A Qualitative Exploration of Fatherhood after Acquired Brain Injury (ABI)

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Thesis Portfolio Abstract

Background: When a person acquires a brain injury their life and the lives of those around them changes irrevocably and profoundly. To date, there is little explicit focus on ABI survivors' experiences of coupled relationships post-ABI. Most research in parenting post-ABI has centred on quantitative studies in this area.

Aims: The aim of the current study was to gain a rich and deep understanding of the phenomenon of how men experience fatherhood after ABI. Following the initial interviews, the systematic review question was refined to explore: what are acquired brain injury survivors' experiences of coupled relationships after brain injury?

Design: This research is presented in the format of a thesis portfolio which includes; a systematic review of qualitative literature exploring survivors' experiences of coupled relationships after ABI, an empirical paper using an IPA approach to explore men's experiences of fatherhood after ABI, an extended methodology chapter and a critical evaluation chapter.

Findings: The systematic review included five studies from which five themes emerged: (1) being a changed partner (2) altered roles as survivors (3) sexuality (4) connectedness and (5) ongoing acceptance, commitment and understanding. The empirical research identified four themes: (1) what being a father means, (2) altered relationships with others, (3) becoming lost and finding their way through, and (4) renewed fatherhood.

Conclusions: The findings from the review point to themes that may both hinder and help relationships after ABI. The findings from the empirical study tentatively support prior research and offer important insights into what it means to be a father with ABI. Both studies are first in the UK exploring these under-represented areas and may aid future clinical and research implications for this brain injury population.

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Chapter 1

A Systematic Review of Qualitative Literature exploring the Experience of Coupled Relationships after Acquired Brain Injury (ABI) in Survivors

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What are acquired brain injury survivors' experiences of coupled relationships after brain injury: a systematic review

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Abstract

To date, there is little explicit focus on ABI survivors' experiences of coupled relationships. This review aims to summarise current literature representing the ABI survivor perspective. A systematic search of databases and hand search of relevant journals was carried out, providing: sufficient depth of information, participant quotations and insight into the coupled experiences of ABI survivors. Identified studies are summarised into a data extraction table and common qualitative themes extracted and discussed concerning relevant literature. Five papers met inclusion criteria and were rated as high quality using the CASP quality rating tool for qualitative research. Five themes were identified: (1) being a changed partner, (2) altered roles as survivors, (3) sexuality, (4) connectedness and (5) ongoing acceptance, commitment and understanding. Findings from the review support the view that survivors' relationship experiences appear vulnerable following the impact of ABI on coupled life. Many of the experiences expressed by survivors' highlight perceived barriers to relationships. Further research focus is warranted exploring possible strengths and facilitators to relationship continuity which clinicians may begin to draw on in working with couples after ABI.

Keywords: Qualitative systematic review, acquired brain injury, partner, relationships, survivor experiences.

Introduction

Acquired brain injury (ABI) is an “umbrella term” encompassing a range of conditions from traumatic brain injuries (TBI) to non-traumatic causes of injury, such as stroke or encephalitis, and varying in severity from mild to severe (Haag et al., 2016). The consequences of ABI are documented in research showing physical, social, cognitive and psychological sequelae after brain injury (Headway, 2015). Research over the past decade has predominantly explored carer or spousal perspectives (Whiffin, Ellis-Hill, Bailey, Jarrett, & Hutchinson, 2017) as well as the familial impact of ABI (Segev, Levinger, & Hochman, 2018; Townshend & Norman, 2018) little research attention appears to have focused on the experience of coupled relationships (Godwin, Kreutzer, Arango-Lasprilla, & Lehan, 2011). This limited focus highlights an increasing need to begin to explore the influence of ABI on coupled relationships (Layman, Dijkers & Ashman, 2005), particularly from the perspective of ABI survivors' experiences. For this review, a coupled relationship will encompass marriage, cohabitation, long-term partners and those who identify as being in an intimate relationship.

Many coupled relationships continue following ABI, others dissolve under the weight of difficulties faced by the survivor and the partner (Blais & Boisvert, 2005). A "social limbo" is created for partners of ABI survivors (Lezak, 1978) because the ABI creates a barrier to the couple resuming appropriate social participation and the non-injured partner may suffer harsh social criticism for leaving the injured partner in the community. Despite ABI being termed "family injury" in much of the research, less empirical investigation of coupled relationships after ABI is noted. The current literature concerning the impact of ABI on partnered relationships, could best be described as confusing and contradictory especially from the viewpoint of the survivor (Godwin, Chappell, & Kreutzer, 2014). To date studies of marital or coupled relationships following brain injury have been diverse and ambiguous in relating their findings of marital satisfaction (Godwin et al., 2014). The significant impacts on the quality of the relationship often include only spousal perspectives without exploring survivor or whole-couple perceptions of change following ABI (Blais & Boisvert, 2005; Moore, Stambrook, Peters, & Lubusko, 1991; Peters, Stambrook, Moore & Esses, 1990).

Research on ABI survivors describes psychosocial and neurobehavioral consequences of ABI that contribute to the deterioration of familial and spousal relationships (Lond & Williamson, 2018). ABI survivors report more limited friendships, increased loneliness and difficulty making new friendships and relationships (Levack, Kayes, & Fadyl, 2010). Specific areas of difficulty include; mood impairments (Jackson, Turner-Stokes, Murray, Leese, & McPherson, 2009), sexual dysfunction (Goldin, Cantor, Tsaousides, Spielman, & Gordon, 2014; Ponsford et al., 2014), increased dependence on the partner (Engström & Söderberg, 2011) as well as an impaired ability to make decisions (Knox, Douglas, & Bigby, 2015). Additionally, an extra layer of difficulty may present in survivors' changed personalities with problems commonly reported in coping with interpersonal strain, negative affect, confidence (Gill, Wall, & Simpson, 2012; Layman et al., 2005), independence and autonomy (Willer, Allen, Liss & Zicht., 1991).

Much of the research that has covered coupled relationships has asserted that spouses as caregivers find themselves in a particularly unique position (Hammond, Davis, Whiteside, Philbrick, & Hirsch, 2011). Non-injured spouses are concerned about their partners’ cognition, lack of insight, decreased autonomy, personality changes and mood swings, forcing them to straddle roles of coupled partner and caretaker at the same time (Bodley-Scott & Riley, 2015).

Gosling and Oddy (1999) found that female partners of men with ABI had difficulties reporting positive aspects of their relationships, but could verbalise their sense of ongoing friendship, affection and commitment. Female partners reported increased responsibilities in the relationship lead to feeling more in control, with an increased perception of gratitude from their injured partner. In other studies, female partners of men with ABI reported resignation and an obligation to maintain the relationship even when it had changed (Gosling & Oddy, 1999; Jumisko, Lexell, & Söderberg, 2005). A couples' adjustment is likely to be impacted following these significant role shifts, loss of intimacy and loss of reciprocal empathic understanding following a partner's brain injury (Blais & Boisvert, 2005). Women of injured partners report a decreased sense of companionship or equitable relationship, with many concerned by a lack of explicit expressions of physical or emotional affection from their injured partner (Willer et al., 1991). Many described finding themselves in changed or new roles within their relationship, which they perceived as caring or even parental but at odds with the role of a sexual partner (Gosling & Oddy, 1999).

Gosling and Oddy's (1999) study examined the quality of marital and sexual relationships in couples after the male partner had sustained a brain injury. The study found females rated sexual and marital satisfaction as significantly lower than did their injured partners following a brain injury. Sexual relationship changes or concerns after ABI are commonly reported in coupled relationships. In a large sample of men and women with ABI, 54% reported a decrease in sexual activity, 41% a decrease in sex drive and 36% a difficulty in achieving orgasm after brain injury (Ponsford, 2003). For non-injured female partners of TBI survivors, Gosling and Oddy (1999) noted decreased satisfaction in intimate relations following injury, as well as a tendency for partners to be less open to the sexual advances of the survivors with some absence of sexual activity altogether. ABI injured spouses may struggle to effectively convey their concerns to their partners challenged by communication, cognitive, emotional and intimate barriers (Godwin et al., 2011). The uncertainty experienced by ABI survivors creates a sense of ambiguity as to whether their caregiving spouses are satisfied with the intimate sexual relationship after injury (Kreuter, Dahllöf, Gudjonsson, Sullivan, & Siösteen, 1998). This indicates that the coupled intimate relationship domain may be particularly vulnerable and challenged in post-injury couples (Gill, Sander, Robins, Mazzei, & Struchen, 2011).

Rates of marital separation or breakdown after ABI are reported between 15 - 78% (Godwin et al., 2011) with little explanation for this considerable variation. It appears separation is more common than divorce, with an increased vulnerability noted in the years five-six after the initial injury (Landau & Hissett, 2008; Wood & Yurdakul, 1997). Gill et al. (2011) have suggested the differences in the reported rates of relationship breakdown may relate to issues with studies sampling using specific clinics. There is also evidence that couples who are older or who were together for more extended periods before injury are more likely to stay together long-term after ABI (Layman et al., 2005). Relationships formed after injury appear more resilient to stressors, possibly as they were established with the full awareness of injury sequelae (Godwin et al., 2014) versus couples with established history that can struggle to adjust resulting in separation or divorce (Gosling & Oddy, 1999).

The culture and environmental context surrounding ABI can contribute towards social isolation of survivors and partners. Negative views of persons with disability combined with a lack of knowledge about ABI and its consequences may be impacting relationships (Gill et al., 2011). Also, uninjured partners may lack the resources and support necessary to adjust to the complex and life-changing long-term needs of their injured partner (Gill et al., 2011). Social support provided by returning to work for both partners after ABI shows better outcomes in social adjustment and social support to maintain relationships and contribute to an increased opportunity to form intimate relationships (Blais & Boisvert, 2005; Katz, Kravetz, & Grynbaum, 2005). Theoretical models aimed at offering an understanding of adjustment processes in couples to date are adapted from either general stress and coping literature (Lazarus & Folkman, 1984), pro-relationship behaviours (Kumashiro, Finkel & Rusbult, 2002) or newly developed through research (Godwin et al., 2014).

Previous research has explored some aspects of coupled relationships after ABI, it appears this has been limited in the exploration of experiences from ABI survivors. A greater amount of studies has primarily focussed on the burden, stress or caregiving aspects of coupled relationships; interviewing spousal, familial or professional perspectives using quantitative methodology. These studies and measures while useful may not provide the perceived facilitators or barriers as understood by individuals with ABI. They may struggle to capture nuanced and rich data around experiences of ongoing relationships. As such an examination of the current qualitative research may guide what is already known from the current peer-reviewed published literature and provide a mutual understanding of survivors' own experiences regarding their coupled relationships.

Review Question

The primary objective of this systematic review is to explore:

- What are acquired brain injury survivors’ experiences of coupled relationships after brain injury?

Explicitly, this review will (1) summarise existing qualitative literature on survivors' experiences of personal relationships after brain injury (2) draw out themes occurring across the eligible articles selected and (3) evaluate the limitations and strengths in the literature presented. Finally, it may offer insights as to what implications or recommendations can be drawn out from the literature for research and clinical applications.

Method

A systematic search strategy was used. This was guided by the framework set out by Khan, Kunz, Kleijnen and Antes (2003) and based on the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA; Moher, Liberati, Tetzlaff, Altman, & The PRISMA Group, 2009). The review question was developed using the PEO method (Population and their problems, Exposure, Outcomes or themes) to form the search terms used (Bettany-Saltikov, 2012). This assists in identifying the key terms to search in answering the research question. These were:

Population and their problems: acquired brain injury (ABI) survivors

Exposure: coupled relationships

Outcomes or themes: experiences of coupled relationships.

The review uses the term acquired brain injury survivors to include all individuals with brain injury and differentiates from accounts of experiences provided by other key stakeholders such as professional or partner.

Eligibility Criteria

The criteria for inclusion of studies were

- Peer-reviewed published research studies about the survivor's experience of coupled relationships after acquired brain injury or part thereof if the survivor data can be extracted when presented jointly as part of the couple's experience.
- Qualitative or mixed articles only

Research studies excluded were:

- Articles not relevant to survivors coupled relationship experience or insufficient data relating to the survivor experience could be extracted.
- Articles that relate to another aspect of their brain injury experience.
- Articles that pertained to spouse, child, family or professional experiences rather than those of the person with ABI.
- Paper was not available in the English language
- Paper was an unpublished thesis
- Paper was a literature review

Information Search Strategy and Terms

The search terms employed to perform the search were identified by consulting relevant literature and adopting terms related to the target identifiers of population, exposure and outcomes. Databases were searched for the following terms:

brain injur* or head injur* or traumatic brain injur* or acquired brain injur* or ABI or TBI

AND

partner relationship* or spous* relationship*, or spous* experience* or marriage or marital or relationship experience* or intimate relationship

AND

qualitative or mixed methods or interview or grounded theory (anywhere in the text)

Specific search terms initially hypothesised to be relevant to the searching included stroke, encephalitis, and romantic however their use did not significantly increase the returned studies. These terms were excluded as relevant studies were deemed captured via broader umbrella terms such as ABI, acquired brain injury and the other terms for coupled relationships based on the keywords and MESH terms utilised in previous studies. The initial search was not limited to title and abstract to widen the search field and the possibility of finding related articles in an area where there is a lack of research. The use of an asterisk at the end of search terms allowed for any variant to be identified for example spouse, spousal, spouses under the spous* search term. Relevant literature was last searched on 10 November 2018 in four electronic databases: CINAHL, Medline EBSCOhost, PsychINFO, and EMBASE. Limits were not applied during the search for the year of publication or publication status; however, English was selected as a language limit.

Study Selection

The review is focused on survivor experiences of coupled relationships using qualitative or mixed methods. The first stage of the search involved including studies that used a qualitative methodology, that were published peer-reviewed research studies and excluded studies that were not written in English. Following this stage, duplicated studies were removed from the search results. Further screening was performed at the title and abstract level for eligibility and relevance, according to the pre-set eligibility criteria. At this point, the full text of the article was screened, and studies excluded. Studies were excluded if they were not relevant to the subject of the review, did not fit the inclusion criteria or included insufficient data about survivor experiences to be extracted. A total of five articles were identified that matched the inclusion criteria of the review question. From these five articles, the reference lists were hand searched to identify additional articles. A further 33 articles were identified through the top-down approach, yet none fit the review criteria for inclusion.

Assessment of Quality

Research professionals are susceptible to using poor value or quality findings during clinical application without critically appraising research used (Rees, 2010). Critiquing research helps the researcher to determine the reliability of findings and judge the perceived value it may add to the research area however there is a lack of consensus as to the best method or the role which quality appraisal plays in assessing qualitative studies (Dixon-Woods, Shaw, Agarwal & Smith, 2004). Structured appraisal tools form part of the audit trail in completing systematic reviews of existing bodies of literature. These tools do not always guarantee or reliably generate ratings that can attest to a reduction in the risk of bias (Woods et al., 2007).They may, however, guide the reviewer in the argument for the choice of papers included and transparency in the apparent quality of articles aggregated into review material.

The studies included were assessed using the Critical Appraisal Skills Programme (CASP, 2014) qualitative quality checklist. This checklist provides a framework for systematically appraising the quality of qualitative research using ten questions that address the qualitative methodology, research design, recruitment, data collection, researcher position, ethical concerns, analysis as well as the relative weight of findings and value in prospective research. Articles were read and re-read to gain familiarity with the main ideas put forward, the findings and themes related to the survivor's experiences of relationships after brain injury. A score between 1, 0.5 and 0 was assigned in response to answering "yes", "can't tell" and "no" from the ten questions employed by the CASP. Summative scores are not recommended due to the qualitative nature of the research, a score summarising the relative quality of articles can guide which studies are included or more appropriately excluded in the final papers. Ratings were ranked according to relatively low quality (0-3), medium quality (3.5-7.5) and high quality (8-10) CASP performance. A table denoting CASP outcomes for each eligible study can be seen in the appendices (see Appendix B). No studies were excluded as all studies were found to represent high-quality research using the CASP tool. A second rater was used to quality assess using the CASP tool. Where there was a difference in scores, this did not impact the relative quality as studies remained in the high range for quality.

Data Analysis

The results were synthesised following Braun and Clark's (2006) inductive thematic analysis where identified themes are strongly linked to the data analysed (Braun & Clarke, 2006). A semantic approach was used to organise and summarise the findings, using only the direct raw quotes extracted from the peer-reviewed published papers. This method utilises qualitative metasummary (Sandelowski, Barroso & Voils, 2007) where the findings of the direct survivor quotes are accumulated and then summarised from the original data rather than transformed as a way of producing a map of the contents of the qualitative studies available in regards to the specific review question asked.

Results

Study Selection

The initial combined results from the databases identified 777 articles which were reviewed for eligibility criteria. When duplicate entries were removed, 263 papers were remaining to be screened at title and abstract of which a further 239 were excluded. After this screening level, 24 articles were reviewed at full text and 19 studies removed. The articles removed included: unpublished thesis or dissertations, review articles, articles which were not from the survivor perspective, did not contain sufficient data to extract the survivor experiences or were abstract only without a full-text article. A total of five studies were included in the final set of papers for review. Figure 1 denotes the study selection process, stages of screening, eligibility and final papers for analysis according to the PRISMA guidelines (Moher et al., 2009).

Data Extraction Procedure

The findings were understood as any qualitative experiences of ABI survivors coupled relationships within the results of each article. It should be noted that where studies have specified TBI, this is the language used. The author will use ABI as an umbrella term to include all types of brain injury from traumatic to non-traumatic as it is intended. Additionally, spouse and partner are used interchangeably across the literature partner will be used across the remainder of this review to indicate those who are married as well as those in committed relationships. Four of the five articles had results which were not based solely on survivor experiences rather mixed with spousal or professional experiences. In the final articles, it was possible to extract survivor findings where direct quotes were reported separately. Study details and findings from the five articles selected for review were extracted and summarised in a table (see Table 1).

