Some research even suggests remaining in existing relationships may negatively affect some brain injury survivors. However very little is known about what it is like to form a new romantic relationship after a brain injury.

Research on brain injury survivors forming new relationships could help identify any potential difficulties, which could inform doctors, psychologists, counsellors and other health and mental health professionals. Conversely there may be other consequences of forming new romantic relationships, which may be useful to other brain injury survivors. Many health and mental health professionals use research like this to help them support and understand the people they work with.

The researcher leading this study is currently a trainee-counselling psychologist undertaking the Counselling Psychology Doctorate at City University and this research is for her thesis.

Why have I been invited?

Typically most research has focused on men, as males are more likely to sustain brain injuries. This means we know little about how women experience living with a brain injury. However the number of women sustaining head injuries is increasing. Therefore it’s becoming important to understand how women report such experiences.

Between six and ten women will be interviewed about their experiences of forming new romantic relationships after sustaining their brain injury.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be asked to sign a consent form. Once you have decided to take part in the study you are still free to withdraw at any time up to and during the interview and up to six weeks after the interview. You do not have to give a reason for withdrawing. You have the right to avoid answering any questions during the interview, which you feel are too personal or intrusive. If you decide to withdraw you will not be penalised or disadvantaged in any way. Once the interview has been completed you will have a six-week period where you have the right to decide whether or not you would like your information to be used in the study. Any notifications of withdrawal must be provided within this six-week period due to the time intensive analytic period this type of research involves. Please email the researcher joanne.ball@city.ac.uk should you wish to withdraw.

What will happen if I take part?

- You will meet the researcher in person or via skype
- You will be interviewed by the researcher and this interview will be audio recorded
- The researcher will use a semi-structured interview to explore your experiences of forming new romantic relationships after your injury
- The interview will last between 60 and 90 minutes
- Usually only one interview is needed but you may have to be available for a further interview should that be required
- A qualitative research method called Interpretive Phenomenological Analysis will be used by the researcher which means conducting a series of in depth interviews with a handful of participants about a very specific experience
- The research will take place in a private room at a Headway Hub

Payments

- You will receive £25 as a token of appreciation for the time you have given towards this study

What do I have to do?

By taking part in this study you will need to attend a Headway Hub where you will meet the researcher. Alternatively if it is not possible to meet the researcher in person the interview will take place via skype. In a private room the researcher will ask you a series of questions about your experience of forming new romantic relationships after your brain injury. The interview will be audio recorded. No one else will be in the room. Once the interview has finished your researcher will provide you with a debrief form which will explain why this research is taking place and why it might be useful.

What are the possible disadvantages and risks of taking part?

Everybody's experiences of forming romantic relationships after brain injury will be different, and some people's experiences might mean upsetting aspects are discussed. If you become upset during your interview please let the researcher know. If you become extremely upset the researcher will stop the interview. Your well-being is far more important than any research. Your researcher will be able to provide you with some information on where you can find further emotional support should you feel you need it. This will be provided in the debrief form your researcher will go through with you once your interview has finished.

What are the possible benefits of taking part?

Some people find contributing to research satisfying as it can inform health professionals, help improve practice and raise awareness of previously unknown issues. Additionally your contribution may be beneficial to other people who are in your position. However please be aware that whilst this is the aim of the research, none if this is guaranteed

Will my taking part in the study be kept confidential?

- Only the researcher and supervisor will have access to your data whilst it is not anonymized
- The audio recording of the interview is used for analytic purposes only and will not appear or be published anywhere nor will it be shared with anyone
- Your personal information shall not be shared with anyone or used by the researcher or the university in the future
- Digital data shall be stored for 10 years and then destroyed according to City University Policy
- Hard copies of data shall be stored at the researchers house and be stored in a locked filing cabinet for 10 years and then destroyed according to City University Policy
- Please be aware that whilst privacy, confidentiality and anonymity will be adhered to, there are limits and your researcher has a duty to report any current violence, abuse, harm to others and criminal activity to the police and self-inflicted harm to your GP. Your researcher will notify you in advance of any such reporting.
- If the project is abandoned before completion then all data will be destroyed immediately according to City University policy

GDPR: What are my rights under the data protection legislation?

City, University of London is the data controller for the personal data collected for this research project. Your personal data will be processed for the purposes outlined in this notice. The legal basis for processing your personal data will be that this research is a task in the public interest, that is City, University of London considers the lawful basis for processing personal data to fall under Article 6(1)(e) of GDPR (public task) as the processing of research participant data is necessary for learning and teaching purposes and all research with human participants by staff and students has to be scrutinised and approved by one of City's Research Ethics Committees.

Further, City considers the processing of special category personal data will fall under Article 9(2)(g) of the GDPR as the processing of special category data has to be for the public interest in order to receive research ethics approval and occurs on the basis of law that is, inter alia, proportionate to the aim pursued and protects the rights of data subjects.

The rights you have under the data protection legislation are listed below, but not all of the rights will be apply to the personal data collected in each research project.

- right to be informed
- right of access
- right to rectification
- right to erasure
- right to restrict processing
- right to object to data processing
- right to data portability
- right to object
- rights in relation to automated decision making and profiling

For more information, please visit www.city.ac.uk/about/city-information/legal

What will happen to the results of the research study?

The aim for this study is to be written up as a thesis, which will hopefully go on to be published in psychological and health research journals where it can be accessed by health and mental health professionals. It will also be shared with Brain Injury charities such as Headway. Your anonymity will remain protected at all times. If you would like to receive a copy of the research once it has been published please email the researcher:

Joanne.ball@city.ac.uk

What will happen if I don’t want to carry on with the study?

Once you have decided to take part in the study you are still free to withdraw at any time up to and during the interview and up to six weeks after the interview. You do not have to give a reason for withdrawing. You have the right to avoid answering any questions during the interview that you feel are too personal or intrusive. If you decide to withdraw you will not be penalised or disadvantaged in any way. Once the interview has been completed you will have a six-week period where you have the right to decide whether or not you would like your information to be used in the study. Any notifications of withdrawal must be provided within this six-week period due to the time intensive analytic period this type of research involves.

What if there is a problem?

If you have any problems, concerns or questions about this study, you should ask to speak to a member of the research team. If you remain unhappy and wish to complain formally, you can do this through the University complaints procedure. To complain about the study, you need to phone 020 7040 3040. You can then ask to speak to the

Secretary to Senate Research Ethics Committee and inform them that the name of the project is**:** *How do female brain injury survivors experience forming new romantic relationships post injury?*

You could also write to the Secretary at:

Secretary to Senate Research Ethics Committee
Research Office, E214
City University London
Northampton Square
London
EC1V 0HB

City University London holds insurance policies which apply to this study. If you feel you have been harmed or injured by taking part in this study you may be eligible to claim compensation. This does not affect your legal rights to seek compensation. If you are harmed due to someone's negligence, then you may have grounds for legal action.

Who has reviewed the study?

This study has been approved by City University London [Psychology Research Ethics Committee.] Research Ethics Committee code, [ETH1819-0345].

Further information and contact details

Student researcher: Joanne Ball
joanne.ball@city.ac.uk
Research Supervisor: Dr Trudi Edginton
Trudi.edginton@city.ac.uk

Thank you for taking the time to read this information sheet.

Appendix V: Participant Consent Form

Title of Study: How do female brain injury survivors experience forming new romantic relationships post injury?

Ethics approval code: ETH1819-0345

Please initial box

1	I confirm that I have had the project explained to me, and I have read the participant information sheet, which I may keep for my records.	
	I understand this will involve:	
	• be interviewed by the researcher	
	• allow the interview to be audiotaped	
	• make myself available for a further interview should that be required	
2	This information will be held by City as data controller and processed for the following purpose(s): *research and lawful basis for processing under General Data Protection Regulation (GDPR) for personal data and special category data (sensitive personal data-if applicable).* Public Task: The legal basis for processing your personal data will be that this research is a task in the public interest, that is City, University of London considers the lawful basis for processing personal data to fall under Article 6(1)(e) of GDPR (public task) as the processing of research participant data is necessary for learning and teaching purposes and all research with human participants by staff and students has to be scrutinised and approved by one of City's Research Ethics Committees. I understand that the following special category data will be collected and retained as part of this research study: *data concerning health or data concerning sex life or sexual orientation* City considers the processing of special category personal data will fall under: Article 9(2)(g) of the GDPR as the processing of special category data has to be for the public interest in order to receive research ethics approval and occurs on the basis of law that is, inter alia, proportionate to the aim pursued and	

	protects the rights of data subjects and also under Article 9(2)(a) of the GDPR as the provision of these personal data is completely voluntary.	
3	I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party. No identifiable personal data will be published. The identifiable data will not be shared with any other organisation.	
	I understand that I will be given a transcript of data concerning me for my approval before it is included in the write-up of the research.	
4	I understand that my participation is voluntary, that I can choose not to participate in part or all of the project, and that I can withdraw up to six weeks after the interview without being penalised or disadvantaged in any way.	
5	I agree to City recording and processing this information about me. I understand that this information will be used only for the purpose(s) set out in this statement and my consent is conditional on City complying with its duties and obligations under the General Data Protection Regulation (GDPR).	

6.	I agree to the arrangements for data storage, archiving, sharing.	
7	I agree to the use of anonymised quotes in publication.	
8	I agree to take part in the above study.	

______________________ ______________________________ ______________
Name of Participant Signature Date

______________________ ______________________________ ______________
Name of Researcher Signature Date

When completed, 1 copy for participant; 1 copy for researcher file.

Note to researcher: to ensure anonymity, consent forms should NOT include participant numbers and should be stored separately from data.

Appendix VI: Debrief Form

Title of study: How do female brain injury survivors experience forming new romantic relationships post injury?

DEBRIEF INFORMATION

Thank you for taking part in this study. Now that it's finished we'd like to tell you a bit more about it.

Why is this researched needed?

So far research has only explored existing romantic relationships of brain injury survivors. We know that relationships that existed before brain injury are more likely to break down after brain injury compared to relationships in the general population. Some research even suggests remaining in existing relationships may negatively affect some brain injury survivors. However very little is known about what it is like to form a new romantic relationship after a brain injury.

Women remain exclusively under researched and under represented in the brain injury literature. Studies that include both male and female participants tend to be dominated by male participants. However, the number of female head injuries has risen by 24% since 2005 and 2006 in the UK. That is why this study focused exclusively on women.

How could this research help?

Exploration on how women experience forming new romantic relationships post brain injury may help mental health professionals and support workers employed in this field to acquire a deeper understanding of any difficulties that arise for women in this position and facilitate appropriate therapeutic support.

Help and support

If you feel the interview has raised any concerns for you that you'd like to address you have a number of options:

- Your GP - make an appointment and tell them what's troubling you. They may be able to refer you for mental health support if both of you feel it's necessary.
- GP out of hours services – you can call 111 for urgent help which is not life threatening
- Samaritans (support charity) - Free helpline number open 24/7 – call 116 123
- Sane (mental health charity) – *Out of hours helpline number - 0300 304 7000 – daily from 4.30pm to 10.30pm*

Alternatively the following charities, associations and groups offer support and advice for people with brain injuries

- Brain and Spine Foundation **-** free helpline staffed by neuroscience nurses to answer questions about all neurological conditions and offer information and support on any medical or related social and emotional issues – 0808 808 1000
- Headway – offer information, support and services to brain injured people - www.headway.org.uk
- The Brain Injury Group offer free legal and welfare advice – 0800 612 9660 or 01737 852203
- Silver Linings aims to engage people affected by brain injury with the wider community and they operate in London, West Midlands, Surrey and Oxford among other places – www.thesilverlining.org.uk
- The following Facebook groups offer online support group for brain injury survivors & their families – Brain Injury and Mental Health Support Group, Traumatic or Acquired Brain Injury Support Group, Traumatic Brain Injury Awareness and Support

How can I find out more about research and brain injury?
Many studies about brain injury can be found on google scholar:

https://scholar.google.co.uk

Just enter your search terms in the same way you would use the normal google.

Further information about this study
We hope you found the study interesting. If you have any other questions please do not hesitate to contact us at the following:

Researcher's email address: joanne.ball@city.ac.uk

Research supervisor's email address: Trudi.edginton@city.ac.uk

This study has been approved by City University London [Psychology Research Ethics Committee.] Research Ethics Committee code, [ETH1819-0345].

Appendix VII: Email of Ethical Approval

Dear Joanne

Reference: ETH1920-0718

Project title: How do female brain injury survivors experience forming new romantic relationships post injury?

Start date: 26 May 2019

End date: 31 Dec 2019

I am writing to you to confirm that the research proposal detailed above has been granted formal approval from the Psychology committee: medium risk. The Committee's response is based on the protocol described in the application form and supporting documentation. Approval has been given for the submitted application only and the research must be conducted accordingly. You are now free to start recruitment.

Please ensure that you are familiar with City's Framework for Good Practice in Research and any appropriate Departmental/School guidelines, as well as applicable external relevant policies.

Please note the following:

Project amendments/extension

You will need to submit an amendment or request an extension if you wish to make any of the following changes to your research project:

- Change or add a new category of participants;
- Change or add researchers involved in the project, including PI and supervisor;
- Change to the sponsorship/collaboration;
- Add a new or change a territory for international projects;
- Change the procedures undertaken by participants, including any change relating to the safety or physical or mental integrity of research participants, or to the risk/benefit assessment for the project or collecting additional types of data from research participants;
- Change the design and/or methodology of the study, including changing or adding a new research method and/or research instrument;
- Change project documentation such as protocol, participant information sheets, consent forms, questionnaires, letters of invitation, information sheets for relatives or carers;
- Change to the insurance or indemnity arrangements for the project;
- Change the end date of the project.