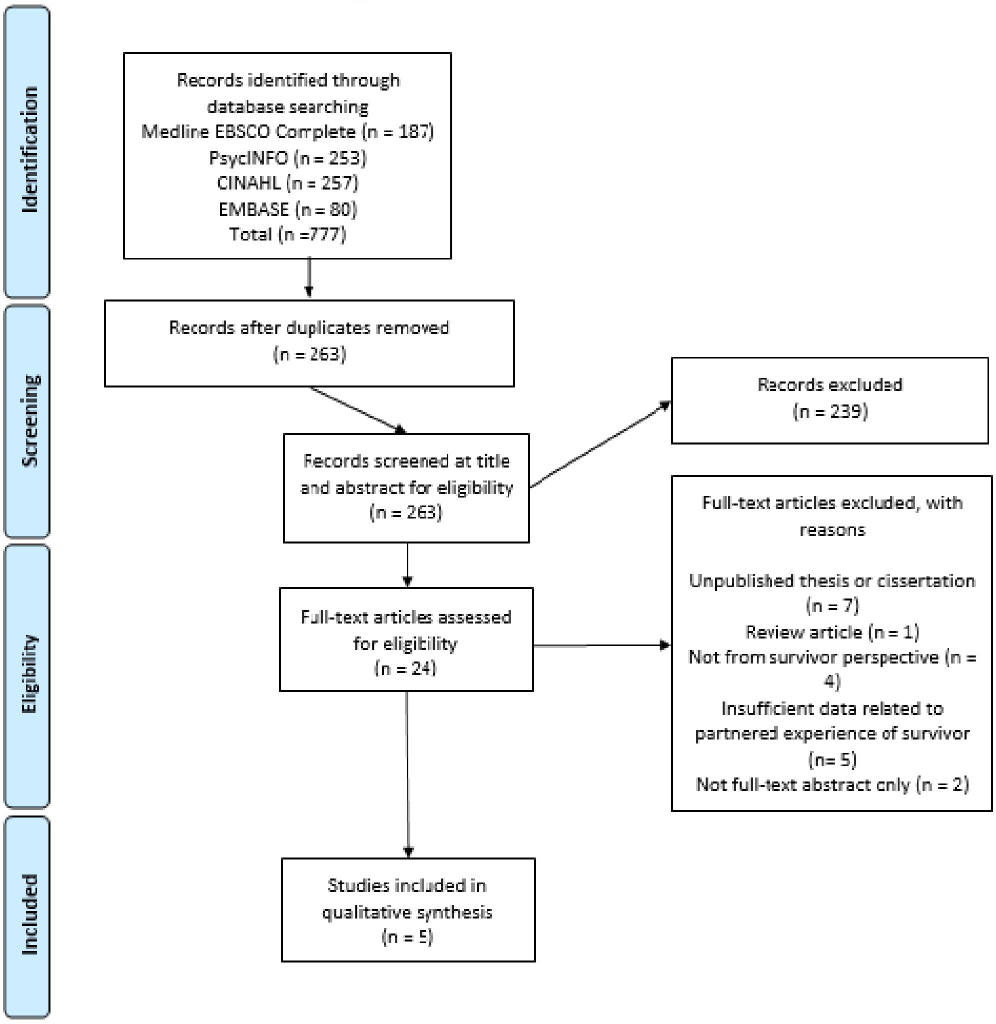

Figure 1. PRISMA Flowchart based on Moher et al. (2009) showing article selection during the systematic review process

Table 1. Summary table of extracted data

Authors & country	Title	Participants	Methodology	Analysis	Primary findings
Gill, Sander, Robins, Mazzei & Struchen, (2011). United States	Exploring experiences of intimacy from the viewpoint of individuals with traumatic brain injury and their partners.	18 couples interviewed individually: 12 female, 6 male, 12 married, 6 not married, 8 relationships of <5yrs, 10 relationships >5yrs. Five begun relationship after TBI and 11 couples had children. TBI severity not discussed.	Qualitative interview study	Grounded theory	"Factors that were perceived as helping relationships remain strong included unconditional commitment, spending time together, open communication, a strong pre-injury relationship, bonding through surviving the injury together, social support, family bonds, spirituality, experience with overcoming hardship, and coping skills. Factors that were perceived as barriers to intimacy included injury-related changes, emotional reactions to changes, sexual difficulties, role conflict and strain, family issues, social isolation and communication issues."
Godwin, Chappell, & Kreutzer (2014). United States	Relationships after TBI: A grounded research study.	41 personal narratives, nine from the survivor perspective. TBI severity not discussed.	Qualitative analysis of narrative texts	Grounded theory	"Five primary themes emerged: Ambiguous Losses, Identity Reformations, Tenuous Stability, Non-Omnes Moriar and The New Us. From these, two grounded theories were developed: Relational Coring and Relational Recycling."

Haag, Caringal, Sokoloff, Kontos, Yoshida, & Colantonio, (2016). Canada	Being a Woman With Acquired Brain Injury: Challenges and Implications for Practice.	11 women with non-stroke related ABI, aged 20-65, with an average of living 14.9 years post-ABI	Qualitative study using focus groups	Interpretive description methodology	"Participants identified significant barriers to achieving optimal health and wellbeing for woman survivors of ABI, including a lack of knowledgeable professionals. We identify three interrelated themes: (1) experiences shaped by gender norms and roles (2) experiences influenced by physiological phenomena, including perceived hormone imbalances; and (3) experiences surrounding interpersonal relationships and sexuality."
Hammond, Davis, Cook, Philbrick, & Hirsch (2012). United States	Relational dimension of irritability following traumatic brain injury: A qualitative analysis.	44 varied participants, of which there were 16 with TBI interviewed, aged 18-66, TBI severity is noted. A range is given between mild-severe, 12 male and 4 female, 14 married.	Qualitative study using focus groups	Grounded theory	"Several theories emerged regarding irritability with respect to spousal relations, all based on the overarching theory that irritability in people with TBI has a strong relational component involved in triggering, experiencing and preventing irritability. Sub-theories supporting this include: (1) irritability breeds further irritability, (2) spousal responses can trigger irritability among persons with TBI and vice versa, (3) difficulties making emotional connections may incite negative interactions, (4) expectations of others may contribute to irritable behaviour, and (5) communication breakdowns may provoke irritability."

Layman, Dijkers & Ashman (2005). United States	Exploring the impact of traumatic brain injury on the older couple: “yes, but how much of it is age, I can’t tell you...”.	21 varied participants, of which there were 8 with TBI interviewed, 4 mild TBI and 4 moderate-severe TBI	Qualitative interview study	Participatory Action Research and Qualitative content analysis	"Variability of relationship experiences (relationship relatedness and persistence of the partnership) was shown across groups. Aspects of relationship commitment to the partnership were revealed. Many individuals with TBI and their partners attributed various changes to ageing and age-related issues and not to the TBI."

Study Characteristics

In the five studies reviewed 52 of 134 participants were ABI survivors. The articles were published between 2005 and 2016, with four published in the United States and one in Canada. Four articles specified TBI with the most recent study referring to ABI as the brain injury population (Haag et al., 2016), although 10 of the 11 participants are characterised as TBI injured with one anoxic brain injury largely representing a TBI population. Four articles directly reference relationships in the title (Gill, Sander, Robins, Mazzei, & Struchen, 2011; Godwin et al., 2014; Hammond, Davis, Cook, Philbrick, & Hirsch, 2012; Layman et al., 2005) only one article referred to relationships as part of the main abstract (Haag et al., 2016).

Study Design

Study designs included an array of qualitative methods such as qualitative interview (Gill et al., 2011), participatory action research using qualitative interview (Layman et al., 2005), qualitative focus groups (Haag et al., 2016; Hammond et al., 2012) and qualitative analysis of personal narrative texts (Godwin et al., 2014). Across the studies varied methods of data analysis were employed. Three of the five studies used grounded theory (Gill et al., 2011; Godwin et al., 2014; Hammond et al., 2012), one used interpretive description methodology (Haag et al., 2016) and the other content analysis (Layman et al., 2005).

Study Participants

The first study (Gill et al., 2011) interviewed 18 individuals with TBI and their partners separately, around experiences of intimacy. They also reported gender, marital status, length of relationship, whether the relationship was pre or post-TBI, and if couples had children.

The second study (Godwin et al., 2014) used 41 individual personal narratives from caregivers, survivors and clinicians as part of research exploring relationships after TBI. From this nine narratives related to the survivor experience of relationships were extracted.

The third study (Haag et al., 2016) interviewed women across two focus groups, around the challenges and implications of being a woman with ABI. They reported experiences surrounding interpersonal relationships and sexuality as a central finding in the study.

The fourth study (Hammond et al., 2012) explored the relational dimension to irritability after TBI, again in focus groups. They interviewed 44 individuals across five groups; TBI survivors (n=16), spouses, parents and healthcare professionals working with individuals over the course of 10 months. Survivor quotes relating to their relationship experiences were extracted and analysed separately.

The final study (Layman et al., 2005) explored the partnered relationship of older couples (50+ years of age) after TBI, in 21 participants including TBI survivors, their partners and a control group of people without TBI or in a relationship with someone with TBI. From this study, eight were TBI survivors and the findings that relate to their experiences of relationships after brain injury were extracted.

Study Gender and Age Demographics

Articles varied in their reporting of gender and age of participants. One article of the five (Godwin et al., 2014) due to the data being based on published personal narratives did not report any demographic details except identifying survivor, caregiver or clinician sources. Of the remaining four articles (Layman et al., 2005; Gill et al., 2011; Haag et al., 2016; Hammond et al., 2012) a total of 32 female survivors and 21 male survivors were noted. In the Gill et al. study (2011) ages ranged between 21-59, in the Haag et al., study (2016) from 20-65, and the Hammond et al. (2012) study included participants 18-66 years of age. The Layman et al. (2005) study explored older person's experiences with survivors aged 62-84.

Time since Injury and Injury Severity

Length of time since injury was noted in three of the five studies. The Gill et al. (2011) study included survivors with the shortest time since injury noting a range of 0.55-25 years post-injury versus the Haag et al. (2016) study with the largest range of time since injury at 5-30 years. The Hammond et al. (2012) study reported 2-16 years post-injury. The two remaining studies did not note time since injury (Godwin et al., 2014; Layman et al., 2005).

The Hammond et al. (2012) study reported mild to severe injury severity for survivors included in their study. The only other study which reported injury severity noted an even split between mild and moderate to severe ABI (Layman et al., 2005).

Study Relationship Status

The Gill et al., (2011) study reported that their sample comprised 12 married survivors and 6 survivors who were in relationships, the Hammond et al., (2012) study reported that their sample comprised 14 married survivors and 2 survivors in relationships, and the Layman et al. (2005) study of older couples reported relationships of eight survivors of greater than 15 years in duration. Haag et al. (2016) or Godwin et al. (2014) did not note relationship status. Only the Gill et al. (2011) study noted of the 18 couples interviewed 11 reported having children together.

Risk of Bias: Methodological and Ethical Rigour

All studies provided their inclusion criteria; however, none clearly stated exclusion criteria. Only one study notes that some potential participants chose not to take part (Layman et al., 2005) yet the reasons for declining were not explicitly noted, rather hypothesised as possible age-related concerns given an older population.

There is little discussion in the studies concerning the process of seeking informed consent and only three studies (Gill et al., 2011; Haag et al., 2016; Hammond et al., 2012) state ethical approval or review in their reporting. Similarly, confidentiality or debriefing following participation is not clearly stated across the studies. Gill et al. (2011) report exit focus groups and follow up interviews, in reference to clarification and member checking of identified results. Hammond et al. (2012) also refer to member checking themes without referring to ethical debriefing and follow up of participants individually or as part of larger groups. Given the sensitive nature of the studies, exploring survivors' experiences of their relationships, this is surprising.

All studies reported a transparent approach to their analysis of data, using second reviewers or team review of data, codes and themes for accuracy (Gill et al., 2011; Haag et al., 2016; Hammond et al., 2012). Two studies (Godwin et al., 2014; Haag et al., 2016) make a note of using triangulation in their analysis, while two studies employed member validity checking of themes during analysis (Haag et al., 2016; Hammond et al., 2012). Only the Hammond et al. (2012) study explicitly refer to epistemological stance stating a constructivist approach clearly.

As all the papers included are qualitative small samples of self-selecting participants this may preclude severe ABI (Godwin et al., 2014) wherein disparate experiences are missed (Layman et al., 2005). The studies note small samples, such that findings might not be representative or generalisable outside of the participants included (Gill et al., 2011; Hammond et al., 2012). Many qualitative researchers would see small size, sensitivity to context and language that comes with this methodology as strengths from qualitative methods. Part of the reason for choosing this specific methodology would be to answer a question of the ‘particular' which is the inherent strength of qualitative research (Braun & Clark, 2006)

Synthesis of Results

All the data related to survivors' experience was used in the synthesis of results, due to the relative scarcity presented in the included papers. Thematic analysis using bottom-up semantic induction of the qualitative findings noted five overarching themes related to survivors’ experiences of coupled relationships. The theme’s identified were (1) being a changed partner (2) altered roles as survivors (3) sexuality (4) connectedness and (5) ongoing acceptance, commitment and understanding.

“Being a changed partner”.

Nearly all survivor accounts expressed difficulties in adjusting to the cognitive, social and emotional changes they recognised in themselves. It appeared that this made their relationships harder to sustain after brain injury. Most survivors expressed difficulties in reconciling guilt due to changes in how they managed their relationships. They reported that they felt they were letting their partners down through having their brain injury and becoming a burden to them noting increased sorrow and sadness at these changes. Survivors expressed difficulty in showing emotional or physical affection to their partners after the brain injury. Changes to cognition impeded the "fun-loving", intimate and spontaneous gestures shared with their partners, "There can't be any unplanned time sharing with each other. I have to mentally know when it's going to happen, so I can prepare because I can't switch gears anymore". (Gill et al., 2011, p. 60). Another survivor shared the importance of these gestures to themselves and their partner in maintaining the relationship "what feeds a relationship is being able to do those little things that people didn’t ask for but they like getting it. I can’t do that as easily or cleverly for the impact - it’s not the same…”. (Gill et al., 2011, p. 60).

Across survivor accounts, cognitive load following injury was mentioned as a difficulty that impacted the relationship. Changes in processing speed and set shifting difficulties affected their ability to apply previous knowledge to their relationships. "And it's difficult, when you're struggling so much to think clearly and recover, it's difficult to have the extra mental capacity to think about these other activities that in the end lead to intimacy and lead to physical affection". (Gill et al., 2011, p. 62). Survivors have a changed way of approaching or anticipating their partner impacting communication between each other.

> “I’m talking to my wife and she says something to me instead of me saying, ‘Yeah, okay, I’ll do it’. It’s (yelling) ‘Yeah, I’ll do it!’ It’s one of those things and I found myself doing this more. And she said, ‘What the hell’s wrong with you?’ Then I got to walk away…... I think this is going to be a great day. Then she gets up and says, ‘What are you up so early for?’ And there it goes out the window”. (Hammond et al., 2012, p. 1290).

The burden of cognitive changes on the survivor can lead to irritation and friction in the relationship, creating strain between partners.

> “Now I can only do one thing at a time. I can’t do multi-tasking anymore...My wife...if I’m doing something in the garage and she comes out and talks to me, and breaks that train that I’m on...boy, that’s it. And she says, ‘I can’t talk to you!’ And then she makes it worse”. (Hammond et al., 2012, p. 1290).

Survivors expressed shame and confusion relating to their emotional reactions to these changes and how they experienced themselves post-injury.

> "It's not easy being the spouse of someone with a brain injury, regardless of how much you care. We are rarely the perfect patient (understatement). We are demanding, hard-headed, seemingly ungrateful and yes – full of independence. At least we think we're independent until we realise how dependent we are on others". (Godwin et al., 2014, p. 405).

“Altered roles as survivors”.

Survivors spoke of a weakened sense of their social roles and abilities as parent, partner, friend and worker recognising that their partners take on more stress, responsibility and financial pressure in their partnered lives as a result. “As a man, some of those difficulties make you feel, you know, like less of a man, like not a complete person, and, as if you're letting the other person down all the time". (Gill et al., 2011, p. 61).

Many survivors also noted partners had little time to spend with them because of shifted responsibilities yet to have time together was viewed as reinforcing to the relationship bonds. Survivors expressed regret for their diminished independence. They reported feeling watched, questioned and treated in a child-like manner by partners due to doubt about their being able to manage independently.

> "She's more or less the leader, whereas I think I had that role previously. So now I have to be a better follower more or less, and that's a change. And when you're a follower, you're less in control of things". (Gill et al., 2011, p. 62)

Survivors reported difficulty resolving their place and responsibilities in the home and family life, being unable to help meaningfully or acknowledge this consistently.

> "what we unknowingly ask of you is way beyond the normal call of duty…your life is undetermined, like the crashing waves of the ocean eating away at the bedrock of your existence, eroding your capabilities and normalities…but remember, we don't know we are affected; we are certainly oblivious to the fact that you are". (Godwin et al., 2014, p. 405).

"Sexuality".

Functional impairments such as physical changes to the body and motor difficulties may impede sexual engagement in ways unforeseen before the injury for the survivors, a further layer is found in the emotional response to these impairments. Survivors noted a "disparaging" view of their changed bodies feeling as though they were now not "normal", and this changed their capacity to feel like "real" men and women. This response creates additional barriers to preserving intimacy after ABI. Survivors reported limitations in sexual arousal and performance that could impact on self-confidence, leading to a sense of inadequacy as intimate partners (Gill et al., 2011). A female survivor expressed that she felt her partner was justified in seeking female companionship elsewhere, as she felt disabled and less interesting and attractive to her partner after ABI (Godwin et al., 2014). Tension can be noted between the survivors' perceived sense of the way they once were, how they are now and the way they wish to function. "Sex is kind of difficult because I cannot perform with her the way I choose to, like I want to". (Gill et al., 2011, p. 61).

Some survivors questioned their abilities to function concerning their gender or gender role and the ability to be a "real woman or real man". One woman described physical limitations obstructing “real” affection for her partner. “Because my right side has been affected, I’m not even able to give him a kiss, like a real kiss”. (Gill et al., 2011, p. 61). Some male survivors also commented on physical and sexual limitations impinging on feeling like a “real man”.

> "You're supposed to be at work, fixing the car and carrying your wife upstairs in your arms and these macho things…before I crashed, they called me the ‘Grand Poobah' from the Flintstones…I ain't the Grand Poobah anymore, and that's really disheartening". (Gill et al., 2011, p. 61).

Some survivors noted differences in their sense of intimacy and interpersonal relationships compared to preinjury. "I've never been where I wanted to be left alone. Now I crave that time". (Haag et al., 2016, p. 568). Others spoke to negotiation or reorganisation of the importance of sex to them and in their lives after ABI.

> “And by talking we decided, how important is sex? If you don’t have any feeling all down your right side, is there any point in having sex? You’re doing it for his benefit, not for your own…and then we think that companionship and doing things

> together is far more important than some of these other things”. (Haag et al., 2016, p. 568).

Another survivor attributed a changed outlook in life and towards sexuality that helped minimise the magnitude going forward.

> “But [orgasms] don’t happen now. And I don’t think it has anything to do with my growing older…and that’s a hard thing to get used to, but I’m not devastated by it. I’m seventy-six…I’m not going to bemoan the fact that it doesn’t happen. And I’m grateful for the times that it did happen. I have to get on with whatever reality is there”. (Layman et al., 2005, p. 916).

“Connectedness”.

Survivors expressed worry over partners feeling obligated to remain in the relationship, seeking reassurance of the partner’s ongoing commitment, fearing eventually that their partners will give up on them.

> “I think that before the injury we were both very independent, you know I had other things on my mind. After the injury we – I’ve been much more dependent on her, so I have to – I have to…by necessity I think I have been, have to be more attentive to her now”. (Layman et al., 2005, p. 914).

One survivor described losing his way of connecting emotionally to his partner due to difficulties sustaining intimate love after the ABI.

> "The worst part of this aspect has been the loss of emotional attachment…to my common-law wife of 12 years. I just don't have the emotional attachment – the love, I'd guess you'd say. I'm in a situation where I don't even know if I CAN

> develop an emotional attachment with someone, and being in a relationship, I can't just find out by trial and error". (Godwin et al., 2014, p. 403).

Survivors expressed deep sadness regarding perceived separation from their partners, when living under the same roof. Living together but living different lives increased survivors' sense of loneliness in their injury (Godwin et al., 2014). Isolation was increased when survivors' functional impairments prevented preinjury activities, with survivors feeling excluded socially especially if the partner went to outings without them (Gill et al., 2011).

Survivors spoke about the shared connections and accountability that maintained intimate relationships. One survivor noted that his children strengthened his commitment to his partner. "We both are totally committed to each other very much…we have a child and one on the way, and that's even more reason to make sure it stays that way". (Gill et al., 2011, p. 64). Other survivors shared that vows made in the partnered relationship were essential pieces that maintained and facilitated the relationship. “I mean I guess we promised each other, right? My wife has always been a good person. She’s not going to just walk away from for better or for worse” (Godwin et al., 2014, p. 407). “We’ve been together for decades. I use my new compensatory strategies, but sometimes I use them just to let the old me shine through and reach him”. (Godwin et al., 2014, p. 408).

Survivors spoke about inter-personal support in the context of the partner just being there to physically and emotionally connect as partners. Some survivors referred to their partners as “there for them” and consider the partners their “best friend”.

> "Now we are a team. I don't have to explain everything anything to him. We can't even put into words what that means to me… Life is never what we imagine, but on most days it's better for us to get what we couldn't have imagined for ourselves" (Godwin et al., 2014, p. 409).

This contrasted with other survivors' experiences wherein they see the disappointment felt in the partners' distance and inability to support them during recovery emotionally. "I value my friendship with people to a greater degree (after the TBI) … I can't count on [husband]…[but] my social interaction, to a large extent the church is important and has remained the same". (Layman et al., 2005, p. 917). Others indicated that continuing outside social connections to that of the relationship was important because they felt they could not rely on limited quality support received from the partner (Layman et al., 2005).

“Ongoing acceptance, commitment and understanding”.

A strength noted by both partners and survivors as facilitating their post-injury relationships was unselfish and unconditional acceptance allowing for the change in function, role and life stress. Survivors expressed that the constancy from partners led to deep appreciation and a feeling of being anchored through recovery with their partners' commitment (Gill et al., 2011; Layman et al., 2005). One survivor shared, "It's amazing. You know, a lot of partners leave when this happens, and she stuck it out through thick and thin…". (Gill et al., 2011, p. 63).

Survivors spoke about working on communication to understand each other’s needs and feelings, despite problems and differences and was appreciated as a crucial form of support from the partner. “I’m not as likely to argue about things that are not important, because I don’t bother” (Layman et al., 2005, p913) and “She has understanding that I can’t do it like I used to do” (Gill et al., 2011, p64).

Some survivors expressed a sense that the relationship had deepened and strengthened following the injury in some ways. "I went through a drastic personality change – a sign of my brain injury…now, for us, I document the miracle of our re-marriage". (Godwin et al., 2014, p409). One survivor spoke about the relationship being fortified through surviving previous past difficulties together, "well I love him" and "we have a love between us" (Layman et al., 2005, p919) others expressed realistic worries and the difficulties in starting over with someone else. It appeared that some resolved to accept the partner's differences and imperfections within the relationship.

> “Well, I think that once you realise that you ain’t as hot as you thought you were… And at this point, I want this relationship to work out, I can’t afford to have it not work out, and, and, that’s definitely as a result of the TBI. When it comes down to it, I’m not so independent any more” (Layman et al., 2005, p. 918).

Other survivors expressed lessons learned from past painful experiences in relationships that added insight into what was needed to maintain and withstand stressors in the current connection. "Similar things that happened – the past move, the job situations, et cetera et cetera – did create problems with the relationship, but I learned from that. It seems to me the difference is that this relationship seems to be able to withstand any of those things. I don't know if it's a factor that I learned from the bad ones when it's bad, it's very bad and so maybe now I feel that things could go wrong, but it never happens…". (Layman et al., 2005, p918).

Discussion

This systematic review aimed to explore the current literature on survivors' experiences of coupled relationships after brain injury. The key findings identified were: ‘being a changed partner', ‘altered roles as survivors', ‘sexuality', ‘connectedness' and ‘ongoing acceptance, commitment and understanding'. This review notes a striking lack of focus on ABI survivors' experiences within the available qualitative research on partnered relationships after ABI. This may reflect a lack of survivor's voice in many aspects of ABI research based on assumptions that people with ABI are not able to reliably provide a perspective.

Methodological quality and limitations of the studies included for review were noted. As previously stated, small sample sizes with limited diversity (Haag et al., 2015) query how representative or generalisable the findings of the studies may be outside of the participants included (Gill et al., 2011; Hammond et al., 2012). In addition, while measures are taken to limit subjective bias there may always be potential for this to influence interpretation (Gill et al., 2011). Studies addressed this using exit groups and follow-up interviews that allowed member checking, clarification and validation of themes identified (Gill et al., 2011; Hammond et al., 2012). The Hammond et al. (2012) study notes strengths in increased participant numbers and discussions yet caveats that the group nature and analysis of retrospect recollections may have impacted findings. This was balanced using individual diaries and selected individual interviews. Further limitations of included studies note self-selecting samples may result in limited or biased narratives that preclude severe ABI due to restrictions on abilities to use the computer (Godwin et al., 2014), wherein disparate experiences may be missed (Layman et al., 2005), the participants are drawn from mostly a mature population (Haag et al., 2015) or from intact coupled relationships (Godwin et al., 2014). Finally, reasons for declining to take part in the studies were not commented upon although noted as a possible limitation in one study (Layman et al., 2005).

In a previous critical review of the quantitative literature (Blais & Boisvert, 2005) it was noted that a clear definition of the construct of adaptation is lacking and there remains a dearth of exploration into what it is that defines a coupled experience. The impact of ABI in coupled relationships may be variable regarding changes in partners' dyadic roles, sexuality, communication and the reasons given by couples for sustaining the relationship offering support of Gosling and Oddy's (1999) prior findings.

Survivors discussed social comparisons to others, worrying their disability left them “not normal”, “disabled” or not “real” men or women. In contrast, partners spoke about social gender expectations, such as male partners sense of inadequacy in wishing to fix the problems on behalf of their female partners and difficulty in admitting the need to seek help from outside. Female partners described struggling to adjust to the new additional aspects of their roles to incorporate work previously thought of as "men's work" into the shared relationship. Across the review, psychological and functional sequelae, as well as social contexts, are identified as barriers to intimate relationships, influencing relationship stability and family supports. After an ABI, difficulties are apparent in maintaining and living a coupled relationship. Problems experienced include decreased communication, decreased quality of interaction and personality changes that appear to add uncertainty and opportunity for misperceptions which undermine the intimate bond.

The Gill et al. (2014) study departs from previous research in that it provides a direct exploration of positive relationship experiences and the social contexts influence on intimacy, while the Haag et al. (2016) study supports the idea that developing new healthy perspectives on meaningful intimate relationships aids the relationship’s future strength. The studies indicate that spousal and family support, as well as good interpersonal abilities in communication, are vital in re-establishing relationship intimacy after ABI. Previous findings of Wallace and Bogner (2000) corroborate findings that highlight social factors provide mediation in post-ABI relationships. Layman et al. (2005) suggested that ABI severity is not the main issue impacting the couple's relationship commitment rather pre-injury ability to cope with the challenge. This appears to add to the relationship’s staying power and ability to adjust. This study presents the view that in contrast to younger survivors, older couples where one person has an ABI, the issues of sexuality and intimacy are less significant, yet the degree to which age-related experiences alter or mask the effects of ABI and sexual intimacy in an older couple is less clear (Layman et al., 2005). An argument can be made that variations in outlook on the relationship may differentially equip partners in managing the impact of ABI.

These identified studies begin a redress of the ABI literature that balances survivor and partner perspectives that speaks to strains and strengthening interactions for relationships. Of note from the Hammond et al. (2012) study is the focus towards centring difficulties within the person with the injury and the concept of the “skull seduction” (Yeates, 2007). The challenges may be viewed as if the problem lies solely within the injured individual’s brain and thus, treatment or intervention is likely then aimed solely toward the survivor. A study by Landau and Hisset (2008) identified that coupled healing necessitated engagement to resolve individual and relational ambiguous losses driven by the couple's continuing commitment to identity reconstruction. They found that relational healing following ABI was dependent on finding a shared view of treatment and the process of approaching a new acceptable, viable relationship identity.

Gill et al.'s (2014) study indicates that the most substantial challenge to a couple's relationship may centre on the couple managing change. The Godwin et al. (2014) study references the greatest challenge facing the clinician is that prior literature guiding this area could be considered inadequate and disjointed. Therefore, in what way is the clinician to draw conclusions regarding the process couples go through following injury such that some couples achieve healing and others do not, some remain connected, and some relationships fall apart.

The stress appraisal coping framework (Lazarus & Folkman, 1984) may contribute to the understanding of emotional adjustment in couples post-ABI. The framework suggests that an individual's understanding of stressors, resources available to them and the meanings attached to situations either exacerbate or improve the outcome of a crisis that can be applied to both partners in managing their relationship afterwards. Similarly, Schulz and Heckhausen’s (1996) primary and secondary control strategies may highlight a similar influence on post-ABI relationships outcomes. Primary control refers to the ability to enact change in a situation, secondary control is the adaptation of personal perspective or behaviour in response to the situation. Access to primary strategies may diminish with cognitive and other changes following ABI, whereas secondary strategies may become increasingly used and essential to the management of loss experienced in life. These models offer possible insight into perception as a mediator for relationship outcome in individuals with ABI and their partners.

The Godwin et al. (2014) study generated two grounded theories which may also be useful in considering how couples manage relationships. The two theories centred on ‘relational coring’ and ‘relational recycling’. Relational coring refers to, ambiguous losses, uncertain stability and identity reformations that deconstruct the relationship. Relational recycling refers to couples where the narrative of healing allows the relationship to continue, a nuanced process where a couple fills their relationship with the reconstructed identity. Therefore, relational coring and relational recycling build on the previously identified complex areas of the relational experience. For couples who remain together and are engaged in their relationship, these experiences are filtered through the retained essence of their previous couplehood which is upheld. Left unattended couples’ relationships may remain fragile and a veneer of their former selves. Recycling references to the mixing of the old relationship into the now, so it is broken down and reformed with the new parts grown out of losses.

Considering these concepts may begin to assist researchers and clinicians in addressing concerns that arise out of the stability and satisfaction studies, such as how couples decide long-term commitment and how they arrive at various points on the satisfaction continuum. The development of this process model may increase recognition of the possible processes involved for coupled partners after ABI towards a framework for services and intervention that validates relational disruption while creating relational possibilities in coupled work that develops relationship hope (Bowen, Yeates & Palmer, 2010)

Highlighted in the review are implications for clinical practice, where there is noted lack of methods for conceptualising couples after ABI or ways the survivor is aided to sustain their coupled relationship. The coupled relationship is a complex mixture of thoughts, feelings and behaviours being played out in a sociocultural context. Therefore, individual survivors and the couple should be addressed holistically taking into consideration life cycle and life stage of partnered relationships. A framework of psychoeducation and normalisation for survivors and their partners is required so that professionals may begin to work within the context of coupled relationships. This is only possible by starting to understand what is known and what may be the future directions for research and clinical practice.

Limitations and Strengths

The purpose of this review was to scope the extent of evidence readily available in the current literature. Through the process of undertaking the systematic search, many unpublished thesis and dissertations were noted to explore this area. Excluding this grey literature has possibly excluded large bodies of rich, nuanced experiential accounts that did not fit the inclusion criteria of published peer-reviewed articles. A further limitation noted is the paucity of research identified by the prespecified inclusion criteria which may influence the quality of themes summarised as part of the systematic review. As hypothesised before the search, stroke and encephalitis studies did not appear to be successfully retrieved through the general terms such as acquired brain injury or ABI as used for the current study. This may represent an inherent bias in how the literature is termed and coded, meaning articles which may have been appropriate to the research question were not captured.

As four out of five papers included in the final set reported theme's mixed between survivor and partner, the methodology of this review relied on extracting direct quotes from survivors in the published papers. This limits the available data set to the included raw quotations identified as survivors in the published papers in comparison to other reviews which would be able to benefit from the larger data of themes the authors extrapolate and discuss across the article.

A strength of employing this method is the qualitative metasummary appropriately reflects and represents the survivor perspective as committed to in the initial review question. A further strength of this review is in the gender representation of survivors. When the Haag et al. (2016) study is subtracted, given its wholly female sample, the remaining ratio of men to women represented is equal. This is an excellent point to note as previous commentators have asserted that women are especially under-represented in ABI research. This is the first review to attempt to summarise the available qualitative literature in this under-researched area. It may provide a useful impetus for further research, clinical intervention and development of models that are inclusive of both partners in the coupled relationship.

Conclusions

This systematic qualitative review has summarised the key themes and findings of five identified research studies that examine the coupled survivor's relationship after brain injury. The articles were rated as high in quality; thus, the key findings may be deemed credible to be summarised, although we acknowledge the subjective quality of the ratings, for which a second rater was employed. The methodology, strengths and weaknesses of each article have been critically reviewed and a thematic analysis on the key qualitative findings undertaken to generate themes into a qualitative metasummary from the available research inductively. Although the focus here has been precisely to explore the experiences of the ABI survivor in relationships, the findings suggest that both the injured partner and survivor are impacted in the wake of brain injury. It highlights that we cannot ignore the reciprocal and interdependent nature of both partners in understanding relationships. The findings point towards vulnerability being present after ABI wherein relationships may continue or dissolve.

Furthermore, many of the themes are indicative of difficulties and concerns inherent in managing relationships well after the injury. One of the reviewed papers specific areas of focus was to explore what may facilitate and strengthen relationships. These are important findings with such limited research in this area and from the perspective of the survivor experiences. Future research using both quantitative and qualitative methodologies is required to grow the evidence base, so clinicians may draw on and guide intervention choice from evidence-based practice to supplement the current assumption which may present as practice-based interventions.

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Chapter 2. Bridging Chapter

This research portfolio aims to develop the understanding of how men experience fatherhood after ABI, using an IPA approach. By exploring this question, the initial literature search into fatherhood after ABI highlighted a very limited amount of research focused on this area. As such the systematic review was broadened to explore the question: what are brain injury survivors' experiences of coupled relationships. The hope was to garner an overarching understanding of how people with brain injury manage coupled relationships from the available literature as this may align alongside the empirical study centred on fatherhood after ABI.

As previously mentioned, given there is a relative lack of focus on survivor experiences, this review is a useful contribution to the knowledge base surrounding coupled relationships after ABI. A review which summarises the existing qualitative literature is necessary such that implications from what is already available can be drawn on to guide research and clinical intervention in future. However, articles summarised represent a North American context and highlight the need for research which is representative of local context. The empirical study aims to address the lack of any UK based qualitative study into the experiences of fathers after brain injury. The study builds on previous research around parenting after ABI (Edwards, Daisley & Newby, 2014) and addresses some of the limitations noted by attending to children's age, participants' marital status and the gendered experience of parenting noted to be critical areas for consideration in future research.

The research in this portfolio is approached from a critical realist stance with a phenomenologist perspective. The ontological and epistemological stance of critical realism allows for both positivist and constructionist approaches to be considered (Fletcher, 2017) without having to reconcile competing epistemological assumptions related to the value or contribution given by differing research. Critical realism does not assume that data directly mirrors reality however may tell us about reality (Harper, 2012) while phenomenology asserts that reality may only be understood through our personal embodied experience and need not be realist or relativist in its approach (Harper, 2012).

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Chapter 3

A Qualitative Exploration of Fatherhood after Acquired Brain Injury (ABI)

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A qualitative exploration of fatherhood after acquired brain injury (ABI)

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Abstract

This study explored how men who were fathers before acquired brain injury (ABI) experience their fatherhood. Seven fathers participated in semi-structured interviews. Interpretative phenomenological analysis (IPA) was used to explore their meaning-making of fathering experiences. Four superordinate themes emerged:(1) what being a father means, (2) altered relationships with others, (3) becoming lost and finding their way through, and (4) renewed fatherhood. Each theme was present in all interviews. This study is the first to explore experiences of fatherhood after ABI in the UK. The findings provide valuable insight into the lived experience and suggest areas to be explored in clinical intervention and research that may be useful for fathers following ABI. A future study could complement this current research by exploring women's experiences of motherhood after ABI.

Keywords: acquired brain injury, ABI, fathers, lived experience, interpretative phenomenological analysis, IPA, identity, reconstruction, adjustment

Introduction

Acquired brain injury (ABI) due to physical trauma or medical conditions radically alters the lives of survivors and those close to them. It often affects working age adults (Turner-Stokes, Pick, Nair, Disler, & Wade, 2015) with lower socioeconomic status (Hyder, Wunderlich, Puvanachandra, Gururaj, & Kobusingye, 2007), where men are 1.5 times more likely to be affected than women (Headway, 2017). ABI results in wide-ranging cognitive, physical, social, emotional and interpersonal changes (Kreutzer, Mills, & Marwitz, 2016; Ownsworth & Haslam, 2016). ABI survivors suffer worse psychological and psychosocial outcomes than people with spinal cord injury (Dahm & Ponsford, 2015) and report inferior quality of life versus other disabilities (Jacobsson, Westerberg, & Lexell, 2010). The complex, long-term, pervasive sequelae of ABI constitute a severe long-term condition, rather than a “one-off event” (Masel & Dewitt, 2010). Adjustment involves a journey to improve self-esteem, make sense of experiences and gain control (Ownsworth, 2014). In their “Enduring Experience of ABI” model, Levack, Kayes, and Fadyl (2010) propose that a successful journey of adjustment involves a “reconstruction” of self-identity, personhood and place in the world, achieved through access to both internal and external resources. It is unsurprising, that when ABI occurs at working age, developmental trajectories of key social roles and responsibilities of adulthood (e.g. working, parenting, managing a household) may be disrupted. This relates not only to changes that survivors perceive in themselves, but also responses of loved ones when these changes are perceived as negative (Bowen, Hall, Newby, Walsh, Weatherhead, & Yeates, 2009).

Identity in ABI

Self-identity refers to iterations and adjustments of self-understanding that become more constant from adolescence onwards (Ownsworth, 2014). Serious life events like ABI disrupt and challenge sense of self, social identity (Gracey, Palmer, Rous et al., 2008; Levack et al., 2010; Nochi, 1998) and well-being (Jones, Haslam, Jetten et al., 2011; Walsh, Muldoon, Gallagher & Fortune, 2015). For some individuals, struggling with the challenges posed by previous self-identity, influences the process of identity resolution (Muenchberger, Kendall, & Neal, 2008). Charmaz (1987) highlights the need for a stigma-free context in which to construct a self-identity beyond that of a socially constructed illness, to one providing hope and future planning. Loss associated with change to bodies and lives can lead to a battle between suffering, shame and dignity (Jumisko, Lexell, & Söderberg, 2005). Gracey and colleagues (2008) suggest survivors need to make sense of themselves in terms of “meaning and doing” so subjective experience and activity come together. Living with impairment requires reframing and retelling of one’s narrative to understand changed capacity, roles and relationships (Klinger, 2005), leaving behind assumptions from the past self to allow the future self to alter (Holloway & Freshwater, 2007). Reformulating one’s identity is an important process that contributes to an individual’s participation in productive activities (Jones & Curtin, 2011).

Masculine Identity

Men are reported to rely on traditionally masculine activities to define and support self-identity before and after ABI than women (Gutman & Napier-Klemic, 1996; MacQueen, Fisher, & Williams, 2018). Post ABI masculine emotional identity faces barriers posed by changing social roles and perceived stigma (Freeman, Adams, & Ashworth, 2015). Jones and Curtin’s (2011) study of men with traumatic brain injuries (TBI) noted that the “breadwinning” role and personal relationships were most disrupted. Men struggled to reformulate their values and altered participation as meaningful. Those men who successfully adopted new viable narratives accessed more adaptive, flexible and dialogic models of masculinity (Jones & Curtin, 2011). Traditional models of health emphasise female-centric approaches relying on help seeking and emotional disclosure, which present further barriers to men (Kingerlee, Precious, Sullivan, & Barry, 2014). Challenges that distance men from caring roles include a limited repertoire of skills and responses combined with the traditional expected public role (Seidler, 2006) but focus on perceived fathering performance can be shifted by the value and meaning parenting provides (Dolan, 2014).

Parenting with ABI

Mental health research suggests that parenting can be significantly impacted by parental illness (Baulderstone, Morgan, & Fudge, 2012; Leinonen, Solantaus, & Punamaki, 2003). Difficulties include becoming less nurturing, orderly and rule-oriented with lower levels of active involvement and difficulty maintaining a warm, responsive relationship (Uysal, Hibbard, Robillard, Pappadopoulos, & Jaffe, 1998). Inhibition and impairments of self-monitoring, noise intolerance, impulsivity and other cognitive deficits may also affect parenting (Smith & Godfrey, 1995). Given the phase of life most individuals sustain ABI, many are likely to be or become parents with ABI (Holloway & Tyrrell, 2016). The national traumatic brain injury study (Stillwell, Hawley, Stilwell, & Davies, 1997) found that 32% of 507 participants had dependants. Edwards, Daisley, and Newby (2014) reported, themes for parents during neurorehabilitation of (1) multiple losses, (2) resignation and uncertainty, (3) family support and (4) hopes and aspirations for parents after ABI. This parenting role may present significant challenges for people with ABI (Edwards, Daisley, & Newby, 2014; Morriss et al., 2013).