Adverse events or untoward incidents

You will need to submit an Adverse Events or Untoward Incidents report in the event of any of the following:

a) Adverse events

b) Breaches of confidentiality

c) Safeguarding issues relating to children or vulnerable adults

d) Incidents that affect the personal safety of a participant or researcher

Issues a) and b) should be reported as soon as possible and no later than five days after the event. Issues c) and d) should be reported immediately. Where appropriate, the researcher should also report adverse events to other relevant institutions, such as the police or social services.

Should you have any further queries relating to this matter, please do not hesitate to contact me. On behalf of the Psychology committee: medium risk, I do hope that the project meets with success.

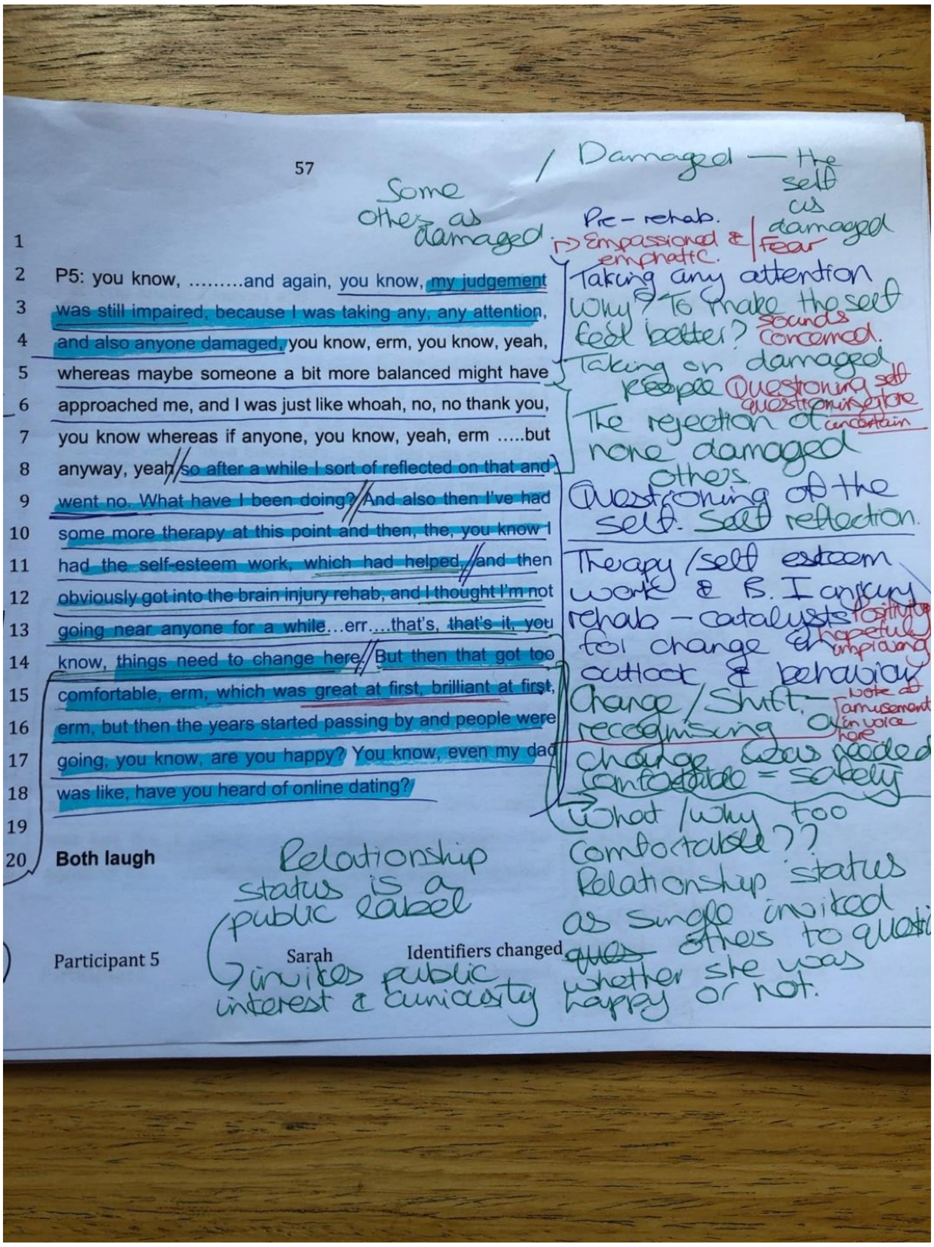
Kind regards

Psychology committee: medium risk

City, University of London

Ethics ETH1920-0718: Joanne Ball (High risk)

Appendix VIII: Example of Initial Note Taking



P5: you know, ………and again, you know, my judgement was still impaired, because I was taking any, any attention, and also anyone damaged, you know, erm, you know, yeah, whereas maybe someone a bit more balanced might have approached me, and I was just like whoah, no, no thank you, you know whereas if anyone, you know, yeah, erm …..but anyway, yeah so after a while I sort of reflected on that and went no. What have I been doing? And also then I've had some more therapy at this point and then, the, you know I had the self-esteem work, which had helped, and then obviously got into the brain injury rehab, and I thought I'm not going near anyone for a while…err….that's, that's it, you know, things need to change here. But then that got too comfortable, erm, which was great at first, brilliant at first, erm, but then the years started passing by and people were going, you know, are you happy? You know, even my dad was like, have you heard of online dating?

Both laugh

Participant 5 Sarah Identifiers changed

Some others as damaged

Damaged — the self as damaged

Pre-rehab.

Empassioned & emphatic.

Fear

Taking any attention Why? To make the self feel better?

sounds concerned.

Taking on damaged people

Questioning self questioning [illegible] uncertain

The rejection of none damaged others.

Questioning of the self. Self reflection.