Fatherhood

In psychosis, Evenson, Rhodes, Feigenbaum, and Solly (2008) found that parenting created prideful purpose for fathers, while Lundwall (2002) found fathers reported being more able to give, listen and offer more overt expressions of love improving their fathering. The role of a father is complex, and societal and cultural expectations influence a father’s concept of himself in that role (Hermansen, Croninger, & Croninger, 2015). Negative self-perceptions of parenting may reduce confidence and self-efficacy in fathers with ABI (Morriss et al., 2013).

There is a clinical need to support identity continuity and reconstruction in the face of changes caused by ABI. Research in post-traumatic growth suggests that personal strengths and possibilities, interpersonal relationships, self-perception, life priorities and appreciation increase over time following injury (Powell, Ekin-Wood, & Collin, 2007). Interventions informed by models such as the Life Thread model (Ellis-Hill, Payne, & Ward, 2008), the Y-shaped model of rehabilitation (Gracey, Evans, & Malley, 2009), the Enduring Experience of TBI model (Levack et al., 2010) and the global self-system model (Ownsworth, 2014) may help fathers move from narrow fixation on loss and change to wider acceptance, understanding, and reconnection to family lives.

Current literature highlights a limited focus on the experience of fathers with ABI (Morriss et al., 2013). A review identified only two studies that exclusively addressed fatherhood after ABI. One centred on parenting challenges and needs for fathers (Morriss et al., 2013) and the other explored a small parenting intervention programme (Weatherhead & Newby, 2008). It is essential that interventions and services reflect a good understanding of the perceptions and lived experiences of people with ABI (Levack et al., 2010), specifically fathers in the current study.

Aim

To gain a rich and deep understanding of the phenomenon of fatherhood after ABI by exploring the lived experiences of fathers with ABI. The research question asked: In what ways do fathers experience being a dad after ABI?

Method

Design

An interview guide was developed and reviewed by peer support workers (n=3) who were fathers with ABI however, participants were free to lead the discussion around fatherhood. A qualitative idiographic approach was employed to generate rich, detailed accounts of the individual meaning-making of fathers. The interviews were semi-structured, moving from description to the lived experiences, audiotaped then transcribed into individual accounts. The study received ethical approval through the University of East Anglia – Faculty of Medicine and Health Research Ethics Committee (Appendix D). Interpretative phenomenological analysis (IPA) was used as it is “committed to the examination of how people make sense of their major life experiences” (Smith, Flowers, & Larkin, 2009, p. 1). It does not identify an epistemology but maintains an openness centred on the researcher’s stance. Critical realism was the position assumed in this research. Reflections and reflexivity were tracked using a reflective journal (Smith, 2011).

Participants

Participants were fathers with dependent young children (13 years or younger) at time of injury, and who felt able to comment on their fathering experiences. The gatekeeper at a local ABI charity approached appropriate participants to gain their consent to being contacted by the researcher. The remaining participants contacted the researcher directly (Appendix M) through charity website research pages. Seven participants of 14 interested fathers were interviewed that adhered to the inclusion and exclusion criteria (Appendix E). Of the seven fathers not included in the study, three did not fit the specified criteria, three were outside a manageable distance for recruitment and one father became ill and unable to participate. Fathers who did not meet criteria were offered a summary of the research findings if they wished (Appendix N). Table 1 illustrates the contextual information of participants.

Data Collection

Fathers were interviewed, by preference, in their charity centre (n=3) or home (n=4). All fathers interviewed were of White British ethnicity and aged 27-66. Written consent was obtained before interviews, following discussion to ascertain their eligibility/capacity to consent. Adaptions for cognitive and communication difficulties used interview guides in large print, regular breaks and checking continued contemporaneous consent. Interviews ranged from 56 to 95 minutes. Debriefing occurred 24–48 hours post-interview. Following the first interview, the topic guide was adapted to include questions about changes that may be noted as “silver linings” in their fatherhood and what they wished other fathers to know after ABI. Following review of the seven interviews, data saturation was noted, and no further participants interviewed.

Table 1. Contextual data for participants

Pseudonym	Age	Ethnicity	Marital status	**Family structure now, age of children** at time of injury	Nature of ABI	Time post-injury	Education	Post-injury employment
Oliver	66	White British	Married	Wife and daughter (2) older son from previous marriage (22)	Road traffic accident (RTA)	18 years	University	Failed return to own business, took early retirement
Harry	50	White British	Divorced post-injury	Living independently, 2 daughters (4, 2)	Encephalitis	6 years	University	Volunteering
George	35	White British	Married	Wife and daughter (3) and son (currently aged 3)	Haemorrhagic stroke	4 years	University	Part-time higher role with increased responsibilities
Noah	27	White British	Cohabiting	Partner and daughter (2)	Encephalitis	1 year	University	No
Jack	46	White British	Cohabiting	Partner and daughter (2), older son and daughter from previous relationship (24,22)	Anoxia	4 years	A-levels	No
Leo	52	White British	Married	Wife and 2 sons (3,2)	Encephalitis	11 years	University	Previously a business owner, working full-time in a different career
Oscar	35	White British	Separated from partner post-injury	With his mother, 2 sons live with partner (7,3)	RTA	7 years	pre-GCSEs	Previously a business owner, now does not work

Analysis

The first author read and reread transcripts employing an idiographic, contextual and iterative process from which emergent themes were generated for each transcript. This highlighted areas of convergence and divergence in the participants' individual experiences. The emergent themes formed patterns of subordinate themes from which superordinate themes were identified in the transcripts. Each superordinate theme was present in the interviews, and each stage of analysis was reviewed by the second author and further verified through collaboration with the third author. The analysis was undertaken by the lead author and a detailed record maintained to increase the transparency, rigour and trustworthiness of the analysis as discussed in Yardley's (2000) paper.

Results

Four superordinate themes emerged as important in making sense of fatherhood after ABI: (1) what being a father means, (2) altered relationships with others, (3) becoming lost and finding their way through, and (4) renewed fatherhood. Each theme was present in all interviews and are organised in Table 2. The pseudonyms for participants were Oliver, Harry, George, Noah, Jack, Leo and Oscar.

Table 2. Summary of superordinate themes and master themes

Superordinate themes	Subordinate themes
1. What being a father means	(a) How fatherhood was shaped (b) Being an unfamiliar father (c) I want to be a role model
2. Altered relationships with others	(a) A different father-child relationship (b) Partner relationships and fathering
3. Becoming lost and finding their way through	(a) Guilt and shame as fathers (b) I just wasn't capable of doing it
4. Renewing fatherhood	(a) Resolving the self in fatherhood (b) Finding a new fatherhood

Theme 1: What being a father means

The participants discussed how living with ABI influenced fatherhood in their lives. They talked about experiences that shaped their sense of what being a father meant pre-injury, changes in how they approached being a father pre- and post-injury, and their hopes for being a role model to their children.

Theme 1a: How fatherhood was shaped.

All fathers shared different ways, before and after injury, that their personal beliefs, attitudes and life experiences shaped understanding and engagement with fatherhood. The accounts from George, Leo, Jack and Oscar emphasised their continuation of being fathered, building upon what they had received, and the importance of duty and responsibility experienced in earlier life.

> What my grandfather said to me was the only thing I can ever give you is a memory. Everything else that I give you, you know, I’ve given you a fountain pen, and it will wear out, and it’ll go. He said right up until the point that you die the things that you’ll keep about me will be the memories that we had, right. And it sticks there. (Oliver)

Oscar shared his sadness of not living up to the promises he made as a father before his accident. He described feeling he had “lied” and betrayed his son by preventing him from engaging in the shared hobby he had learned from his father before him.

> When he grew up, he's always been beside me, and because I had my accident in racing I've always told him, when get to 12, I'll buy him a Mini, so but now I've had this accident I feel like I've lied to him, because I'm not putting him in a banger. You can see me now; do you know what I mean? That's not happening. (Oscar)

George particularly noticed having an idealised picture of fatherhood in mind. He identified that this did not represent his father but struggled with negative self-comparisons to this imagined “good” father figure. To remain consistent with his values he reinvented his fathering.

> I could see myself being a good dad, that is possibly why I beat myself up a bit about things I can’t do because I have – you have this ideal picture in your head about what a dad does and what he can do… When you see TV adverts and stuff we’ve got kids on the shoulders with their dad walking through the forest and things like that and think to have these days out things. I’ve got to remind myself. I still do those things. I still take them out. Well, I can’t have them on my shoulders and carry them about or hold their hand as I walk along. I can get my electric wheelchair, zoom after them chase him around the park. Chase them around the

> garden. I'll have to mind, I do remind myself, but you do have this ideal picture of what a dad should be. I remind myself, and I'm reminded by others constantly I'm a good dad, and I still am able to do that, so I don't have any issue so much anymore. (George)

Theme 1b: Being an unfamiliar father.

Fathers discussed difficulties with feeling unbalanced and not good enough. They highlighted the concurrent struggle in attending to their recovery or their children, where focusing on one of these parts overlooked the other.

> I think it's been very different being the father with a brain injury to being a father without the brain injury. My wife says that the time whatever that I spent with Matt before is much more than I've done with Hope because my patience is so much less. That's a big difference when my patience is so much less. Ummm, I did enjoy, I have enjoyed playing with her and whatever, but it's not been as extended as it was, and I think she suffered because of it. (Oliver)

Struggling in this changed fatherhood, half the fathers found ways of adapting that increased self-acceptance and benefitted their ongoing fathering.

> Now with my disability, if I'm feeling … I sometimes have to have rest in the afternoon. Even if it's just half an hour, just lying on the bed, listening to the radio, and then I'll get up, and … there are times where I just think, "I could just take another half an hour," but then I push myself, and I think – (excuse me) I think there are times when I think about that, just lying in bed and not interacting with them, when I hear themselves playing and stuff, and I'm not playing with them outside and stuff, I think I'm being a bad dad then. Then I remind myself that to be

> a good dad, I've got to do these things in order to be ready and fit and awake to do things later. It's about balancing again. (George)

Theme 1c: I want to be a role model.

All the fathers spoke of wanting to be looked up to and set an example for their children over time. Oliver, Harry, George, Noah and Leo discussed offering a role model their children could learn from as their father. This appeared to be strengthened by experiencing ABI and was an area they developed as fathers.

> I think I want to be a role model. I want to act with integrity and to be … It is very important for me to be a good role model for them. I'm their male role model. I think it's very important. I really want to be that as well. I want to be their role model. That's very important to keep up… I suppose, what I would hope is that they would learn how the way of being, like, way of being with life and way of approaching the world. I would hope that they would learn something from me about that. (Harry)

George uniquely focused on "handing down knowledge, and a way of acting" i specifically skills no longer possible in the same way, e.g. playing the guitar. George noted his ABI experience created a time of being reparented by his father as an adult. His father experienced a significant health event and, in the process, modelled moving from rumination and uncertainty to finding ways of adapting and coping. George's father helped him re-enact fatherhood by being a role model and aiding his understanding.

> It's that role of a dad, a teacher and support. He's still going that in the same way, I'd like to obviously continue with my children. It's nice to see a few generations. These moments in life, you reflect on it, don't you? I think that you reflect on what

> the role of a dad is and what he’s doing for me and then what I can do for my children in turn. That’s what builds up generation on generation. That’s really nice to see in a way and nice to stop and reflect on those things occasionally. That’s something positive to take out. (George)

Theme 2: Altered relationships with others

Though discussion of parent-child relationships often a sense emerged of ABI influencing the interconnectivity and interdependence across other relationships. This was woven through fathers’ subjective experiences of changed relationships, which appeared to influence how they felt “present” as fathers at times.

Theme 2a: A different father-child relationship.

Almost all the fathers shared shifts they felt within roles and responsibilities as fathers. These changes appeared to impact on fathering and influenced fears they held about their children’s future.

> I worry the effects it’s having on them. They seem to be coping actually fine, but you never know quite what’s going on inside and what they’ve taken on board. I do worry that the combination of the brain injury and divorce is putting quite a legacy on them really. (Harry)

Fathers faced a struggle to remain assured in their parenting when ABI challenged previously known fathering skills and abilities. Oliver described an early loss of control in his fathering role: “I’ve got to tell you it gets very irritating and aggravating at times as well because you sort of think you’re the parent, you know, stop telling me what to do!” which as his daughter has gotten older helps him to manage his difficulties.

> The other thing is as she’s got older the roles have changed very much, there are times where she and I are out, and she becomes the parent. Right … and when she sees that things are getting too bad for me, she becomes quite protective, that’s what I’m saying, she becomes the sort of parent as it were and am deals with, she’s pretty good like that. (Oliver)

Many of the fathers expressed sadness that their children had not received “full value” (as Oliver worded it) after ABI. Most said they felt their children had “suffered” and continued to be affected due to father’s injury. Oscar perceived himself as being less of a father to his children; however, his oldest sons’ reminders of knowing a different before-father perpetuated his suffering. Oscar’s ‘stuckness’ in prior fatherhood and the new parenting experiences appeared to devalue his sense of self rather than motivate, as the other fathers reported.

> The trouble is the youngest boy he don't really know me, the oldest boy do because he was always with me no matter what, every time he's always with me. He said, "You were a lot better before dad when you were not--. But I try my hardest you know, that’s all I can do the thing is, I have to tell him day in and day out what's wrong with me, and that get to me as well because that makes me fucking remember. Excuse my language, but it makes me remember, it makes me have to go over it. That's the hard bit. It makes you re-live it, even if you don't want to. (Oscar)

Theme 2b: Partner relationships and fathering.

Oliver, Harry, Noah and George noticed the struggles after ABI impacted on not only their parenting but also their partner's parenting; things that were lost to the father were picked up by the mother, at times leaving less time for a mother's role.

> We were fighting to survive my wife and I… At the time she wanted to be a mother to her child as well, so there's a certain bit of resentment from her because she wanted to have the time and me having the accident swapped those roles around. (Oliver)

Elements that once sat as part of their father's domain were maintained by assimilation of the breadwinner role, increased responsibility and confidence through the mother.

> She was never the leader, she was always led, right, but what's happened is this caterpillar, okay, right has changed completely. She's held our relationship together, she's seen where you know I'm no longer capable of doing the things that I could do, she has accepted that and gone with it. (Oliver)

This changed coupled landscape appeared to affect how fathers perceived their parenting. Fathers who remained coupled increased their focus on their children, working to maintain family life, while others now single were forced to navigate continued fathering from an unknown isolated place. Highlighted by Harry's sense that he had been quietened, broken down and shut out from his family home.

> [I] think because of the brain injury, she just completely rejected me…just absolutely not my wish at all. The reason is, and I'm not sure quite how to put this, but my wife has such a negative view of my brain injury, such a negative view [at this point the feeling in the room was of heaviness highlighted by the barren

> environment of his single bedroom flat]. In her eyes, it is completely wholly bad, and I'm much less of a person for it. (Harry)

Similarly, Jack and Oscar shared the sense they were alone, left to figure out how to parent from an unfamiliar place which impacted on their relationships with their children. "If you didn't cause this [having an affair that split the family up] I'd have my kids every day". (Oscar)

Theme 3: Becoming lost and finding their way through

All fathers spoke about how their emotional responses to changes impacted fatherhood. Additionally, they spoke about how changes to their bodies and cognition influenced how they viewed themselves as capable fathers to their children.

Theme 3a: Guilt and shame as fathers.

All fathers, except George, commented on experiencing guilt and shame, which affected the view they had of themselves as fathers. Oliver referred to "shared memories" that were central to his experiences growing up. He feared his own most difficult time may have indelibly marked his daughter's life which she would carry through life.

> I think the most surprising things, and the things I'm really ashamed of is that period when that 10 to 11 (his daughter's age at the time). Where I told you about, where I was really running out of patience and couldn't be bothered with her and whatever, you know what I mean, that is a disappointment, very much a disappointment and I'm hoping it's not stayed with her but you can be pretty – I mean she doesn't mention it, and she hasn't but you can be pretty sure that people

> don’t forget bits clashing or whatever. As I said initially you know, I always remember what my grandfather said about memories. That’s all you ever give your children, you know is your memories and that’s what comes back to me, memories you know of the relationship with my parents. I remember the good ones, I remember the bad ones, and so you wanna give your kids the good memories. (Oliver)

Many of the fathers alluded to the weight of outside scrutiny on their family lives, worrying about how they may be perceived or judged as fathers. Oscar, through his mother taking responsibility away from his parenting, felt undermined. He struggled with understanding himself and found her inability to see his perspective further isolating in managing his ABI and being enabled as a father.

> When I first came out (rehabilitation centre), I got a meeting set up for her to go in there so she could understand what I’m like and understand what to respect. Did she go? Did she fuck, she went, “I know my fucking son, I don’t need no one telling me about my son.” “But you do mom because I don’t even know about myself. How can I?" But if she went, they would have told her like what to watch out for and stuff. What happens when … and it got me down. (Oscar)

He expressed feeling alone in his ABI, misunderstood by everyone as who else “could know” what it means to have “my brain injury” as it was his life that was forever changed.

> Now I go, “I need help.” Who’s there helping me? No one. Not a fucking one person. All my mates are gone everything. All I’m left with is me [clears throat]. (Oscar)

In contrast, when George struggled with difficult emotional thoughts relating this to others and his lifeworld pulled him back and engendered a sense of positivity.

> It’s always those thoughts about being a dad and family that pull me out of those negative… Rather than making it worse, they would be the things that pull you back… When I get negative thoughts, it’s always family and being a dad that’s the thing that is the shining light in the sky that’s being positive. (George)

Theme 3b: I just wasn’t capable of doing it.

Throughout Oliver’s interview his responses to his experiences of loss centred on capability and self-expectation in being an “able” father.

> Yeah, yeah and you become really ummm you feel that you’re not as capable and you’re not able to offer your child what you feel you should be offering them, and it’s through no fault of your own, but you find that pretty frustrating and you try to do more. And, with this brain thing the more you try to do the work out becomes, you know? You know the brain got messed up and I was just like jelly, and I was of no use whatsoever, and I just felt, you know, just felt like a right dick basically, sorry, you know built everyone up that I was gonna help him do this (put together fitted wardrobes) and then I just wasn’t capable of doing this, you know. Stupid cunt… ugh. (Oliver)

For Noah, his feeling less “able” as a father resonated through his memory loss. It felt “unreal” to rely on his partner for his own experiences beginning fatherhood.

> It’s a bit weird because when you’re shown a picture, you don’t know whether you’re then creating a false memory because you’ve seen that picture or whether you actually remember it. It’s incredible being told things that happened. Then, trying to imagine them happening. (Noah)

He grappled with his disconnection from his memory of fathering and feared this untethered sense of himself as a father may continue. “Me never having fully recovered from the encephalitis and her [his daughter] having to learn how to deal with that”. (Noah)

Theme 4: Renewing fatherhood

Almost all the fathers noted new ways of fathering that resonated with reforming as fathers in their families. Additionally, they shared gratitude and appreciation for their continued presence in their children’s lives and hope for their shared futures together.

Theme 4a: Resolving the self in fatherhood.

Jack spoke with sadness about the loss of parts of his previous self-identity. However, putting his children’s needs before his own, allowed him to continue as “provider”,

> Well, yeah. I can’t be Mr Stressful anymore. I like it. If somebody came around and argued with me or something like that, I’d end up fighting or things like this. It’s just a male thing how I’ve been brought up, but now that’s really took away by the heart attack, ticker being flimsy… I don’t want to cause harm to my children and all the rest of that. I don’t want to have that on my head. (Jack)

For Leo, the reciprocity of mutual love and support experienced throughout the family helped him to reformulate his own father identity over time.

> I think it is to be patient with yourself it sounds a bit of cliché but to understand that things do change over time, don’t expect an instant and it will all be different now, it doesn’t happen like that. It’s an adaptation and be kind to yourself and accept that things change. But be positive you can still have good relationships

> with children and family and you’re still a role model for them, so you still have a lot to do, and there’s a lot that, you still have a lot of talents and skills and abilities, and it is important to recognise that and don’t be too hard on yourself. I’ve talked about the whole family situation, and so we’ve had to maintain, or to look at it as a sort of mission at the moment, is maintaining stability in the family, with difficulty, but someone is going to work, and someone is in hospital; in fact, we will have great challenges to meet, but how we still help each other and support each other, and around giving each other time and a type of understanding, and there’s also on a positive note that things do improve in time and that things, so don’t think past the end, nothing will ever change, because things do change. (Leo)

Theme 4b: Finding a new fatherhood.

Many of the fathers grieved the loss of their previously held sense of themselves as fathers. Additionally, they emphasised finding new ways that allowed them hope, comfort and purpose as fathers over time. Harry shared his increased appreciation and gratitude for life with his girls, specifically referencing post-traumatic growth as enabling him.

> My life has been completely devastated to be honest, by brain injury and then divorce. I have had to find myself a new purpose and a new role for myself. As so it’s, now, it’s very important for me that I pursue work and volunteering that is somehow meaningful. It’s all about how you provide meaning. One thing around that is the girls and being dad, and the other thing is around work, work on pay or voluntary work. Both those things are really key. (Harry)

Oliver said that the continued love and acceptance from his children gave him hope for their futures together. Having this acceptance allowed him to be the father of his earlier beliefs, without feeling constrained by times when it does not go right.

> Life isn’t a rehearsal, and so because of that it’s one of the big lessons that comes from this sort of thing, and so you really just want your kids to sort of enjoy. (Oliver)

For George, when challenged by difficulties, he consistently found ways to overcome or positively reframe his fathering not to become stuck. Partly, this related to normalising the ups and downs of parenting.

> I guess it’s a coping mechanism in a way. When I get down or feel like low and thinking, oh, why did this happen, one of things I remind myself is I’m so lucky to have these opportunities. There have been things like silly little things, things my dad told me again, things my dad passed to me, he’s been there all my life, and then he’s still there in the background chipping in points of wisdom. He used to say to me so many bad things will happen or it's affected in so many bad ways. He really has to look at the positives, and he really does remind me of that himself, actually. Again, I’m still taking that from him the same way that I’m doing to my children. (George)

Discussion

This study used IPA to explore the question: In what ways do fathers experience being a dad after ABI? Four superordinate themes were identified: (1) what being a father means, (2) altered relationships with others, (3) becoming lost and finding their way through, and (4) renewing fatherhood. The descriptive richness of experiences varied among participants, possibly reflecting the impact of ABI on cognitive and emotional abilities. The current research provides insight that adds to prior literature and has implications for future research and clinical interventions.

What being a father means

Previous literature on parenting and fatherhood after ABI has focused on adapting pre-injury identity to post-injury circumstances. In contrast, the current study provides insights into the specific issue of fatherhood. The theme of "what being a father means" highlights how their own experiences and self-perceptions influenced the fathers, in their ideas of fatherhood and wishes to set a good example for their children. This appears consistent with Morriss et al. (2013), who found fathers contrasted themselves against what they "should be like" as parents but differs from Lundwall's (2000) study, which noted parents' power and identity appeared to change for the worse with disability. The theme of being a role model appeared to allow consistency with their prior values and ways forward so that they could be "good" fathers and role models. Edwards, Daisley, and Newby (2014) reported specific difficulties centred on multiple losses as parents whereas the current study expressed adaptation and compensation in the fathering role. Our findings resonate with aspects of post-traumatic growth (Powell et al., 2007) and support MacQueen et al.'s (2018) finding that adaptation motivates fathers to feel enabled in their roles.

Altered relationships with others

The current study supports Charles, Butera-Prinzi, and Perlesz (2007) findings that post ABI parents struggled in their parental relationships. Unlike Edwards, Daisley, and Newby (2014), distance in the parental relationship was noted by only one father. Their study like Morriss et al. (2013) described issues in parental contributions of knowledge, skills and applied parenting after ABI, but this was not discussed by the fathers in the current study. This may indicate a different perspective of parenting was shared as part of the fathers' lived experience not freely generated through this study. In the present study, the fathers spoke of a disadvantaged child for having a father with ABI. Over half the fathers directly highlighted meaning, value and prideful purpose as fathers in their accounts of their parental relationships, which resonates with Dolan's (2014) findings regarding fathers with ABI and Evenson et al.'s (2008) concerning fathers with psychosis.

Threaded through all the fathers' accounts were experiences of underlying relationship difficulties that influenced feelings of guilt, burden and shame in line with previous reports (Freeman et al., 2015). This supports the idea that coupled relationships may be vulnerable and challenged by ABI (Gill et al., 2011). In contrast to previous research (Morriss et al., 2013), over half the fathers were in coupled relationships that appeared to have weathered post-ABI challenges. Many fathers in the present study found ways of coping with and continuing their relationship through interpersonal adaptions by both partners. Additionally, family-based adaptations supported their fathering role and motivated them to fulfil their partnered role. This was particularly noted in Leo's account of finding mutuality in and among family members that allowed give and take across the parent-child relationships and the parent coupled relationship.

Becoming lost and finding their way through

The fathers in the current study shared difficulties with physical and cognitive changes but this was interpreted as emotional responses to feeling less capable or able to reliably respond as fathers, like under the theme of self-perception in the MacQueen et al. (2018) study. The fathers here focused on the emotional impact of changes in the context of being part of a family. In contrast to the Morriss et al.’s (2013) study, only one of the fathers reported low self-confidence and self-efficacy in their perceived parenting ability. Another study noted when family narratives were misaligned, survivors feel isolated experiencing a “moving out” from the family (Whiffin, Ellis-Hill, Bailey, Jarrett & Hutchinson, 2017). Similarly, “conflicts and gulfs” in the narratives between family members have been noted to damage relationships (Couchman, McMahon, Kelly & Ponsford, 2014).

The examples fathers gave highlighted where they felt they had failed themselves and others through their inaction or inability, their rumination, and managing emotions like guilt and shame. This supports the findings of embarrassment and shame reported in MacQueen and colleagues (2018) study, although less reported in previous research around masculine identity (Freeman et al., 2014) or parenting after brain injury (Edwards, Daisley, & Newby, 2014; Morriss et al., 2013). Additionally, the fathers reported feelings of loss and isolation about their fathering role and spread across other roles and areas of their lives. This mirrors what Simpson, Mohr, and Redman (2000) reported, that individuals reported experiences of social isolation and stigma after ABI. The fathers here shared experiences like the oscillatory movements in adapting and adjusting to their parent role described by Edwards, Daisley, and Newby (2014).

Renewing fatherhood

Ruppen, Waldvogel and Ehlert’s (2016) study of fathers noted that being a father and occupying a fathering role has varying degrees of fulfilment and perceived constraint. This may have both positive and negative impacts on men’s well-being; however, the range and salience of roles open to men are related to the centrality this fathering role played in their lives prior to the injury and whether this has shifted (Rane & Mcbride, 2000). George’s account highlighted management of challenges and increased coping, drawing on his past values and meanings as a father. He offered himself a flexible repertoire of narratives reinforced by his partner, family, family of origin and work colleagues, and suggested that other fathers can find “ways of adapting” or “ways to overcome”.

Most of the fathers in the current study expressed hope from continued fathering abilities. Kingerlee (2012) noted that men, and particularly those who identify with ideal traditional masculinity, are culturally normed to seek ways to save face and retain status; instead of resonating with the emotional difficulties and areas of perceived weakness that impact on recovery and well-being. Hoskins and Leseho (1996) note that multiple possible selves and expanded roles in society allow survivors opportunities to develop. This was evident in most fathers’ accounts, although those of Noah, Jack and Oscar describe struggling to move from evaluation, to a place of hope, that allows reformulation of self and father identities. It may be that in these cases dominant hegemonic masculinity is perpetuated at the expense of working on areas for acceptance of new viable roles and responsibilities in familial and cultural contexts (Kingerlee, 2012).

The findings here demonstrate a constant interplay between pre- and post-injury comparisons of self and social identities as seen in the study by Muenchberger et al. (2008). The theme of hope and aspiration noted in the study of Edwards, Daisley, and Newby (2014) and the theme of re-evaluating life and values in MacQueen et al.’s (2018) study are also supported through this study. Nochi (1998) noted that individuals at a most fundamental level must change the appearance of the past and future, revising self-narratives in recovering self-identity after TBI. The fathers in this study sought different ways to find meaning and value. Through employing different ways to engage in meaningful occupation and find merit in their changed family life.

Limitations and Strengths

The research is bound by the underpinning tenets of IPA, particularly idiography and hermeneutics. The findings are representative of the fathers interviewed and may not be transferable or generalisable beyond these accounts. Also, it may be argued asking individuals to contrast present and past allows idealisation of the former self (Ponsford, Kelly, & Couchman, 2014). However, the main focus for IPA studies and this research is towards sense-making rather than a factual account. The findings are the singular interpretation of the lead researcher and do not claim to offer an absolute truth, as the double hermeneutic process allows other interpretations may be considered. A strength of this research is the methodology of IPA, exploring lived experience of meaning-making, that may guide future research directions to grow the literature base for fathers after ABI.

Clinical Implications

The findings support the concept of reformulated male identity (Jones & Curtin, 2011; MacQueen et al., 2018). Highlighted is a complex dynamic between personal and relational narratives, at individual and systemic levels, in reformulating fatherhood identity. Specifically, the themes highlight the need to assess relationship functioning for fathers after injury, in both parenting and partner roles. As well as exploring when appropriate surrounding areas of intense emotion such as guilt, blame and shame noted here that appear to influence wider system and individual functioning for fathers post-ABI. Considering the differing themes from the Edwards, Daisley, and Newby (2014) parenting after ABI study and this research assessment questions may be more appropriately considered at longer time points post-injury towards later adjustment. This remains dependent on service providers aligning with personal and family trajectories for assessment and tailored intervention, versus distress and deterioration triggering referral processes.

From the study findings, interventions that explore relational work with children and partners, as well as full family therapy intervention after brain injury (Bowen, Yeates, & Palmer, 2010), could be beneficial for fathers. This speaks to the themes of ‘what being a father means’ and ‘managing altered relationships’. The multiple-family group interventions piloted by Charles and colleagues (2007) appear specifically useful areas to develop further as their study identified positive changes related to isolation and shame, opportunity for mutual support, sharing of difficult experiences, and increased compassion. This may lead towards collaborative learning drawn on lived experiences but guided through clinical formulation. It may be useful clinically, to draw on the work of Gracey, Evans and Malley (2009) in resolving the interpersonal and intrapersonal discrepancies to help fathers towards this later adjustment in personal growth and social participation.

Leading into individual interventions that may use compassion-focused therapy (Gilbert, 2010), narrative therapy (Butera-Prinzi, Charles, & Story, 2014; Weatherhead & Todd, 2013) and acceptance and commitment therapy (Hayes, Strosahl, & Wilson, 2009), given the findings representing stigma, shame, guilt, ability, loss and isolation threaded in the themes reported by the fathers. This could create connections with their past selves as well as working with the positive representations in Whiffin et al.’s (2017) study to build into the theme around renewing fatherhood. Through increased understanding, we may enable fathers to find new ways to resolve, reformulate, and connect with essential values to move into future fathering identities. This may also help clinicians to understand meaning-making, so that intervention choice aligns for individual fathers.

Research Implications

A study of mothers and motherhood would enhance understanding of gendered identity experiences after brain injury. However, this future research could be widened to explore concepts at the individual and family level using qualitative collective or multiple-case study approaches, to account for the relational contexts identified in the current study. Further research is needed to explore how fathers approach possible future selves and the reconstruction of identity. Specifically, utilising existing models such as the life thread model (Ellis-Hill, Payne, & Ward, 2008), the Y-shaped model of rehabilitation (Gracey et al., 2009), the Enduring Experience of TBI model (Levack et al., 2010) and the global self-system model (Ownsworth, 2014). These first two models may confer in the first instance a personal rehabilitation narrative around working the life threads of past identity, situation and future possibility, while attending to the enduring experience model (2010) that explores the internal and external resources that help move a father between disconnection and reconstruction. The Ownsworth model (2014) fits with the fathers hopes for resolved and future possible selves while addressing values, wishes and motivations to reach flexibly individuals' value and meaning, (Gracey et al., 2009), and expose viable protective roles and identities engendered through a father's position.

Conclusions

The current findings suggest fathers may benefit from work in personal identity issues that contribute to, and are woven into, the complex role of parenting in the family. This is highlighted through; finding appropriate models that are most salient to the individual father for formulation however aligned to intervention choice based on the themes identified through the current research. These findings also provide an initial understanding around meaning-making of fathering experiences after ABI, a beginning from which to grow further literature in this underrepresented area. Future research may complement this study by exploring experiences of mothers after ABI to guide family-based work and research knowledge.

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Chapter 4. Extended Methodology

Chapter Overview

This chapter presents a discussion of a richer deeper nature related to the epistemological position of the approach taken, Interpretative Phenomenological Analysis (IPA) and situates this within the context and position of the first author. Presented alongside this are further reflections relating to the rationale for this particular approach, the concepts which underpin IPA, as well as researcher reflexivity throughout the process. Further detail relating to participants, recruitment, ethical considerations, interviewing, as well as analysis and write-up is also considered here.

Ontology and Epistemology

When selecting a study design to answer the research question posed, a researcher must consider what the most appropriate method may be dependent on the concepts of ontology and epistemology. To begin the researcher must question what the research hopes to explore and the researcher's relative position concerning the nature of reality (ontology) and the nature of knowledge (epistemology) respectively. Ontology examines the idea that there is a distinct reality to be known outside of experiences which are separate from our understanding. Epistemology references what we may know and how we can obtain this knowledge through undertaking research (Braun & Clark, 2013). The epistemological stance for this study was phenomenology. In exploring a person's lived experience of a phenomenon one research methodology primarily used is Interpretative Phenomenological Analysis.

Interpretative Phenomenological Analysis

Interpretative Phenomenological Analysis (IPA) is 'committed to the examination of how people make sense of their major life experiences' (Smith, Flowers & Larkin, 2009, p. 1).

It considers a person’s lived experience, how they make sense of their experiences and puts the individual at the centre of their sense-making (Smith, 2011). IPA seeks to detail the subjective experience of the individual so that we may begin to understand specific phenomena while challenging the concept that knowledge is unbiased and objective (Smith et al., 2009). The core tenets of IPA are made up of Phenomenology, Hermeneutics and Idiography. IPA is often an approach employed to study under-researched, novel or nebulous phenomena (Smith & Osborn, 2008). It was deemed to be an appropriate methodology as the study is phenomenologically based on how each father subjectively experiences fatherhood after ABI. IPA does not advocate a prescribed method for analysis but suggests an open and flexible approach to analyse the data. As the researcher was new to IPA, the process followed Smith et al.’s (2009) guiding text, and closely attends to Yardley’s (2000) recommendations for methodological rigour: sensitivity to context; commitment and rigour; transparency and coherence; and impact and importance.

Phenomenology, Hermeneutics and Idiography

Phenomenology refers to the focus around how people perceive and talk about events or objects, which is the sense-making of the study of experience, as well as a philosophical approach (Shinebourne, 2011). It is particularly focused on the things which matter to us (Smith, 2011). Hermeneutics is interested in the theory of the interpretation in so much that researchers cannot ‘know’ the world of the person directly however may try to make sense of the person’s world through their interpretations. The researcher as such plays a role in the co-construction of meaning-making such that there are two connected levels of interpretation. The participants experience and the researcher’s interpretation of the subjective experience, filtered through their own experiences referred to as the “double hermeneutic”. The researcher is “making sense of sense-making” (Smith et al., 2009, p. 35). Finally, idiography is interested in the study of individual cases or events. The aim of which is commitment to a finely textured analysis of actual life and lived experiences through focus on the detailed-particular (Smith et al., 2009). IPA draws on these underpinning theoretical tenets to inform the epistemological and research framework (Shinebourne, 2011).

As Braun and Clark (2013, p. 181) have noted: “IPA studies tend to focus on significant life experiences that often have implications for our identities, as they unfold in particular contexts”. Lived experience is used as a term ‘to encompass the embodied, socio-culturally and historically situated person who inhabits an intentionally interpreted and meaningfully lived world’ (Eatough & Smith, 2007, p.181). The philosophical underpinnings of IPA lie somewhere between Critical Realist and Social Constructionism (Larkin, 2006). IPA does not identify an epistemological position rather maintains an openness which is more centred on the researcher’s stance, being able to reflect on this and reflexively draw on how this may be part of the data collected and analysed (Smith, 2011).

Researcher Context

To add context to the current research and the researcher’s position, I am a 32-year-old white-Irish childless female trainee clinical psychologist. Much of my prior experience before beginning my doctorate was in brain injury and neuropsychologically based services. One of my last most memorable experiences working in this area involved undertaking joint work involving a father after stroke. The work centred around adjusting to his changed work and family life. I recollect the intensity of the experience of engaging with this man and the difficulties he shared in being able to manage his changed life across different spheres following brain injury. Reflecting on my choice of research question and the path which may have led me to explore this area, an image from the work with that father kept returning to my mind. This image in some ways I think has driven my curiosity and passion to explore this area. The image that I refer to is of this father sat in his living room, in his beautiful home, with his lovely children. The evidence of his drive, status and success all around - holding his hands to his face to shut out the world. The difficulties in applying his previous life skills and knowledge lost to him. All the while powerful undercurrents are expressed through the magnitude of the difficulties and changed life course when surrounded by his family. This was my first experience of really resonating with adjustment after brain injury and the impact it may have on the person as well as a family.

I think this is important to note as this has influenced my sense of emancipatory action in researching an area that has received little attention to date. My own context, assumptions and other experiences may subjectively influence the research undertaken and as such reflexivity was a vital consideration to be used across the study. This helps to notice when my own position may be influential and can be put aside bracketed for later exploration as appropriate to the research.

Researcher Position

Critical realism will be the position assumed by this researcher in this research project. Critical Realism offers a framework for exploration of key questions that may capture “a small part of a deeper and vaster reality” across three levels of reality. The levels offered are (1) “the realm of events as we experience them”, the empirical level; (2) where there “is no filter of human experience” where events occur whether we experience them or not, the actual level; and (3) where there is “causal structures or causal mechanisms” which “exist”, the real level (Fletcher, 2017). It allows that a social world exists independent to the subjective experience of the individual, the meaning of which is socially produced and reproduced but only made accessible through interpretations. There is an external reality expressed however different vantage points give way to different types of understanding dependent on the context (Fletcher, 2017).

Reflexivity

Qualitative research considers the researcher as the interpreter of, and influenced by, the research in a reciprocal process. Reflexivity is an integral part of the research process involved in IPA as researchers in addition to participants bring assumptions, narrative and values into the research (Braun & Clark, 2013). Qualitative research recognises that a valuable part of the research process includes reflexivity; that is why personal reflexivity is noted and acknowledged (Braun & Clark, 2013). As such best practice involves keeping a reflective diary across the study. This diary or journal tracks the analysis and decision-making processes of the researcher. It also holds any impressions of ideas the researcher initially makes such that they can be returned to later a process called ‘Bracketing’ (Braun & Clark, 2013). It can be interpreted as noting the inter-subjective dynamics between researcher and the researched (Finlay & Gough, 2003) by critical self-reflection of how the researcher’s position, personality, personal background, social context and behaviour may impact during collection and analysis of the data (Lipson, 1991). The influence of Heidegger’s formulation of phenomenology notes that this may be something which is only partially achieved at times due to the complex, dynamic and cyclical movement between fore-structures and interpretation (Smith et al., 2009). This bracketing need was held in the first author's mind from the beginning of the research and a Dictaphone was used as a reflective journal to record thoughts and feelings throughout the process.