Therapy / self esteem work & B. I. injury rehab – catalysts for change in outlook & behaviour

positive hopeful [illegible]

Change / Shift – recognising a change was needed

Note of amusement in voice here

comfortable = safety

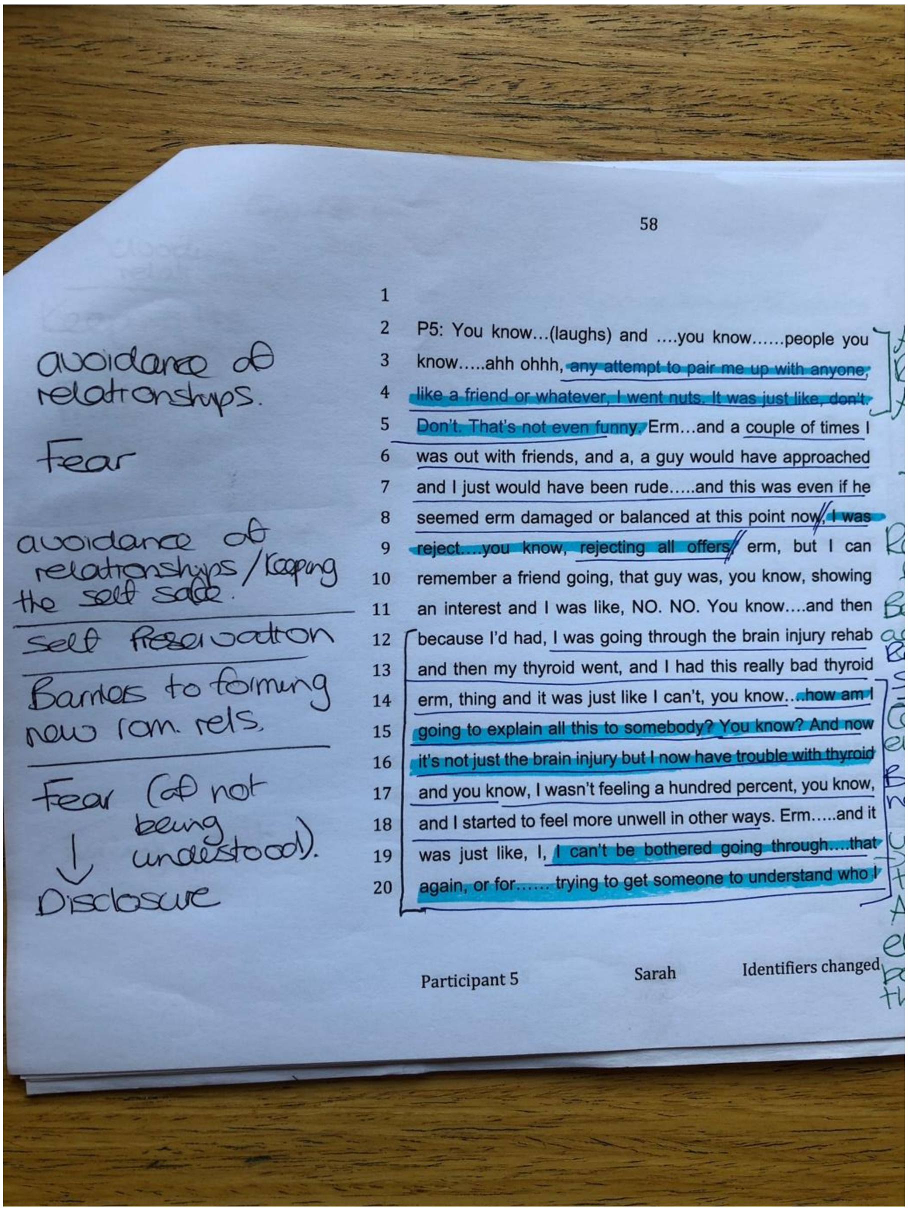
What / why too comfortable??

Relationship status as single invited ~~ques~~ others to question whether she was happy or not.

Relationship status is a public label

invites public interest & curiosity

Appendix IX: Example of Identifying Emergent Themes



58

P5: You know…(laughs) and ….you know……people you know…..ahh ohhh, any attempt to pair me up with anyone, like a friend or whatever, I went nuts. It was just like, don't. Don't. That's not even funny. Erm…and a couple of times I was out with friends, and a, a guy would have approached and I just would have been rude…..and this was even if he seemed erm damaged or balanced at this point now, I was reject….you know, rejecting all offers, erm, but I can remember a friend going, that guy was, you know, showing an interest and I was like, NO. NO. You know….and then because I'd had, I was going through the brain injury rehab and then my thyroid went, and I had this really bad thyroid erm, thing and it was just like I can't, you know….how am I going to explain all this to somebody? You know? And now it's not just the brain injury but I now have trouble with thyroid and you know, I wasn't feeling a hundred percent, you know, and I started to feel more unwell in other ways. Erm…..and it was just like, I, I can't be bothered going through….that again, or for…… trying to get someone to understand who I

avoidance of relationships.

Fear

avoidance of relationships / Keeping the self safe.

Self Preservation

Barriers to forming new rom. rels.

Fear (of not being understood).
↓
Disclosure

Participant 5 Sarah Identifiers changed

Appendix X: Extract from Master Table of Themes

Feeling Disconnected	Ref	Quote
	3.11	*"I don't feel like I can join in"*
	3.11	*"I feel like a stranger"*
	3.12	*"I described it before as being like a brick wall, trying to move a brick wall, trying to get through…that….nothing will….you push harder, nothing happens, nothing"*
	59.10	*"To not feel normal makes me feel guarded, it makes me feel I want to withdraw from society. I don't want people to know"*
	54.3	*"I was still feeling again, still adrift, still so adrift"*
	15.5	*"I got a lot of misunderstanding and I didn't know how to express…..how I felt"*
	29.16	*"It was sort of like looking through a window…..where like everyone else was on the outside and it was just me sort of by myself"*
	26.16	*"It was getting to grips with the idea that I wasn't like everybody else as well"*
	28.13	*"I do get tired really easily, I do get really bad headaches you know, I do lose my balance if I get drunk you know….and all of those things lead…to a feeling of sort of…sort of us, and, us and like them and me. Where you know it was like everyone else was able to do everything that I wanted to do…."*
	112.6	*"I like being able to communicate quite frequently, [ ], whereas a lot of people who have brain injuries will be unable to do that so, which is why I'm very lucky"*
	82.7	*"I've only got little bits really that are still struggling, at least I can smile and chat and I go to all the Silver Lining Meetings and stuff, and the people there are just so, so much more brain damaged"*
	82.11	*"I find it quite therapeutic to go to those meetings and feel very lucky [ ] to be alive really and yeah not more brain damaged really"*
	59.6	*"..dating is a nightmare for anyone, anyway so….it doesn't matter if you've got a brain injury or not….I don't think it's changed in the, in the time that I've been dating"*

PART II

Research Article for Psychology & Health

How do female brain injury survivors experience forming new romantic relationships post injury?

An interpretative phenomenological analysis

HOW DO FEMALE TRAUMATIC BRAIN INJURY SURVIVORS EXPERIENCE FORMING NEW ROMANTIC RELATIONSHIPS POST INJURY? AN INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS

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HOW DO FEMALE TRAUMATIC BRAIN INJURY SURVIVORS EXPERIENCE FORMING NEW ROMANTIC RELATIONSHIPS POST INJURY? AN INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS

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Traumatic brain injury (TBI) can leave survivors with a complex and enduring range of physical and psychological sequalae. Brain injuries can result in relationship breakdown, yet little remains known about what it is like for survivors to begin new relationships post-injury. This study aims to explore how female brain injury survivors experience forming new romantic relationships post injury. The qualitative method of interpretative qualitative analysis (IPA) was used to investigate these experiences of five women with traumatic brain injuries. The major themes that emerged were: Investment in the self and self-preservation; Fear; and Inner conflict, confusion and uncertainty. This article explores the barriers to forming romantic relationships, and the implications for practice are considered.

Keywords: brain injury; TBI; Women; Relationships; Qualitative

Introduction

Traumatic brain injuries are often sudden, unexpected events which can require significant psychological adjustment resulting in global upheaval to one's personal life. There are reported to be 1.3 million people living with the effects of traumatic brain injury in the UK with an estimated cost to the economy of £15 billion (Menon, 2018). Males are twice as likely to be affected by TBIs than females (Whitfield et al, 2009). The age group most at risk of sustaining a traumatic brain injury in the UK is 15 to 24 years (Dombrowski, Petrick & Strauss, 2000) meaning many survivors will live with associated impairments for many years. Brain injury can result in a range of sequalae such as physical impairments, cognitive impairments and psychiatric disorders. Functional impairments and psychological consequences of brain injury have been associated with social limitations and difficulties (Draper, Ponsford & Schönberger, 2007; Bowen et al, 2009) and negative attitudes towards brain injury survivors have been evidenced in wider society (Ralph & Derbyshire, 2013).

Previous literature has explored the impact of brain injury upon romantic relationships extensively, but little research has exclusively investigated the establishment of new romantic relationships post injury. This paucity of literature is concerning due to several reasons, especially as relationship breakdown is not uncommon after injury (Wood and Yurdakul, 1997**;** Kreutzer, Marwitz, Hsu, Williams and Riddick, 2007). In addition, there is evidence to suggest poorer post injury outcomes across several domains for single brain injury survivors (Kaplan and Michael, 2000; Donker-Cools, Birgit, Wind & Frings-Dresen, 2016). In addition to this, social isolation has been identified as both prevalent and problematic for many survivors (Sander & Struchen, 2011). Given the evidence highlighting how integral intimacy and connection are to overall wellbeing for people in wider society (Braithwaite and Holt-Lunstad, 2017), together with growing evidence of the beneficial roles close relationships can play in adjustment post injury (Bowen, Yeates & Palmer, 2018). It is crucial for counselling psychologists and other professionals working with brain injury survivors to develop a greater understanding of any problems or challenges that arise for survivors pursuing romantic attachments thus enabling the provision of appropriate therapeutic support and rehabilitation.

As research into brain injury has developed, a generation of studies have begun to adopt the views of people living with brain injury and as such there is a growing body of literature reflecting the subjective accounts of brain injury survivors (Howes, Benton & Edwards, 2005; Erikson, Karlsson, Borell & Tham, 2007; Brown, Lyon & Rose, 2006; Lorenz, 2010; Edwards, Daisley & Newby, 2014; Salas, Casassus, Rowlands, Pimm & Flanagan, 2016). However, the number of studies exploring the subjective viewpoints of female brain injury survivors remains small (Howes, Benton & Edwards, 2005; Haag et al, 2016; St Ivany et al, 2018; Nalder et al, 2016; Fabricius, D'Souza, Amodia, Colantonio & Mollayeva, 2020). Females have for the most part been both exclusively under researched and underrepresented in the brain injury literature (Colantonio, 2016). Studies including both male and female samples tend to be dominated by male participants. This over-representation is thought to reflect the higher incident rates of brain injury in males (Whitfield et al, 2009), although there is an indication that head injuries in females are increasing (Tennant, 2015). However, there is growing evidence brain injury affects females differently. Sex-based differences include higher mortality rates (Ottochian et al, 2009) and differences in severity (Munivenkatappa, Agrawal, Shukla, Kumaraswamy & Devi, 2016). There is also a growing awareness of gender-based differences such as the relationship between women and intimate partner violence and TBI (Corrigan, Wolfe, Mysiw, Jackson & Bogner, 2003). Given that gender can refer to a set of social processes (Butler, 1990) together with evidence that points to existing sex differences pertaining to relational factors in young adult brain injury survivors (Lindsay et al, 2016) there is likely to be significant merit in exploring males and females separately when investigating social processes such as forming romantic relationships.

While quantitative research has contributed enormously to the field of brain injury and benefitted survivors worldwide, this type of enquiry imposes limitations on the nature and the extent of what we can know about brain injury survivors. Qualitative research enables human experiences to be studied in a more holistic way instead of focusing on specific parts of experience (Moustakas, 1994). Furthermore, qualitative approaches such as Interpretative Phenomenological Analyses (IPA) are likely to compliment and enrich areas of research dominated by quantitative methods. Research which focuses on the voices and perspectives of brain injury survivors is helpful in challenging professional and academic assumptions about what is most important and can generate meaningful future lines of enquiry (Martin, Levack & Sinnott, 2015). Such approaches also benefit those who work with survivors both therapeutically and in terms of rehabilitation by increasing their awareness of how certain facets of life are experienced by survivors (Howes, Benton & Edwards, 2005).

IPA is a type of qualitative approach that seeks to elicit subjective accounts of specific real-life experiences from respondents who share similar characteristics such as gender and health situation. By adopting the perspective of those most affected by a particular phenomenon, credence is given to personal accounts and subjectivity as opposed to attempting to yield objective descriptions of objective events. This strong commitment to the particular as opposed to the general (Pietkiewicz and Smith, 2014) together with a focus on individual detail means sample sizes are usually small (Smith, 2004). IPA acknowledges that how people interpret and make sense of their experiences can be affected by social processes and interactions with others (Willig, 2013). Adopting an approach with an appreciation of interpersonal aspects is respectful and ethical when working with brain injury survivors as they have been found to experience negative treatment from others (Hellem, Førland, Eide & Ytrehus, 2018) and be more vulnerable to stigma and discrimination (Ralph & Derbyshire, 2013). IPA is increasingly being employed to explore the lived experience of brain injury survivors as well significant others who are also affected by this lifelong disability (Howes, Benton & Edwards, 2005; Brunsden, Kiemle & Mullin, 2015; Townshend & Norman, 2018; O'Keeffe, Dunne, Nolan, Cogley & Davenport, 2020; Martin, Levack & Sinnot, 2015). IPA uses semi-structured interviews which facilitates fine-grained and in-depth explorations of the research topic (Eatough & Smith, 2008). The aim of applying IPA is to produce deep, compelling and descriptive insights into how individuals are thinking about and responding to important and personally meaningful life events whilst dealing with a complex and enduring disability. Therefore, this study hopes to build upon the existing small but important corpus of IPA literature by exploring how female brain injury survivors experience forming new romantic relationships post-injury.