Ethical Considerations

The study received ethical approval through the University of East Anglia – Faculty of Medicine and Health Research Ethics Committee (Appendix D). It adhered to the ethical and practice codes of the Health and Care Professionals Council, the British Psychological Society and the standards for institutional committees on human experimentation within the Helsinki declaration.

Capacity and informed consent.

Brain injury and changes to the brain can mean that capacity to make specific decisions can fluctuate; however, the Mental Capacity Act (2005) recommends that capacity should always be presumed. Gatekeepers were employed to approach participants who may be appropriate to take part in the research study given the introduction to the research sheet (Appendix F) and the inclusion/exclusion criteria (Appendix E). Gatekeepers working with the fathers noted no concerns, and the fathers received the participant information sheet (Appendix G) at least 72 hours before the interview to allow time to discuss with loved ones or trusted staff as part of their decision making. Written informed consent was taken immediately before the interview; however, continuing contemporaneous capacity to consent was checked at each different stage of the interview process. Adaptations were made to support cognitive or communication issues such as the accessibility of the participant information sheet, time and support to consider the information provided by the researcher in advance of the interview, as well as extra processing time and regularly checking in were put in place to enable informed consent (British Psychological Society, 2010). Fathers were given the opportunity to ask any questions before consenting to the interview, during the interview and afterwards, in the debrief phone call. The fathers interviewed were informed: that their involvement was entirely voluntary, they did not have to share anything they felt uncomfortable discussing, they could withdraw from the study for any reason (with no impact on their involvement with their recruiting centre) up to 2 weeks after the interview when information would be transcribed and analysed.

Confidentiality.

The fathers interviewed were assured of confidentiality and anonymity in undertaking the research; however, that verbatim quotes would be used from their accounts in writing up the findings of the study. Fathers were assured their identities, their loved one's identities and any identifiable information would be removed or changed to protect them. Pseudonyms were assigned after the interviews were completed and allow the research to remain true to the representation of real lived experiences of interviewees (Braun & Clark, 2013).

Debriefing.

The fathers were followed-up by phone call 24-48 hours after the interview. At the end of their interview they were provided with a debrief sheet (Appendix K) and made aware of the possibility that by engaging with the process of being interviewed it may influence their thoughts, mood and recollections over the coming days.

A risk management plan was devised and discussed in supervision if risks or distress from particpants occurred during interview or afterwards (Appendix L).

Data protection.

Each interview was recorded on an encrypted Dictaphone and transferred onto UEA servers then erased from the Dictaphone. No personally identifiable information was saved on the researcher's laptop at any time, to ensure safe storage. Where necessary, other identifying details were amended or removed from the transcripts to ensure anonymity. Participant information will be stored in line with the UEA Data Management Policy (2015) and the Data Protection Act (1998). After the study (or as soon as no longer required, all personally identifiable information will be destroyed. Anonymised research data and research files will be archived at UEA. All information is stored for ten years with the primary supervisor assuming overall responsibility for acting as the data custodian after the researcher has completed their studies.

Interview

An interview guide was created based on available literature and guided by neurorehabilitation professionals in the area. Multi-part questions were developed, and open-ended prompts used to aid experiences shared as well as acknowledging the possible impact of cognitive difficulties on communication. Peer reviewers noted that the language level and required comprehension level appeared appropriate. The interview guide explores questions related to fatherhood guided by prior research (Appendix C) and was used across the interviews. A semi-structured interview was used to explore fathers' experiences following brain injury. This is recommended by Smith & Osborn (2008) to allow structure yet flexibility in the interviewing process so that participants may feel comfortable and engaged. Equally the interview guide was printed to assist in reducing worry and cognitive load for fathers during the interview. They were told there was no right or wrong way to answer or go through the interview and questions were to draw out their reflections on their personal experiences of fathering. We could refer to the interview guide across the session, however their stories and experiences would lead the conversation and our interview.

Many of the fathers interviewed had high-perceived social status gained through education and professional occupations before the injury, which may have influenced their willingness, ability and choice of experiences shared upon which the findings are based. Therefore, these findings are representative of these seven fathers accounts and fit the exploratory aim to study how fathers experience fatherhood after ABI.

During the interviewing, the lead author was cognisant of the possible gender differences in a childless female researcher questioning male participants. Additionally, at times anger and aggression were expressed on the part of a small number of participants towards the researcher. This added to wondering whether being female and childless may have been perceived as an ‘othering’ experience for the fathers. It was hypothesised that the topics of anger and aggression in relation to parenting challenges may be discussed as part of each interview however these areas were not directly reported with frequency by the fathers during the study. It had been presumed this may be a possible area of greater discussion given its presence in previous research in this and other areas of brain injury. Some fathers directly enquired about child and relationship status which add credence to the possibility that certain elements of the accounts shared by some of the fathers could have been sanitised. The limits of confidentiality were discussed as part of consenting to the study however given the sensitive nature of enquiring about fatherhood fathers may have felt inhibited or worried to share any narratives that may allow them to look unsafe as fathers. These differing areas were reflected upon often as part of the analysis and reflexivity employed during analysis and write-up of the study.

Transcription

The audio recordings were transcribed with identifiable information removed and participants assigned a pseudonym. Professional transcription of some interviews was arranged, and the fathers were made aware of this when consenting to the study. The lead researcher chose to utilise professional transcription to allow a fresh focus to each interview and to add bracketing off to some degree. It also allowed for the cognitive load on the researcher to be lessened. The initial professionally transcribed scripts were listened to several times and cleaned by the lead researcher during the process of managing the transcription of final scripts from interviews.

Analysis and Write-up

An IPA approach to analysis of the data was undertaken. This employs a six-stage framework recommended when new to the IPA approach (Smith et al., 2009). The different stages include:

- Stage 1 – engage with the data by reading and re-reading transcripts to enter the lifeworld of the participants. Listening to the audio recording is recommended in following the transcript in this initial phase as well as utilising the reflective diary to capture researcher impressions and 'bracket' these off for now.
- Stage 2 – exploratory coding of transcripts line-by-line or through chunking of text representing meaning to identify a range of objects discussed relating to the phenomenon of fatherhood following brain injury for fathers beginning to sort descriptive, linguistic and conceptual ideas behind the comments (Appendix O)
- Stage 3 – beginning to develop exploratory comments into emergent themes, through the application of the double hermeneutic the researcher begins to interpret the interpretation given by participants. The exploratory and emergent themes were developed in a single excel file including the main transcript to stay with the lived experiences and reflections shared during the interview.
- Stage 4 – moving to find ways of contextualising the emergent themes, how they draw together or pull apart. The themes were moved and adjusted eventually forming patterns of connections between related subordinate themes
- Stage 5 – analysis is completed on a case-by-case basis (Appendix P), moving to the next case in the analysis before progressing to cross-case analysis for superordinate themes
- Stage 6 – cases are examined for the subordinate themes and patterns are identified that are overarching among the cases included (Appendix Q). These form the superordinate themes which are connected and resonate across accounts.

Across the analysis, the reflective diary was used to note thoughts, feelings, impressions, challenges experienced by the researcher in engaging with the research. This helped to bracket off previous experiences and theoretical knowledge as much as possible to approach each transcript in a way that allowed the researcher to remain true to the experiences, meaning-making and new knowledge given over by the participants through their accounts.

Cross-checking of interpretation was undertaken by the research team, not to encourage a correct interpretation but to ascertain the credibility and validity of the interpretation offered by the lead researcher. Multiple interpretation and perspectives may be possible from the nature of the research. This step endeavours to revisit the coding and interpretation to strengthen the case of the singular interpretation offered in this instance and context by the lead researcher.

The researcher aimed to stay with the uniqueness of the individual experiences yet choose selected quotes from the representative transcripts that most clearly portrayed the lived experiences of the phenomenon as understood through the superordinate themes identified. Additionally, as this research appears at the time of writing to be the first IPA study exploring fathers experienced of fatherhood after brain injury and situated in the local UK context it addresses a significant gap in the literature. This study may impact on clinical and research directions in future emphasising the importance of having undertaken the current research.

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Chapter 5. Overall Discussion and Critical Evaluation

The purpose of this chapter is to summarise and evaluate the systematic review and empirical paper with respect to each other. Also, the wider clinical and research implications of each paper will be critiqued for the unique and novel contributions they may offer to the research area.

Summary of Findings

The findings of both papers explore qualitative phenomenon. Both papers in this thesis portfolio are related, as the systematic review is concerned with exploring the research question centred on the coupled experience for survivors, which could be considered part of father's experiences after ABI explored in the empirical paper.

Systematic Review

Defining the research question used search terms that relied on defining ABI and coupled experiences. It was noted from the returned studies that this represented a paucity of research in this area was identified using the prespecified inclusion criteria. During the course of searching and finding eligible studies; it was hypothesised that the methods used by the databases for returning the eligible studies may not always reliably capture all literature relevant to the systematic review question. It may represent a flaw in how the literature is termed and coded for retrieving all useful data yet not readily captured using the prescribed and generic terms more commonly used given the relative scarcity of research into this under researched area.

A caveat of this systematic review is that it was framed to explore ABI. Although ABI was applied in the search strategy terms and the research question, the final papers could be seen to be more representative of a TBI population. Though many of the papers returned during the initial search were not relevant to the research question, a widened search stratgey may capture less well labelled or termed studies that may be useful for future reviews. Where this review to be undertaken again this would be an area for greater consideration to address this issue.

The papers included in the current review mainly reflect interviews of coupled dyads in the North American context. Further research in this area could provide a larger variety, and heterogeneous population than that which was reviewed and noted. However, as previously stated no previous systematic reviews have reviewed this specific question so a relative strength is the importance for burgeoning research.

During this review, it was noted that there was a larger body of grey literature returned versus peer-reviewed published studies to fit the prespecifiedinclusion criteria at the final papers stage of the review. This grey literature represents unpublished theses, and dissertations however was excluded under the prespecified criteria, which hoped to summarise the current state of published peer-reviewed literature. It is interesting to note the amount and relevance of studies within the grey literature and it begs the question what has prevented this useful research from progressing to publication that adds to the evidence-based research. Future reviews may build from here to incorporate grey literature in the analysis of findings. This may uncover useful research and clinical implications less readily represented that contribute to the research.

Given the findings that coupled relationships are vulnerable to breakdown after ABI, increased awareness and intervention may be helpful for couples in managing their relationships, and positing ways in which relationships may find continuity. It is hoped an increased literature base of peer-reviewed published findings may be created so clinicians can draw on evidence-based research to guide practice-based intervention. Currently the lack of research from the survivor perspective may indicate this is not the case and may be practice driven during intervention.

Empirical Study

As is the case with much quantitative research caution must be taken in generalising the findings from the current research. This research represents the views of the seven fathers interviewed and does not claim to be representative of all fathers with ABI. However, these findings may provide a guide for future research and clinical work in this area and may drive exploring multiple IPA perspectives on the specific phenomena of interest, fatherhood after ABI.

Transcription was undertaken primarily by professional transcription services and had each interview been transcribed immediately this may have aided the exploration of emerging themes explored in following interviews. However, the use of batch professional transcription services was necessary due to the time constraints of the doctoral level thesis. Also, it hoped this may reduce any influences of subjective bias from the researcher as much as possible. It offered the interviewer less need to be bracketed from previous participants and emerging themes and allowed emergent themes to be explicitly identified when working case-by-case during analysis.

Further reliability, transparency and credibility of themes may have been enhanced by member checking however this was not possible in the scope of this research and timings. In future, this may be a useful area for consideration and could allow for increased participant engagement, analysis and interpretation towards participatory action research.

The empirical study directly addresses an area highlighted for further research by the MacQueen, Fisher and Williams (2018) study. They suggested that further research attention on the experiences of fathers following ABI may be useful given the themes noted during their research. It is noted researcher gender may alter aspects of speech content or topics explored by participants. The parenting program for fathers implemented by Weatherhead and Newby (2008) suggests that gender alignment and lived experience in the facilitators may impact on the father's experiences of the parenting intervention. It may be that in the empirical study this influence was present in the heterogeneous gender and experiences between researcher and participants. In planning future research and intervention gender or parenthood could possibly be matched to attend to possible influences on the experiences shared.

During the current study there may have been a bias of social desirability inherent in the experiences reported by the fathers. It was felt at times that the richness of difficult experiences relating to fathering was varied. This was expected in some ways to have greater representation and importance during the interviews however overall fathers appeared to describe positive reinterpretations of difficulties and events.

The researcher was aware during the analysis of interviews of a draw towards those which were perceived as richer and more nuanced. In contrast to interviews where the emotional impact of the interviews (noticing frustration during one interview and experiencing anger from the participant in another interview) made it more challenging for the researcher to engage with the interviews and embed in the idiographic nature of these accounts. This was managed through thinking reflexively, noticing this and using the reflective diary to try to bracket the emotional responses. As the researcher, experiencing this during the process required continued commitment to actively work towards finding the nuance and richness of each interview. Re-engaging each time with each transcript anew.

Outside of the noted emotional impact of some of the interviews, at times the changed communication and cognitive abilities of the father's combined in creating a challenge to the engagement with the data. The researcher noticed becoming lost in the volume of data explored and the confusing nature of what was being relayed during the interviews. This feeling lost was important to reflect upon when guiding interpretation, to follow whether the researcher was connecting to the double hermeneutic of sense-making or being driven by unbracketed personal sense-making. Constant self-reflection and checking assisted the researcher in bracketing off and finding the meaning-making from the participants accounts. Only after analysis was complete and the findings had begun to take shape did the researcher revisit initial literature in this area to reduce the subjective bias from prior readings.

The findings represented in the empirical study will be further supported by continued research with larger more diverse samples. To date, no consideration has been given to non-nuclear or same-sex couples and families as regards parenting following brain injury. Additionally, quantitative investigations towards family functioning, coupled relationships as well as parenting knowledge and skills may identify the degree to which intervention objectively impacts outcomes and enhances self-identity and father's or mother's identity within families.

Conclusions

To our knowledge, both papers are the first of their kind to explore these novel experiences; survivors experiences of coupled relationships after brain injury and men's experiences of fatherhood following ABI. The findings suggest it may be necessary to explore how specialist gendered interventions and programs may be applied following brain injury, with specific focus around support and intervention into parenting and coupled relationships that assists these client groups.

Findings across both papers are representative of the idiographic focus of qualitative research. In undertaking the studies, they highlight under-represented perspectives and sampling in the current literature. They offer important information that highlights gaps in these research areas and point to a need for future research to develop these areas. The studies represent unique preliminary research however highlight the need to grow the evidence base. It is hoped that over time multiple research perspectives from both qualitative and quantitative methodologies may develop this further.

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Appendices

Appendix A: Journal Guidelines for Neuropsychological Rehabilitation

Instructions for authors

Thank you for choosing to submit your paper to us. These instructions will ensure we have everything required so your paper can move through peer review, production and publication smoothly. Please take the time to read and follow them as closely as possible, as doing so will ensure your paper matches the journal's requirements. For general guidance on the publication process at Taylor & Francis please visit our Author Services website.

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4. Between 5 and 5 **keywords**. Read making your article more discoverable, including information on choosing a title and search engine optimization.
5. **Funding details.** Please supply all details required by your funding and grant-awarding bodies as follows:
   For single agency grants
   This work was supported by the [Funding Agency] under Grant [number xxxx].
   For multiple agency grants
   This work was supported by the [Funding Agency #1] under Grant [number xxxx]; [Funding Agency #2] under Grant [number xxxx]; and [Funding Agency #3] under Grant [number xxxx].
6. **Disclosure statement.** This is to acknowledge any financial interest or benefit that has arisen from the direct applications of your research. Further guidance on what is a conflict of interest and how to disclose it.
7. **Data availability statement.** If there is a data set associated with the paper, please provide information about where the data supporting the results or analyses presented in the paper can be found. Where applicable, this should include the hyperlink, DOI or other persistent identifier associated with the data set(s). Templates are also available to support authors.
8. **Data deposition.** If you choose to share or make the data underlying the study open, please deposit your data in a recognized data repository prior to or at the time of submission. You will be asked to provide the DOI, pre-reserved DOI, or other persistent identifier for the data set.
9. **Geolocation information.** Submitting a geolocation information section, as a separate paragraph before your acknowledgements, means we can index your paper's study area accurately in JournalMap's geographic literature database and make your article more discoverable to others. More information.
10. **Supplemental online material.** Supplemental material can be a video, dataset, fileset, sound file or anything which supports (and is pertinent to) your paper. We publish supplemental material online via Figshare. Find out more about supplemental material and how to submit it with your article.
11. **Figures.** Figures should be high quality (1200 dpi for line art, 600 dpi for grayscale and 300 dpi for colour, at the correct size). Figures should be supplied in one of our preferred file formats: EPS, PS, JPEG, TIFF, or Microsoft Word (DOC or DOCX) files are acceptable for figures that have been drawn in Word. For information relating to other file types, please consult our Submission of electronic artwork document.
12. **Tables.** Tables should present new information rather than duplicating what is in the text. Readers should be able to interpret the table without reference to the text. Please supply editable files.

13. **Equations.** If you are submitting your manuscript as a Word document, please ensure that equations are editable. More information about mathematical symbols and equations.
14. **Units.** Please use SI units (non-italicized).

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Please include all relevant safety precautions; and cite any accepted standard or code of practice. Authors working in animal science may find it useful to consult the International Association of Veterinary Editors' Consensus Author Guidelines on Animal Ethics and Welfare and Guidelines for the Treatment of Animals in Behavioural Research and Teaching. When a product has not yet been approved by an appropriate regulatory body for the use described in your paper, please specify this, or that the product is still investigational.

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Authors are further encouraged to cite any data sets referenced in the article and provide a Data Availability Statement.

At the point of submission, you will be asked if there is a data set associated with the paper. If you reply yes, you will be asked to provide the DOI, pre-registered DOI, hyperlink, or other persistent identifier associated with the data set(s). If you have selected to provide a pre-registered DOI, please be prepared to share the reviewer URL associated with your data deposit, upon request by reviewers.

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Updated 8-02-2019

Appendix B: CASP Quality Table

	Gill, Sander, Robins, Mazzei & Struchen, (2011).	**Godwin, Chappell& Kreutzer, (2014).**	**Haag, Caringal, Sokoloff, Kontos, Yoshida & Colantonio, (2016).**	**Hammond, Davis, Cook, Philbrick, & Hirsch, (2012).**	**Layman, Dijkers & Ashman, (2005).**
1. Clear statement of aims of the research?	1(1)	1(1)	1(1)	1(1)	1(1)
2. Is a qualitative methodology appropriate?	1(1)	1(1)	1(1)	1(1)	1(1)
3. Was the research design appropriate to address the aims of the research?	1(1)	1(1)	0.5(1)	1(1)	1(1)
4. Was the recruitment strategy appropriate to the aims of the research?	1(1)	0.5 (0.5)	0.5 (0.5)	1(1)	1(1)
5. Was the data collected in a way that addressed the research issue?	1(1)	1(1)	1 (0.5)	1(1)	1(1)

6. Has the relationship between researcher and participants been adequately considered?	1(1)	0.5 (1)	0.5 (1)	1(1)	1(1)
7. Have ethical issues been taken into consideration?	0.5 (0.5)	0.5 (0)	1(0)	1(1)	0.5 (0.5)
8. Was the data analysis sufficiently rigorous	1(1)	1(1)	1 (1)	1(1)	1(1)
9. Is there a clear statement of findings?	1(1)	1(1)	1(1)	1(1)	1(1)
10. How valuable is the research?	1(1)	1(1)	1(1)	1(1)	1(1)
Total rating: **1st (2nd) Rater**	**9.5 (9.5)**	**8.5 (8.5)**	**8.5 (8)**	**10 (10)**	**9.5 (9.5)**

Appendix C: Interview Guide

Being a dad with brain injury: Interview questions

1. **What is it like being a dad**?
    a. For example, tell me about what it's like being a dad for you? What you do, feel, show, think …
    b. To do with playing and activities perhaps?
    c. To do with domestic life, like cooking etc.?
    d. How about school related things like homework?
    e. What would other people say about being a dad right now? What kind of dad would other people tell me you were? What do you think your children would say if they were here now?