Method

Participants

All five participants were recruited through two nationwide brain injury support charities, Headway and Silverlinings UK and via recruitment adverts on social media. Participants were aged between 25 and 50 years old with a mean age of 43 years. Four of the participants were single at the point of injury and fifth participant became single immediately following injury. At the time of interview two participants were in long term romantic relationships and three participants were single but had had various new romantic experiences since sustaining their injuries. All the participants had sustained traumatic brain injuries. Level of brain injury ranged from moderate to severe and time since injury ranged from three years to 31 years, with a mean of time since injury of 14 years. Levels of severity ranging from mild to moderate were specified on the recruitment adverts and were accepted as either self-reported or clinically confirmed levels of injury. Two of the participants were diagnosed with initial severe injuries that subsequently became moderate and so they were included in the study. All participants received in-patient rehabilitation following admission for their brain injury. Post discharge support varied greatly. Also given the research topic, it was imperative that participants lived with daily effects of their brain injury. See Table 1 for demographic information. Pseudonyms have been used within all the extracts which extends to all third parties, and any identifying information has been removed.

Interview Schedule

The interviews were semi-structured and contained several questions and prompts to facilitate discussion relating to the research topic. Whilst the interview schedule included questions relating to the area of interest, it was by no means prescriptive and therefore afforded participants respect by allowing them to contribute to the direction of the interviews (Eatough & Smith, 2008).

Data Collection

All participants were provided with an information sheet along with the opportunity to raise any queries with the researchers. Ethical approval was granted by Psychology Research Ethics Committee at City, University of London, and informed, written consent was obtained prior to the interviews, one of which took place in person in a private room at City University with the remainder conducted remotely via video link. Participants were asked to provide basic sociodemographic information, and each received £25 as token appreciated of their time. All interviews were recorded on a digital recording device and transcribed verbatim.

Table I: Demographic information of participants

Pseudonym	Age	Injury	Severity	Time Since Injury	Pre/ post-injury Occupation	Romantic Status at point of injury/ current	Children	Living	Mobility status	Sexual Orientation
Participant 1 (P1) “Mia”	25	TBI	Moderate	10 years	Student/ 999 100 Operator	In a relationship/ long term relationship	No	Independently	Fully mobile	Heterosexual
Participant 2 (P2)“Chrissie”	47	TBI	Severe	3 years	Software engineer/ Legal consultant	Single/ Single	Yes/ Pre-injury	Independently	Fully mobile	Heterosexual
Participant 3 (P3) “Charlie”	48	TBI	Moderate to severe	31 years	Student/ Part time volunteer	Single/ Single	No	At home with support	Fully mobile Supported travel	Heterosexual
Participant 4 (P4) “Ruth”	50	TBI	Severe	10 years	Administrator/ Full time volunteer	Single/ Single	No	Independently	Fully mobile	Heterosexual
Participant 5 (P5) “Sarah”	45	TBI	Moderate	22 years	999/100 Operator Part time student	Single/ long term relationship	No	Independently with support	Limited mobility	Bisexual

Analysis

All interviews were analysed using IPA as outlined by Smith (1996). The first transcript was read several times and during this process sections of interest were highlighted. Initial noting led to the identification of emerging themes which were grouped according to shared relationships. This process was repeated for each transcript individually before moving on to analyse the accounts collectively. The accounts were also reviewed to elucidate divergence, contrasts and comparison further broaden and deepen identified themes. Themes which emerged from the cross-case analysis reflected connections and conceptual similarities across the group and were determined as recurrent if they occurred for at least half of the participants (Smith, 2009). Once a set of meaningful links and connections were identified, an overarching superordinate theme emerged which comprised of three related subordinate themes all of which were felt to reflect the whole group and capture the essence of the participants' lived experience pertaining to the research question. Transcripts and themes were peer reviewed and discussed with an academic supervisor with the aim of enhancing the rigour of the work produced.

Results

The experiences of the participants in this study culminated in the development of one superordinate theme, *Barriers to forming romantic relationships,* which captured the difficulties and challenges experienced in developing romantic connections whilst living with a traumatic brain injury. This superordinate theme comprised of three subordinate themes (i) Investment in the Self & Self Preservation (ii) Fear (iii) Inner Conflict and Confusion and Uncertainty.

Investment in the self & self-preservation

All the participants had been involved in near death experiences which caused their traumatic brain injuries resulting in initial substantial functional impairments, and they all played purposeful and active roles in recovering from these injuries. This began with a focus on physical, cognitive and emotional recovery and over time moved towards a more psychological recovery as well as contemplating romantic relationships with others.

> “*When I was in hospital and everything I did have to learn to walk and talk again*”. *(Ruth)*

For many of the participants this acute phase of their recovery was a frightening and overwhelming experience especially given at this point they were unaware of the exact nature of any lasting consequences. Four of the participants were single at the point of injury, and this often meant they embarked on their journey of recovery alone.

> *“I did sort of isolate myself but, with a view to, with a reason why [ ] rather than just being frightened by life, it was because I wanted to work on myself to get myself better”. (Chrissie)*

This strong sense of determination to improve as well as self-reliance was expressed by all the participants. Some of the participants were also motivated by desires to return to their pre-injured selves.

> *“I just wanted to get back to the way I was before the accident”. (Sarah).*

> *“I described it before as being like a brick wall, trying to move a brick wall, trying to get through…that…nothing will…you push harder, nothing happens. Nothing”. (Charlie)*

However, often such efforts were futile as a return to their pre-injured state was not possible which resulted in feelings of frustration, sadness and loss. For some, the enduring and pervasive consequences of their injuries led to confronting their post-injury differences, which often meant recognising a different self.

> *"I'm not fine, I'm not the same person at all. It…things changed, you know, instantly, the moment it happened". (Chrissie)*

This represents a shift common to many of the participants in that initially after injury there was a focus on physical, cognitive and emotional recovery which over time moved towards focusing on the self in a more psychological manner. But this approach too was both purposeful and active requiring effort and motivation.

> *"..that took a lot of work to realise I am not going to be that person I was when I was 22, you know, erm…. And that took long. Hard. Work. (Sarah)*

Acceptance did not come about as a result of the passage of time but instead involved a long and emotionally difficult process requiring dedication and commitment.

> *"…those first ten years were sheer hell, and I came through a lot, and I realise that…[ ]….I'm very protective of it….and if someone rejected me because of that, that would be……devastating". (Sarah)*

For some, acceptance was reached and became a part of their recovered selves but the risk of being invalidated through romantic rejection after all they had been through was perceived as a huge concern. However, acceptance did not occur for everyone, and it is interesting to note that the participant who had lived with her injury the longest was the least accepting. For many, post injury progress and recovery became something to be guarded and as such a priority which emerged for many was the need for self-preservation.

> *"I feel like I've got to protect myself a lot more". (Chrissie)*

> *"before the brain injury I didn't give a shit about risk, [ ] I was far more free and easy". (Chrissie)*

This need to protect themselves from the threats that romantic relationships may pose was a distinct departure from their pre-injured selves and represented a more vulnerable self that had emerged from the brain injury.

> *"It was fear of…having to open up…about my brain injury…let someone in, for this thing that I'd worked so hard to be able to manage, and it was like I can't let anyone interfere with that [ ] I wanted to protect myself I think, so that was a big thing". (Sarah)*

The prospect of becoming romantically involved with someone was associated with risk and uncertainty and evoked fear of contending with the unknown which echoed characteristics akin to their journeys of recovery. Interestingly, the investments they had made towards their improvements led to a particular relationship with their brain injury.

> *"I think in terms of your brain injury, it's something to protect. [ ] Something to nurture and no-one can mess with that". (Sarah)*

The language the participants used implied they were fiercely protective of their recovery indicating they regarded it as fragile. Having lived through near death experiences meant maintaining stability post injury was crucial, stability that prospective romantic rejection and emotional upheaval could threaten.

Fear

The prospect of forming romantic relationships evoked fear and trepidation for many of the participants, all of which related to their brain injuries.

> *"I thought I mightn't be good enough in that respect [ ]. I thought I would let someone in and then have the disappointment and the rejection of being told, you're not enough because of your brain injury, cause they can't handle it". (Sarah)*

> *"…I was worried that he, you know, he'd just be like nah, it's too much baggage, because it is, it is quite a lot of baggage". (Mia)*

Concerns centred around being judged, unwanted and rejected as well worries about being a burden. These cognitions were unpinned by low self-esteem and perceived stigma and evoked emotionally painful and distressing reactions. Concern also extended to being seen by a romantic other with their brain injury symptoms present which brought about a sense of vulnerability.

> *"I didn't want to show him everything….like you know, strip myself bear as it were…….and for him to go woah, you know, if…..I think I almost had like a hierarchy of like things about me that were scary". (Mia)*

There was also significant unease regarding the lack of knowledge regarding brain injury in wider society highlighting the difficulty of living with an ‘invisible disability’.

> *“I think I, I felt…reluctant to start a relationship because of people not…. of a man not understanding…not being able to understand. I don’t work, and that’s one, been one of the biggest things for me, not being in paid work, paid employment, so, if someone didn’t understand that because, there’s absolutely nothing to see that, it’s completely hidden, you know?”. (Charlie)*

The experiences of the participants indicate the depth and range of specific fears evoked in anticipation of forming new romantic relationships post injury, most of which were underpinned by concerns regarding stigma and perceived stigma. They highlight certain cognitive processes and behavioural reactions such as self-doubt, low-self-esteem and avoidance of being emotionally hurt, all of which were distressing for the participants. The concerns many of the participants voiced highlights the complexity of the interface where the personal meets the interpersonal and illustrates the unique psychological challenges brain injury survivors face when contemplating developing romantic relationships.

Inner Conflict, Confusion & Uncertainty

The prospect of forming new romantic relationships evoked overwhelming ambivalence in many of the participants as they recognised that fulfilling their romantic desires meant exposing themselves to further vulnerability and increasing risk when they craved stability. The inner conflict and uncertainty the prospect of a romantic relationship prompted illustrates the differences having a brain injury makes when contemplating relationship options.

> *"I don't like to think of me spending the rest of my life on me own but, [ ]…I do feel like (laughs) I'd never be able to live with someone again". (Ruth)*

The ambivalence Ruth felt in relation to her romantic future is clear. The way Ruth laughed indicated bemusement as she realised the paradox she was halfway through expressing. This terse summary of competing desires represents the experiences of many of the participants; on the one hand there is an innate desire for romantic connection, but it is constantly competing against the need for certainty, familiarity, stability and safety. For Charlie, conflict, confusion and uncertainty centred around past personal decisions resulting in unexplored romantic opportunities.

> *"I know that there has been times that I have got a little further when I haven't felt attracted to them but I think, I perhaps take it too seriously that…. why not? Why couldn't I just try with someone? Why couldn't I just take it further? Why couldn't I just have a date with someone or…?". (Charlie)*

Charlie's recollections led to self-interrogation and her use of questioning suggests regret and frustration at herself. There is also a sadness conveyed in here, and a sense of grief and mourning for missed opportunities lost in time. For many, the prospect of becoming romantically involved with someone prompted an evaluation of the self in the context of being a romantic partner with a brain injury which often resulted in a position of stalemate in that it led to uncertainty regarding the best way to move forward. Concerns regarding everyday types of social expectations potential partners may have of the participants were common and anxieties about not being to meet these expectations due to the limitations their brain injury imposed seemed to exacerbate negative self-concept.

> *"Part of me was like, yes I'd be very happy being single if that's my choice, but then it was starting to be no, I'm not happy, I think I need to, try again, but I was feeling oh, well what [ ] can I bring?….you know…..I'm not working, I have this brain injury". (Sarah)*

Uncertainties at times kept some of the participants stuck as they became paralysed by indecision. These experiences intensified when the participants met someone to whom they were attracted.

> *"I don't know what I want, that's the thing and I…but all the time I'm not doing this, I've got no way of knowing…. what it is that I do want". (Chrissie)*

Mia recalls how she felt when what she had initially perceived to be a casual sexual relationship seemed to be developing into something more serious. Mia's repetition of the word sick suggests she was physically fearful of letting someone in and developing emotional closeness.

> *"I woke up at 3am one morning and I sat bolt upright and I went oh no. Like, I, I felt sick at the idea of being in a relationship. I felt absolutely sick at the idea". (Mia)*

All the participants described how they believed their brain injury had significantly impacted their attitudes towards forming romantic relationships as their post-injury experiences were so drastically different to what they had known before.

> *"…this is what confuses me about relationships now because, what it feels like I've lost is that ability to take a risk, that ability to, to trust in the universe a bit and think…..yeah they might be alright for me, [ ], they might be a mistake, but you're not gonna get it right first time, there's gonna be plenty of duffs". (Chrissie)*

Overall, participants were more vulnerable and had become more cautious and risk averse towards developing emotional closeness and intimacy with others post injury. The weight that considerations regarding romantic relationships carried demonstrates how significant and distressing these types of decisions can be for survivors. The fact all the participants harboured desires to be in a romantic relationship, whilst feeling deeply conflicted about it happening is indicative of just one of the many dilemmas they are faced with. Being held back from exploring romantic opportunities was a common experience and heavily influenced by a different set of priorities the brain injury had brought about, namely self-preservation. For the most part forming new romantic relationships was associated with becoming more vulnerable, relinquishing control and entering the unknown.