2. **Tell me about any specific times where you've really been a dad? Or times when you feel you haven't been as dad like. Specific instances and occasions, more like that or different to that?**
    a. How did that feel? What did it mean to you at the time?
    b. Is this what you thought you would be doing at this point?
    c. How might 'that' change going forwards?

3. **Before being a dad what did you think it may be like?**
    a. What was your life as a dad like before (without a brain injury)

4. **How do you see yourself now as a dad?**
    a. What comes to mind when I say that?
    b. What does that mean to you as a man or husband
    c. Have changes occurred? (to your role as a dad?)
    (Prompts re: busy environment, managing emotions, leisure time together)

5. **Have you allowed yourself to think about the future?**
    a. What do you think you may be like as dad in the future?
    b. What will that mean for you?
    c. What that means to you as a man or a dad or a husband.
    d. How might things change for you as a dad as your children get older?

6. **Are there unforeseen parts like silver linings or positives you never imagined you would take away from your experiences?**

7. **What drew you to share your experiences today?**

8. **Anything else that you wanted to say about what's it's like to be a dad now?**

9. **Anything else you wished to share with me that would be useful for us to know/other dads?**

Appendix D: Ethical Approval

Faculty of Medicine and Health Sciences Research Ethics Committee

Research & Innovation Services
Floor 1, The Registry
University of East Anglia
Norwich Research Park
Norwich, NR4 7TJ

Email: fmh.ethics@uea.ac.uk

Web: www.uea.ac.uk/researchandenterprise

Karen Cregan
MED

7.2.18

Dear Karen,

Title: Fatherhood after acquired brain injury (ABI): In what ways do men experience being fathers after ABI? An Interpretative Phenomenological Analysis.
Reference: 2017/18 - 70

The submission of your above proposal has been considered by the Faculty Research Ethics Committee and we can confirm that your proposal has been approved.

Please could you ensure that any further amendments to either the protocol or documents submitted are notified to us in advance and also that any adverse events which occur during your project are reported to the Committee. Please could you also arrange to send us a report once your project is completed.

Yours sincerely,

Professor M J Wilkinson
Chair
FMH Research Ethics Committee

CC Fergus Gracey

Appendix E: Inclusion and Exclusion Criteria

Inclusion criteria

- Be a father before they received their ABI
- Aged 18 years and over with an ABI (which would be considered Moderate-Severe excluding Mild ABI) confirmed by the attendance with a charitable brain injury service.
- Time since their ABI to be over 1 year with a reasonable understanding and recollection of their fathering pre-and post-injury.
- Have dependent young children or where participants are able to comment on their experiences of being a father when the children were under 13.

Exclusion criteria

- Became a father following their ABI
- Mild ABI.
- Significant communication, cognitive, emotional, or substance misuse difficulties that would prevent valid engagement in research interview. This is after allowing for appropriate adaptions to support cognitive or communication issues such as the accessibility of the participant information sheet, time and support to consider the information provided by the researcher.
- A father who does not feel able to describe their fathering experiences.

Appendix F: Gatekeeper Information Sheet

Norwich Medical School,

Postgraduate Research Office,

Elizabeth Fry Building,

University of East Anglia,

Norwich,

NR4 7TJ

E: k.cregn@uea.ac.uk

T: 07708 993865

Guide for clinicians discussing the research study with potential participants/fathers

"In what ways do fathers make sense of the lived experience of being a father after Acquired Brain Injury (ABI)?

Dear Colleague,

Thank you for taking the time to consider whether my research is appropriate for your clients. This research aims to explore how fathers make sense of the experience of fatherhood following an acquired brain injury. The participant information sheet provides detailed information about the study and there is also a lay summary to explain this in plain English for participants. This letter aims to highlight the key points that might be relevant to explain the research to appropriate clients, so they can decide if they want to know more and take part.

Information you may wish to discuss with a client/father:

- The research project aims to explore with fathers what it is like to be a father after an acquired brain injury.
- The research is not connected to treatment and will not impact their involvement with your service.
- The client does not have to take part if they do not wish to, only if they are interested, meet the inclusion criteria and feel comfortable to do so.
- It is hoped that exploring this little-researched area further may inform future rehabilitation programs that provide support to fathers who have had an acquired brain injury.
- There is a participant information sheet and lay summary which details the research for the participant and all participants will need to read this before taking part. I will review everything before they give written consent to take part in the research.

- This research is being run by Karen Cregan, a Clinical Psychologist in Training at the University of East Anglia (UEA). Taking part will mean the participant meeting with Karen for approximately 60 to 90 minutes at the recruitment centre or at the client's home, according to the participant's preference. Lone working policies of both UEA and Cambridge and Peterborough Foundation Trust (CPFT) will be adhered to in these instances. At the meeting, Karen will ask questions about what it is like being a father with an acquired brain injury.

Lay summary

After an acquired brain injury (ABI), often people have changes to many parts of life. There can be changes to everyday life, to thinking and memory skills, to self-understanding and to roles like parenting. This study will ask fathers with a brain injury what being a father is like for them after this life changing event. So far there have been very few studies which have asked fathers about their lives and their role as a father after a brain injury. Possible interviewees will be contacted through staff at non-NHS brain injury services and charities. The study will mean meeting with the researcher for an interview that takes about one hour. The interview will be a conversation with a few questions at times. These questions ask how the person makes sense of being a father after their brain injury. It asks fathers to share their personal experience with the researcher. Before this only 2 studies have asked questions about father's lives after brain injury in this way. This study would be the first in the UK to ask fathers about their experiences to improve our understanding and increase our knowledge. It could help to think about specific father focused supports and services after brain injury. Others working with fathers after brain injury could read what will be written as the results will be published into a research paper.

The next steps are:

- If the client is interested in finding out more about taking part in the research, please complete the consent to share contact details form supplied.
- Completing this form does not mean that the client is agreeing to take part.
- Karen will then contact them to discuss participation in the research further.

Thank you for taking the time to read this and for supporting this research project. If there are any questions or queries, please feel free to contact me with the details noted above.

Karen Cregan,
Clinical Psychologist in Training,
University of East Anglia

Appendix G: Participant Information Sheet

Norwich Medical School,

Postgraduate Research Office,

Elizabeth Fry Building,

University of East Anglia,

Norwich,

NR4 7TJ

E: k.cregn@uea.ac.uk

T: 07708 993865

Information guide about the research

"In what ways do fathers make sense of the lived experience of being a father after Acquired Brain Injury (ABI)?

'My name is Karen Cregan. I am training to be a clinical psychologist at UEA. As part of my training I am running a research study. I would like to invite you to take part in this research study. Before you decide if you would like to take part, I would like you to know more about why this research is being done and what it would involve for you.

Please read this information sheet, and feel free to talk to others such as staff at your service, group or centre as well as friends or family to help decide if you would like to take part. If you would like to contact me to speak more please use the study mobile number **07708 993865**

It's up to you if you decide to take part. If you agree I will ask you to sign a consent form for the study. I will give you a copy of the consent form along with this information sheet. You can withdraw from taking part up until 2 weeks after the interview without giving a reason.

This sheet has two sections, part 1 tells you about why the research study is being done and what would be asked from you. Part 2 gives information about the conduct of the study.

Part 1:
What is the purpose of the study?

This study is aimed at exploring how fathers make sense of their life being a father after ABI. This would focus on your experience of fathering and may also relate to your self-identity. It is hoped that your participation will help the researcher understand what the ABI experience is like for fathers. Also through sharing that understanding if there are ways that future practice working with fathers who have ABI could be improved.

Why have I been asked to take part?
As a father who has experienced an ABI you have a unique perspective. This study is for fathers between the age of 18 and 64 years of age who have experienced an ABI when they were fathers and had children aged between 2-13 years of age at the time of their ABI.

Do I have to take part?
You do not have to take part in the study. If you decline or withdraw this will not affect your involvement with the centre or charity in any way. You can withdraw your consent up to 2 weeks after our interview. After this your information has been anonymised and is difficult to remove from others.

What happens to me if I take part?
If you would like to find out more by speaking with me, you will be asked to sign a form that allows me to contact you directly. The staff member will give you this form which is titled the "consent to contact form" and they will then share your contact details with me.

We will arrange a time and a place to meet either the centre or at your home whatever feels comfortable for you. When we meet you can ask any questions you have about the research. If you would like to take part, I will make sure you understand what taking part involves. Then I will ask you to sign a form to say you are agreeing to take part – the consent to participate form I will then ask you some background information questions Afterwards we would arrange where and when to meet to have our interview. Depending on how tiring the meeting has been thus far we could carry on to have the interview or split it across another meeting.

The interview is likely to last 60-90 minutes. This allows us extra time to have breaks or to slow down as needed. I will ask you questions about what it is like for you as a father living with an acquired brain injury. I will encourage you to do most of the talking so that our conversation is meaningful to your life experiences. You should only share with me the things that you feel comfortable sharing. You do not have to talk about anything which you do not want, and you can tell me that you would prefer not to talk about something at any point.

Our meeting will be recorded so that I can listen back to our conversation. The recording will be transferred onto UEA servers where it is held securely. The conversation will be typed up into a document either by the researcher from the UEA servers accessed remotely or depending on the researcher's workload by paid transcription services identified through the UEA clinical psychology department. I will look at your experience and the experience of other fathers interviewed to see if there are connections unique to individuals and shared.

Will my taking part be kept confidential?

All the information we collect from you for the research (the background information and the interview) will be anonymised so it won’t be possible for anyone to identify you. Any personally identifiable paper documents will be in a locked drawer at the University of East Anglia. Any digital personal information will be stored on UEA servers securely. This will be kept separate to data collected for the study. Study findings may be published but you will not be personally identified. The direct quotes used in the final project will be carefully considered to make sure that they do not contain identifying information and are anonymised. Following the UEA research data management policy the data collected in the research study will be kept securely stored for 10 years at the University of East Anglia. All personal identifiable information about you will be destroyed as soon as we no longer need it for the study. If you chose to stay in touch so we can tell you about the results, we will keep your contact details then destroy them after the results have been sent to all participants after May 2019. All data will be destroyed after 10 years.

If there is anything we talk about which you feel has caused you some distress and you feel you would like to follow up on what we've discussed, we would decide at the time how this is best done for example you could discuss with your care team or with your GP. If I am concerned about a risk of harm to yourself or others, then I will discuss this with you and will have to share this information with others. I will always try to discuss this with you first.

What are the possible benefits of taking part?

The study aims to contribute to the understanding of what it is like to be a father who has experienced an acquired brain injury. The information from this study will help to improve professionals understanding about the impact and consequences of acquired brain injury for fathers. By sharing your experiences, you may help other fathers and support future rehabilitation. Very little research from fathers has been done before and this study would be a first for new knowledge. We are likely to meet only once for the interview so this will not provide therapy or counselling. However, you may find the process of talking about your experiences as a father with ABI is helpful for you.

What are the possible disadvantages of taking part?

The topic of the interview is one which is a very personal topic for you. It may be that talking about your experiences as a father after brain injury may be upsetting and difficult at times. If you experience upset and or distress during our interview, I will pause the interview to check how you are. You will have the choice of continuing, taking a break or stopping and withdrawing from the study. We will also discuss sources of support that might be helpful, if you would like to.

What happens when the interview is over?

After the interview, the information is collected so that it can be transcribed, analysed and rewritten in a report. This final report will contain direct quotes from what you and other fathers have said in our interview. One aim of the research is for it to be published in academic journals and also presented at conference. If you would like a summary of this report, I am happy to send you one after the work has been completed or meet with you in person to feed it back.

Part 2

What will happen if I do not wish to carry on with the study?

You are free to withdraw from the study at any time up until 2 weeks after the interview. You can contact me and let me know you want to withdraw, and you do not have to give a reason for not wanting to continue.

If you do not wish to carry on with the study and it is longer than 2 weeks after the interview, your information will be anonymised, and I will have started to analyse the interviews making your information difficult to remove.

What if there is a problem?

If you have a worry about any part of this study, you can speak to me and I will do my best to answer your questions. You can also contact my supervisor, Dr Fergus Gracey. You may contact us using the contact details given below. If you remain unhappy following this and wish to complain formally, you can do this by contacting professor Ken Laidlaw at the University of East Anglia, 01603-593076.

Who organises and fund this research?

This research is being conducted as part fulfilment of a Doctor of Clinical Psychology Course at the University of East Anglia. There is no additional funding for this research.

Who has reviewed the study?

This study has been reviewed and approved by academic staff within the Department of Clinical Psychology at UEA. The study procedures have been reviewed by the Faculty of Medicine and Health Sciences (FMH) ethics board at UEA and the relevant managers at your charity or centre.

Further information and contact details

Karen Cregan (Clinical Psychologist in Training)
Email. k.cregan@uea.ac.uk
Telephone: 07708 993865

Supervised by Dr Fergus Gracey (Senior Research Fellow)
Email. F.gracey@uea.ac.uk
Telephone: 01603-592898

Thank you for taking the time to read this information sheet. I hope it has been helpful to understand the research and it is much appreciated.

Appendix H: Consent to Contact Information Form

Norwich Medical School,
Postgraduate Research Office,
Elizabeth Fry Building,
University of East Anglia,
Norwich,
NR4 7TJ
E: k.cregn@uea.ac.uk
T: 07708 993865

CONSENT TO CONTACT FORM

Title of Project: "In what ways do fathers make sense of the lived experience of being a father after Acquired Brain Injury (ABI)?

Name of Primary Researcher: Karen Cregan

(Please initial the following boxes, if discussing consent in a telephone conversation the gatekeeper should initial the appropriate boxes)

1. I confirm that I have received the Participant Information Sheet (version 1, dated 22nd June 2017) for the above study.
2. I give consent for my gatekeeper (professional working in the designated recruitment agency) to share my contact details below with the researcher named in the above study.
3. My preferred contact details are: (telephone or email contact)

   ____

   ____

Name of Participant	Date	Signature (if present)
Name of Gatekeeper	Date	Signature (if present)

Appendix I: Consent to Participate Form

Norwich Medical School,
Postgraduate Research Office,
Elizabeth Fry Building,
University of East Anglia,
Norwich,
NR4 7TJ
E: k.cregn@uea.ac.uk
T: 07708 993865

CONSENT TO PARTICIPATE FORM

Title of Project: "In what ways do fathers make sense of the lived experience of being a father after Acquired Brain Injury (ABI)?

Name of Primary Researcher: Karen Cregan

(Please initial the following boxes)

1. I confirm that I have read and understand the Participant Information Sheet for the above study. I have had time to consider the information, ask questions and receive satisfactory answers.
2. I understand my participation is voluntary and that I am free to withdraw at any time, up until 2 weeks after the interview has taken place, without giving any reason.
3. I understand an audio recorder will be used in the interview and that what is said may be quoted directly into the final report and publication of this research. I understand that identifying information about me as a participant will not be used.
4. I understand that responsible individuals, from the University of East Anglia or from regulatory authorities, may look at sections of my research notes if audited, where it is relevant for research audit purposes. I give permission for these individuals to have access.
5. I understand that all discussion with the researchers is confidential and will not be shared with carers or treatment team unless I say something that raises concerns about serious risks to myself or others

6. I agree to take part in the above research study.

7. I consent to my contact details being passed from my centre or charity to the coordinating site (UEA)

   I wish to receive a written summary of the findings from the above study.

   My preferred contact details are: (either telephone or email contact)

   ____

____

Name of Participant Date Signature (if present)

____

Name of Gatekeeper Date Signature (if present)

Appendix J: Demographic Information Sheet

This sheet helps to collect information for context (in initial participant meeting).

Name:	
Age	
Ethnicity:	
Marital status:	
Child and/or children: (please include - the gender - age(s) of children)	
Family structure: (please include - whose else is around at home - other family supports)	
Nature of ABI: (please include - date of ABI - nature of ABI (stoke, TBI, how the ABI was sustained, note time since ABI)	
Education: (please include - how many years - highest level - what age left school)	
Employment (pre-injury and post-injury)	

Appendix K: Debrief Sheet Post-Interview

Norwich Medical School,
Postgraduate Research Office,
Elizabeth Fry Building,
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T: 07708 993865

Debrief Sheet

Thank you for talking with me and taking time to be part of this research study. Your time and what you have shared today about your experiences as a father is greatly appreciated.

After an acquired brain injury (ABI), often people have changes to many parts of life. There can be changes to everyday life, to thinking and memory skills, to self-understanding and to roles like parenting. This study will ask fathers with a brain injury what being a father is like for them after this life changing event. So far there have been very few studies which have asked fathers about their lives and their role as a father after a brain injury. It asks fathers to share their personal experience with the researcher. Before this only 2 studies have asked questions about father's lives after brain injury in this way. This study would be the first in the UK to ask fathers about their experiences to improve our understanding and increase our knowledge. It could help to think about specific father focused supports and services after brain injury. Others working with fathers after brain injury could read what will be written as the results will be published into a research paper.

What will happen next?

What we have spoken about today will be written down and analysed. If you decide that you would not like for your information to be used and included in the study, you can contact me with the above details. You can ask to withdraw in this way from the study up to 2 weeks after we have met. You do not have to give a reason and your care with those who introduced the study to you will not be affected in any way as a result.

If you told me, you would like a summary of the findings of the research you will receive this once the final report has been written. This is likely to be after May 2019. Further information about this is in the Participant Information Sheet which was given to you.

What if the interview has caused me distress?

During our interview it is likely that we spoke about very personal experiences in your life. These can be tricky to think about and share at any time for anyone. However, if you find yourself experience significant upset or distress following our conversation today then you can consider how you would like to be supported with this

- You may find discussing this experience with family and friends is something which would be helpful.
- You may find that you would like to share with your charity's gatekeeper person, the individual who introduced the study to you. You could decide with them what would the best next steps for you and in what ways you could be offered aftercare support through your charity.
- You could seek free, confidential help and support over the phone from either The Samaritans on 116 123 or the Campaign Against Living Miserably (CALM) on 0800 58 58 58 which is a dedicated helpline for men in the UK who are down or have hit a wall for any reason.
- Outside of working hours, you could contact the GP out of hour's service in your area if you were worried that you may hurt yourself.
- A self-referral to your local wellbeing service, formal counselling and/or suitable therapeutic groups may be possible in your charity or centre or with your GP

Your experiences and meaning-making as a father with a brain injury are very important to this study and future research. Thank you for sharing today, your support is gratefully appreciated,

Karen Cregan,
Clinical Psychologist in Training, University of East Anglia.
Supervised by Dr Fergus Gracey, Senior Research Fellow, University of East Anglia.

Appendix L: Risk Management Plan

Immediate distress or risk identified during the interview

The gatekeeper will be asked to employ their clinical judgement as to whether any risk may be posed by interviewing the participant at home before the interview location is decided. The researcher will clearly explain prior to commencing the interview under what circumstances a breach in confidentiality may occur, such as concern about the person's safety or the safety of another individual. It will be explained that breaching confidentiality under these circumstances will require the researcher to contact his named individual with his recruitment centre, who may be able to clinically manage any distress or follow-up related to this disclosure on the part of the participant. The researcher's duty of care may require other relevant third parties are made aware to ensure that any risks are properly managed. This may include primary supervisor, site manager or any safeguarding which may need to be reported and followed. Breaching confidentiality and what happens at that time is explained as part of the participant information sheet (Appendix B) and the participant will be reminded at each stage of the study. The researcher will hold in mind the role they are occupying, utilise their clinical skills in the moment and seek supervision if needed.

Severe and immediate risk or distress

If in the case where severe and immediate risks were identified involving the participant, a child or any other individual, this may require the researcher to use clinical judgment and seek emergency services. Guidance may be sought from the local safeguarding team or board if this is deemed necessary at the time. As soon as possible thereafter the primary supervisor will be made aware of a serious incident occurring, to be documented and the relevant person's part of the research process made aware. If the participant were to become highly distressed, they would be offered options as to how they would like to manage such as take a break, stop, or arrange the interview for another day.

Safety of researcher

The University of East Anglia lone worker and the Cambridge and Peterborough NHS Foundation Trust 'Working Alone in Safety' policies will be adhered to for researcher safety. However, if researcher safety becomes a concern at any point, the researcher will follow the instructions outlined in the UEA lone worker policy (UEA, 2013). Where the research visits are conducted outside of working hours or in the participants home the researcher will check in prior to the interview to ascertain phone signal in the area with the primary supervisor and give details of who they are with, where they are and when they are to be finished to expect the end of appointment check in phone call. If for any reason this does not occur the primary supervisor is able to escalate the concern and check researcher safety, a suitable coded message will be identified to use in instances of emergency phone contact.

Post-interview aftercare

All participants will be telephoned 24-48 hours after interview having allowed time to have processed the interview experience to check-in and check their participant wellbeing. If anything is noted at this stage the researcher will appropriately manage any risk identified in line with the risk management plan and if distress noted signpost appropriately. They will remind the participant of their options wrote on their debrief sheet (Appendix K). All participants will be given a debrief sheet with contact details of services and supports to access post interview if they become distressed. They will be urged to all take the sheet and also where possible an identified member of staff noted who may support them afterwards if they feel unable to make a self-referral.

Appendix M: Recruitment Flyer

Fatherhood after acquired brain injury (ABI): In what ways do men experience being fathers after ABI? An Interpretative Phenomenological Analysis.

Project Supervisors: Dr Fergus Gracey, Dr Cat Ford, Dr Audrey Daisley
Researcher: Karen Cregan

Hi! My name is Karen Cregan and I am a Clinical Psychologist in Training from the University of East Anglia. I am looking to speak with fathers who have experienced an acquired brain injury for my study. I am looking to explore father' experiences to share the meaning and understanding of being a father after brain injury

To take part in the study would mean meeting with the researcher for an interview that takes about one hour, perhaps more with adaptations. The interview will ask questions about how you make sense of being a father after brain injury. I hope fathers would share their side of these experiences with the researcher.

So far there have been 2 studies which have asked fathers about their lives and their role as a father after a brain injury. This study would be the first in the UK to ask fathers about their experiences to improve our understanding and increase our knowledge. It could help our thinking about specific father focused supports and services after brain injury, for other professionals in this area through sharing research.

I would like to invite you to participate in this study if:

You are a father with a brain injury:

- Aged 18 years and over with a moderate-severe ABI.
- You were already a father when you had your ABI
- You have dependent young children
  - Where the children are aged up to 12 years so as to be considered children
  - OR if your children are now adolescents however you feel you can remember and share your experiences of being a father when your children were under 13.

Unfortunately you are not able to participate if:

You are a father with a brain injury:

- That has a mild brain injury.
- Who struggles with significant communication, thinking, emotional, or substance misuse difficulties. This is after allowing for appropriate adaptions by the researcher.
- A father who does not feel able to describe their fathering experiences.

If you think you would be interested in taking part in this study, or have more questions, please contact me at k.cregan@uea.ac.uk or call me on (study mobile number inserted here).

Appendix N: Declined Study Participation Letter

Dear (insert name here),

Re:

Fatherhood after acquired brain injury (ABI): In what ways do men experience being fathers after ABI? An Interpretative Phenomenological Analysis.

Project Supervisors: Dr Fergus Gracey, Dr Cat Ford, Dr. Audrey Daisley
Researcher: Karen Cregan

Thank you very much for your enquiry and consideration of the above study. We are specifically seeking fathers with moderate-severe brain injuries and you have expressed a wish to take part. There has been a large amount of interest in the study and at this time we are unable to offer for you to take part in the study. As such we will not be able to meet in person to have a conversation together.

Given your interest, following the study it would be possible to send you a summary of the results and findings if you wish. Alternatively, if you have any further questions about the study, or would like to speak to me by telephone, please feel free to call me on the study mobile phone: (insert study phone number here).

Again, thank you kindly for your interest in the study and time.

Best wishes,

Karen Cregan,
Clinical Psychologist in Training,
University of East Anglia
Norwich Research Park,
Norwich,
NR4 7TJ,
UK

Appendix O: Example Exploratory Comments and Emergent Themes

emergent themes	exploratory comments	interview
		demographic details preamble Interviewer: now it’s more towards what the study is asking questions about P: about being a dad okay interviewer: asking about what it’s been like to be a dad and the language is completely up to you maybe call yourself dad or father it depends on each person I just say dad because it’s…
self as a Father or self as dad	sometimes variation in what way he will be addressed. *he slides in and out of father as a description between himself and his father*. depending on how they are being perceived by the child	P: okay well I think that it’s dad however my daughter will ring me now and again and say “hello father” so I don’t know that’s coming from but she um um (lost track)
		interviewer: so, if you are thinking back to
Different knowing of as dad, relying on others	Different knowing of dad by different children. One child that really hasn’t known me. Everything became a whole mess, business and family difficulties. Pronoun use of she decided to sell the business and she managed it. Relying on support from his parents. she thought she could	P: it’s been quite interesting because of one child that knew me prior to the accident and one child that really hasn’t known me because… That’s another thing. I left out of superglue (wife) went umm I’m sorry now how do I remember this because what happened was umm I had to close my business because there were problems are running it without me we had people who are running it but they were stealing and all sorts of other things going on okay so a whole mess so Karen decided to try and sell it in fact in the end she managed to sell it to somebody but when she did and she was trying to we we ah were running short of money for various things we were getting some support from my parents but we didn’t want to take most of it and umm Karen would do the odd job and she got an interior job to do and thought that she could leave me home with Hope and I used superglue to repair something and left it out and

	leave me home with Hope. superglue was left out and Hope glued her eyes shut	Hope got a hold of it and managed to stick her eyes together with it you know her eyelids and that was the things that occurred with, sorry I'm going backwards
		Interviewer: no P: talking to somebody with a brain injury this is what happens Interviewer: so it's asking what is it like being a dad now, what is like being a dad over those years
the very different father pre/post, loss of the patient self, the suffering child, the child-parent	is different being a dad with brain injury and without. Patience is a lot less as such wife says the time is very different, better before. The time with the first child was perceived as much more told to him by his wife. Suffering for child who has dad with brain injury. as she aged she became the parent, the roles changed	P: I mean, I think it's been very different being the father with a brain injury to being a father without the brain injury. My wife says that the time whatever that I spent with Marc before is much more than I've done with Hope because my patience is so much less. That's a big difference when my patience is so much less. Ummm I did enjoy, I have enjoyed playing with her and whatever, but it's not been as extended as it was and I think she suffered because of it. The other thing is as she's got older the roles have changed very much, there are times where she and I are out and she becomes the parent. Right.
		Interviewer: Ok, right, are you thinking of a specific example or..

		P: yeah on one or two occasions, one or two of the things she's really like me, we both really really love… I had an absolutely ridiculous um record collection you know CDs and whatever um my first wife was PA to the chairman of the CBS records. I mean I was into music before I met because of that relationship I took advantage of it and she would always get records or if like Bob Dylan brought out a new album and Stevie wonder who wasn't on CBS was on Motown which was an EMI label should ring up the guy at EMI and say look listen the new Stevie Wonder I'll swap it for a copy of Dylan, you know and she give it to me and or I'd go out and buy whatever and um anyway because of that I had a tremendous, I mean we're really talking you know couple of thousand records and um so because of that we were always playing music and it was like you know tape in the old days you used to make up tapes, before your day. Interviewer: Mhm hum off the radio
environmental influences on the child	they've shared his music, shes been influenced by her environment, yet he's surprised she has inherited his tastes. Will this later make reference to other ways her environment i.e. him as dad has shaped her?	P: not MP3s or whatever and play them in the car or whatever. so, Hope has always listened to music and her music tastes go back to the sort of quite a lot of the period… You know like the reason that I said that were going to Ireland to see Elton John that surprisingly enough he's one of the artists that she wanted to see. You know although she'll like I dunno whatever the latest something that's like beyond Ed Sherran she still likes a lot of the old, because she's heard it in her environment.
		Interviewer: it sounds like something that you've maybe shared with her P: yeah I think it is, I think it is, I think it's what you do share my wife has her own run of artists and things and it all blends in but I mean probably people from your time.. I'm not being rude but I imagine your age difference isn't too great to Hope's, you know what I mean I'm not being rude. I mean you would associate with artists like Joni Mitchell or things like that because there were probably from a period, unless you parents played them to you. Interviewer: yeah I think if you have people around you who introduce you

the generational influencer, managing environmental demands and stress, protective child swings into the child-parent	parents are influential in how their children turn out. Recognising he needs to manage his own environment as a parent with a brain injury. She takes on a protective role, reversing roles? "she becomes the sort of parent as it were and am deals with, she’s pretty good like that"	P: that becomes the influence...and am anywhere where am I going so only very recently, I’ve not been able to do it very often and has to be quite small venues hence the reason why you are seeing Elton John in Ireland because there is a much smaller venue then the ones in the UK am am Hope because my wife doesn’t want to go but Hope does she and I will go together and when she sees that things are getting too bad for me she becomes quite protective, that’s what I’m saying, she becomes the sort of parent as it were and am deals with, she’s pretty good like that.
		Interviewer: so what does it look like?
frustration, irritation aggravation. The loss of control in swapped roles	frustration and aggravation at the roles being swapped in whose parenting who. Some of this appears to be related to the general parent child relationship as it ages - increasing concern for health	P: am I’ve got to tell you it gets very irritating and aggravating at times as well because you sort of think you’re the parent, you know, stop telling me what to do, and she’s quite umm all sorts of.. I’m diabetic as a result of all of this umm so she’s quite pedantic about what I’m allowed to buy to eat. You know, I might go and buy an ice cream or something that’s got quite a lot of sugar and she’ll change it for a yoghurt or something do you know what I mean. You know like if I buy an ice cream cone and they have those yoghurt flavours that are so much healthier

Appendix P: Example Case Coding for Subordinate Themes

Oliver

unbalanced changed self	**a differnet dad/made known father**	**the changes to the child relationship**	**capable/doing father**	**intergenerational influences and personal values**	**a changed personal relationship**	**capability and inability**	**family matters**
1. self as a Father or self as dad	2. Different knowing of as dad, relying on others	3. the suffering child, the child-parent	19. a doing dad, others 'do' so much to help him function	5. the generational influencer	11. wife as decider and guider.	21. illness as inability. A problem to be solved. Bombardment from family. Reliable capability	45. being a good dad and a mate. Memories as a familial legacy
10. retreating to safety. Loss of social identity. A living nightmare	3. the very different father pre/post, loss of the patient self	4. environmental influences on the child	12. the important of the being a 'present' parent. Sharing and immortalising the memory legacy. Feeling capable	12. Sharing and immortalising the memory legacy. Feeling capable	20. wife as decider and guider.	58. really really bad times	64. Family remains while expected it’s a choice they make
18. the unworkable brain. Irritation. Discombobulated brain	12. the important of the being a 'present' parent.	5. protective child swings into the child-parent	39. The incapable self.	14. family scripts, the self-sufficient child	24. Hidden emotional struggle. wife-protector of him.	60. self-expectation. Ruminating. being in a right state	65. The reinforcement of different self-roles by family. Contracts/duty changed
20. Sense of confusion. Brain not working.	29. made known father	6. frustration, irritation aggravation. The loss of control in swapped roles	46. capable and doing. Creating memories together	15. his mother as guider and decider	39. The unfair role divisions.	61. self-expectation. Not by your own fault, no control or agency over this thing	80. dad is a problem to be managed at times

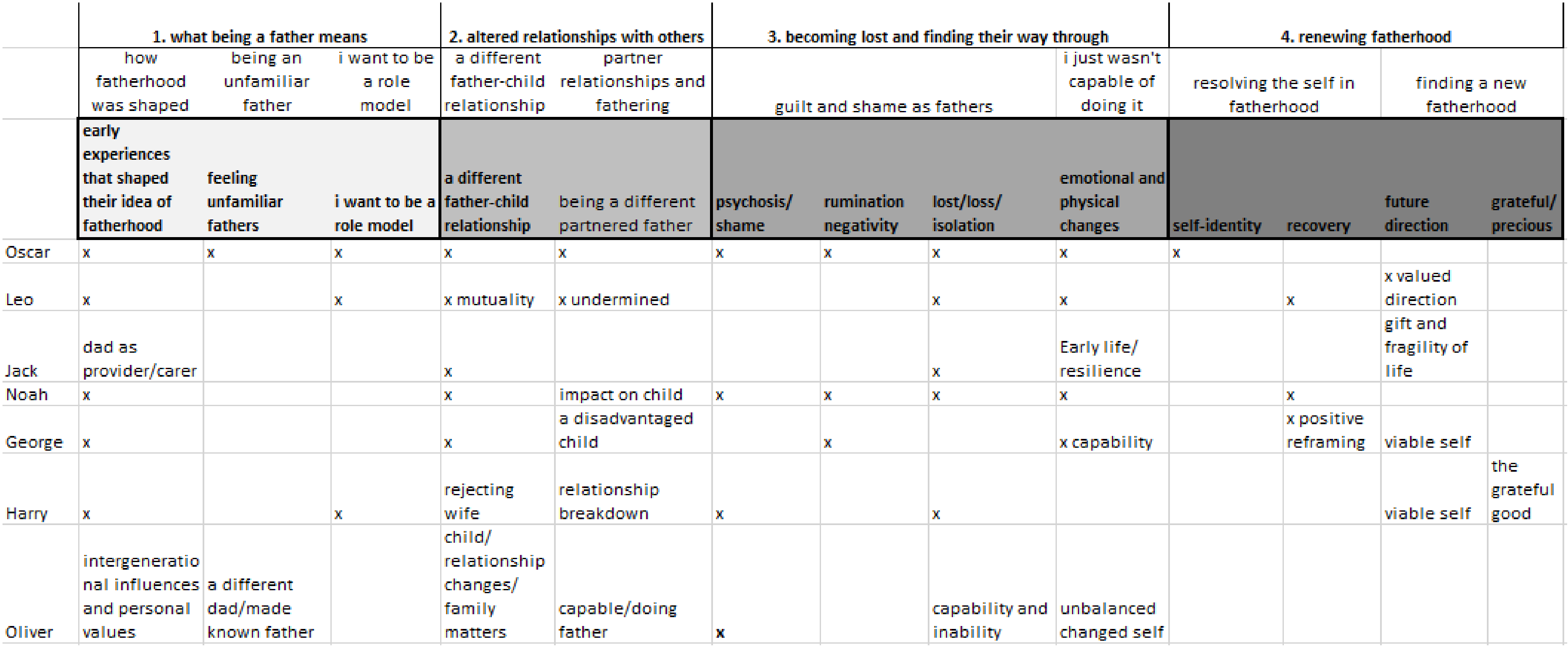
Harry

how to be a dad	loss/isolation/comparison	relationship breakdown	psychosis	the grateful good life	viable self	rejecting wife	dad as role model
1. valuing being a dad	2. the changed role in being able to be dad	3. the devastation to the marriage. Never the same.	4. negative impact of psychosis. Frightening?	8. the changed sense of self. Pressure to act. Unemployed self. The grateful alive.	31. choosing himself to choose to place himself in a better situation. Cannot express how bad it was, remains faithful to his wife	16. unaccepting wife. Wife abandoning and ignoring the BI and as such him	29. gratitude to have this time for life. Being a role model. Living genuinely.
11. children had to be a core part of me	6. a lost intimate family life	5. the ripples i.e. divorce is more damaging than the initial BI		10. "a good life"	36. reframing difference as positive for girls. Guilt at their "good lives" not as he hoped for them	17. she sees him as the disabled incapable spouse.	38. male role model. Acting with integrity. Contrast to wife acting poorly.
14. valuing being there for them	7. good times and memories. Constrained by a lost family intimacy	12. nice times are shared even though it feels as though everything has fallen apart		13. leading "a good life", now he's been marooned.	46. engaging in valued meaningful activity Increased insight. The forced change permitted the new identity to be forged	25. rejected BI survivor.	50. unconditional father. Role model
19. Appreciation to continue as their father	8. the loss of the in-between unscripted moments. the changed sense of self. Pressure to act. Unemployed self. The grateful alive.	34. the chain of events with far reaching events - ripple in the pond		15. it could have been worse. Privileging what remains to be offered	54. forced resolve into a new possible self	35. the rejected partner. Concern for future judgement. Cognitive changes. The future dad. The learnt relational self from the marriage failure	51. role model. Genuine authentic person. Unconditional person

George

how to be a dad	loss/isolation	positive reframing	viable self	changes to roles in relationship	capability	rumination/negativity	a disadvantaged child
1. the joyful nurturing achievement. A culmination of yourself in another	3. the spontaneous self	6. a very lucky man. Latent anger reframing negative into positive. Loss of agency. Locus on control outside oneself. Reminding self	57. holding hope. Visualisation of the future self.	8. Sense of ownership versus loss of agency. Discomfort at the primary breadwinner role lumbered to partner.	9. dad as abled doer.	17. letting everyone down	22. A disadvantaged child.
2. valued shared (intimate) family moments	4. loss of independence	7. reframing promotes coping. Why me? Depressed and low. A reminded self. lucky opportunistic self.	58. experiential moments of realisation over time	13. partner takes responsibility for the whole. removed as decider of own faith	20. Bad incapable dad.	18. the bad dad, self-comparison	26. the children's safety
5. quality time. The fortunate self-balancing the less able self. Self-reassurance	10. loss of control	8. Forced luckiness, as consolation for losses. Reminding self		14. loss of agency. uninvolved. Reassurance seeking.	23. the perception of being weak. Not coping.	29. self-comparison. Feeling a failure. New possibilities	28. tension between the active idolised dad and the possible dad. A disadvantaged child
24. The idealised dad. Self-comparison.	11. holding back chaos	9. Gratitude for a continued life. Disability. "at least I'm here". Reminding self	85. reparenting aids new viable identity. Models positive reframing	21. tolerating uncertainty. Retaking a breadwinning role	25. the able and active dad.	35. feeling a failure. Rumination on negative	76. I'm ok if their ok

Appendix Q: Superordinate and Subordinate Themes



	1. what being a father means			2. altered relationships with others		3. becoming lost and finding their way through				4. renewing fatherhood			
	how fatherhood was shaped	being an unfamiliar father	i want to be a role model	a different father-child relationship	partner relationships and fathering	guilt and shame as fathers			i just wasn't capable of doing it	resolving the self in fatherhood		finding a new fatherhood	
	early experiences that shaped their idea of fatherhood	**feeling unfamiliar fathers**	**i want to be a role model**	**a different father-child relationship**	being a different partnered father	**psychosis/ shame**	**rumination negativity**	**lost/loss/ isolation**	**emotional and physical changes**	**self-identity**	**recovery**	**future direction**	**grateful/ precious**
Oscar	x	x	x	x	x	x	x	x	x	x			
Leo	x		x	x mutuality	x undermined			x	x		x	x valued direction	
Jack	dad as provider/carer			x				x	Early life/ resilience			gift and fragility of life	
Noah	x			x	impact on child	x	x	x	x		x		
George	x			x	a disadvantaged child		x		x capability		x positive reframing	viable self	
Harry	x		x	rejecting wife	relationship breakdown	x		x				viable self	the grateful good
Oliver	intergenerational influences and personal values	a different dad/made known father		child/ relationship changes/ family matters	capable/doing father	**x**		capability and inability	unbalanced changed self				