Discussion

The findings of this study demonstrate that the prospect of forming new romantic relationships post-injury gives rise to a unique set of challenges and concerns in the following three areas: self-preservation, fear, and inner conflict, confusion and uncertainty. These themes indicate this a specific period of adjustment whereby the self and personal needs are re-evaluated, which has the potential to impact survivor wellbeing as well as romantic based decisions and behaviours.

What was synonymous for all participants was the relationship they developed with their brain injury and recovery which began with an active and purposeful approach towards recuperation. For many of the participants this developed into a lifelong partnership where the brain injury was given priority when considering decisions regarding romantic relationships. It is not unusual for brain injury survivors to be action orientated in terms of their recovery (Nochi, 2000; Chamberlain, 2005). Recovery had become a fragile part of the brain injured self which needed protecting from the threat new romantic relationships may pose. Having first-hand experience of how responsive brain injuries can be to active and sustained efforts may have contributed towards participants fearing the reverse could also be true. Perhaps recovery attributed to the self leaves in its wake a legacy of concerns that human endeavours from others could be just as instrumental in its destruction.

The theme of *Investment in the Self & Self-preservation* could be understood in the context of threat appraisal (Folkman, 1984). In the current study desires to form new romantic relationships conflicted with a need to protect a vulnerable, brain injured self. At times this tension made some participants weary of developing intimate and emotional closeness with others and as such they became avoidant of pursuing romantic opportunities. Riley (2004) found threat appraisals and subsequent avoidance were common in TBI survivors in relation to social situations. This current study adds to these findings by illustrating threat appraisal and subsequent avoidance can also extend to the development of romantic relationships. However, at times self-preservation came at the cost of developing intimate and potentially supportive romantic relationships.

Decisions related to romantic relationships elicited fear, conflict, confusion and uncertainty in many of the participants which related to self-doubt and stigma as well as caution and hesitancy at the prospect of becoming a romantic partner. This reflects how risk averse some of the participants had become since sustaining their brain injury as well as demonstrating their need to re-evaluate what it may mean to have a relationship as a brain injury survivor. Many of the participants experienced the prospect of a romantic relationship as a stressful event which impacted their decision-making ability. Interestingly, Krpan et al. (2007) discovered that negative assessments in relation to stressful circumstances made by TBI survivors correlated with an increase in executive dysfunction. This led Krpan et al. (2007) to suggest that the same neural substrate was involved in both coping and executive functioning. It is therefore unsurprising that the prospect of romantic relationships provoked uncertainty and inner conflict.

Given the challenges participants faced in relation to developing romantic relationships, it is useful to consider that rehabilitation approaches for single brain injury survivors tend to be high individualised compared to the relational approaches offered to couples and families who learn to negotiate the consequences and relational impacts of the brain injury together. The absence of relational and community rehabilitation may mean single brain injury survivors do not learn how to be in relation to others at a time when they most need to re-develop interpersonal skills to help reconcile painful feelings of difference and establish supportive relationships, including those of an intimate and romantic nature.

Having a brain injury was not a permanent prohibitive factor in establishing romantic relationships but being a survivor made developing these relationships more challenging and distressing as participants sought to navigate desire alongside protecting their more vulnerable selves whilst maintaining a sense of stability. Participants were clear that their outlooks towards romantic relationships post injury were a demarcation from their pre-injured selves thus attributing all associated differences to the acquisition of their brain injury. The fear expressed by many was underpinned by stigma, or perceived stigma and concerns regarding disclosure. Living with an invisible disability often means that disclosure becomes part of a how a survivor manages their relationships with others (Jones et al, 2014). The distress caused by stigma in addition to dealing with cognitive and neurological changes means it is often difficult for survivors to create new social relationships (Jones, Jetton, Haslam & Williams, 2014). This current study supports this research and lends support to findings which have highlighted how the opinions and behaviours of non-brain injured others impacts the social participation of survivors (Gelech & Desjardins, 2011). Novel, but perhaps not unexpected findings generated by the current study highlight how issues surrounding disclosure contribute towards difficulties in developing closeness with prospective romantic partners due to concerns regarding stigma and revealing a brain injured self. The current study placed within the context of existing research provides a broad framework from which to begin to consider and explore the complex interactions between psychological and social processes as survivors attempt to establish meaningful romantic relationships after sustaining their injuries. Working with single brain injury survivors in relational ways may facilitate the development of supportive romantic relationships post injury which in turn could lead to further positive psychosocial outcomes.

Methodological Limitations

The sample size in this study was small and the fact this study was exploratory in nature means the findings should not be made to all single brain injured women. Further to this, all participants were of Caucasian descent and British. It is important for this to be held in mind when considering the research findings as the experiences described are only reflective of white British Caucasian women. Although all the participants had traumatic injuries, different parts of the brain had been affected and injuries ranged from moderate to severe. The current research emphasises the importance of recognising the relational components, concerns and difficulties brought about as the result of sustaining an invisible disability with enduring consequences which extend beyond the acute phase of recovery well and into the chronic period. The findings support other research that has challenged the notion that relationship difficulties are solely brought about as a result of functional impairments and post-injury social loss by highlighting the importance of psychological appraisals of both the self, others and wider society.

Implications for Practice

In view of the present study's findings, it is important for all professionals working with single brain injury survivors to recognise their potential needs and desires to form new romantic relationships post-injury. Therapeutic support is likely to help increase psychological flexibility in relation to some of the barriers that inhibit the development of romantic relationships. Accessing support would be more likely during the chronic phase of recovery and as such may not be sought exclusively from rehabilitation or brain injury services. As such specialised training could be developed and delivered for professionals working in services to which survivors can self-refer such as the NHS Improved Access to Psychological Therapies (IAPT).

In terms of the nature of appropriate psychological support, interventions could normalise the challenges faced by single brain injury survivors as well as work specifically with fear, acceptance and perceived stigma. Interventions designed to help manage distress can help improve executive function which in turn helps with decision making (Krpan et al, 2007). Given the individualistic focus in the acute recovery phase, group work may help survivors develop confidence regarding interpersonal skills. Rehabilitation professionals should include the relationship goals of single brain injury survivors into recovery plans as this could indicate more relational and systemic ways of working are necessary.

Conclusions

This study has made an original contribution to brain injury research by addressing a knowledge gap within the existing literature as until this current study little was known about what it was like to form new romantic relationships post injury. As such this research has provided fresh insights highlighting the challenges that exist at the intersection of being single, female and brain injured and in pursuit of a romantic relationship. This qualitative approach has raised awareness of the social and emotional worlds of survivors as they adjust to the prospect or reality of developing emotional closeness and intimacy with a significant other and has illustrated the unique stressors their brain injuries bring about as they adjust to this stage in their lives. As such this has brough to the forefront a potential unmet need in this specific population which could be addressed by the provision of specialist information and support during rehabilitation.

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Declaration of Interests

There are no interests to declare.

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